

# **DISAGGREGATING LATINA/O SURVEILLANCE HEALTH DATA ACROSS THE LIFECOURSE: BARRIERS, FACILITATORS, AND EXEMPLARS**

Carmela Alcántara<sup>1</sup> and Leopoldo J. Cabassa<sup>1</sup>  
Shakira Suglia<sup>2,3</sup>  
Irene Perez Ibarra<sup>1</sup>  
A. Louise Falzon<sup>4</sup>  
Elliot McCullough<sup>1,3</sup>  
Talhah Alvi<sup>5</sup>

<sup>1</sup>Columbia University School of Social Work, <sup>2</sup>Emory University, <sup>3</sup>Mailman School of Public Health Columbia University, <sup>4</sup>Columbia University Medical Center, <sup>5</sup>Teacher's College Columbia University

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\*Joint first-authors

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## TEAM BIOGRAPHIES

### Investigative Team

**Carmela Alcántara**, PhD is Assistant Professor at Columbia University School of Social Work, Faculty of the Columbia Population Research Center, and Faculty of the Social Intervention Group at Columbia University. She is a clinical psychologist with postdoctoral training in public health and behavioral medicine. Her interdisciplinary program of research integrates frameworks and methodologies from psychology, public health, social work, and medicine to understand how structural and social factors (e.g., nativity status, socioeconomic status, discrimination stress, and neighborhood factors) affect sleep, mental health, and cardiovascular health, particularly in racial/ethnic and immigrant communities. Dr. Alcántara is committed to the development of culturally tailored, evidence-based behavioral interventions that promote health equity. Her work has been supported by the National Heart, Lung, and Blood Institute, the National Institute of Mental Health, the Robert Wood Johnson Foundation, the W.K. Kellogg Foundation, the Irving Institute for Clinical and Translational Research, and the Office of the Provost at Columbia University.

**Leopoldo J. Cabassa**, MSW, PhD is Associate Professor at the Columbia University School of Social Work and the Assistant Director of the New York State Center of Excellence for Cultural Competence at the New York State Psychiatric Institute. He received his MSW and PhD from the George Warren Brown School of Social Work at Washington University in St. Louis and completed a postdoctoral fellowship at the University of Southern California Suzanne Dworak-Peck School of Social Work. His research blends quantitative and qualitative methods, implementation science, intervention research, and community engagement to examine health disparities among racial/ethnic minorities with serious mental illness (e.g., schizophrenia and bipolar disorder) and to inform development and implementation of interventions to reduce these health inequities. His work has been supported by the National Institute of Mental Health, the Substance Abuse and Mental Health Services Administration, the Robert Wood Johnson Foundation, and the New York State Office of Mental Health. He is a fellow of the New York Academy of Medicine and the Society for Social Work and Research and a standing member of the Health Disparities and Equity Promotion study section of the National Institutes of Health.

**Shakira Suglia**, MS, ScD is Associate Professor of Epidemiology at Emory University. Dr. Suglia's research takes a multi-disciplinary approach toward understanding health disparities, examining the impact of environmental exposures and social stressors on disease and health. She focuses in particular on the health of children and adolescents, and on their relation to social and environmental issues such as childhood adversity, violence, housing, and traffic exposures.

**Andrea Louise Falzon** is an Information Specialist at Columbia University Center for Behavioral and Cardiovascular Health. She has 18 years of experience in the area of health research and has specialized expertise in searching methods for systematic reviews and meta-analyses. For the past 10 years, Ms. Falzon has played an active role in the Cochrane Collaboration as a Trials Search Coordinator within the Behavioral Medicine Field, and she is currently coordinating a Cochrane Review for the Metabolic Endocrine Disorders Review Group.

**Irene Perez Ibarra**, PhD is a social ecologist by training. She is Associate Research Scientist at Columbia University School of Social Work and coordinator of the Sleep, Mind, and Health research program. She has substantial experience in project management and the conduct of systematic reviews and qualitative research.

**Talhah Alvi**, BA is an MS student in the Clinical Psychology program at Teachers College, Columbia University. He is interested in cultural and neuropsychological aspects of mental illness.

**Elliot McCullough**, BA is a joint MSW and MPH student at Columbia University. He is interested in social determinants of health.

### **Advisory Board**

**Margarita Alegría**, PhD is Chief of the Disparities Research Unit at Massachusetts General Hospital and Professor in the Department of Psychiatry at Harvard Medical School. Dr. Alegría is currently the principal investigator of four National Institutes of Health-funded research studies: the International Latino Research Partnership; Effects of Social Context, Culture, and Minority Status on Depression and Anxiety; Building Community Capacity for Disability Prevention for Minority Elders; and Mechanisms Underlying Racial/Ethnic Disparities in Mental Disorders. She is also the PI of a Patient-Centered Outcomes Research Institute project: Effectiveness of DECIDE in Patient-Provider Communication, Therapeutic Alliance, & Care Continuation. Dr. Alegría has published over 200 papers, editorials, intervention training manuals, and book chapters on topics such as improving healthcare service delivery for diverse racial and ethnic populations; conceptual and methodological issues with multicultural populations; and bringing community perspectives into the design and implementation of health services.

**Dolores Acevedo-Garcia**, PhD is Samuel F. and Rose B. Gingold Professor of Human Development and Social Policy, and Director of the Institute for Child, Youth and Family Policy at the Heller School for Social Policy and Management, Brandeis University. Her research focuses on the social determinants (e.g. residential segregation, immigrant adaptation) of racial/ethnic inequities in health; the role of social policies (e.g. housing policies, immigrant policies) in reducing those inequities; and the health and well-being of children with special needs. She received her B.A. in public administration from El Colegio de Mexico (Mexico City), and her MPA-URP and Ph.D. in Public Policy with a concentration in Demography from the Woodrow Wilson School of Public and International Affairs at Princeton University. She is Project Director for [www.fordiversitydatakids.org](http://www.fordiversitydatakids.org), a comprehensive database of indicators on child well-being and opportunity by race/ethnicity across multiple sectors (e.g., education, health, neighborhoods) and geographies, funded by the Robert Wood Johnson Foundation and the W.K. Kellogg Foundation.

**Larissa Avilés-Santa**, MD, MPH joined the National Heart, Lung, and Blood Institute (NHLBI) in 2006. She is an expert on the study and prevention of diabetes and cardiovascular disease in underserved populations, particularly among Hispanic communities. Dr. Avilés-Santa is currently Project Director for the Hispanic Community Health Study: Study of Latinos (HCHS-SOL), which was initiated on October 1, 2006. HCHS-SOL is the largest study to date to examine the prevalence of common heart disease risk factors—high blood pressure, high cholesterol, obesity, diabetes, and smoking—within a diverse Hispanic/Latino population. HCHS-SOL has enrolled over 16,000 adults of different backgrounds, including Cuban, Dominican, Mexican, Puerto Rican, Central American, and South American. Dr. Avilés-Santa received her MD from the University of Puerto Rico, School of Medicine. She then completed her residency training in internal medicine at the University Hospital in San Juan. She pursued subspecialty training in endocrinology, diabetes, and metabolism at the University of Texas Southwestern Medical Center at Dallas. After finishing her fellowship, Dr. Avilés-Santa joined the faculty of the Endocrine Division at UT Southwestern, during which time she also earned an

MPH at the University of Texas School of Public Health. She is board certified in internal medicine and endocrinology.

Final Draft

## **EXECUTIVE SUMMARY**

Latina/os are heterogeneous, originating from over 25 countries in the Caribbean and Central and South America (Borrell & Crawford, 2009). Each ethnic group has a unique sociopolitical history, as well as different demographic, socioeconomic, acculturation, and settlement patterns that contribute to ethnic variations in initial health outcomes and health trajectories over time (Daviglius et al., 2012; Portes & Rumbaut, 2014; Villarruel et al., 2009). Despite the substantial heterogeneity, Latina/os are often treated as a monolithic group in national and state surveillance health surveys. As such, only aggregated health information—that is, information for all Latina/os—is collected, thereby obscuring the identification of significant within-group differences in health. In this report, the disaggregation of health data is defined as separating data from surveillance health surveys on U.S. Latina/os into subgroups, including: racial, ethnic (culture of origin), nativity, acculturation (language use), gender, age, and/or socioeconomic status (education, employment, income).

The primary aim of this project was to identify barriers and facilitators that either prevent or promote collection of disaggregated surveillance health data on U.S. Latina/os. A secondary aim was to review exemplars of disaggregated surveillance health surveys to identify promising measures, approaches, and techniques. A systematic literature review and 12 qualitative interviews with key stakeholders (e.g., nationally recognized Latina/o health researchers, local representatives from departments of health and mental health, and representatives of national organizations) were conducted to achieve these aims.

### **Summary of Results from Systematic Review**

Overall, only 9.7% of articles published between 2006 and 2016 on Latina/o child and adult surveillance health provided disaggregated health estimates, and the mean number of articles published during this 10 year period was also quite low at 15.9 (SD=6.3). In addition, a disproportionate amount of this scholarship focused on adults, resulting in significant gaps in knowledge concerning Latina/o child health data disaggregation. We identified the use of 22 different types of data disaggregation categories among published studies during this period.

While the most commonly used disaggregation types did not differ substantially across the lifecourse and included mostly demographic factors (age, gender, economic indicators, nativity status), a higher number of child health studies published during the period provided disaggregated health estimates by acculturation status. A limited number of the included studies (8.3%) used established instruments to capture sources of heterogeneity in the Latino/a community. These results suggest the need for programmatic initiatives to promote Latina/o health data disaggregation in research design, data collection, and measurement, as well as in manuscript reporting and publication.

### **Summary of Results from Stakeholder Interviews**

Stakeholders identified a series of barriers to the disaggregation of Latina/o health data. These included sample sizes too small to conduct precise analyses; lack of resources, funding, training and cultural competence to support the collection of such health data in the Latina/o community; concerns regarding the validity of measures to capture disaggregated data across multiple domains; and lack of a strong economic argument for the collection and use of disaggregated data.

Stakeholders also identified a series of facilitators to address these barriers, including creating standards and guidelines for collecting disaggregated measures relevant to the U.S. Latina/o population; promoting an immigration and ethnicity lens to inform this area of research; targeting funding to collect high-quality disaggregated health data; developing marketing campaigns to



articulate the value and significance of this work; investing in mentoring and training programs to expand Latina/o health research; promoting disaggregation through legislation; making disaggregated data publicly available; and conducting mixed-methods research to advance the science of health data disaggregation.

## **Recommendations**

The key findings from the systematic review and the stakeholder interviews generated 15 recommendations to advance Latina/o health data disaggregation across research, funding, policy, and priority area domains.

## **Research**

*Recommendation #1:* Develop clear guidelines for ethnic health data disaggregation and a standardized set of survey items that reflect the disaggregation types most relevant to the Latina/o community.

*Recommendation #2:* Move beyond the inclusion of demographic factors and include other important social determinants of health—among them race, country of origin, place-based factors, English language proficiency, discrimination, and acculturation.

*Recommendation #3:* Use an intersectional lens in the design, collection, and analysis of disaggregated health data that considers the intersections of migration, ethnicity, and social conditions.

*Recommendation #4:* Mandate the collection of Latina/o ancestry (country of origin), generational status, duration of residence in the United States, and language proficiency data in all publicly funded surveys.

*Recommendation #5:* Conduct mixed-methods research to develop reliable, valid, and culturally equivalent instruments across Latina/o ancestry/heritage groups.

*Recommendation #6:* Develop a free and accessible repository of reliable and valid measures and survey items that capture essential disaggregation characteristics pertinent to the Latina/o community.

*Recommendation #7:* Address potential roadblocks to publication by developing special issues in top-tier journals that focus on this topic.

*Recommendation #8:* Educate journal editors and reviewers to reduce publication bias and to highlight the importance of this topic. Review committees for the National Institutes of Health (NIH) and the National Science Foundation (NSF), and other funding agencies should also include reviewers with research expertise in Latina/o health across the lifecourse.

## **Funding**

*Recommendation #9:* Invest in research training and mentoring programs at all stages of career development (e.g., high school, undergraduate, graduate, post-doctoral, junior faculty, mid-career) to support careers in Latina/o health research across the lifecourse.

*Recommendation #10:* Develop targeted funding announcements and opportunities to support the collection and analysis of disaggregated health data across the lifecourse. For example, the National Institutes of Health could develop a supplementary funding award to cover research

expenses (e.g., translation and validation of measures) beyond the \$500,000 funding cap for R01 grants that focus on Latina/o health.

### **Policy**

*Recommendation #11:* Develop a strong economic and scientific argument for Latina/o health data disaggregation that can be disseminated across sectors to promote Latina/o health data disaggregation. Examples of disseminable materials include policy briefs, white papers, letters to editors, etc.

*Recommendation #12:* Engage key stakeholders from multiple sectors—including government agencies, private foundations, non-governmental agencies, and businesses—to prioritize Latina/o health and develop a concerted marketing campaign on Latina/o health prevention and treatment across the lifecourse.

*Recommendation #13:* Develop a set of decision tools to help stakeholders determine when, how, and on what to disaggregate across the lifecourse.

### **Priority Areas**

*Recommendation #14:* Create flexible and adaptable data-collection systems that can be easily changed to capture important disaggregation characteristics aligned with the dynamic and changing demography of the U.S. Latina/o population.

*Recommendation #15:* Support the inclusion of critical dimensions shaping the Latina/o population that go beyond demographic disaggregation characteristics and include language use, parental ancestry, generational status, racial identity, and documentation status.

## INTRODUCTION

Latina/os are the largest racial/ethnic minority group in the United States, representing 16.3% of the U.S. population (Ennis, Rios-Vargas, & Albert, 2011), and one of the most heterogeneous U.S. populations. By 2050, one in every four people living in the U.S. will be of Latina/o descent (Humes, Jones, & Ramirez, 2011; Passel & Cohn, 2008). In the aggregate, the disproportionate distribution of poverty, language barriers, and discrimination, as well as lack of health insurance and access to quality health care, places Latina/os relative to non-Latino Whites at elevated risk of morbidity and mortality (Dominguez et al., 2015).

