

Target Populations Toolkit | 2018

Hispanic and Latino/Latina Populations

I. Historical and Current Issues Regarding Research Population

A. *Contested Definitions*

There is not one universally accepted term that refers to the population often described as Hispanic, Latino, or Latinx.

Since the 1970s, Hispanic has been the official US government term identifying people living in the country who are of Latin American and/or Spanish descent.¹ Latino is defined by Merriam-Webster as “a native or inhabitant of Latin American,” or “a person of Latin American origin living in the US;” the origins of the word are from the Spanish language.² Some writers point to the advantages of using Hispanic as a way to ensure continued access to government resources, and that using other terms would lead to confusion and restricted access.³ Other writers suggest that the term Latino is more appropriate because it has a more grassroots origin and because it unifies people of Latin American descent living in the United States, and has emerged from the community rather than being imposed from external sources.⁴ In the 2010 Census, the Census Bureau established greater flexibility in its definition, saying ““Hispanic or Latino” refers to a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.”⁵ In practice, the decision on who is considered Hispanic or Latino is left up to the respondent.⁶

Criticisms of the term Latino has come from its gendered nature. Like several other languages, many Spanish words have masculine and feminine versions. When referring to a group of men and women, the masculine term is also used as the term for a mixed-gender group, even if women outnumber men.⁷ Some have used Latino/Latina or Latino/a as a way to push back against the male gender dominance. More recently, Latin@ has emerged as an alternative that seeks to incorporate both genders into one word.⁸ Another alternative is Latinx, which is inclusive of both traditional genders as well as non-binary individuals.⁹ This term, however, has been criticized as a buzzword and a form of linguistic imperialism.¹⁰

All these terms, however, are oversimplifications. There are profound historic, socioeconomic, and identity differences between people whom the terms describe. For instance, people moving from Cuba to the United States in the late 1950s and early 1960s were often middle- to upper-class, fleeing the political revolution in that country, and were welcomed by the US government. Around the same time, the Chicano Movement was a grassroots push by Mexican-Americans, who were mostly low-income farm workers, already living in the US for economic and political rights.¹¹ The differences between these groups illustrate the difficulty in grouping together people from vastly diverse backgrounds.

The differences have consequences not just for people’s identities, but also for the outcomes and health-seeking behaviors of each population. Overall data for mental health suggest that Latinx Americans use mental health services less frequently than non-Hispanic whites.¹² However, when the data are separated by place of ancestry and birth, Puerto Ricans and Latinx born in the US use mental health services at higher rates than Mexican-Americans and Latinx immigrants.¹³ An intervention to increase use of counseling services among all Latinx people would be inefficient if the goal is to reduce disparities; instead, such an intervention should focus on Mexican-Americans and immigrants.

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Self-identity provides no clear solution. A Pew Research Center study found that over half (54%) of Hispanics say they typically use their ancestors' origins (i.e., Mexican, Dominican, etc.) to describe themselves. A slightly larger share identify as American (23%) than do Hispanic or Latino (20%). When asked specifically about Hispanic or Latino, 50% said they had no preference, 33% preferred Hispanic, and 15% preferred Latino.¹⁴

This section is not intended to solve this debate or provide a singular recommendation, but rather, to highlight the varied definitions people use and the ways they identify themselves. The toolkit will use several different terms throughout, typically following the lead of the source being discussed.

B. A Growing Presence in the United States

As defined by the Census, Hispanics already make up a sizable contingent of the US population. In 2014, the Census Bureau estimated there were 55 million Hispanics living in the country, comprising 17% of the total population and making this group the most populous minority. By 2060, the number is expected to top 119 million, with the share of the population growing to 29%.¹⁵

C. Health and Other Disparities

The Hispanic population faces many health and socioeconomic disparities. The top-level statistic of life expectancy for Hispanics appears good: compared with non-Hispanic Whites, higher life expectancies exist for both Hispanic men (79.1 years versus 76.5 years) and women (83.8 years versus 81.2 years). Beneath the surface, however, several worrying situations exist. In 2014, median household income for Hispanics was over \$20,000 lower than for non-Hispanic Whites, and a much greater proportion of Hispanics were below the poverty line (23.6%) than the national average (14.8%). Hispanic workers in agriculture and construction face an increased risk of heat-related death than their non-Hispanic White counterparts. Additionally, Hispanic youth aged 2-19 are more likely to be obese than non-Hispanic White youth (21.9% versus 14.7%). In 2012, the age-adjusted prevalence of diabetes was 14.8% for Puerto Ricans living in the US, 13.9% for Mexican-Americans, 9.3% for Cuban-Americans, and 8.5% for Central and South Americans; for non-Hispanic Whites, it was 7.6%.¹⁶

D. Multiple Sources of Identity

An individual's ethnic identity should be viewed in the context of multiple identities. In addition to ethnicity, their race, sexual orientation, gender identity, citizenship status, class, and many other aspects influence how they view themselves and their risk and resilience factors for health outcomes. Recognizing these dynamics is a critical step to building relationships with research participants.

