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Authors

Anunziata, Florencia
Cisneros, Cynthia
Natale Castillo, Maria
et al.

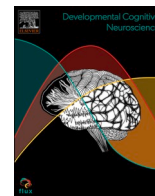
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¿Donde están? Hispanic/Latine inclusion, diversity and representation in the HEALthy Brain and Child Development Study (HBCD)

Florencia Anunziata^{a,*}, Cynthia Cisneros^b, Maria Isabella Natale Castillo^c, Alexandra Perez^d, Valeria Rodriguez^e, Sheila De La Cruz^c, Karla Estrada^f, Abigaile Durbal^d, Mishaska Jaramillo^g, Lidia Enriquez Marquez^h, Janet Nuñezⁱ, Myriam Peralta-Carcelen^j, Jessica Lee Wisnowski^{b,k}, on behalf of the HBCD Spanish Language and Culture Committee

^a Department of Pediatrics, University of California San Diego, San Diego, CA, USA

^b Department of Pediatrics, Children's Hospital Los Angeles, Los Angeles, CA, USA

^c Division of Newborn Medicine, Boston Children's Hospital, Harvard Medical School, Boston, MA, USA

^d Emory University School of Medicine, Atlanta, GA, USA

^e Center for Health Sciences, Oklahoma State University, Tulsa, OK, USA

^f Center for Human Development, University of California San Diego, San Diego, CA, USA

^g Department of Pediatrics, Children's Hospital of Philadelphia, Philadelphia, PA, USA

^h Substance Use Research and Education (SURE) Center, College of Pharmacy, University of New Mexico, Albuquerque, NM, USA

ⁱ Feinberg School of Medicine, Northwestern University, Chicago, IL, USA

^j Department of Pediatrics, University of Alabama at Birmingham, Birmingham, USA

^k Department of Pediatrics, University of Southern California, Los Angeles, CA, USA

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ABSTRACT

The HEALthy Brain and Child Development (HBCD) Study, a multi-site prospective longitudinal cohort study, will examine human brain, cognitive, behavioral, social, and emotional development beginning prenatally and planned through early childhood. Central to its mission of reducing health disparities is the establishment of the Spanish Language and Culture Committee (SLCC) within the HBCD framework, a significant step towards demographic representation and inclusivity in research. By addressing linguistic and sociocultural barriers and embracing the diverse identities of Hispanic/Latine individuals nationwide, the SLCC aims to promote inclusion, equity, and representation of all Hispanic/Latine subgroups, a population that has been historically misrepresented in health research. In this paper we describe the role of the SLCC in advocating for Hispanic/Latine families within the study, ensuring their inclusion from inception. This report also provides an overview of the SLCC organization, workflow, challenges and lessons learned thus far to reduce stigma and improve study outcomes, highlighting recruitment and retention strategies for the Hispanic/Latine population, and expanding outreach to promote inclusion across diverse Hispanic/Latine subgroups in the United States.

1. Introduction

The HEALthy Brain and Child Development (HBCD) Study is a NIH-funded multisite prospective longitudinal cohort study that aims to understand how the environment shapes development across the first decade of life (Nelson et al., 2024). More than 7000 pregnant individuals from diverse environments will be recruited to participate in HBCD. Cognitive, behavioral, social, and emotional development will be assessed together with structural, functional, and neurochemical

markers of brain development beginning prenatally and continuing through age 10. The overarching goal is to better understand the short- and long-term effects of both risk and protective factors, including prenatal substance exposure, mental and physical health, stress, socioeconomic factors, biological and genetic factors, parent/child interactions, and societal factors, on the trajectory of child development. This approach will enable us to identify the key developmental windows during which exposures may be most impactful on developmental outcomes.

* Correspondence to: UC San Diego, Department of Pediatrics, 9500 Gilman Drive, MC 0828, La Jolla, CA 92093-0412, USA.

E-mail address: fanunziata@health.ucsd.edu (F. Anunziata).

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In this paper, we present the premise for including the Spanish Language and Culture Committee (SLCC) among the core HBCD Working Groups. Additionally, we describe the role of the SLCC in ensuring inclusion and equity, namely, that Latine families are represented in the HBCD cohort and that neither language nor any other sociocultural barriers hinder their access to participation in HBCD or the results of HBCD to inform Latine communities. This report also provides an overview of the SLCC organization and workflow, challenges and lessons learned thus far, highlights recruitment and retention strategies for the Hispanic/Latine population and discusses plans for future outreach fundamental to the work of the committee.

1.1. Defining Hispanic / Latine (LatinX) in HBCD

Race and ethnicity are social constructs, that is, defined by society, including its governing bodies. The history of race in the United States (US) extends to colonial times. Every US Census, starting with the first in 1790, has categorized the race of individuals who were counted; however, despite the long history of Latine residents in the US, there was no systematic effort to count – or define – this group in the Census until the late 20th century. Today, there are several overlapping terms used to characterize individuals who trace their ancestry or heritage to the regions that span southward from Mexico to Chile/Argentina as well as parts of the Caribbean. The oldest term is Hispanic, which, defined by the US Office of Management and Budget, refers to individuals who trace their origin or ancestry to Spain or the 19 primarily Spanish-speaking countries in North, Central, and South America or the Caribbean. This definition leaves out individuals from related non-Spanish speaking countries such as Brazil and the Caribbean while including individuals whose ancestry is limited to Spain. For these reasons, many individuals prefer the terms Latino/Latina as a more inclusive term or gender-neutral constructs, LatinX and Latine, depending on local cultural preferences and attitudes toward gender-neutral language. In this paper, we will preferentially use the term Latine to refer to all individuals who trace their ancestry to the regions above, as this term is gender inclusive and is not limited by the language of ancestry or the language(s) spoken at home. However, we will also use Hispanic and other terms, as needed, in context.