However, morbidity and mortality patterns—particularly the prevalence of cardiovascular disease, related risk factors (e.g., obesity, hypertension, diabetes), asthma, and physiological profiles—differ by Latina/o nativity status, country of origin, and duration of residence in the United States (Daviglus et al., 2012; Dominguez et al., 2015; Kaestner, Pearson, Keene, & Geronimus, 2009). For example, in recently published research from the largest and most comprehensive study of Hispanic health conducted in the United States to date, the Hispanic Community Health Study/Study of Latinos, the unadjusted prevalence of self-reported coronary heart disease (CHD; 1.3 vs. 2.1) and stroke (0.7 vs. 1.8) was lower among foreign-born versus U.S.-born Latina/os (Daviglus et al., 2012).

In addition, there are differences in the prevalence of asthma depending on Latina/o country of origin (Lara, Akinbami, Flores, & Morgenstern, 2006; Ledogar, Penchaszadeh, Garden, & Iglesias, 2000; Pleis, Ward, & Lucas, 2010). According to data from the National Health Interview Survey, Puerto Ricans have the highest prevalence of asthma in the U.S. mainland (16%) compared to non-Latina/o Whites (7.7%) (Moorman et al., 2007). In contrast, Latina/os of Mexican origin have the lowest prevalence of asthma (5.4%), lower than the average prevalence rate among non-Latina/o Whites and Blacks (11.2%). Interestingly, Mexicans born in Mexico have a lower prevalence of asthma compared to Mexicans born in the United States, but the association is reversed among Puerto Ricans. Puerto Rican children living in Puerto Rico have a higher prevalence of asthma compared to those living in the United States (Cohen, Canino, Bird, & Celedon, 2008; Perez-Perdomo, Perez-Cardona, Disdier-Flores, & Cintron, 2003).

Physiological profiles also vary by important sociodemographic characteristics, these varying profiles may be important contributing factors to the differential distribution of morbidity and mortality observed across country of origin and sociodemographic groups. For example, physiological profiles of cumulative stress were found to vary by duration of U.S. residence, such that recently arrived Mexican immigrants aged 45–60 had lower allostatic load, measured with 10 biomeasures (systolic and diastolic blood pressure, BMI, glycated hemoglobin, albumin, creatinine clearance, triglycerides, C-reactive protein, homocysteine, and total cholesterol), than U.S.-born Mexican Americans, non-Latina/o Whites, and Blacks (Kaestner et al., 2009). This advantage disappeared over time, such that Mexican immigrants living in the United States for 20 years or longer had twice the likelihood of having high allostatic load as U.S.-born non-Latina/o Whites and equal probability as U.S.-born Mexican Americans and non-Latina/o Blacks (Kaestner et al., 2009). As such, nativity status, country of origin, and duration of residence in the United States emerge as unique and important contributors to disease risk among Latina/os.

Similarly, rates of psychiatric disorders, and the risk and protective factors that shape the development of psychopathology, vary by country-of-origin groups and acculturation factors such as nativity status and age of migration (Alcantara, Chen, & Alegria, 2014; Alegria et al., 2008; Cabassa, 2013). For instance, Puerto Ricans report significantly higher rates of common

psychiatric disorders (e.g., anxiety, substance use) when compared to other Latina/o groups in the United States (Alegría et al., 2008). Moreover, foreign nativity acts as a protective factor for most psychiatric disorders among Latina/os, but its impact varies by Latina/o subgroups and types of disorder. For example, foreign-born Mexican Americans reported significantly lower rates of any depressive, anxiety, and substance-use disorder than U.S.-born Mexican Americans and U.S.-born, non-Latina/o Whites (Grant et al., 2004). In contrast, foreign nativity among Puerto Ricans and Cubans was only protective for substance-use disorders (Alegría, Canino, Stinson, & Grant, 2006).

The diversity of the Latina/o community poses unique challenges for clinicians and policymakers. Understanding the sources of heterogeneity and their association with health will allow development and implementation of effective, culturally and linguistically appropriate, health services and policies optimally designed to reduce health disparities. Understanding within-group differences across the lifecourse (in, for example, cardiovascular disease, asthma, depression, and allostatic load) would elucidate, genetic, epigenetic, biological, and potential environmental pathways that protect some Latina/o groups from disease while exacerbating risk in others.

Our study was guided by a pathways model of health disparities. This model emphasizes the mediating factors linking distal factors (e.g., race/ethnicity) to proximal health outcomes, with the goal of identifying modifiable intervention targets (Diez Roux, 2012). We used this conceptual model as a guiding framework to address the following research questions.

### **Research Questions**

- How common is Latina/o health data disaggregation among contemporary published research on Latina/o child and adult health?
- To what extent do state/national surveillance health surveys capture and describe the heterogeneity of factors that shape Latina/o health and mental health across the lifecourse?
- What are commonly reported disaggregation characteristics?
- What proxy measures or validated instruments are used to report on Latina/o health? How are they used?
- What barriers and facilitators do stakeholders (e.g., researchers, national leaders) identify as affecting the collection and use of disaggregated Latina/o health data?
- What promising approaches or techniques to Latina/o health data disaggregation can be used in existing surveillance data sources or state-of-the-art population-level health surveys?

As such, this project aimed to identify barriers and review promising approaches to disaggregating surveillance health data on U.S. Latina/os. By disaggregation of health data, we mean separating data from surveillance health surveys on U.S. Latina/os into subgroups, including: racial, ethnic (culture of origin), nativity, acculturation (language use), gender, age, and/or socioeconomic status (education, employment, income). We conducted a systematic literature review and in-depth qualitative interviews with 12 key stakeholders to achieve this aim. The rationale, methods, and key results for each approach are described below, followed by a series of recommendations that emerged from this project.

## SYSTEMATIC LITERATURE REVIEW METHODS

### Rationale and Objectives

Demographic changes in the U.S. population correspond to the proliferation of published empirical research on Latina/o health, though the number of empirical articles focused on Latina/o health data disaggregation—that is, the identification and understanding of health differences within the Latina/o ethnic category—is unclear. To address this question, we conducted a comprehensive and systematic review of the scientific literature. Our primary objectives were to: (1) determine the proportion of literature that reported disaggregated Latina/o health data; (2) describe the most common disaggregation characteristics reported; (3) identify the extent to which validated instruments, indexes, or proxy measures were used to capture the social, economic, and cultural heterogeneity of the U.S. Latina/o population; and (4) review exemplars of disaggregated surveillance health surveys to identify promising measures, approaches, and techniques. This systematic review is registered as: PROSPERO 2016:CRD42016041879 (see Appendix A for the complete PROSPERO protocol). We followed the reporting guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Liberati et al., 2009).

### Selection Criteria and Search Strategy

We conducted a systematic literature review of peer-reviewed, English-language, empirical articles published between January 2006 and June 2016 that reported Latina/o child and adult health estimates derived from state/national surveillance health surveys based in the United States. Primary adult outcomes included: cancer, heart disease, stroke, unintentional injuries [accidents], diabetes mellitus, any depression, any anxiety disorders, and insomnia. Primary child outcomes included: asthma, obesity, attention deficit hyperactivity disorder (ADHD)/developmental disabilities, autism, depression, anxiety, and conduct disorder. The health conditions of primary interest represent the top five leading causes of death for Latina/o adults (Dominguez et al., 2015; Heron, 2013), and the most prevalent health or mental health conditions in children and adults. These disorders may have co-occurred with other health conditions.

Potentially relevant articles were identified by searching the biomedical electronic databases Ovid MEDLINE, EMBASE, PsycINFO, JSTOR, and Sociological Abstracts. Databases were searched from January 2006 to June 2016. All relevant subject headings and free-text terms were used to represent surveillance health data, Latina/o populations, and the health conditions under investigation. Terms were applied to limit results to observational studies and to populations sampled in the United States. Additional records were identified by scanning the reference lists of relevant studies and reviews, using the Similar Articles feature in PubMed and the Cited Reference Search in ISI Web of Science. Relevant study and registry websites were searched, in addition to other sources of grey literature. Searches were limited to articles published in English language. The full electronic search strategy can be found in Appendix B.

### Data Extraction

We used a two-stage process for data extraction. First, four review authors (EPM, IP, TA, LF) independently scanned the abstract or title or both of every record retrieved, to determine which passed the initial screen. After the initial screen, full articles were retrieved for further assessment if the information given suggested that the study (1) included child or adult participants who self-identified as Hispanic/Latina/o; (2) reported information on primary health and mental health outcomes; (3) used state or national surveillance health data; and (4) reported disaggregated health outcomes. Herein, we defined *disaggregation* as separating data from surveillance health surveys on U.S. Latinas/os into subgroups, including: racial, ethnic

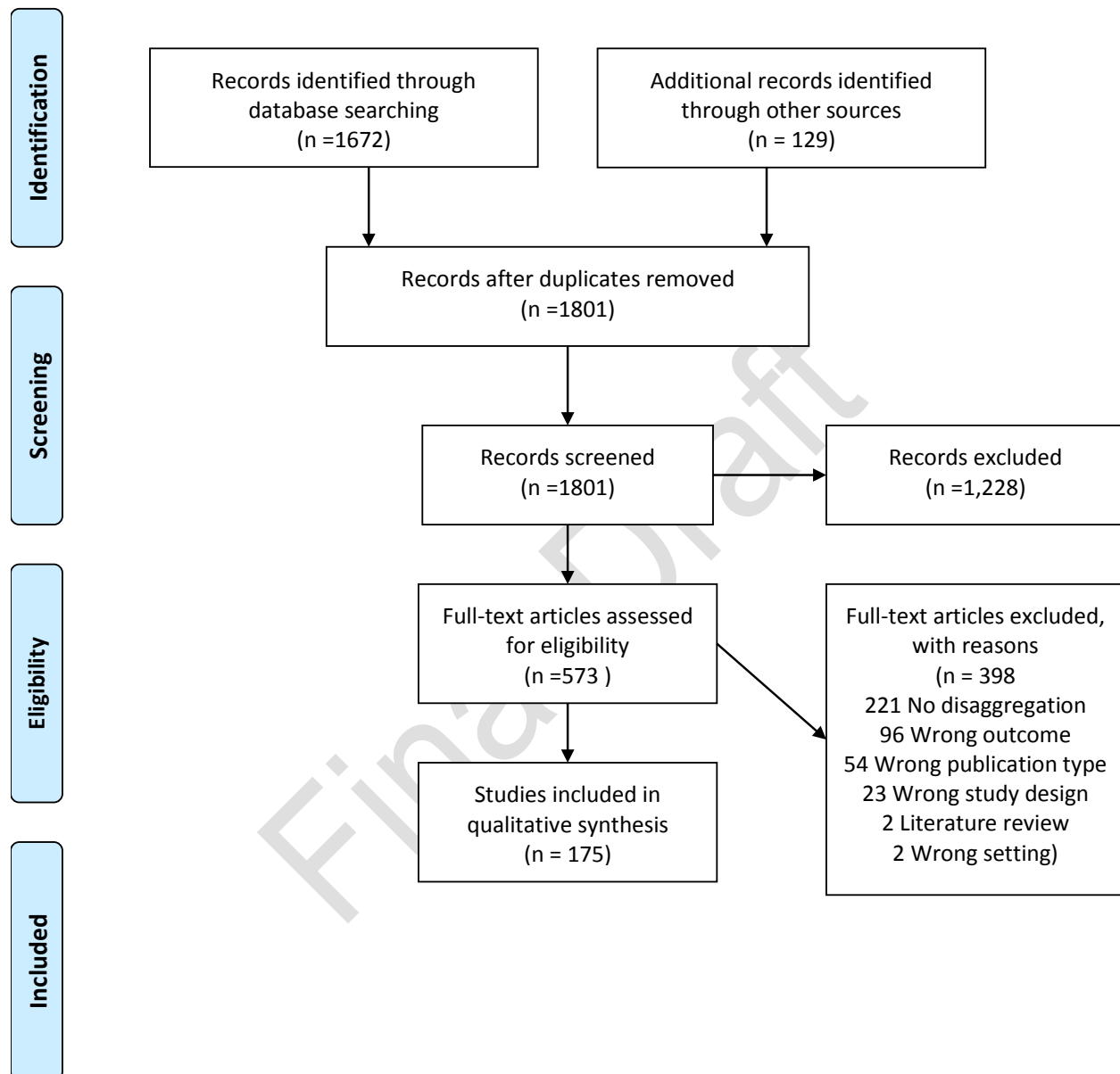
(culture of origin), nativity status, acculturation (e.g., language use), gender, age, and socioeconomic status (education, employment, income). If, after reading the title and abstract, review authors had any doubt about whether these criteria were met, the full article was retrieved for clarification. For studies that met the inclusion criteria, three review authors (EPM, IP, TA) independently abstracted key study and disaggregation characteristics. Study characteristics included total sample size; Latina/o sample size; percentage female; percentage Black; percentage foreign born; name of surveillance health survey; specified outcomes; type of disaggregation characteristic (age, gender, race, education, marital status, economic indicators, health insurance, assets, ethnicity, duration of residence in the United States, acculturation, documentation status, reasons for immigration, generational status, ethnic identity, rural/urban, neighborhood characteristics, region of the country, discrimination, social support, food security); whether a proxy measure, index, or validated instrument was used to measure the disaggregation characteristic; and whether disaggregation was presented in the descriptive statistics, the main analyses, or both. All discrepancies were resolved through consensus or recourse to a third review by two additional review authors (CA, LJC).

## **SYSTEMATIC LITERATURE REVIEW RESULTS**

### **Study Selection**

Overall, 1,801 unique records were identified and screened (**Figure 1**). The original search yielded 1,672 records, identified through database searching, and an additional 129 records, identified through other sources (e.g., grey literature). A total 1,228 records were excluded after the initial screen if the record did not focus on self-identified Latina/o children or adults, did not include the primary outcomes of interest, and did not use state or national surveillance health data: 573 full-text articles were then assessed for eligibility; of these, 398 full-text articles were then excluded. Reasons for exclusion included: did not report a disaggregated outcome, wrong outcome, wrong design (e.g., randomized controlled trial), wrong participant population, wrong setting (not U.S. mainland, Puerto Rico, or U.S. territories), wrong language (i.e., not English), and not empirical (i.e., literature reviews). This resulted in a total of 175 articles that met inclusion criteria and were included in the final qualitative synthesis (see Appendix C for a list of included studies). As such, 9.7% of the unique records retrieved reported disaggregated Latina/o health data (**Figure 1**).