E. Participatory Research

Traditional, researcher-led initiatives have often failed to address the needs of Latino/Latina communities. Some researchers have come to Latino/Latina communities, gathered data, and then left, with the community left in the dark about the findings, implications, and uses of the research. As a result, many Latinos and Latinas are hesitant to work with researchers.¹⁷ A possible response to this situation is to use a community-based participatory approach to one's research. In participatory research, the population being studied is an active

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participant in the research, from problem identification through design, data collection, and analysis, to dissemination. In addition to the normal research goal of advancing knowledge, it adds an additional goal of making practical use of that knowledge. When community partnerships function well, the resulting action can be the spark to identify other problems, starting the cycle over again.¹⁸ See Section V, Recruitment and Retention Best Practices, for further information.

F. Translation Services

Thinking about language is very important for investigators working with Latino/Latina communities. About a third of Hispanics in the US do not speak English well,¹⁹ making translation necessary for many stages of research. These can include translating flyers, consent forms, and questionnaires from English to Spanish, and translating qualitative research data from Spanish to English. One recommended company is MedEase, <http://www.medeaseinc.com/>, which provides translation for medicine and many other subjects.

¹ Oboler, S. (1995). *Ethnic Labels, Latino Lives: Identity and Politics of (Re)Presentation in the United States*. Minneapolis, MN: University of Minnesota Press, p. xiii.

² Latino: Definition of Latino by Merriam-Webster. (2018 January 29). Retrieved from <https://www.merriam-webster.com/dictionary/Latino>.

³ Oboler, p. 4.

⁴ Oboler, p. 4.

⁵ Humes, K.R., Jones, N.A., & Ramirez, R.R. (2011 March). *Overview of Race and Hispanic Origin: 2010*. Washington, DC: US Census Bureau. Retrieved from <https://www.census.gov/prod/cen2010/briefs/c2010br-02.pdf>.

⁶ Passel, J.S., & Taylor, P. (2009 May 28). Who's Hispanic? *Pew Research Center – Hispanic Trends*. Retrieved from <http://www.pewhispanic.org/2009/05/28/whos-hispanic/>.

⁷ Demby, G. (2013 January 7). 'Latin@' Offers A Gender-Neutral Choice; But How To Pronounce It? *NPR*. Retrieved from <https://www.npr.org/sections/thetwo-way/2013/01/07/168818064/latin-offers-a-gender-neutral-choice-but-how-to-pronounce-it>.

⁸ Michaeli, O. Latin@: Its Pronunciation and Meaning. *Noodle*. Retrieved from <https://www.noodle.com/articles/latin-what-it-means-and-how-to-say-it>.

⁹ Salinas, C. (2017 November 16). Mapping and recontextualizing the evolution of the term Latinx: An environmental scanning in higher education. *Journal of Latinos and Education*. DOI: 10.1080/15348431.2017.1390464.

¹⁰ Guerra, G., & Orbea, G. (2015 November 19). The argument against the use of the term "Latinx." *The Phoenix*. Retrieved from <http://swarthmorephoenix.com/2015/11/19/the-argument-against-the-use-of-the-term-latinx/>.

¹¹ Oboler, pp. 10, 60.

¹² Cabassa, L.J., Zayas, L.H., & Hansen, M.C. (2006 May). Latino Adults' Access to Mental Health Care: A Review of Epidemiological Studies. *Administration and Policy in Mental Health and Mental Health Services Research*, Vol. 33, No. 3, 316-330.

¹³ Alegria, M., Mulvaney-Day, N., Woo, M., Torres, M., Gao, S., Oddo, V. (2008). Correlates of past-year mental health service use among Latinos: results from the National Latino and Asian American Study. *American Journal of Public Health*. Vol. 97, No. 1, 76-83.

¹⁴ Lopez, M.H. (2013 October 22). 3. Hispanic Identity. *Pew Research Center – Hispanic Trends*. Retrieved from <http://www.pewhispanic.org/2013/10/22/3-hispanic-identity/>.

¹⁵ Colby, S.L. & Ortman, J.M. (2015 March). *Projections of the Size and Composition of the US Population: 2014 to 2060*. Washington, DC: US Census Bureau.

¹⁶ Velasco-Mondragon, E., Jimenez, A., Palladino-Davis, A.G., Davis, D., & Escamilla-Cejudo, J.A. (2016). Hispanic Health in the USA: a scoping review of the literature. *Public Health Reviews*, Vol 37. DOI: 10.1186/s40985-016-0043-2.

¹⁷ Mora, J., & Diaz, D.R. Introduction – Participatory Action Research: A New Vision and Practice in Latino Communities. (2004). In Mora, J., & Diaz, D.R. (Eds.), *Latino Social Policy: A Participatory Research Model* (pp. 1-24). Binghamton, NY: The Hawthorn Press.

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¹⁸ Mora & Diaz, pp. 6-7.

¹⁹ Krogstad, J.M., Stepler, R., & Lopez, M.H. (2015 May 12). English Proficiency on the Rise Among Latinos. *Pew Research Center: Hispanic Trends*. <http://www.pewhispanic.org/2015/05/12/english-proficiency-on-the-rise-among-latinos/>.