**Figure 1.** PRISMA flow diagram.



### Study Characteristics

Of the 175 included studies, 76.0% focused on adult health, 21.1% focused on child health, and 2.9% provided estimates for both child and adult health (**Table 1**). Sample size characteristics were provided for 175 studies. The mean total sample size was 573,680.1 (SE=5,177,729.0), and the mean Latina/o sample size was 14,435.5 (SE=50,551.1). The mean percentage of participants who are female was 54.4%, and the mean percentage of participants who are Black was 15.8%. Only 24% of studies reviewed included foreign-born participants. Of studies that

included foreign-born participants, the mean percentage of the total sample that was foreign-born was 33.0% (SE=27.3).

Among the included studies, cancer was the most common outcome (n=70; 40.0%), followed by diabetes mellitus (n=39; 22.3%), obesity (n=29; 16.6%), depression (n=25; 14.3%), anxiety (n=17; 9.7%), heart disease (n=12; 6.9%), autism (n=5; 2.9%), asthma (n=4; 2.3%), unintentional injuries (n=4; 2.3%), ADHD/developmental disabilities (n=3; 1.7%), and insomnia (n=2; 1.1%). We retrieved results from 45 different surveillance health surveys (see full list in Appendix D). The five most-used surveillance health surveys included: National Health and Nutrition Examination Survey (NHANES) (n=35; 20.0%); Surveillance, Epidemiology, and End Results Program (SEER) (n=28; 16.0%); California Cancer Registry (CCR) (n=19, 10.9%), National Health Interview Survey (NHIS) (n=13, 7.4%); and National Survey of Children's Health (NSCH) (n=12, 6.9%).

**Table 1.** Characteristics of the included studies (N=175).

	N	N	%	Mean	SE
<b>Total N</b>	175*	-	-	573,680.1	5,177,729.0
<b>Latino N</b>	165*	-	-	14435.5	50551.1
<b>Population</b>	175				
Adult		133	76.0	-	-
Children		37	21.1	-	-
Both		5	2.9	-	-
<b>Setting</b>	175				
U.S. mainland		173	98.9		
Puerto Rico		2	1.1		
Other U.S. territories		0	0.0		
<b>% Female</b>	126*	-	-	54.4	23.2
<b>% Black</b>	86*	-	-	15.8	13.8
<b>% Foreign-born</b>	42*	-	-	33.0	27.3
<b>Outcomes</b>	175				
ADHD/developmental disability		3	1.7	-	-
Anxiety <sup>a</sup>		17	9.7	-	-
Asthma		4	2.3	-	-
Autism		5	2.9	-	-
Cancer <sup>b</sup>		70	40.0	-	-
Comorbidity <sup>c</sup>		1	1.4	-	-
Incidence		35	50.0	-	-
Mortality		12	17.1	-	-
Prevalence		1	1.4	-	-
Risk		2	2.9	-	-
Stage		2	2.9	-	-
Survival		24	34.3	-	-



	N	N	%	Mean	SE
Type		2	2.9	-	-
Conduct disorder		1	0.6	-	-
Depression <sup>d</sup>		25	14.3	-	-
Diabetes mellitus		39	22.3	-	-
Heart disease		12	6.9	-	-
Insomnia		2	1.1	-	-
Obesity		29	16.6	-	-
Unintentional injuries		4	2.3	-	-
<b>Surveillance Health Surveys</b>					
<b>(n = 45)</b>	175				
ACS		1	0.6	-	-
ADDSP		1	0.6	-	-
BPR		1	0.6	-	-
BRFSS		5	2.9	-	-
CCR		19	10.9	-	-
CHIS		6	3.4	-	-
CINA		2	1.1	-	-
CPES		3	1.7	-	-
ECLS		1	0.6	-	-
FCDS		2	1.1	-	-
HCHS/SOL <sup>e</sup>		17	9.9	-	-
HHANES		2	1.1	-	-
ICPSR		1	0.6	-	-
L.A.FANS		1	0.6	-	-
LAMHA		1	0.6	-	-
MD		1	0.6	-	-
MNCS		1	0.6	-	-
NAACCR		7	4	-	-
NABC		1	0.6	-	-
NCDB		2	1.1	-	-
NCI		1	0.6	-	-
NCSR		4	2.3	-	-
NESARC		2	1.1	-	-
NHANES		35	20	-	-
NHIS		13	7.4	-	-
NLAAS		7	4	-	-
NLMS		1	0.6	-	-
NLSAH		1	0.6	-	-
NLSY		4	2.3	-	-
NNDSS		1	0.6	-	-
NPCR		2	1.1	-	-
NSAL		2	1.1	-	-

	N	N	%	Mean	SE
NSCH		12	6.9	-	-
NS-CSHCN		1	0.6	-	-
NSDUH		1	0.6	-	-
NVSS		1	0.6	-	-
NYCDOHMH		1	0.6	-	-
NYSR		1	0.6	-	-
PRAMS		1	0.6	-	-
SABE		1	0.6	-	-
SEER		28	16	-	-
TCR		4	2.3	-	-
UFW		1	0.6	-	-
USC		1	0.6	-	-
YRBS		1	0.6	-	-

Note: See Appendix D for the names of the surveillance health surveys.

\* Not all articles provided information on extracted variables; as such Ns may not total 175.

<sup>a</sup>Anxiety includes all DSM-IV anxiety disorders and anxiety risk.

<sup>b</sup>Cancer includes the following cancer sites/types: Bladder, brain and other nervous system, breast, bronchus, cervical, cervix, colon, colorectum, corpus uterus, endometrial cancer, esophagus, gastric adenocarcinoma, gastric cancer, gynecologic, head and neck, hematologic, hepatocellular carcinoma, hodgkin's disease, kidney, larynx, leukemia, liver, lung, lymphoma, melanoma, myelogenous leukemia, myeloma, non-hodgkin's lymphoma, oral cavity, oropharynx, ovary, pancreas, pharynx, prostate, rare cancers, rectum, renal pelvis, skin melanoma, small-bowel cancer, soft tissue, stomach, testis, thyroid, upper-tract urothelial, urinary bladder, uterine cervix, uterine corpus, uterus, vagina, and vulva.

<sup>c</sup>Comorbidity refers to a diagnosis of cancer and one of the following conditions: hypertension, heart disease, asthma, or diabetes.

<sup>d</sup>Depression includes major depressive disorder, depressive symptoms, and postpartum depression.

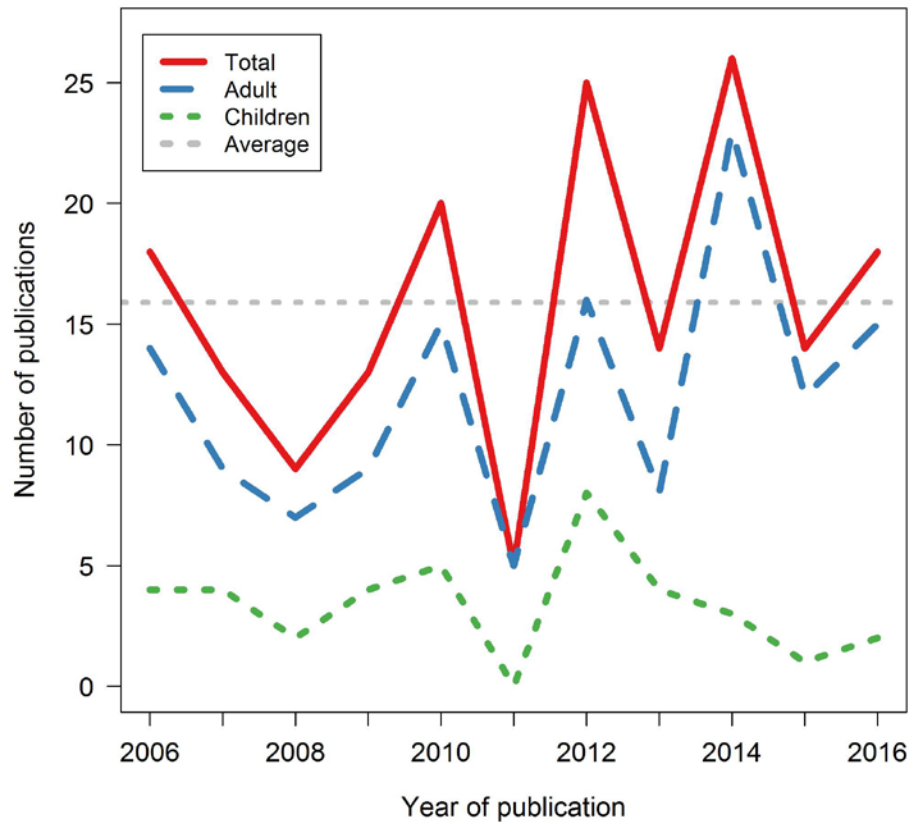
<sup>e</sup>HCHS/SOL includes HCHS/SOL, HCHS/SOL Sociocultural Ancillary Study, and HCHS/SOL Youth.

### Publication Trends over Time

The number of articles per year of publication that provided disaggregated Latina/o health data varied across the 2006 to 2016 time period (**Figure 2**). Overall, the mean number of articles published per year was 15.9 (SD=6.3). The greatest number of papers (n=26) on Latina/o health data disaggregation were published in 2014. In contrast, the fewest number of papers (n=5) on Latina/o health data disaggregation were published in 2011.

Publication trends over the 10-year period differed across the lifecourse. For example, in 2012 the greatest number of articles were published on disaggregated Latina/o child health data (n=8), whereas in 2011 the fewest number of articles were published on disaggregated Latina/o child (n=0) and adult health estimates (n=5). Similarly, in 2014 there was an uptick in the total number of Latina/o adult articles published, but that increase was not observed in Latina/o child data disaggregation literature. In 2014, in fact, only three articles were published. The mean number of articles published per year on Latina/o adult health data disaggregation was 12.1 (SD=5.2), and the mean number on Latina/o child health data disaggregation was 3.7 (SD=1.9). The number of publications reached a nadir in 2011 with only five published for both adult and child literature.

**Figure 2.** Number of articles published per year of publication from 2006-2016 (N=175).

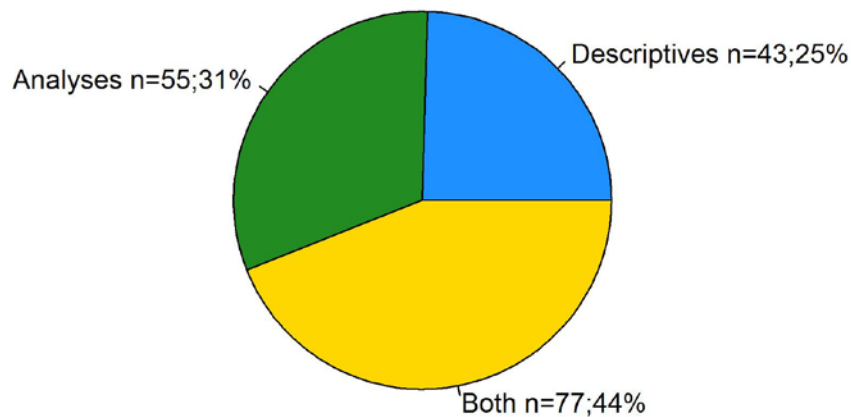


Note: Grey line shows the mean number of publications. Total: mean = 15.9; sd = 6.3; Adult: mean = 12.1 ; sd = 5.2; Children: mean = 3.7; sd = 1.9.

### Disaggregation Use, Characteristics, and Types

The majority of studies provided disaggregated health estimates in both descriptive results and analytic models (n=77; 44.0%) (**Figure 3**). Only 43 studies (25.0%) provided unadjusted disaggregated health estimates (prevalence, etc.) in descriptive results, and 55 studies (31.0%) provided adjusted disaggregated health estimates in the analytic models.

**Figure 3.** Use of disaggregation in the included studies (N=175).



In the final set of studies, 22 different types of disaggregation characteristics were identified (**Table 2**). Gender was the most common disaggregation characteristic (n=108, 22.5%). It was followed by age (n=73, 15.2%); nativity status (n=46, 9.6%); economic indicators such as income, poverty level (above/below), income to poverty ratio, and receipt of welfare (n=39, 8.1%); ethnicity (n=36, 7.5%); education (n=31, 6.5%); acculturation (n=25, 5.2%); marital status (n=21, 4.4%); duration of residence in the United States (n=20, 4.2%); and neighborhood characteristics such as ethnic density, ethnic enclave, neighborhood safety, neighborhood socioeconomic status, poverty census track, and neighborhood disadvantage (n=19; 4.0%). Disaggregated health estimates by health insurance, race, region of country, generational status, employment status, rural/urban, discrimination, documentation status, social support, ethnic identity, food security, and reasons for immigration were the least common, occurring in less than 3% of the included studies (**Table 2**).

By and large, distribution of the five most common disaggregation characteristics in included studies was identical across the lifecourse. They included age, gender, economic indicators, and nativity status. However, a slight variation was observed by age. Acculturation (n=8, 10.4%) was the fourth most commonly reported disaggregation characteristic among studies on Latina/o child health data, and ethnicity (n=31, 8.0%) was the fifth most commonly reported disaggregation characteristic among studies on Latina/o adult health data.

### Measures

The overwhelming majority of disaggregation types was assessed using proxy measures (91.7%) (**Table 2**). Indeed, only 8.3% of included studies used a validated instrument or index to measure the disaggregation characteristic. The only disaggregation types measured with a validated instrument or index in order of highest to lowest percentage used were: neighborhood characteristics (35.0%), economic indicators (27.5%), acculturation (27.5%), rural/urban region (2.5%), discrimination (2.5%), ethnic identity (2.5%), and food security (2.5%). Regardless of assessment method, structural and psychosocial exposures such as discrimination and social support were among the least commonly assessed disaggregation characteristics, (less than 2%).

### Publication Trends in Disaggregation Types

We explored publication trends in the most commonly reported disaggregation types in included studies (publication of more than 20 papers over the 2006–2016 period) (**Figure 4**). Over the 10-year period, gender, socioeconomic status, ethnicity, and nativity status were consistently the most commonly assessed disaggregation types. There was minimal variation in the percentage of studies that reported disaggregated estimates for each of these types over time.

### Disaggregation Priority Areas by Surveillance Health Survey

We also examined the extent to which the included articles presented disaggregated health estimates on priority disaggregation characteristics, namely acculturation, ethnicity, generational status, and nativity status by surveillance health survey (see Appendix E). At least 10% of the included studies in each of the aforementioned disaggregation characteristics came from the following surveillance health surveys: CCR, CHIS, HCHS/SOL, LAFANS, NCSR, NHANES, NHIS, NLAAS, NSCH, and SEER.