II. Health and Research Practice

A. Best Practices and Interventions

Characterization of the Hispanic or Latino Population in Health Research: A Systematic Review
<https://link-springer-com.proxy.cc.uic.edu/article/10.1007%2Fs10903-013-9773-0>

Common Themes of Resilience Among Latino Immigrant Families: A Systematic Review of the Literature
<https://doi-org.proxy.cc.uic.edu/10.1606/1044-3894.4003>

Defining and measuring acculturation: A systematic review of public health studies with Hispanic populations in the United States
<https://doi.org/10.1016/j.socscimed.2009.05.011>

High-Impact HIV Prevention: CDC's Approach to Reducing HIV Infections in the United States
https://www.cdc.gov/hiv/pdf/policies_NHPC_Booklet.pdf

The Immigrant and Hispanic Paradoxes: A Systematic Review of Their Predictions and Effects
<https://doi.org/10.1177/0739986313499004>

Interventions to Improve Quality of Life, Well-Being, and Care in Latino Cancer Survivors: A Systematic Literature Review
<https://doi.org/10.1188/16.ONF.374-384>

School-Wide Programs Aimed at Obesity Among Latino Youth in the United States: A Review of the Evidence
<http://onlinelibrary.wiley.com.proxy.cc.uic.edu/doi/10.1111/josh.12144/full>

Sexual Health Behavior Interventions for U.S. Latino Adolescents: A Systematic Review of the Literature
<https://doi.org/10.1016/j.jpap.2011.09.011>

A Systematic Review of Barriers and Facilitators to Mammography in Hispanic Women
<https://doi.org/10.1177/1043659614530761>

A Systematic Review of Barriers and Facilitators to Minority Research Participation Among African Americans, Latinos, Asian Americans, and Pacific Islanders
<https://doi.org/10.2105/AJPH.2013.301706>

B. Databases and Other Searchable Resources:

Healthy People 2020 Best Practice Research Search
<https://www.healthypeople.gov/2020/tools-resources/Evidence-Based-Resources>

CDC Wonder
<https://wonder.cdc.gov/>

III. National and Local Data

A. General Data

Centers for Disease Control and Prevention: Health of Hispanic or Latino Population
<https://www.cdc.gov/nchs/fastats/hispanic-health.htm>

Pew Research Center

Key facts about how the U.S. Hispanic population is changing
<http://www.pewresearch.org/fact-tank/2016/09/08/key-facts-about-how-the-u-s-hispanic-population-is-changing/>

Maps and Data about the Hispanic Population
<http://www.pewsocialtrends.org/2012/03/19/maps-and-data-about-the-hispanic-population/>

Statistical Portrait of Hispanics in the United States, 2014
<http://www.pewhispanic.org/2016/04/19/statistical-portrait-of-hispanics-in-the-united-states-key-charts/>

Office of Minority Health, Health and Human Services: Profile – Hispanic/Latino Americans
<https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=64>

US Census Bureau

Changes in Self-Employment: 2010 to 2011
<https://www.census.gov/library/publications/2013/acs/acsbr11-21.html>

Disparities in STEM Employment by Sex, Race, and Hispanic Origin
<https://www.census.gov/library/publications/2013/acs/acs-24.html>

Educational Attainment in the United States: 2015
<https://www.census.gov/library/publications/2016/demo/p20-578.html>

Facts for Features: Hispanic Heritage Month 2017
<https://www.census.gov/newsroom/facts-for-features/2017/hispanic-heritage.html>

Poverty Rates for Selected Race & Hispanic Groups by State and Place: 2007-11
<https://www.census.gov/library/publications/2013/acs/acsbr11-17.html>

School Enrollment in the United States: 2011
<https://www.census.gov/library/publications/2013/demo/p20-571.html>

Selected Population Profile, Hispanic Population, 1-Year Estimates, 2015
<https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmmk>

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B. State and Local Data

Chicago Metropolitan Agency for Planning

Demographic and Housing Trends in Latino Population

http://www.cmap.illinois.gov/about/updates/-/asset_publisher/UIMfSLnFfMB6/content/demographic-and-housing-trends-in-latino-population

Latino Population Growth Drives Metropolitan Chicago's Population Growth

http://www.cmap.illinois.gov/about/updates/-/asset_publisher/UIMfSLnFfMB6/content/latino-population-growth-drives-metropolitan-chicago-s-population-growth

Race and ethnicity in the CMAP Region

http://www.cmap.illinois.gov/about/updates/-/asset_publisher/UIMfSLnFfMB6/content/race-and-ethnicity-in-the-cmap-region

Latino Policy Forum: Tracking Latino Population Density and Voting Age Population in Illinois

http://gis.depaul.edu/shwang/CommunityOutreach/GEO242_Service_Learning_Project/GEO242_Win1213_LatinoVotingAgePopulation.pdf

Pew Research Center: Demographic profile of Hispanics in Illinois, 2014

<http://www.pewhispanic.org/states/state/il/>

Pew Research Center: Hispanic Population and Origin in Select U.S. Metropolitan Areas, 2014

<http://www.pewhispanic.org/interactives/hispanic-population-in-select-u-s-metropolitan-areas/>

Rob Paral and Associates: Chicago Community Area Data

<http://www.robparal.com/ChicagoCommunityAreaData.html>

Rob Paral and Associates: Illinois' Undocumented Immigrant Population

http://robparal.com/downloads/Illinois_undocumented_report_0.pdf

US Census Bureau

Chicago Quick Facts

<https://www.census.gov/quickfacts/fact/table/chicagocityillinois/HSD410215>

Illinois Community Facts

https://factfinder.census.gov/faces/nav/jsf/pages/community_facts.xhtml?src=bkmk

Illinois Quick Facts

<https://www.census.gov/quickfacts/IL>

IV. Ethical and Regulatory Issues

A. Consent for Participants Who Do Not Read or Write English

When conducting research with Hispanic populations, it is likely that investigators will encounter people who do not read or write English, or who prefer to communicate in another language, most often Spanish. A Pew Research Center report suggests that, though English proficiency is increasing, 1 in 3 Hispanics do not speak English well.²⁰ Federal regulations require that investigators must either provide an ethical and scientific justification for excluding non-English speakers, or include them in their research. When obtaining consent, researchers can use a translated copy of the consent form or a short form consent document stating that the elements of consent have been described to the participant. The IRB determines which approach should be used, but only the former approach can be used at the UIC College of Medicine. Even after written consent has been obtained, the research team should continue to ensure non-English speaking participants are voluntarily consenting to participate in the research. Additionally, other written materials, such as diagnostic tools and final reports to be shared with the community, should be translated into the participants' language. See <http://research.uic.edu/node/761> for further information.

When translating materials, there are two routes the research team can take. The preferred route is that someone on the team who is fluent in both languages should write the consent in Spanish first. Then, someone else should translate this document into English, and the team can review it to ensure it conveys the information correctly. If no one on the team is bilingual, another person or a translation service can take the English version and translate into Spanish; then, someone who did not do the first translation should translate the document back into English. The research team then compares both English versions of the document. They need not match 100%, but the concepts should remain consistent. Regardless of the method chosen, both the English and Spanish versions should be submitted to the IRB. Additionally, a bilingual research team member should obtain consent, or a professional translator should be present. Having family or friends informally translate is not recommended.²¹

B. Issues Related to Documentation Status

The Pew Research Center estimates that, as of 2014, there were approximately 8.2 million undocumented immigrants from Mexico, Central American, and South America living in the United States.²² In Illinois, there are over half a million undocumented residents, most of whom live in the northeast area – Chicago, suburban Cook County, and the collar counties.²³ People without legal authorization to live in the country may be reluctant to participate in research, fearing their status will be revealed to immigration authorities. Researchers should take these concerns seriously. They should have data protections in place that reduce the risk of exposure. Documentation status should not be recorded unless it is truly necessary for their research, and then it should be stored separately from identifying information. Investigators who receive funding from the National Institutes of Health can also apply for a Certificate of Confidentiality, which provides an additional layer of protection for participants' data.²⁴ These measures, and any threats to privacy and confidentiality, should be communicated to research participants.

UIC investigators are not required to inquire about documentation status for the purposes of providing compensation for participation in research. However, if payments exceed \$200 in a calendar year, the

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University of Illinois System's policy is that their tax information should be reported. If payments reach or exceed \$600 in a year, a tax form must be filled out. The tax form will depend on whether the participant is known to be undocumented or not. See <https://www.obfs.uillinois.edu/bfpp/section-8-payments-reimbursements/payments-human-subjects> for a more thorough explanation, including how to contact University Payroll and Benefits for further guidance.

²⁰ Krogstad, J.M., Stepler, R., & Lopez, M.H. (2015 May 12). English Proficiency on the Rise Among Latinos. *Pew Research Center: Hispanic Trends*. <http://www.pewhispanic.org/2015/05/12/english-proficiency-on-the-rise-among-latinos/>.

²¹ Anderson, E.E., & Corneli, A. (2018). *100 Questions (and Answers) About Research Ethics*. Thousand Oaks, CA: Sage Publishing.

²² Unauthorized Immigrant Population Trends for States, Birth Countries, and Regions. (2016 November 3). *Pew Research Center: Hispanic Trends*. <http://www.pewhispanic.org/interactives/unauthorized-trends/>.

²³ Tsao, F. (2014 February). Illinois' Undocumented Immigrant Population: A Summary of Recent Research by Rob Paral and Associates. *Illinois Coalition for Immigrant and Refugee Rights*. http://robparal.com/downloads/Illinois_undocumented_report_0.pdf.

²⁴ See <https://humansubjects.nih.gov/coc/background> for more information.

V. Recruitment and Retention Best Practices

A. Community-Based Participatory Research in Latinx Communities

As mentioned in Section I, Community-Based Participatory Research (CBPR) is one method for addressing the hesitance some Latinx people have for participating in research. A major tenet is that community members (either on their own or through organizations) have a real voice in setting the research agenda, planning, implementing the plan, and realizing outcomes. Relatedly, the community should benefit from the process in addition to the generation of knowledge that benefits the researcher. A challenge is that, in order to obtain funding to do research, much of the agenda setting and planning must be done prior to submitting a proposal. One route is to find a funder who is willing to give substantial leeway within a broad framework.²⁵ Another approach is to do the initial relationship building and planning before applying for a grant. Investigators can also begin discussions with community-based organizations and volunteer to fill a need or help with existing projects. Similarly, if researchers have funding for a small, short-term study, this can be a way to build the groundwork for a more substantial partnership.²⁶ These approaches may require more hours for both the researchers and the community partners. Ultimately, though, they can result in a stronger partnership because of the shared commitment that everyone builds together.

After the initial period of relationship building, a few key considerations can help the partnership transition into a robust engagement. Creating a community advisory board (CAB) is essential to the process. Potential members should be committed to the project and be willing to work with their contacts in the community to build further support for the project. Members should come from multiple organizations or places in the community to ensure continuity if one organization reduces its support of the project. Convening a CAB helps bring accountability to the project, but it also is a signal to others in the community that buy-in from their community is already present. Beyond convening the CAB, it is important for the researcher to attend events outside the project, and to be physically present for meetings, to demonstrate their commitment.²⁷

Researchers who embark on CBPR should have or develop certain qualities to make them stronger partners. A willingness to learn as well as to teach is key. They should have access to resources they can share with community partners, whether these are funds, access to facilities, other experts, etc. Additionally, they should be patient and understand that change and ambiguity often come with community work.²⁸ Developing these qualities can increase the chances of a successful project.