**Table 2.** Characteristics of the disaggregation\* types in the total included studies (adult and child) (N=175).

Disaggregation type	Total n = 480 <sup>+</sup>		Proxy n = 440 <sup>+</sup>		Instrument n = 40 <sup>+</sup>	
	N	%	n	%	n	%
Gender	108	22.5	108	24.5	0	0.0
Age	73	15.2	73	16.6	0	0.0
Nativity status	46	9.6	46	10.5	0	0.0
Economic indicators <sup>a</sup>	39	8.1	28	6.4	11	27.5
Ethnicity	36	7.5	36	8.2	0	0.0
Education <sup>b</sup>	31	6.5	31	7.0	0	0.0
Acculturation <sup>c</sup>	25	5.2	14	3.2	11	27.5
Marital status <sup>d</sup>	21	4.4	21	4.8	0	0.0
Duration in U.S.	20	4.2	20	4.5	0	0.0
Neighborhood characteristics <sup>e</sup>	19	4.0	5	1.1	14	35.0
Health insurance	13	2.7	13	3.0	0	0.0
Race	9	1.9	9	2.0	0	0.0
Region of the country	9	1.9	9	2.0	0	0.0
Generational status	6	1.3	6	1.4	0	0.0
Employment	5	1.0	5	1.1	0	0.0
Rural/Urban	5	1.0	4	0.9	1	2.5
Discrimination	4	0.8	3	0.7	1	2.5
Documentation status	4	0.8	4	0.9	0	0.0
Social support <sup>f</sup>	3	0.6	3	0.7	0	0.0
Ethnic identity	2	0.4	1	0.2	1	2.5
Food security	1	0.2	0	0.0	1	2.5
Reason for immigration	1	0.2	1	0.2	0	0.0

\*The definition of disaggregation is to separate data from surveillance health surveys on U.S. Latina/os into subgroups, including: racial, ethnic, nativity status, acculturation, gender, age, and socioeconomic status.

\*Note that studies may have examined more than one disaggregation type.

<sup>a</sup>Economic indicators include income, poverty level (above/below), income-to-poverty ratio, welfare.

<sup>b</sup>Education includes education and parental education.

<sup>c</sup>Acculturation includes acculturation and language (preference, proficiency).

<sup>d</sup>Marital status includes marital status and parents' marital status.

<sup>e</sup>Neighborhood characteristics include ethnic density, ethnic enclave, neighborhood safety, neighborhood SES, poverty census track, and neighborhood disadvantage.

<sup>f</sup>Social support includes family and friend support, family cohesion, negative family interaction, support at home or school, and relationship.

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**Table 3.** Characteristics of disaggregation\* types in the included studies focused on adults (n=133).

Disaggregation type	Total n = 388 <sup>+</sup>		Proxy n = 358 <sup>+</sup>		Instrument n = 30 <sup>+</sup>	
	n	%	n	%	n	%
Gender	80	20.6	80	22.3	0	0.0
Age	58	14.9	58	16.2	0	0.0
Nativity status	38	9.8	38	10.6	0	0.0
Ethnicity	31	8.0	31	8.7	0	0.0
Economic indicators <sup>a</sup>	28	7.2	23	6.4	5	16.7
Education <sup>b</sup>	28	7.2	28	7.8	0	0.0
Marital status	20	5.2	20	5.6	0	0.0
Duration in U.S.	19	4.9	19	5.3	0	0.0
Acculturation <sup>c</sup>	17	4.4	8	2.2	9	30.0
Neighborhood characteristics <sup>d</sup>	17	4.4	4	1.1	13	43.3
Health insurance	11	2.8	11	3.1	0	0.0
Region of the country	9	2.3	9	2.5	0	0.0
Race	7	1.8	7	2.0	0	0.0
Employment	5	1.3	5	1.4	0	0.0
Discrimination	4	1.0	3	0.8	1	3.3
Generational status	4	1.0	4	1.1	0	0.0
Rural/Urban	4	1.0	3	0.8	1	3.3
Documentation status	3	0.8	3	0.8	0	0.0
Ethnic identity	2	0.5	1	0.3	1	3.3
Social support <sup>e</sup>	2	0.5	2	0.6	0	0.0
Reason for immigration	1	0.3	1	0.3	0	0.0
Food security	0	0.0	0	0.0	0	0.0

\*The definition of disaggregation is to separate data from surveillance health surveys on U.S. Latina/os into subgroups, including: racial, ethnic, nativity status, acculturation, gender, age, and socioeconomic status.

\*Note that studies may have examined more than one disaggregation type.

<sup>a</sup>Education includes education and parental education.

<sup>b</sup>Economic indicators include income, poverty level (above/below), income-to-poverty ratio, welfare.

<sup>c</sup>Acculturation includes acculturation and language (preference, proficiency).

<sup>d</sup>Neighborhood characteristics include ethnic density, ethnic enclave, neighborhood safety, neighborhood SES, poverty census track, and neighborhood disadvantage.

<sup>e</sup>Social support includes family and friend support, family cohesion, negative family interaction, support at home or school, and relationship.

**Table 4.** Characteristics of the disaggregation\* types in the included studies focused on children (n=37).

Disaggregation type	Total n = 77 <sup>+</sup>		Proxy n = 67 <sup>+</sup>		Instrument n = 10 <sup>+</sup>	
	n	%	n	%	n	%
Gender	24	31.2	24	35.8	0	0.0
Age	11	14.3	11	16.4	0	0.0
Economic indicators <sup>a</sup>	11	14.3	5	7.5	6	60.0
Acculturation <sup>b</sup>	8	10.4	6	9.0	2	20.0
Nativity status	5	6.5	5	7.5	0	0.0
Education <sup>c</sup>	3	3.9	3	4.5	0	0.0
Ethnicity	3	3.9	3	4.5	0	0.0
Health insurance	2	2.6	2	3.0	0	0.0
Neighborhood characteristics <sup>d</sup>	2	2.6	1	1.5	1	10.0
Race	2	2.6	2	3.0	0	0.0
Documentation status	1	1.3	1	1.5	0	0.0
Duration in U.S.	1	1.3	1	1.5	0	0.0
Food security	1	1.3	0	0.0	1	10.0
Generational status	1	1.3	1	1.5	0	0.0
Marital status <sup>e</sup>	1	1.3	1	1.5	0	0.0
Social support <sup>f</sup>	1	1.3	1	1.5	0	0.0
Discrimination	0	0.0	0	0.0	0	0.0
Employment	0	0.0	0	0.0	0	0.0
Ethnic identity	0	0.0	0	0.0	0	0.0
Reason for immigration	0	0.0	0	0.0	0	0.0
Region of the country	0	0.0	0	0.0	0	0.0
Rural/Urban	0	0.0	0	0.0	0	0.0

\*The definition of disaggregation is to separate data from surveillance health surveys on U.S. Latina/os into subgroups, including: racial, ethnic, nativity status, acculturation, gender, age, and socioeconomic status.

\*Note that studies can examine more than one disaggregation type.

<sup>a</sup>Economic indicators include income, poverty level (above/below), income-to-poverty ratio, welfare.

<sup>b</sup>Acculturation includes acculturation and language (preference, proficiency).

<sup>c</sup>Education includes education and parental education.

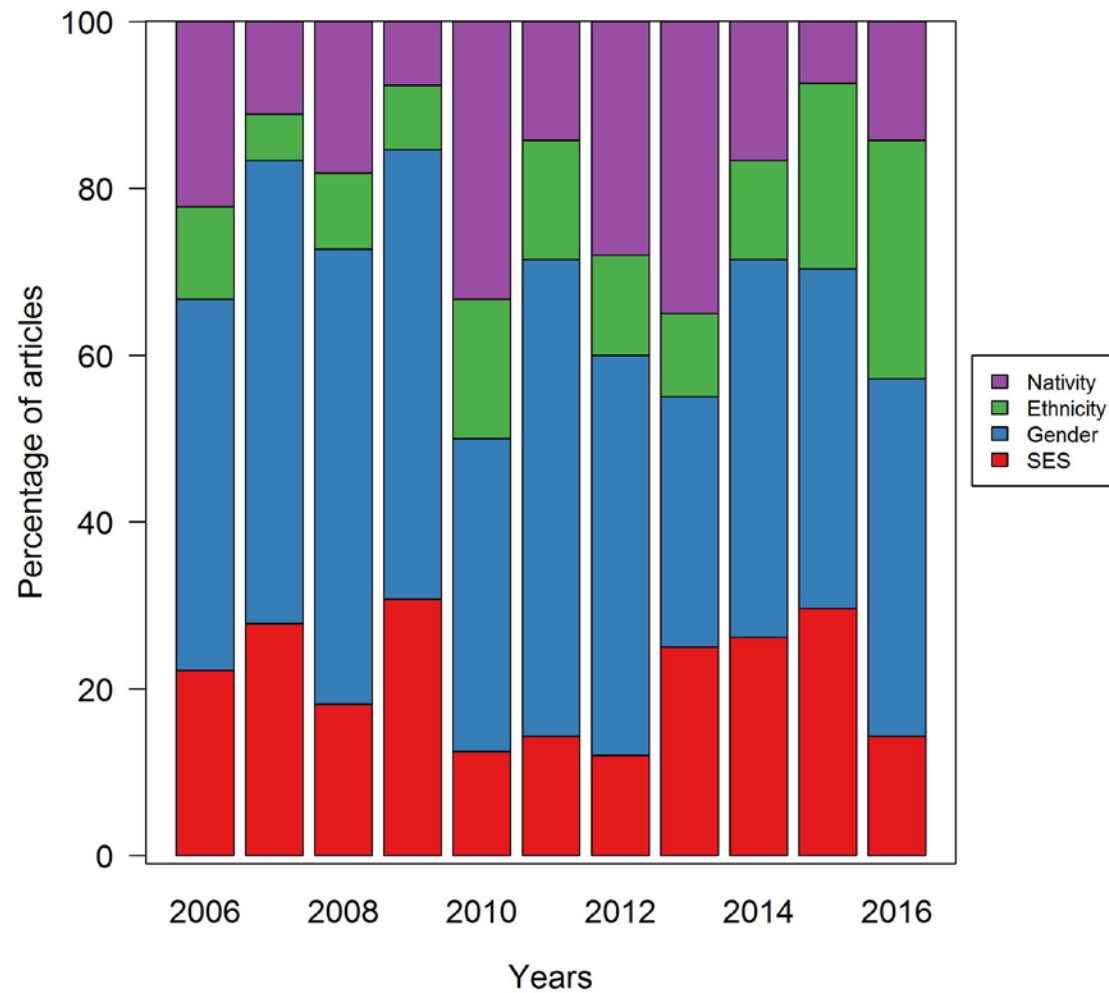
<sup>d</sup>Neighborhood characteristics include ethnic density, ethnic enclave, neighborhood safety, neighborhood SES, poverty census track, and neighborhood disadvantage.

<sup>e</sup>Marital status refers to parents' marital status.

<sup>f</sup>Social support includes family and friend support, family cohesion, negative family interaction, support at home or school, and relationship.



**Figure 4.** Percentage of articles including different disaggregation types per year of publication.



Note: SES refers to socioeconomic status and includes the disaggregation types education and economic indicators.

## EXEMPLARS OF LATINA/O HEALTH DATA DISAGGREGATION

In this section, we describe two existing surveillance data sources and two state-of-the-art population-level health surveys to illustrate exemplars of Latina/o health data disaggregation across the lifecourse. For each study (three focused on the adult population, one focused on the child population), we summarize design, measures, and Latina/o sample characteristics, and briefly discuss findings that illustrate the scientific value of and contributions made by examining disaggregation in Latina/o health data across the lifecourse. In each case, examination of Latina/o health data disaggregation reveals marked within-group differences in cancer survival, depression (and other psychiatric disorders), cardiovascular disease, and asthma profiles.

### Exemplars of Existing Data Sources

#### *California Cancer Registry*

The California Cancer Registry (CCR) is a statewide population-based cancer surveillance system that participates in the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program. CCR includes more than 99% of all invasive cancers diagnosed in the state of California. To date, CCR has collected detailed information on more than 7 million cases of cancer among Californians diagnosed since 1988; more than 175,000 new cases are added annually (<http://www.ccrca.org/index.shtml>). It collects a variety of data from patient medical records, including patient characteristics at the time of diagnosis (age, sex, race, ethnicity, residence) and tumor characteristics (disease severity, tumor characteristics, and first course of treatment).

The CCR is also linked with state and national databases, and routinely obtains vital-status and causes-of-death updates. Hispanic ethnicity is collected from medical records and uses additional information such as race and ethnicity of parents, maiden name, surname, birthplace, or death records to determine Hispanic ethnicity. In some instances, the North American Association of Central Cancer Registries' Hispanic Identification Algorithm is used to improve classification of Latina/o ethnicity. Address of residence at time of diagnosis is also collected and geocoded by the CCR to determine census block regions.

Using CCR data, Schupp, Press, and Gomez (2014) examined differences in prostate cancer survival by nativity status and neighborhood-level characteristics in a sample of 35,427 Hispanic men in California. Schupp et al. (2014) found that foreign-born Hispanic men had a 19% lower risk of cancer-related death ( $HR=0.81$ ,  $[0.75-0.88]$ ) compared to U.S.-born Hispanic men. When the authors examined the joint effect of neighborhood characteristics and nativity status on cancer survival they found evidence of an additive effect. Neighborhood ethnic enclave was measured with a well-validated index that included: percentage linguistically isolated, percentage linguistically isolated who speak Spanish, percentage speaking limited English, percentage Spanish-speaking who spoke limited English, percentage recent immigrants, percentage Hispanic, and percentage foreign-born. Ethnic enclave was turned into quintiles and then dichotomized into high and low ethnic enclave. Schupp et al. (2014) found that foreign-born Hispanic men with prostate cancer who lived in high ethnic enclave neighborhoods had an even greater reduction in risk of death compared to their U.S.-born counterparts. These findings illustrate: (1) how neighborhood factors interact with nativity status to confer either excess or reduced cancer risk for Latino men, and (2) the importance of examining the joint effect of multiple sociodemographic categories (in this case, nativity status and geography) in shaping disease risk.

*National Longitudinal Study of Adolescent to Adult Health (Add Health)*

The Add Health study is a longitudinal study of the health-related behaviors of adolescents, and their outcomes across the lifecourse. The study recruited 20,745 U.S. adolescents from 1994-1995 who were part of a probability sample and thus representative of the U.S. school-based population in grades 7 through 12. Participants were interviewed at four different time points: twice in adolescence, again in 2001-2002 (mean age 21), and again in 2007-2008 (mean age 29). In addition to neighborhood information data, Add Health collected data from participants and their parents, school administrators, romantic partners, friends, and siblings on topics including (but not limited to) social demographics, health services use, violence exposure, mental health, beliefs, and health behaviors. Height and weight were collected during in-home assessments at the four observation points. During the young adulthood home visit, additional anthropometric measures were included, as well as assessments of blood pressure and inflammatory, immune, metabolic and cardiovascular markers. Among Latinos in the Add Health cohort, immigration generation status has been associated with higher likelihood of suicide attempts, and problem alcohol and drug use than foreign-born Latino youth (Pena et al., 2008).

## Exemplars of State-of-the-Art Population Level Health Surveys

### *National Latino and Asian American Study (NLAAS)*

The NLAAS is a nationally representative household epidemiological study conducted between 2000 and 2003 among Latina/os and Asian Americans living in the United States

(<http://www.massgeneral.org/disparitiesresearch/Research/pastresearch/NLAAS-study.aspx>). This study examined the prevalence of mental disorders and mental health service use and assessed the role of ethnicity/race, acculturation, socioeconomic status, and environmental context in explaining social and environmental determinants of mental disorders and mental health service use in Latina/os and Asian American adults. The NLAAS Latina/o respondents included: Mexicans (n = 868), Cubans (n = 577), Puerto Ricans (n = 495) and other Latina/os (n = 614).

The NLAAS illustrates the importance of disaggregating health data when examining the distribution of mental disorders in the Latina/o adult population. First, in the aggregate, Latina/os consistently report lower rates of lifetime psychiatric disorders than non-Latina/o Whites (Alegría et al., 2008). Second, when prevalence rates are disaggregated by Latina/o subgroups, significant differences are revealed. Compared to Mexicans and Cubans, Puerto Ricans report higher risks for any psychiatric, anxiety, and substance-use disorders; yet no significant differences in the rates of depressive disorders are observed among these country-of-origin groups. The rates of psychiatric disorders among Puerto Ricans approach those of non-Latina/o Whites (Alegría, Mulvaney-Day, et al., 2007; Alegría et al., 2008). Third, stratifying Latina/os by country-of-origin subgroups and nativity status uncovers important differences. Foreign nativity is a protective factor for depressive and anxiety disorders among Mexicans. It is also a protective factor for substance-use disorders for Mexicans, Cubans, and other Latina/o groups, but not for Puerto Ricans. Lastly, acculturation (e.g., generational status, time in the United States, context of entry, and age of immigration) and cultural factors (e.g., perceived discrimination, family cultural conflict, family cohesion) influence the risk of psychiatric disorders among Latinos. The longer Latina/o immigrants remain in their country of origin, the lower their risk of psychiatric disorders. But once in the United States, Latina/o immigrants experience risk of onset similar to that of U.S.-born Latina/os of similar age (Alegría, Sribney, Woo, Torres, & Guarnaccia, 2007).

Several cultural factors may explain the pathways linking acculturation to the mental health status of Latina/os. For instance, perceived discrimination and family cultural conflict play a significant role in explaining the association between time spent in the United States and the likelihood of Latina/os experiencing a psychiatric disorder (Cook, Alegría, Lin, & Guo, 2009).

### *The Hispanic Community Health Study/Study of Latinos (HCHS/SOL)*

The HCHS/SOL is a multicenter, prospective, population-based study that examines risk and protective factors in the development of cardiovascular disease and prospectively evaluates morbidity and mortality (<https://www2.csc.unc.edu/hchs/>). This study included 16,415 self-identified Hispanic/Latino/a participants aged 18 to 74, recruited from randomly selected households in four communities in the United States: the Bronx; Chicago; Miami; and San Diego). Participants underwent clinical examination to determine baseline cardiovascular prevalence and identify risk and protective factors. Baseline evaluation included personal and family health history, acculturation (including language and cultural food preferences), physical activity, diet, sleep, occupation, demographics, and socioeconomic factors. Clinical assessments included hearing, vision, and dental exams, and blood tests. HCHS/SOL included Latina/os from Cuban, Puerto Rican, Mexican, Dominican, Central American, and South American backgrounds.

Study findings uncovered important differences in the prevalence of cardiovascular disease (CVD) and stroke by Latina/o subgroup, gender acculturation and socioeconomic status. The prevalence of coronary heart disease was highest among Puerto Rican men and women, and the prevalence of stroke was highest among Dominican men and Puerto Rican women (Davignus et al., 2012). Moreover, the prevalence of negative CVD risk profile (e.g., obesity, hypertension) was higher among Puerto Ricans than other Latina/o subgroups and was associated with lower socioeconomic status and higher acculturation levels such as U.S. birth and longer duration of residence in the United States (Davignus et al., 2012). These findings illustrate significant differences in the prevalence and risk of CVD among Latina/o subgroups.

## **STAKEHOLDER INTERVIEW METHODS**

### **Rationale**

Stakeholders, such as Latina/o health research experts, leaders of national organizations in charge of conducting surveillance health surveys, and representatives from departments of health and mental health, bring an insiders' perspective into the design, collection, and use of disaggregated health data. Semi-structured qualitative interviews were conducted with stakeholders to explore barriers and facilitators for disaggregating Latina/o health data. This study was approved by the Institutional Review Board (IRB) of Columbia University.

### **Recruitment**

A purposive sample of 12 stakeholders was recruited. It included four nationally-recognized Latina/o health researchers, four local representatives from departments of health and mental health involved in the collection and use of local surveillance health data, and four representatives of national organizations in charge of conducting national surveillance health surveys. Multiple strategies were used to identify and recruit stakeholders, including nominations from the study's community advisory board members, nomination from experts in the field known to the investigators of this project, nominations and referrals of colleagues of stakeholders interviewed, and detailed searches performed by the research team.

A total of 30 stakeholders were identified and invited via email to participate. Of these, six refused participation, stating that they were not interested in being interviewed; ten did not respond; and scheduling difficulties made it not possible to schedule interviews with two interested stakeholders. The response rate for the study was 40%. A total of 12 stakeholders were enrolled and interviewed between August and October 2016. Each participant received a written informed-consent form to read, review, ask questions about the study, and sign. Each received a \$100 gift card for his or her participation in this study.

### **Qualitative Interviews**

The semi-structured qualitative interviews lasted approximately 60 minutes and were conducted by the principal investigators or a co-investigator via telephone to accommodate participants' availability. Interviews were audiotaped and professionally transcribed. An interview guide consisting of open-ended questions followed by short probes was used (see Appendix F for a copy of the interview guide). Questions included: *How have you used disaggregated health data in your work? What surveillance health survey study-design or data-collection factors facilitate the disaggregation of Latino health data? What kinds of policies could be created to promote increased collection and reporting of disaggregated health estimates for Latina/os?*

Stakeholders also completed a brief self-administered demographic survey used to collect information about each stakeholder's title, years working in current position, academic degree and profession, years working with Latina/os, and general demographic information (e.g., age, race/ethnicity). Interviewers completed interview summaries after each interview to describe general impressions about participants' responses as well as lessons learned from the interview.

### **Data Analysis**

Frequencies and measures of central tendencies were used to describe stakeholders' characteristics. To analyze our qualitative data, we used a thematic content analysis approach (Bernard, 2002). Drs. Alcántara and Cabassa independently read interview transcripts and summaries, noting emerging themes and patterns that focused on three dimensions: barriers to and facilitators of data disaggregation, as well as recommendations for improving the disaggregation of Latina/o health data. We then developed an analytical memo in which we synthesized key emerging findings across these dimensions. We used established strategies—such as developing an audit trail, to document our analytical decisions, presentations of emerging findings to our advisory board, and peer-debriefing meetings—to ensure the rigor and trustworthiness of our analytical approach (Padgett, 1998).

## **STAKEHOLDER INTERVIEW RESULTS**

### **Stakeholder Characteristics**

Twelve stakeholders participated in our study: four Latina/o health researchers, four representatives from state and local health departments and organizations, and four leaders working in national organizations (see **Table 5**). On average, participants had worked 14 years at their respective organizations and had worked with Latina/o health data for 22 years. The majority had doctorates (75%) and all had masters degrees. The majority of participants were female (75%) and non-Latina/o Whites (66.7%) with an average age of 50 years.

**Table 5.** Stakeholder characteristics (N=12).

	N	%	Mean	S.E.
Stakeholder group				
Health researcher	4	33.3	-	-
Local representative	4	33.3	-	-
National representative	4	33.3	-	-
Time current organization (in years)	-	-	13.9	8.1
Time health data ( in years)	-	-	21.9	9.0
Academic degrees				
MD	2	16.6	-	-
PhD	7	58.3	-	-
MPH	1	8.3	-	-
MPA	1	8.3	-	-
MA/MS	7	58.3	-	-
BA/BS	2	16.6	-	-
MSMPH	1	8.3	-	-
MPA-URP	1	8.3	-	-
Masters in economics	1	8.3	-	-
Age			50.3	8.3
Gender				
Female	9	75.0	-	-
Male	3	25.0	-	-
Ethnicity				
Non-Hispanic	8	66.7	-	-
Hispanic/Latino	4	33.3	-	-
Ethnicity for Hispanic/Latino				
Mexican	3	75.0	-	-
No response	1	25.0	-	-
Race				
White	9	75.0	-	-
Hispanic	1	8.3	-	-
Other: Argentina	1	8.3	-	-
No response	1	8.3	-	-

**Barriers**

Stakeholders identified a series of barriers to the disaggregation of Latina/o health data. We summarize the barriers that emerged from these interviews below (see Appendix G for illustrative quotes).

***Small sample sizes to conduct meaningful and precise disaggregated analyses.***

The majority of stakeholders reported small sample sizes and low statistical power, particularly for Latina/o country-of-origin subgroups, as a critical barrier. These issues prevented the reporting of precise estimates of health issues impacting Latina/o subgroups.

***Lack of resources and funding to conduct rigorous surveillance health studies that collect disaggregated data.*** The majority of stakeholders also mentioned insufficient resources and funds to conduct rigorous health surveillance studies that facilitate the collection of various disaggregation characteristics as an important barrier. This issue highlights inadequate funding for critical design elements, including the recruitment of representative samples of Latina/os that include meaningful representation of different Latina/o subgroups, added costs of hiring and training bilingual and culturally competent staff, and additional costs associated with rigorous and comprehensive linguistic (English to Spanish) and cultural translation and validation of instruments.

***Lack of cultural humility and cultural competence in data collection.*** Another common barrier discussed by several stakeholders focused on the limited use, or absence, of culturally appropriate methodologies and strategies to recruit participants and collect data. These comments included issues that went beyond language sensitivity and pointed toward incorporating cultural norms valued by Latina/o groups—such as *respeto*, *simpatia*, and *familismo*—in the approaches and study protocols used to engage, recruit, and collect data. Stakeholders mentioned that lack of attention to cultural humility and competence can negatively affect recruitment efforts and the quality of the data being collected.

***Concerns regarding the validity of measures and the lack of systematic measures to capture disaggregated data across multiple domains (e.g., immigration status, mixed-race/ethnicity).*** A number of measurement issues were discussed as important barriers. These included concerns about the validity and language equivalency of measures used in health surveillance surveys; respondent burden; lack of systematic measures and clear guidelines for capturing disaggregated data across multiple domains—including immigration status, acculturation, mixed race and ethnicity, ancestry, generational status, and documentation (legal status, among others). Several stakeholders also mentioned the absence of more nuanced data (e.g., immigration experiences, social conditions, and social identity) to appropriately examine and understand the inherent heterogeneity of the U.S. Latina/o population.

***Lack of a strong economic argument for collecting and using disaggregated health data.*** This barrier focused on not having a clear rationale and consensus to illustrate the economic value of collecting and using disaggregated health data. This issue was identified as a major obstacle to providing a strong case that could convince policy makers, funders, researchers, and the general public to allocate resources to support this type of research.

***Lack of diverse faculty who could inform the design, collection, and analysis of disaggregated health data.*** The underrepresentation of racially and ethnically diverse faculty members and researchers was also identified as a critical barrier. This lack of diversity was seen as detrimental to cultivating culturally sensitive approaches and valuable insider perspectives that could be used to inform the design, collection, and analyses of disaggregated health data in the Latina/o community.

## **Facilitators**

Stakeholders discussed a series of facilitators for supporting and improving the collection and use of disaggregated health data pertaining to the U.S. Latina/o population. We summarize each of these facilitators below (see Appendix G for illustrative quotes).

***Create standards or guidelines for collecting disaggregated measures relevant to the U.S. Latina/o population.*** A number of stakeholders talked about the need for the



development and dissemination of federal standards or guidelines that would systematize the collection of pertinent measures and capture essential characteristics of the U.S. Latina/o population. Stakeholders suggested standards to inform the collection of measures, such as immigration status, nativity, duration of residence in the United States, and ancestry. Going one step further, several stakeholders suggested that these standards be converted into policies that mandate the collection of such data in all publicly funded surveys. Other stakeholders talked about developing a free and accessible repository of reliable and valid measures and survey items.

***Promote an immigration or ethnicity lens in the design, collection, and analysis of these data.*** Several stakeholders recommended using a conceptual lens to capture the immigration experience and the social conditions and determinants of health impacting the U.S. Latina/o population. This conceptual lens could help strengthen the design, collection, and analysis of disaggregated health data and deepen the understanding of health issues in the Latina/o population by providing more comprehensive targets for potential health interventions and policies.

***Offer targeted funding to collect high-quality disaggregated health data.*** Stakeholders also mentioned the need for funding that takes into consideration the complexities, expenses, and resources needed to collect high-quality disaggregated health data. This call for more targeted funding was seen as critical to support costly methodologies, such as oversampling of Latina/o subgroups; translation and validation of measures in English and Spanish and across countries of origin; and the hiring of bilingual and culturally competent staff—all of which are necessary to conduct rigorous surveillance health studies in the Latino/a community.