B. Considerations for Working in Latino/Latina Communities

While acknowledging the diversity of Latino/Latina communities, some characteristics are common and should be considered when doing research with Latino/Latina Americans. Acculturation is a relevant process for many Latino/Latina Americans. Several models try to explain this process. The unidimensional model sees cultural orientation as a trade-off: as someone becomes more oriented toward one culture, they must become less oriented toward another culture. The bidimensional model positions orientations to different cultures independently. Thus, people could be marginalized (identifying with neither culture), bicultural (identifying with both cultures), or somewhere in between. Complicating this situation is that, within one community, there are likely to be several generations who have spent varying numbers of years in the US and their country of origin (if they have ever been there, in the case of second or later generations).²⁹ Understanding this dynamic

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can be useful whether studying acculturation directly, as a component of other analyses, or simply as a way to gauge their interest in your research.

Another important consideration is where to recruit participants. Previous research has shown that racial and ethnic minorities are less likely to seek professional mental health support until their symptoms are severe, instead seeking support from a primary care clinic or informal sources.³⁰ Additionally, Latino/Latina Americans are the racial/ethnic group least likely to have health insurance.³¹ Thus, recruiting Latino/Latina research participants from care settings is less likely to be successful; outreach must be done more broadly.

²⁵ Dorrington, C., & Solis, B. Building Community, Research, and Policy: A Case of Community Health and Central Americans in Los Angeles. (2004). In Mora, J., & Diaz, D.R. (eds.). *Latino Social Policy: A Participatory Research Model* (pp. 89-118). Binghamton, NY: The Haworth Press.

²⁶ D'Alonzo, K.T. (2010 July 11). Getting Started in CBPR: Lessons in Building Community Partnerships for New Researchers. *Nursing Inquiry*, Vol. 17, No. 4, pp. 282-288.

²⁷ D'Alonzo, pp. 283-284.

²⁸ Mora, J. Expanding Latino Community Capacity for Sustainable Programs Through Researcher-Community Partnerships. (2004). In Mora, J., & Diaz, D.R. (eds.). *Latino Social Policy: A Participatory Research Model* (pp.245 - 257). Binghamton, NY: The Haworth Press.

²⁹ Furman, R., Negi, N.J., Iwamoto, D.K., Rowan, D., Shukraft, A., & Gragg, J. (2009 April). Social Work Practice with Latinos: Key Issues for Social Workers. *Social Work*, Vol. 54, No. 2, pp. 167-174.

³⁰ Furman et al.

³¹ Centers for Disease Control and Prevention. (2015). Summary Health Statistics. *National Health Interview Survey*. https://ftp.cdc.gov/pub/Health_Statistics/NCHS/NHIS/SHS/2015_SHS_Table_P-11.pdf.

VI. Recruitment Templates

General Outreach Templates and Best Practices

<http://www.ccts.uic.edu/content/recruitment-templates>

FDA Research Volunteer Brochure

http://go.uic.edu/FDA_Research_Volunteer_Brochure

Flyer Templates

Latino Boy: http://www.ccts.uic.edu/sites/default/files/res_flyer_HISP_M_child.doc

Latina Girl: http://www.ccts.uic.edu/sites/default/files/res_flyer_HISP_F_child.doc

Latina Woman 18-30: http://www.ccts.uic.edu/sites/default/files/res_flyer_HPC_F_18-30.doc

Latinx Family: http://www.ccts.uic.edu/sites/default/files/res_flyer_HISP_family.doc

50+ Latina Woman: http://www.ccts.uic.edu/sites/default/files/res_flyer_HPC_F_50.doc

Simplified Recruitment Language

http://go.uic.edu/Simplified_Recruitment_Language

Supporting Enrollment & Engagement in Clinical Research

<http://www.ccts.uic.edu/sites/default/files/uploads/Example%202.pdf>

<http://www.ccts.uic.edu/sites/default/files/uploads/Example%203.pdf>

VII. Community Engagement Resources

A. Local Organizations

Alivio Medical Center

<http://aliviomedicalcenter.org/>

Bickerdike Redevelopment Corporation

<http://www.bickerdike.org/>

Casa Central

<http://www.casacentral.org/>

Centro Comunitario Juan Diego

www.ccjuandiego.org

Centro Romero

www.centroromero.org

Chicago Hispanic Health Coalition

www.chicagohispanichealthcoalition.org

Christopher House

www.christopherhouse.org

Community Health Partnership of Illinois

www.chpofil.org

Corazón a Corazón NFP

<http://www.corazon-chicago.com/>

El Valor

www.elvalor.org

Enlace Chicago

www.enlacechicago.org

Erie Neighborhood House

www.eriehouse.org

Healthcare Alternative Systems Inc.