***Develop marketing campaigns that articulate the value and significance of collecting and reporting disaggregated health data.*** Another important facilitator discussed by several stakeholders was the need to develop marketing campaigns that articulate and illustrate the value and importance of collecting and reporting disaggregated health data. Some stakeholders suggested that the campaign include talking points that advocates can use to influence policy makers and funders to support these types of studies and data collection. Others mentioned the need for a broader marketing campaign focused on Latina/o health and prevention, given the growth of the Latina/o population in the United States and its contributions to the cultural, economic, and political progress of this nation.

***Invest in mentoring and training programs for researchers that focus on Latina/o health.*** The need to invest in mentoring and training programs in Latina/o health research was suggested by several stakeholders. These career development investments would increase the number of researchers working in this area and would develop and sustain the necessary research infrastructure, particularly in Hispanic serving institutions, to support the future of this field.

***Promote disaggregation through legislation.*** Several stakeholders talked about how legislation could be used to promote the disaggregation of health data. These individuals observed that legislation could include specific language and mandates that target health disparities in the Latina/o community and provide the allocation of resources to collect and use disaggregated health data. In other words, legislation can serve as a vehicle to support and sustain the use of these data, informing services and programs to address health inequities in the Latina/o community. As part of this process, training and briefing for staffers that work closely with legislators can be used to communicate the significance and value of health

disparities research and the importance of using disaggregated health data to inform better policies and services. These briefings can also be used to galvanize leaders from different sectors (e.g., health care, education, business) to advocate for the disaggregation of ethnic data.

***Liberate data by making it publicly available and accessible.*** Another important facilitator focused on making disaggregated health data publicly available and accessible. Stakeholders talked about the need to “liberate data” so that advocates, community leaders, and service organizations can use the available data to better understand the health needs in their communities, identify gaps in care, and advocate for better policies and services. Efforts to “liberate data” should ensure data security, using mechanisms to protect confidentiality and privacy.

***Conduct mixed-method research to advance the science of disaggregated health data.*** Several stakeholders talked about the need to fund and conduct mixed-methods research to advance the science of collecting and using disaggregated health data. Mixed-methods research aims to deepen the field’s understanding of how people interpret and answer survey questions on race, ethnicity, identity, and country of origin and to develop evidence for the reliability and validity of these different measures and indicators.

## RECOMMENDATIONS

This project aimed to identify barriers and promising approaches to Latina/o health data disaggregation using systematic review methods and qualitative interviews. What follows is a brief synthesis of the key findings from our study and a list of 15 recommendations categorized into research, funding, policy, and priority areas.

### Research

Results of the systematic review overwhelmingly indicate that reporting of Latina/o health data disaggregation was quite low, a result that was consistent for both child and adult health outcomes. Specifically, only 9.7% of articles examining Latina/o child and adult surveillance health data published from January 2006 to June 2016 provided disaggregated estimates; more than 76% of this scholarship focused on adults. The low percentage of literature spanning the lifecourse may stem from limitations in design, data collection, measurement, or reporting, as well as from publication domains that require further attention.

### ***Design and data collection***

A total of 22 different data disaggregation types were identified in the systematic review. Most of the published articles provided disaggregated health estimates for demographic factors (e.g., gender, age, nativity status, education), and often analyzed health estimates for a single disaggregation characteristic at a time. Further, stakeholders often commented about the lack of standard questions for capturing less well-studied disaggregation types, such as country of origin and acculturation. Taken together, findings from the systematic review and stakeholder interviews underscore the need for specific strategies to standardize the design and collection of disaggregated data. These include:

**Recommendation #1:** Develop clear guidelines for ethnic health data disaggregation and a standardized set of survey items that reflect the disaggregation types most relevant to the Latina/o community.

Recommendation #2: Move beyond the inclusion of demographic factors and include other important social determinants of health—among them race, country of origin, place-based factors, English language proficiency, discrimination, and acculturation.

Recommendation #3: Use an intersectional lens in the design, collection, and analysis of disaggregated health data that considers the intersections of migration, ethnicity, and social conditions.

Recommendation #4: Mandate the collection of Latino ancestry (country of origin), generational status, duration of residence in the United States, and language proficiency data in all publically funded surveys.

### ***Measurement***

A limited number of the included studies (8.3%) used established instruments to capture sources of heterogeneity in the Latina/o community. Stakeholders mentioned measurement concerns regarding the reliability, validity, and cultural equivalency of existing measures across Latina/o ancestry groups as contributing factors to current trends in data disaggregation and limited use of more nuanced instruments. Efforts to address these methodological challenges should consider:

Recommendation #5: Conduct mixed-methods research to develop reliable, valid, and culturally equivalent instruments across Latina/o ancestry/heritage groups.

Recommendation #6: Develop a free and accessible repository of reliable and valid measures and survey items that capture essential disaggregation characteristics pertinent to the Latina/o community.

### ***Reporting and publications***

The mean number of published articles on Latina/o data disaggregation was low, at 15.9 articles per year between 2006 and 2016. Given the growth of the Latina/o population and observed differences in health trajectories by Latina/o subgroups and other dimensions, a multipronged strategy to address reporting and publication biases is critically needed. Strategies to address these reporting and publication biases may include:

Recommendation #7: Address potential roadblocks to publication by developing special issues in top-tier journals that focus on this topic.

Recommendation #8: Educate journal editors and reviewers to reduce publication bias and highlight the importance of this topic. Review committees for the National Institutes of Health (NIH) and the National Science Foundation (NSF), and other funding agencies should also include reviewers with research expertise in Latina/o health across the lifecourse.

### ***Funding***

Limited funding and resources contribute to methodological barriers and limitations in the design, data collection, and/or use of disaggregated Latina/o health data. Stakeholders mentioned concerted investments and targeted funding for training programs and research as necessary to address these important issues.

### ***Training***

Stakeholders mentioned the need to invest in mentoring and training programs in Latina/o health research. These career development investments can be used to increase the number of researchers working in Latina/o health to support the future of this field.

Recommendation #9: Invest in research training and mentoring programs at all stages of career development (e.g., high school, undergraduate, graduate, post-doctoral, junior faculty, mid-career) to support careers in Latina/o health research across the lifecourse.

## Research

Given the complexities, expenses, and resources needed to collect high-quality disaggregated health data, stakeholders recommended the development of targeted funding opportunities. This call for funding is critical to support costly methodologies necessary for conducting state-of-the-art surveillance health studies in the Latina/o community. These methodologies include oversampling of Latina/o subgroups; translation and validation of measures in English and Spanish and across countries of origin; and the hiring and retention of bilingual and culturally competent staff.

Recommendation #10: Develop targeted funding announcements and opportunities to support the collection and analysis of disaggregated health data across the lifecourse. For example, the National Institutes of Health could develop a supplementary funding award to cover research expenses (e.g., translation and validation of measures) beyond the \$500,000 funding cap for R01 grants that focus on Latina/o health.

## Policy

Stakeholders expressed direct and indirect frustrations about the absence of policies that promote racial/ethnic health data disaggregation in general, and Latina/o health data disaggregation, in particular. Our analysis of stakeholder interviews also revealed complex and multi-faceted tensions concerning what we termed the *politics of disaggregation*, the extent to which competing demands (e.g., research vs. policy needs) limit the individual and political will to create, promote, and develop racial/ethnic data disaggregation policies. Strategies to address the creation, promotion, and enforcement of specific policies could include:

Recommendation #11: Develop a strong economic and scientific argument for Latina/o health data disaggregation that can be disseminated across sectors to promote Latina/o health data disaggregation. Examples of disseminable materials include policy briefs, white papers, letters to editors, etc.

Recommendation #12: Engage key stakeholders from multiple sectors—including government agencies, private foundations, non-governmental agencies, and businesses—to prioritize Latina/o health and develop a concerted marketing campaign on Latina/o health prevention and treatment across the lifecourse.

Recommendation #13: Develop a set of decision tools to help stakeholders determine when, how, and on what to disaggregate across the lifecourse.

## Priority Areas

Latina/o health data disaggregation initiatives must account for the changing demographic trends in the U.S. Latina/o community. Examples of these important trends include: (a) decline in immigration, (b) expansion of U.S.-born Latina/o population, (c) high rates of intermarriage, (d) increasing percentages of mixed race and mixed ethnicity Latina/o children, and (d) increase of English as the dominant language in Latina/o households. These demographic trends are likely to affect notions of identity. Notions of identity have important implications for who self-identifies as Latina/o, and subsequently Latina/o health estimates generated from surveillance health surveys. These demographic changes may create a more heterogeneous population and potentially contribute to the diffusion or broadening of Latina/o ethnic identity and experiences. These demographic trends support the following additional recommendations:

Recommendation #14: Create flexible and adaptable data-collection systems that can be easily changed to capture important disaggregation characteristics aligned with the dynamic and changing demography of the U.S. Latina/o population.

Recommendation #15: Support the inclusion of critical dimensions shaping the Latina/o population that go beyond demographic characteristics and include language use, parental ancestry, generational status, racial identity, and documentation status.

Final Draft

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## APPENDICES

### APPENDIX A. PROSPERO protocol

UNIVERSITY of York  
Centre for Reviews and Dissemination

  
National Institute for  
Health Research

#### PROSPERO International prospective register of systematic reviews

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##### **A systematic review of Latino surveillance health data across the life-course to understand barriers and facilitators to disaggregation**

*Carmela Alcántara, Leopoldo Cabassa, Shakira Suglia, Elliot McCullough, Talhah Alvi, Louise Falzon*

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##### **Citation**

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##### **Review question(s)**

The primary objectives of this systematic review are as follows:

1. To determine the proportion of literature using national or state surveillance health data that reports disaggregated Latino health data.
2. To identify specific survey measures that are or can be used in surveillance health surveys to capture the social, economic, and cultural heterogeneity of the US Latino population.
3. To evaluate the quality of the publication and the quality of the measures (psychometric properties) and their utility (e.g., ease of use, language, length, reading level) for capturing the heterogeneity in Latino sociodemographic characteristics and health outcomes.

A secondary objective is to review exemplars of disaggregated surveillance health surveys (e.g., National Latino and Asian American Survey; Hispanic Community Health Study/Study of Latinos) to identify promising measures, approaches, and techniques.

##### **Searches**

Potentially relevant articles will be identified by searching the biomedical electronic databases Ovid MEDLINE, EMBASE, PsycINFO, JSTOR and Sociological Abstracts.

Databases will be searched from January 2006 to June 2016.

All relevant subject headings and free-text terms will be used to represent health surveillance data, Latino populations and the health conditions under investigation. Terms will be applied to limit to observational studies and to the United States. Additional records will be identified by scanning the reference lists of relevant studies and reviews, by employing the Similar Articles feature in PubMed, and the Cited Reference Search in ISI Web of Science. Relevant study and registry websites will be searched in addition to other sources of grey literature.

The searches will be limited to English language.

See also search strategy attached (PDF document, link provided below).

##### **Link to search strategy**

[http://www.crd.york.ac.uk/PROSPEROFILES/41879\\_STRATEGY\\_20160524.pdf](http://www.crd.york.ac.uk/PROSPEROFILES/41879_STRATEGY_20160524.pdf)

##### **Types of study to be included**

We will include English language articles conducted in the United States and published in peer-reviewed journals that report findings from observational studies sponsored by state or national surveillance health studies that include cross-sectional, retrospective, designs that report health estimates for the Latino population in the U.S.

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We will exclude studies reporting findings from randomized controlled trials or comparative effectiveness studies conducted in the United States and published in peer-reviewed journals.

#### **Condition or domain being studied**

The health conditions of primary interest represent the top five leading causes of death for Latino adults, and the most prevalent health or mental health conditions in children and adults. The primary adult outcomes will include: cancer, heart disease, stroke, unintentional injuries [accidents], diabetes mellitus, any depression, any anxiety disorders, and insomnia. The primary child outcomes will include: asthma, obesity, ADHD/developmental disabilities, autism, depression, anxiety, and conduct disorder. These disorders may be co-occurring with other health conditions.

#### **Participants/ population**

We will include studies of child and adult participants identified or self-identified as Latino/a or Hispanic in the United States mainland, Puerto Rico, or US territories. Participants may be from any race so long as they report Hispanic ethnicity.

We will exclude studies that were conducted outside of the United States.

#### **Intervention(s), exposure(s)**

All studies stating that they use state or national surveillance health surveys to report Latino health estimates will be included. Examples of state or national surveillance health surveys include: New York City Community Health Survey, National Health and Nutrition Examination Survey, National Health Interview Survey, Behavioral Risk Factor Surveillance System, Youth Risk Behavior Surveillance System, California Health Interview Survey.

We will exclude national or regional studies that did not use surveillance health data, or studies that did not report Latino health estimates.

#### **Comparator(s)/ control**

Not applicable.

#### **Context**

Studies may have been conducted in community settings throughout the United States using community or national samples. Studies may have also been conducted in person, via telephone, or self-administered surveys.

#### **Outcome(s)**

##### **Primary outcomes**

To be included in the review, studies must have measured or reported one or more of the primary outcomes. The primary adult outcomes will include: cancer, heart disease, stroke, unintentional injuries [accidents], diabetes mellitus, depression, anxiety, and insomnia. The primary child outcomes will include: asthma, obesity, and ADHD.

##### **Secondary outcomes**

None.

#### **Data extraction, (selection and coding)**

We will use a two-stage process for data extraction. First, two review authors (EPM, IP) will independently scan the abstract or title or both of every record retrieved to determine which pass the initial screen. After the first initial screen, full articles will be retrieved for further assessment if the information given suggests that the study (1) includes child or adult participants who self-identified as Hispanic/Latino (2) reports information on the primary health and mental health outcomes, (3) uses state or national surveillance health data, and (4) reports disaggregated health outcomes. Herein, the definition of disaggregation is to separate data from surveillance health surveys on US Latinos into subgroups, including: racial, ethnic (culture of origin), nativity status, acculturation (language use), gender, age, and socioeconomic status (education, employment, income). If there is any doubt regarding these criteria from the information given in the title and the abstract, the full article will be retrieved for clarification.

We will resolve any discrepancies through consensus or recourse to a third review author (CA, LC, SS). If resolution of a disagreement is not possible, we will add the article to those "awaiting assessment" and we will contact study

authors for clarification. We will follow the reporting guidelines of the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses), and as such include a flow-chart illustrating the process of study selection (Liberati 2009).

For studies that meet the inclusion criteria, two review authors (EPM, IP) will independently abstract key participant and intervention characteristics. We will report data on efficacy outcomes and adverse events using standard data extraction templates. We will resolve any disagreements by discussion or if required by consultation with a third and fourth review authors (CA, LC, SS).

We will extract the following data using a data extraction form:

- 1 General information: published/unpublished, title, authors, surveillance health source, contact address, setting, year of publication, duplicate publications.
- 2 Study characteristics: aims, hypotheses, use of theory or health disparities model/frameworks.
- 3 Design characteristics: sample size (total, and Latinos), sampling approach, design, location(s), statistical approach.
- 4 Measures that reflect sociodemographic heterogeneity of Latino population (social, cultural, economic).
- 5 Participants' sociodemographic characteristics: gender, age, race, ancestry group, socioeconomic status (education, income, employment/occupation status), nativity status.
- 6 Outcomes: outcomes specified above, what was the primary outcome assessed in the study
- 7 Results: for specified outcomes.

#### **Risk of bias (quality) assessment**

Three review authors (CA, LC, SS) will independently assess the risk of bias of each included study, and the quality of the measures used in the exemplar studies. We will resolve any disagreements by consensus, or by consultation with our consultants (MA). In cases of disagreement, we will consult the rest of the review authors and make a judgment based on consensus. If adequate information is not available from study authors, study protocols or both, we will contact study authors for missing data on 'Risk of bias' items. We will use a modified version of the ACROBAT-NSRI tool (Sterne, Higgins, Reeves, 2014), as well as the NHLBI Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (<http://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort>) to evaluate the quality and the risk of bias of each study across several domains (bias due to confounding, bias in selection of participants into the study, bias due to missing data, bias in measurement of outcomes, bias in selection of reported results). To evaluate the quality of the measures included the exemplar studies, we will use a modified version of the COSMIN (Consensus based Standards for the selection of health status Measurement INstruments) checklist (Mokkink, Terwee, Patrick, et al., 2010).

#### **Strategy for data synthesis**

A narrative or descriptive synthesis is planned.

#### **Analysis of subgroups or subsets**

We will present results by age subgroup to reflect the life course perspective. As such, we will report findings for children, adolescents, adults, and older adults.

#### **Dissemination plans**

We plan to write and submit the findings from this systematic review as a final report to the Robert Wood Johnson Foundation, and for presentation at any relevant RWJF meetings. We also plan to (at a later date) submit a manuscript version of the final report for publication in a peer-reviewed top tier journal, and to present the results of this review at relevant national scientific conferences. Once the manuscript has been published, we will promote the study findings on relevant websites and also conduct our own publicity push to notify relevant audiences of the study findings.

**Contact details for further information**

Carmela Alcántara

Columbia University School of Social Work

1255 Amsterdam Avenue

New York, NY, 10027

ca2543@cumc.columbia.edu

**Organisational affiliation of the review**

School of Social Work, Columbia University

<http://socialwork.columbia.edu/>

**Review team**

Dr Carmela Alcántara, Columbia University School of Social Work

Dr Leopoldo Cabassa, Columbia University School of Social Work

Dr Shakira Suglia, Columbia University Mailman School of Public Health

Mr Elliot McCullough, Columbia University School of Social Work

Mr Talhah Alvi, Columbia University Teacher's College

Ms Louise Falzon, Columbia University Medical Center

**Collaborators**

Dr Tina Kauh, Robert Wood Johnson Foundation

**Details of any existing review of the same topic by the same authors**

Not applicable

**Anticipated or actual start date**

01 June 2016

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**Conflicts of interest**

None known

**Language**

English

**Country**

United States of America

**Subject index terms status**

Subject indexing assigned by CRD

**Subject index terms**

Ethnic Groups; Healthcare Disparities; Health Status; Health Status Disparities; Hispanic Americans; Humans;

Poverty; Public Health Surveillance; Socioeconomic Factors; United States

**Stage of review**

Ongoing

**Date of registration in PROSPERO**

13 July 2016

**Date of publication of this revision**

13 July 2016

Stage of review at time of this submission	Started	Completed
Preliminary searches	No	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

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**PROSPERO**

**International prospective register of systematic reviews**

The information in this record has been provided by the named contact for this review. CRD has accepted this information in good faith and registered the review in PROSPERO. CRD bears no responsibility or liability for the content of this registration record, any associated files or external websites.

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## APPENDIX B. Search strategy

### A Systematic Review of Latino Surveillance Health Data Across the Life-course to Understand Barriers and Facilitators to Disaggregation: Search Strategy

#### MEDLINE (Ovid)

1. exp Health Surveys/
2. exp Nutrition Surveys/
3. ((health or population or risk) adj5 (survey or surveillance or interview)).tw.
4. cancer registr\$.tw.
5. or/1-4
6. (city or states\$ or region\$ or federal or national or texas or florida or new york or california or illinois).tw.
7. 5 and 6
8. nhanes.tw.
9. brfss.tw.
10. (Healthcare Cost Utilization Project or hcup).tw.
11. (Medical Expenditure Panel Survey or meps).tw.
12. National Childrens Study.tw.
13. NSDUH.tw.
14. NSFG.tw.
15. NIS.tw.
16. (National Vital Statistics System or NVSS).tw.
17. (State Local Area Integrated Telephone Survey or SLAITS\$).tw.
18. (National Home Hospice Care Survey or NHHCS).tw.
19. (Surveillance Epidemiology End Results Program or SEER).tw.
20. (National Hospital Ambulatory Medical Care Survey or NHAMCS).tw.
21. or/7-20
22. exp United States/
23. Puerto Rico/
24. exp Micronesia/
25. United States Virgin Islands/
26. American Samoa/
27. (united states or usa or america\$ or peurto rico or guam or mariana island\$ or virgin island\$ or american samoa).tw.
28. or/22-27
29. exp Hispanic Americans/
30. (hispanic\$ or latino\$ or latina\$).tw.

31. ((spanish or central or south) adj american\$.tw.
32. (mexican\$ or puerto rican\$ or cuban\$ or dominican\$.tw.
33. (costa rican\$ or guatamalan\$ or honduran\$ or nicaraguan\$ or panamanian\$ or salvadoran\$.tw.
34. (argentinean\$ or bolivian\$ or chilean\$ or colombian\$ or ecuadorian\$ or paraguayen\$ or peruvian\$ or uruguayan\$ or venezuelan\$.tw.
35. or/29-34
36. exp Neoplasms/
37. (cancer\$ or neoplasm\$ or carcinoma\$ or malignan\$ or leuk?emi\$.tw.
38. exp Heart Diseases/
39. ((coronary or cardiac or heart or isch?emi\$) adj (disease\$ or syndrome\$)).tw.
40. (acs or acd or chd or cad).tw.
41. exp Stroke/
42. cerebrovascular.tw.
43. ((brain or vascular or lacunar or venous or cerebral or isch?emic) adj2 (accident\$ or infarct\$ or event\$ or attack\$)).tw.
44. exp Accidents/
45. accident\$.tw.
46. ((unintentional or unintended) adj injur\$.tw.
47. exp Diabetes Mellitus/
48. diabet\$.tw.
49. exp Depressive Disorder/
50. Depression/
51. depress\$.tw.
52. exp Anxiety Disorders/
53. Anxiety/
54. (anxiet\$ or anxious\$.tw.
55. exp "Sleep Initiation and Maintenance Disorders"/
56. insomnia\$.tw.
57. exp Asthma/
58. Asthma\$.tw.
59. exp Obesity/
60. obes\$.tw.
61. Developmental Disabilities/
62. (developmental adj2 (disabilit\$ or disorder\$)).tw.
63. Attention Deficit Disorder with Hyperactivity/

64. (Attention Deficit Disorder or adhd).tw.
65. Autistic Disorder/
66. (autis\$ or kanner\$ syndrome).tw.
67. Conduct Disorder/
68. conduct disorder\$.tw.
69. or/36-68
70. Epidemiologic studies/
71. exp case control studies/
72. exp cohort studies/
73. Case control.tw.
74. (cohort adj (study or studies)).tw.
75. Cohort analy\$.tw.
76. (Follow up adj (study or studies)).tw.
77. (observational adj (study or studies)).tw.
78. Longitudinal.tw.
79. Retrospective.tw.
80. Cross sectional.tw.
81. Cross-sectional studies/
82. or/70-81
83. and/21,28,35,69,82
84. limit 83 to (english language and yr="2006 - 2016")



## APPENDIX C. List of included studies

- Afable-Munsuz, A., Gregorich, S. E., Markides, K. S., & Perez-Stable, E. J. (2013). Diabetes risk in older Mexican Americans: effects of language acculturation, generation and socioeconomic status. *Journal of Cross-Cultural Gerontology*, 28, 359-373. doi:http://dx.doi.org/10.1007/s10823-013-9200-y
- Ai, A. L., Pappas, C., & Simonsen, E. (2015). Risk and protective factors for three major mental health problems among Latino American men nationwide. *American Journal of Men's Health*, 9, 64-75. doi:http://dx.doi.org/10.1177/1557988314528533
- Ai, A. L., Weiss, S. I., & Fincham, F. D. (2014). Family factors contribute to general anxiety disorder and suicidal ideation among Latina Americans. *Womens Health Issues*, 24, e345-352. doi:http://dx.doi.org/10.1016/j.whi.2014.02.008
- Alegria, M., Canino, G., Shrout, P. E., Woo, M., Duan, N., Vila, D., . . . Meng, X. L. (2008). Prevalence of mental illness in immigrant and non-immigrant U.S. Latino groups. *American Journal of Psychiatry*, 165, 359-369. doi:10.1176/appi.ajp.2007.07040704
- Alegria, M., Canino, G., Stinson, F. S., & Grant, B. F. (2006). Nativity and DSM-IV psychiatric disorders among Puerto Ricans, Cuban Americans, and non-Latino Whites in the United States: results from the National Epidemiologic Survey on Alcohol and Related Conditions. *Journal of Clinical Psychiatry*, 67, 56-65.
- Alegria, M., Mulvaney-Day, N., Torres, M., Polo, A., Cao, Z., & Canino, G. (2007). Prevalence of psychiatric disorders across Latino subgroups in the United States. *American Journal of Public Health*, 97, 68-75. doi:10.2105/ajph.2006.087205
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- Aschebrook-Kilfoy, B., Ward, M. H., Sabra, M. M., & Devesa, S. S. (2011). Thyroid cancer incidence patterns in the United States by histologic type, 1992-2006. *Thyroid*, 21, 125-134. doi:http://dx.doi.org/10.1089/thy.2010.0021
- Avery, C. L., Holliday, K. M., Chakladar, S., Engeda, J. C., Hardy, S. T., Reis, J. P., . . . Zeng, D. (2016). Disparities in Early Transitions to Obesity in Contemporary Multi-Ethnic U.S. Populations. *PLoS ONE [Electronic Resource]*, 11, e0158025. doi:http://dx.doi.org/10.1371/journal.pone.0158025
- Aviles-Santa, M. L., Hsu, L. L., Arredondo, M., Menke, A., Werner, E., Thyagarajan, B., . . . Cowie, C. C. (2016). Differences in Hemoglobin A1c Between Hispanics/Latinos and Non-Hispanic Whites: An Analysis of the Hispanic Community Health Study/Study of Latinos and the 2007-2012 National Health and Nutrition Examination Survey. *Diabetes Care*, 39, 1010-1017. doi:http://dx.doi.org/10.2337/dc15-2579
- Aviles-Santa, M. L., Schneiderman, N., Savage, P. J., Kaplan, R. C., Teng, Y., Perez, C. M., . . . Cowie, C. C. (2016). Identifying probable diabetes mellitus among hispanics/latinos from four u.S. Cities: Findings from the hispanic community health study/study of latinos. *Endocrine Practice*, 22, 1151-1160. doi:10.4158/ep151144.or



- Bandiera, F. C., Arguelles, W., Gellman, M., Castaneda, S. F., Barnhart, J., Gonzalez, P., . . . Lee, D. J. (2015). Cigarette Smoking and Depressive Symptoms Among Hispanic/Latino Adults: Results From the Hispanic Community Health Study/Study of Latinos (HCHS/SOL). *Nicotine & Tobacco Research*, 17, 727-734. doi:10.1093/ntr/ntu209
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## APPENDIX D. Surveillance health surveys

Surveillance Health Survey	Acronym
American Community Survey	ACS
Arizona Developmental Disabilities Surveillance Program	ADDSP
Boston Puerto Rican Health Study	BPR
Behavioral Risk Factor Surveillance Survey	BRFSS
California Cancer Registry	CCR
California Health Interview Survey	CHIS
Cancer in North America	CINA
Comprehensive Psychiatric Epidemiology Surveys	CPES
Early childhood longitudinal program	ECLS
Florida Cancer Data System	FCDS
Hispanic Community Health Study/Study of Latinos	HCHS/SOL
Hispanic Health and Nutrition Examination Study	HHANES
Hispanic Established Population for the Epidemiologic Study of the Elderly	ICPSR
Los Angeles Family and Neighborhood Survey	L.A.FANS
Latino Adolescent Migration, Health, and Adaptation	LAMHA
Medicare database	MD
Mexican National Comorbidity Survey	MNCS
North American Association of Central Cancer Registries	NAACCR
Neighborhood and Breast Cancer	NABC
National Cancer Data Base	NCDB
National Core Indicators	NCI
National Comorbidity Survey Replication	NCSR
National Epidemiological Study of Alcohol and Related Conditions	NESARC
National Health and Nutrition Examination Survey	NHANES
National Health Interview Survey	NHIS
National Latino and Asian American Study	NLAAS
National Longitudinal Mortality Study	NLMS
National Longitudinal Study of Adolescent to Adult Health	NLSAH
National Longitudinal Survey of Youth	NLSY
National Notifiable Diseases Surveillance System	NNDSS
National Program of Cancer Registries	NPCR
National Survey of Children with Special Health Care Needs	NS-CSHCN
National Survey of American Life	NSAL
National Survey of Children's Health	NSCH
National Survey on Drug Use and Health	NSDUH
National Vital Statistics System	NVSS

New York City Department of Health and Mental Hygiene	NYCDOHMH
New York State Cancer Registry	NYSCR
Pregnancy Risk Assessment Monitoring System	PRAMS
SaludBienestaryEnvejecimiento	SABE
Surveillance, Epidemiology, and End Results	SEER
Texas Cancer Registry	TCR
United Farm Workers of America	UFW
U.S. Census	USC
Youth Risk Behavior Surveillance System	YRBS