www.hascars.org

Illinois Coalition for Immigrant and Refugee Rights

www.icirr.org

Illinois Hispanic Chamber of Commerce
www.ihccbbusiness.net

Instituto
<https://www.institutochicago.org/>

La Casa Norte
www.lacasanorte.org

Latino Policy Forum
<http://www.latinopolicyforum.org/>

Latinos Progresando
<https://latinospro.org/>

Logan Square Neighborhood Association
www.lsna.net

Pilsen Alliance
<http://www.thepilsenalliance.org/>

Puerto Rican Cultural Center
www.prcc-chgo.org

The Resurrection Project
www.resurrectionproject.org

Universidad Popular
www.universidadpopular.us

B. National Organizations

National Institute for Latino Policy
<http://www.nilpnetwork.org/>

National Latino Education Institute
<http://www.nlei.org/>

National Museum of Mexican Art
www.nationalmuseumofmexicanart.org

Unidos US (Formerly National Council of La Raza)
<https://www.unidosus.org/>

VIII. Researchers at UIC and C3 Working on the Issue

Please note: This list is intended to be illustrative rather than exhaustive. Resources to find additional researchers include <https://projectreporter.nih.gov/reporter.cfm>, <https://clinicaltrials.gov/>, <https://www.researchgate.net/>, and <https://scholar.google.com/>.

A. UIC

Xóchitl Bada, PhD

<https://lals.uic.edu/lals/people/faculty/x%C3%B3chitl-bada>

Christopher Boyer, PhD

<https://lals.uic.edu/lals/people/faculty/christopher-boyer>

Ralph Cintrón, PhD

<https://lals.uic.edu/lals/people/faculty/ralph-cintron>

Andreas Feldmann, PhD

<https://lals.uic.edu/lals/people/faculty/andreas-feldmann>

Lorena Garcia, PhD

<https://lals.uic.edu/lals/people/faculty/lorena-garcia>

Adam Goodman, PhD

<https://lals.uic.edu/lals/people/faculty/adam-goodman>

Elena Rebeca Gutiérrez, PhD

<https://lals.uic.edu/lals/people/faculty/elena-gutierrez>

Patrisia Macias-Rojas, PhD

<https://lals.uic.edu/lals/people/faculty/patrisia-macias>

Joel Palka, PhD

<https://lals.uic.edu/lals/people/faculty/joel-palka>

Amalia Pallares, PhD

<https://lals.uic.edu/lals/people/faculty/amalia-pallares>

Cristián A. Roa-de-la-Carrera, PhD

<https://lals.uic.edu/lals/people/faculty/cristi%C3%A1n-a-roa-de-la-carrera>

María de Los Angeles Torres, PhD

<https://lals.uic.edu/lals/people/faculty/mar%C3%ADa-de-los-angeles-torres>

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B. Northwestern

Frances R. Aparicio, PhD

<http://www.spanish-portuguese.northwestern.edu/people/faculty/teaching-research-faculty/aparicio-frances.html>

Héctor Carrillo, PhD

<http://www.sociology.northwestern.edu/people/faculty/core/hector-carrillo.html>

Henry Godinez, MFA

<https://communication.northwestern.edu/faculty/HenryGodinez>

C. University of Chicago

Micere Keels, PhD

<https://humdev.uchicago.edu/directory/micere-keels>

Agnes Lugo-Ortiz

<https://rll.uchicago.edu/faculty/lugo-ortiz>

Laura Gandolfi

<https://newfaculty.uchicago.edu/page/laura-gandolfi>

Mauricio Tenorio

<http://rll.uchicago.edu/faculty/tenorio>

Dexter Voisin

<https://www.ssa.uchicago.edu/ssascholars/d-voisin>

IX. Measuring Instruments

A. A Note on Measuring Race and Ethnicity

The US Census Bureau recently announced that the 2020 Census will use a two-question format to ask about ethnicity and race, similar to what was used in the 2010 Census.³² However, the ethnic and racial categories in the Census may not provide sufficient levels of detail for some studies, and they may not match people's perceptions of ethnicity and race. The Food and Drug Administration suggests that, when appropriate, more detailed categories can be used. Researchers should take care to ensure the categories can be mapped back onto the standard two choices for ethnicity (Hispanic or Latino, or not Hispanic or Latino) and race. An example would be asking research participants about whether they are Hispanic or Latino and offering several categories, such as Mexican, Puerto Rican, Cuban, and other Hispanic/Latino/Spanish origin, as well as no or none.³³ This allows greater precision for one's study and remains consistent with standard categories.

B. Other Measuring Instruments

Acculturation, Habits, and Interests Multicultural Scale for Adolescents

<https://doi.org/10.1177/02731602022003001>

Acculturation Rating Scale for Mexican Americans-II

<https://doi.org/10.1177/07399863950173001>

Adolescent Reports of Academic Support by Mothers, Fathers, Teachers, and Friends in Latino Immigrant Families

<https://doi.org/10.1177/0739986304273968>

Adolescent Survey-Based Smoking-Related Cognitions Scale

<https://doi.org/10.1016/j.ypped.2004.04.007>

The Bidimensional Acculturation Scale for Hispanics (BAS)

<https://doi.org/10.1177/07399863960183002>

Brief Acculturation Scale for Hispanics

<https://doi.org/10.1177/07399863960181004>

Brief Acculturation Rating Scale for Mexican Americans-II

<https://doi.org/10.1177/0739986305281423>

Coping With Acculturative Stress in American Schools (CASAS-A) Scale

<https://doi.org/10.1177/1534508413500983>

Diabetes Knowledge Scale for Low-Literate Hispanic/Latinos

<https://doi.org/10.1177/1524839912474006>

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Dimensionality and Validity of the Rosenberg Self-Esteem Scale for Use With Latino Adolescents

<https://doi.org/10.1177/0739986310387275>

Electronic Health Literacy Scale (For Older Hispanic Adults)

<http://dx.doi.org/10.1111/jocn.13763>

Factor Structure and Psychometric Properties of English and Spanish Versions of the Edinburgh Postnatal Depression Scale Among Hispanic Women in a Primary Care Setting

<http://dx.doi.org/10.1002/jclp.22101>

Guide to Psychological Assessment with Hispanics

<http://proxy.cc.uic.edu/login?url=https://link.springer.com/book/10.1007%2F978-1-4614-4412-1>

Hispanic Women's Social Stressor Scale

<https://doi.org/10.1177/0739986308316178>

Immigrant Barriers to Health Care Scale: Hispanic Version

<http://proxy.cc.uic.edu/login?url=http://onlinelibrary.wiley.com/doi/10.1111/j.1442-2018.2009.00446.x/full>

Measure to Assess Linguistic Self-Esteem in Adolescent Latino Bilinguals

<https://doi.org/10.1177/0739986311423354>

Measurement Equivalence of the Center for Epidemiological Studies Depression Scale for Latino and Anglo Adolescents

<http://dx.doi.org/10.1037/0022-006X.73.1.47>

Migrant Stress Inventory

<http://dx.doi.org/10.1037/a0018665>

Multi-Dimensional Measures of Race/Ethnicity on the Self-Reported Health Status of Latinos

<https://doi.org/10.1017/S1742058X15000120>

Multidimensional Safety Climate Scale

<https://doi.org/10.1016/j.ssci.2012.11.006>

Parenting Strategies for Eating and Physical Activity Scale-Diet (PEAS-Diet), Modified

<https://doi.org/10.1016/j.appet.2015.12.003>

Parental Engagement of Families from Latino Backgrounds

<http://dx.doi.org/10.1037/a0036167>

Perceived Social Support for Undocumented Hispanic Immigrants

<https://doi.org/10.1177/0739986315577894>

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Personal Growth Initiative Scale-II

<http://dx.doi.org/10.1037/cou0000075>

The Psychometric Properties of the Generalized Anxiety Disorder-7 Scale in Hispanic Americans with English or Spanish Language Preference

<http://dx.doi.org/10.1037/a0036523>

The Reliability and Validity of the Brief Sensation Seeking Scale (BSSS-8) with Young Adult Latino Workers: Implications for Tobacco and Alcohol Disparity Research

<http://dx.doi.org/10.1111/j.1360-0443.2007.01958.x>

Revised 28-Item Racial and Ethnic Microaggressions Scale (R28REMS)

<https://doi.org/10.1080/01488376.2014.987944>

Social Support Among Spanish-Speaking Immigrant Latino Gay Men

<https://doi.org/10.1177/0739986312446290>

³² Census Bureau Statement on 2020 Census Race and Ethnicity Questions. (2018 January 26). *US Census Bureau*. Retrieved from <https://www.census.gov/newsroom/press-releases/2018/2020-race-questions.html>.

³³ Collection of Race and Ethnicity Data in Clinical Trials: Guidance for Industry and Food and Drug Administration Staff. (2016 October 26). *FDA Office of Minority Health*. Retrieved from <https://www.fda.gov/downloads/regulatoryinformation/guidances/ucm126396.pdf>.

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X. Program Announcements for Grants

A. MSI and HSI Designation

UIC has been designated as a Minority Serving Institution (MSI) based on its full-time undergraduate enrollment. Furthermore, in 2015, it was granted Hispanic Serving Institution (HSI) status. UIC researchers focusing on Latinx populations may qualify for special grants and opportunities. See <https://research.uic.edu/minority-serving-institution-status> for more information.

B. Grant Programs

The grants programs below expire no earlier than 2019.

The Commonwealth Fund

<http://www.commonwealthfund.org/grants-and-fellowships/new-faq-page>

National Institutes of Health: R21s are listed; links to related R01s can be found on each page.

Collaborative Minority Health and Health Disparities Research with Tribal Epidemiology Centers
<https://grants.nih.gov/grants/guide/pa-files/PA-17-483.html>

Health Promotion Among Racial and Ethnic Minority Males
<https://grants.nih.gov/grants/guide/pa-files/PA-18-162.html>

Health Services Research on Minority Health and Health Disparities
<https://grants.nih.gov/grants/guide/pa-files/PA-18-287.html>

Reducing Health Disparities Among Minority and Underserved Children
<https://grants.nih.gov/grants/guide/pa-files/PA-18-169.html>

Patient-Centered Outcomes Research Institute

<https://www.pcori.org/funding-opportunities>

Tinker Foundation: Field Research Grants for Study in Latin America

<http://www.tinker.org/content/field-research-grants>

William T Grant Foundation: Reducing Inequality Grants

<http://wtgrantfoundation.org/focus-areas/reducing-inequality>

XI. Community Stakeholder Involvement

A. Latino/Latina Specific Resources

UIC Chancellor's Committee on the Status of Latinos
<http://ccsl.uic.edu/>

UIC Integrated PASEO
<http://publichealth.uic.edu/uicip>

UIC Latin American and Latino Studies Program
<https://lals.uic.edu/lals>

UIC Latin American Recruitment and Educational Services program (LARES)
<https://lares.uic.edu/>