Final Draft

**APPENDIX E. Number of included studies reporting priority disaggregation characteristics by surveillance health survey**

Surveillance Health Survey	Acculturation <sup>a</sup> (n = 26)		Ethnicity <sup>b</sup> (n = 43)		Generational status <sup>c</sup> (n = 9)		Nativity <sup>d</sup> (n = 57)	
	n	%	N	%	n	%	n	%
ACS	0	0.00	0	0.00	0	0.00	1	1.75
ADDSP	0	0.00	0	0.00	0	0.00	0	0.00
BPR	1	3.85	0	0.00	0	0.00	0	0.00
BRFSS	0	0.00	0	0.00	0	0.00	0	0.00
CCR	0	0.00	1	2.33	0	0.00	6	10.53
CHIS	1	3.85	1	2.33	1	11.11	4	7.02
CINA	0	0.00	0	0.00	0	0.00	0	0.00
CPES	0	0.00	1	2.33	0	0.00	3	5.26
ECLS	0	0.00	0	0.00	0	0.00	0	0.00
FCDS	0	0.00	0	0.00	0	0.00	0	0.00
HCHS/SOL	6	23.08	16	37.21	0	0.00	7	12.28
HHANES	0	0.00	0	0.00	1	11.11	0	0.00
ICPSR	1	3.85	1	2.33	0	0.00	0	0.00
L.A.FANS	0	0.00	1	2.33	1	11.11	1	1.75
LAMHA	1	3.85	0	0.00	0	0.00	0	0.00
MD	0	0.00	0	0.00	0	0.00	0	0.00
MNCS	0	0.00	0	0.00	0	0.00	1	1.75
NAACCR	0	0.00	1	2.33	0	0.00	0	0.00
NABC	0	0.00	0	0.00	0	0.00	0	0.00
NCDB	0	0.00	0	0.00	0	0.00	0	0.00
NCI	0	0.00	1	2.33	0	0.00	1	1.75
NCSR	0	0.00	2	4.65	0	0.00	3	5.26
NESARC	1	3.85	1	2.33	0	0.00	0	0.00
NHANES	4	15.38	4	9.30	1	11.11	7	12.28
NHIS	1	3.85	3	6.98	0	0.00	5	8.77
NLAAS	4	15.38	5	11.63	3	33.33	4	7.02
NLMS	0	0.00	0	0.00	0	0.00	1	1.75
NLSAH	0	0.00	0	0.00	0	0.00	0	0.00
NLSY	0	0.00	0	0.00	0	0.00	0	0.00
NNDSS	0	0.00	0	0.00	0	0.00	1	1.75
NPCR	0	0.00	0	0.00	0	0.00	0	0.00
NSAL	0	0.00	1	2.33	1	11.11	1	1.75

NSCH	4	15.38	0	0.00	1	11.11	4	7.02
NS-CSHCN	1	3.85	0	0.00	0	0.00	0	0.00
NSDUH	0	0.00	1	2.33	0	0.00	1	1.75
NVSS	0	0.00	0	0.00	0	0.00	1	1.75
NYSCR	0	0.00	1	2.33	0	0.00	0	0.00
PRAMS	1	3.85	0	0.00	0	0.00	1	1.75
SABE	0	0.00	0	0.00	0	0.00	0	0.00
SEER	0	0.00	1	2.33	0	0.00	4	7.02
TCR	0	0.00	0	0.00	0	0.00	0	0.00
UFW	0	0.00	0	0.00	0	0.00	0	0.00
USC	0	0.00	0	0.00	0	0.00	0	0.00
YRBS	0	0.00	0	0.00	0	0.00	0	0.00
NYCPOHMH	0	0.00	1	2.33	0	0.00	0	0.00

<sup>a</sup> Acculturation includes acculturation and language (preference, proficiency).

<sup>b</sup> Ethnicity refers to the racial or ethnic identity.

<sup>c</sup> Generational status refers to first-generation, second-generation, etc.

<sup>d</sup> Nativity Status refers to US-born vs non-US born.

## **APPENDIX F. Interview guide**

### **Purpose:**

The purpose of this one-on-one interview is to identify the barriers and facilitators that either prevent or promote the collection of disaggregated surveillance health data on US Latinos. By disaggregation of health data, we mean: to separate data from surveillance health surveys on US Latinos into subgroups, including: racial, ethnic (culture of origin), nativity, acculturation (language use), gender, age, and/or socioeconomic status (education, employment, income). You have been identified as an important stakeholder with a unique perspective that could be used to shape the local and national policies for collecting, analyzing, and reporting surveillance health data. I will ask you a few open-ended questions to start, but please feel free to interrupt me and share whatever information you think would be important for us to consider while we evaluate this topic. This interview should take about 60 minutes, and will be audio-recorded.

### **Do you have any questions before we begin?**

1. What type of work do you do with Latino health? Probe: Tell me about your experiences working with Latino health data.
2. How have you used disaggregated health data in your work?
3. How have you used disaggregated health data to understand the health of the Latino population?
4. In your experience, what surveillance health survey study design or data collection factors hinder the disaggregation of Latino health data? Probe: How so?
5. In your experience, what surveillance health survey study design or data collection factors facilitate the disaggregation of Latino health data? Probe: How so?
6. What are the most common measures used to disaggregated surveillance health data for Latinos? Are these sufficient? Why or why not?
7. What kinds of policies could be created that would promote more people to collect and report disaggregated health estimates for Latinos?
8. In an ideal world, what do you consider as the most important factors (i.e., social identity, acculturation, language) that should be measured in surveillance health surveys focused on understanding within Latino group differences? Probe: Any others?



## APPENDIX G. Summary of stakeholder themes and illustrative quotes

Themes	Illustrative quotes
Barriers	
Small sample sizes to conduct meaningful and precise disaggregated analyses	<ul style="list-style-type: none"> <li>• “[B]ut when you start breaking them down the numbers get smaller and smaller and you are less able to make statements with any precision” (Researcher)</li> <li>• “the sample sizes don’t always allow analysis by Latino subgroup” (Researcher)</li> </ul>
Lack of resources and funding to conduct rigorous surveillance health studies that collect disaggregated data	<ul style="list-style-type: none"> <li>• “[W]hen a lot of these places get funding or contract to do interviewing, they have very limited Spanish speaking staff or very poor methods to respond to Spanish speakers, so I think that affects the overall quality of data . . . ” (Researcher)</li> </ul>
Lack of cultural humility and cultural competence in data collection.	<ul style="list-style-type: none"> <li>• “I do think it is very critical to capture it sensitively and with the right language competency . . . cultural competency, but if I had to prioritize, I would put that second, not first . . . Because to me it is a little bit like if you want to raise a happy child, first you have to have a child, and then you have to provide the right environment. You can’t provide the right environment and not have a child. . . Right, and that is not to say that cultural and language competency is not important. I see it as one is fundamental, and they are both important. They are both fundamental, but one can exist without the other. The other cannot exist without that.” (Researcher)</li> </ul>
Measurement concerns regarding the validity of measures and the lack of systematic measures to capture disaggregated data across multiple domains (e.g., immigration status, mixed-race/ethnicity)	<ul style="list-style-type: none"> <li>• “Spanish is just not Spanish. Depending on where you are from, people speak Spanish differently, so when you are doing a formal questionnaire, I think it is not easy to get perfectly attuned interpretation of all of the questions” (Researcher)</li> <li>• “With all categorization of race/ethnicity, there are challenges in accurate measurement, and in how do you categorize people of mixed ethnicity.” (Researcher)</li> <li>• “I think that we should really be able to understand how Latinos, the whole process of what their experiences are and how they retain or not retain their Latino identity within this environment and how that impacts health. Health access, health status, all of those things.” (National Leader)</li> <li>• “I think again, drilling down, creating a standardized measure to drill down to origin, and either acculturation or length of time in the U. S., or something like that would really help tell that story.” (Researcher)</li> </ul>
Lack of strong economic argument for collecting and using disaggregated data	<ul style="list-style-type: none"> <li>• “I also think there needs to be some probably economic demonstration of why disaggregation is important . . . Why is it important to disaggregate the data? Is it because you want to direct funds to a Hispanic community that maybe has poorer health outcomes? Well then, I think that needs to be proven. And I say economic argument because that is always what drives a lot of awareness.” (Researcher)</li> </ul>

Lack of diverse faculty that can inform the design, collection, and analysis of disaggregated data	<ul style="list-style-type: none"> <li>“Number one is not having a diversified faculty. Less than 1 percent of faculty in medical schools are Hispanic. And if they are on medical school faculty they are usually doing a million things and can’t do research. They are on the wards training the residents and medical students, they are in the clinics seeing the patients, they are involved in minority affairs, recruiting the students, and they are being used for a million things besides, so if they want to do research and they go to a Stanford or a Harvard or a major research institution, the Latino faculty are wearing multiple hats. I think that the second thing is that if they are in research they are not working with other Latino researchers because there is very few. We need to connect researchers with mentors so that the junior researchers can stay in the career and get supported. Third thing is they can’t get funding out of NIH because it is more competitive, so it’s hard if they are just starting out, they have to be part of research teams that can have a track record to get funded. They need to be supported.” (National Leader)</li> </ul>
<b>Facilitators</b>	
Create standards or guidelines for collecting disaggregated measures relevant to the US Latino population	<ul style="list-style-type: none"> <li>“I think there needs to be, much like there is a standard health status question, and a standard race question, and a standard income question, we should have a standard, I don’t even want to say Hispanic, but sort of Latino/Hispanic background question. But I also think that needs to be combined with acculturation measures, because so much changes after not even a full generation.” (Researcher)</li> <li>“I think the federal government has put out fairly strong recommendations about how to collect race/ethnicity data, including self-reported, and how to collect mixed race. But I think the same sort of work that hasn’t necessarily been done around ethnicity in detail, and I think that one could really argue for promoting a culture of being aware of immigration status of everybody, meaning one’s ancestry and how long one has been here. We are a country of immigrants, and that could be more mainstreamed, and looking at health through that lens could be more mainstreamed.” (Researcher)</li> </ul>
Promote an immigration or ethnicity lens in the design, collection and analysis of these data	<ul style="list-style-type: none"> <li>“We are a country of immigrants, and that could be more mainstreamed, and looking at health through that lens could be more mainstreamed.” (Researcher)</li> <li>“People are very conditioned to look by the 3 to 5 major race/ethnic categories. They are conditioned. So it takes conditioning to look through an immigration ancestry lens, and it takes conditioning to assess whether your data could be broken out further and to just make sure that you measured race/ethnic subgroup in the first place.” (Researcher)</li> </ul>
Targeted funding to collect high-quality	<ul style="list-style-type: none"> <li>“Having a call or concerted effort from funders (NIH, foundations, federal government, state government) that really advocates to this type of data collection.” (Researcher)</li> </ul>

disaggregated health data	
Marketing campaigns that articulate the value and significance of collecting and reporting disaggregated health data	<ul style="list-style-type: none"> <li>• “Why is this important, and I mention an economic argument earlier, but even if it is not economic, what are some common language that we can all use to explain why these things are important. We have touched on some now, and I am sure someone who is more eloquent could come up with some really nice, abbreviated talking points, but I think that is important, that message to get out, that work with RWJ, other foundations also, very good at delivering concise, effective messages, so I think that would be very helpful.” (Researcher)</li> <li>• “[T]he Robert Wood Johnson is a . . . leader in calling attention to the nation for health care future strategies, to push the envelope forward. So I would think that the Robert Wood Johnson could have a campaign, maybe not just on disaggregating data, but a campaign on Latino health . . . like they did with nurses, the future of nursing. How about the future of America in terms of Hispanic health? That would go a long way. (National)</li> </ul>
Investments in mentoring and training programs for researchers that focus on Hispanic health research	<ul style="list-style-type: none"> <li>• Create the infrastructure at the Hispanic serving institution to begin to do this, because that is where it’s important. (National)</li> <li>• “[W]e need to have more of those researchers that may not be Hispanic and know anything about Latino community get training on how to do research on Hispanics and to collaborate with Hispanic populations or community leaders, clinics, that have the populations.” (National)</li> </ul>
Promote disaggregation through legislation	<ul style="list-style-type: none"> <li>• “Mandates for collecting Latino subgroup data on publicly-funded surveys”</li> <li>• “Include language in legislation to target health disparities and addressing within group differences in health 21<sup>st</sup> Century Cures Act” (National)</li> <li>• “Partner with institutional leaders/ build a broad coalition with the decision makers” (National)</li> </ul>
Liberate data by making it publicly available and accessible	<ul style="list-style-type: none"> <li>• “Public use data sets, both at the federal and state and municipal level. There could be encouragement, pressure, to display . . . Having sat on both sides, I don’t think that there is a simple mechanism. I think it is a combination of raising awareness in the scientific literature, raising awareness among policy makers. I think funding sponsors can require it. Community based organizations can demand it and over time, things change. . . That is a really important question and I think as a nation I give us a B on how we are doing. More and more NIH is requiring researchers to generate public use data sets. That is very important. If you are going to pay me 4 million dollars to do a study, I should make it public use at some point so that it gets maximally used and as a funding sponsor, the NIH or some other federal agency could say we want you to collect and share information on this race/ethnic subgroup. So I think funding agencies</li> </ul>

	<p>and funding sponsors, both foundation and federal could make that a requirement, to liberate the data, get it out. That is what we did with New York City HANES, it is up and it is public use, all its race/ethnic subgroups, and all its ancestry is available. We have only just begun to publish it but it is available to everybody. And I think that government historically is very good at controlling data. And being the proprietor of the data is the old model for how government had the power and leverage. It has power and leverage in a number of ways, but I do think that it is increasingly recognized by government agencies that <u>liberating the data</u> is the new norm and is very important and a new way of having power and status and governance. I just think it takes a long time. New York City Health Department does a pretty good job, it has a lot of public use data sets. It could do even more. Other health departments around the country are probably not as far along. Some are, some aren't." (Researcher).</p>
Conduct mixed-method research to advance the science of disaggregated health data	<ul style="list-style-type: none"> <li>• "I think it would be really valuable. You can almost see someone really devoting a K grant or something to it and just use these sort of mixed methods that are becoming more en vogue to really understand it. And that is I think it's almost foundational. We're all using these questions that have evolved over time. And they're probably pretty good. But none of them probably received the treatment that they probably should have using these diverse methods and scientific method, research method." (Researcher)</li> </ul>