UIC Latino Cultural Center
<http://latinocultural.uic.edu/>

UIC Resources for Undocumented Students
<http://dream.uic.edu/>

B. General Resources for Individuals

National Institutes of Health – Clinical Research Trials & You
<https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics>

Research Fundamentals for Activists
<http://www.treatmentactiongroup.org/sites/default/files/201305/RFA%20FINAL.pdf>

Research Match (search for clinical trials to join)
<https://www.researchmatch.org/>

C. General Resources for Organizations

Alliance for Research in Chicagoland Communities, Northwestern University

Assessing your Organization's Research Environment and Capacity
<http://arccresources.net/wp-content/uploads/2013/08/Assessing-your-Organizations-Research-Environment-Capacity.pdf>

Community-Based Participatory Research 101
<http://arccresources.net/wp-content/uploads/2014/01/CBPR-101-2014expanded.pdf>

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Community-Engaged Research Funding & Grantwriting Tips and Strategies

<http://arccresources.net/wp-content/uploads/2015/01/CEnRFunding.GrantwritingTips.Strategies.pdf>

Community Partner Resources

<http://arccresources.net/category/community-partners/>

Considering and Developing Your Organization's Research Purpose

<http://arccresources.net/wp-content/uploads/2013/08/Considering.Developing-Your-Organization%E2%80%99s-Research-Purpose.pdf>

Introduction to Qualitative Research Methods

<http://arccresources.net/wp-content/uploads/2015/09/Intro-to-Qualitative-Research-Methods.pdf>

Introduction to Research Design

<http://arccresources.net/wp-content/uploads/2013/08/Intro-to-Research-Design.pdf>

NIH Biosketch for Community Partner

<http://arccresources.net/wp-content/uploads/2015/06/NIH-Biosketch-for-Community-Partner.pdf>

Patient and Stakeholder Engagement (PCORI)

<http://arccresources.net/wp-content/uploads/2013/12/Patient-and-Stakeholder-Engagement-in-Patient-Centered-Outcomes-Research-PCORI.pdf>

University 101

<http://arccresources.net/wp-content/uploads/2014/12/University-101full.pdf>

Center for Clinical and Translational Sciences

<http://www.ccts.uic.edu/>

Recruitment, Retention, and Community Engagement Program

<http://www.ccts.uic.edu/content/recruitment-retention>

Clinical Trials Database

<https://clinicaltrials.gov/>

Community Based Participatory Research 101: From a Community Partner Perspective

Harlem Community & Academic Partnership

<https://ccph.memberclicks.net/assets/Documents/CNREI/cbpr%20101%20presentation.pdf>

A Quick Start Guide to Conducting Community-Engaged Research

Southern California Clinical and Translational Science Institute, Office of Community Engagement

http://oprs.usc.edu/files/2013/01/Comm_Engaged_Research_Guide.pdf

UIC Office of Community Engaged Research and Implementation Science

<https://cancer.uillinois.edu/outreach-program>

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UIC Office of Community Engagement and Neighborhood Health Partnerships
<https://oceanhp.uic.edu/>

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XII. Team Readiness to Work with Special Populations

A. Cultural competency training

Cultural Competence Assessment Instrument (CCAI)

<http://ccbmdr.ahslabs.uic.edu/wp-content/uploads/sites/5/2014/04/CCAI.pdf>

Cultural Competence with LGBTQ Clients

Cultural Competence in HIV Care

<http://www.matec.info/programs/illinois>

National Research and Training Center (NRTC) Training and Education: Toolkit and Training on Assessing Cultural Competency in Peer-Run Mental Health Programs

<http://www.cmhsrp.uic.edu/nrtc/starcenter.asp>

B. Team diversity representation

Making sure that the research team has some representation of the target special population group helps establish trust, understanding, and credibility. For example, when conducting research related to cervical cancer in Humboldt Park, having Puerto Rican women as team members can help to build trust and understanding between the research team and community members. This step, however, is not sufficient by itself: other efforts described elsewhere in this toolkit should also be used to garner community support and involvement.

C. Implicit-association test (IAT) – Offers a way to probe unconscious biases

Implicit Association Test (IAT)

<http://projectimplicit.net/nosek/iat/>

Look Different's Implicit Association Tests

<http://www.lookdifferent.org/what-can-i-do/implicit-association-test>

Project Implicit

<https://implicit.harvard.edu/implicit/>

D. LH-STEP – Helps assess an individual's capabilities by measuring skills, abilities, and potential for success.

http://www.creativeorgdesign.com/tests_page.php?id=477

E. Resources to Evaluate Attitudes and Train Skills Necessary for Working with Latinx Communities

Recommendations for Working in Partnership with Latino Communities: A Guide for Public Agencies and Other Social Service Practitioners (form on page 7)

<http://anrcatalog.ucanr.edu/pdf/8206.pdf>

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Citing the CCTS's Target Population Toolkit

The LGBT Target Population Toolkit was developed by the UIC Center for Clinical and Translational Science's Recruitment, Retention and Community Engagement Program.

The National Institutes of Health requires that investigators cite the CTSA grant if they used any CCTS services or resources to support their research. The CCTS relies on these citations as a critical performance measure when reporting annual productivity to NIH.

To cite the CCTS, the following text is recommended:

“The University of Illinois at Chicago Center for Clinical and Translational Science is supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1TR002003. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.”

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