2. Inclusion of Hispanic/Latine individuals in the HBCD study

2.1. Epidemiology

Critical to HBCD is the inclusion of a diverse sample that is representative of pregnancy and early childhood in the United States. This is necessary to ensure that the results are generalizable and able to inform public policy. According to the US National Vital Statistics, there are over 3.6 million live births annually, of whom, approximately one quarter are born to parents of Hispanic heritage, as defined above (Oskerman et al., 2023). As noted in the introduction, Hispanic or Latine individuals are not a homogenous group, but rather a diverse population of individuals who draw their ancestry from at least 21 different countries. The US does not include ancestry data among the publicly available birth data. However, the US Census does, and these data indicate that the origins of Latine adults in the US are shifting as immigration patterns change while the distribution of these populations varies widely across major metropolitan areas. Presently, the five largest Latine populations in the US by origin are Mexicans, Puerto Ricans, Salvadorans, Dominicans, and Cubans, while the fastest-growing are Venezuelans, Dominicans, and Guatemalans (Moslimani et al., 2023).

It is important to note that the vast majority of Latine individuals are US citizens and that approximately one quarter are third generation or later, meaning they were born to two US-born parents (Antman et al., 2022). Furthermore, Latine women no longer account for the majority of immigrant births (Livingston, 2019). At the same time, Latine children are more likely than other racial and ethnic groups to have at least one

parent who was born in another country, and as many as one quarter may have a parent who is not authorized to live in the US. These children are at risk for experiencing stresses associated with having a parent who is an unauthorized immigrant, making their inclusion critical to HBCD and our understanding of environmental stress on early child development in the US.

Language is another key consideration. Spanish language is commonly spoken in Latine households, with 85 % reporting that they speak Spanish to their children (Lopez et al., 2017). However, spoken language varies across immigrant generations: among immigrant parents, nearly all (97 %) report speaking Spanish to their children, while this falls to fewer than 50 % by the third generation. To date, research, most of which has been conducted on small samples, has been mixed regarding the presence of a bilingual advantage or disadvantage on cognitive performance (Bailey et al., 2020). Critical factors to consider include the timing of language acquisition, i.e., early (before age 6) vs late, whether the languages are learned simultaneously or sequentially, and whether language acquisition is balanced or English/Spanish dominant. Additionally, to date, there haven't been studies with sufficient sample size to look at the intersecting effects of language and other environmental factors on a child's cognitive development. Thus, HBCD aims to not only include a representative sample of Hispanic families but also families who are English and Spanish-speaking.

2.2. Latine individuals have been historically underrepresented in research

To date, historically minoritized populations, including Latine individuals, have been underrepresented in research, hindering our ability to generalize research findings to these groups. While 19.1 % of the US population is Hispanic; only 11 % of participants in clinical trials self-identify as Latine/Hispanic (Dreyfus et al., 2023). There are several, ultimately, unsurprising reasons that perpetuate this discrepancy, including mistrust, lack of access to information, competing demands limiting the time available for participation, fear of unintended outcomes, stigma, concerns over legal status, cultural values, acculturation, and language barriers (Aponte-Rivera et al., 2014; Eghaneyan and Murphy, 2020; George et al., 2014; Taylor et al., 2021).

The most highlighted barriers found in the literature are language and cultural barriers. For instance, differences in symptom reporting are due to language barriers (e.g. English as a second language) and health literacy barriers (e.g. monolingual Spanish speakers being less likely to seek medical care, especially when there is no access to Spanish-speaking providers) (Diaz et al., 2001; Valdez et al., 2011). A closer look at methodological concerns when conducting research with Hispanic Americans by Lange (2002), acknowledges that studies that recruit Spanish-speaking participants require ample time and resources. Additionally, cultural considerations must be made when designing studies that will include Hispanic Americans given that non-Hispanic investigators may unintentionally incorporate cultural biases into study instruments, data collection procedures, and interpretation of results. Though taking necessary steps may require additional efforts, attrition rates are lower in Hispanic participants when data collectors speak Spanish and originate from their culture (Lange, 2002).

2.3. Disparities in health outcomes

While several studies exist on health disparities and child outcomes in general (Hartwell et al., 2022; Howell et al., 2018), there is a gap in the literature on health disparities experienced specifically by Latine pregnant persons and the health outcomes of their children. This is consistent with the overall underrepresentation of Latine people in clinical research discussed above. Health disparities can generally be defined as differences in quality of care due to socio-demographic factors (Riley, 2012). This is not to say that there are specific biological factors that make Latine pregnant persons more prone to poor health

outcomes, as race/ethnicity are social constructs, rather it is to say that there may be environmental barriers or cultural buffers that may positively or negatively influence development (Gadson et al., 2017; Louis-Jacques et al., 2017).

Studies have indicated that racial-ethnic disparities in insurance stability may contribute to health disparities that affect Latine pregnant people and their children. Lower-income Latine pregnant individuals demonstrated a notably higher likelihood of being uninsured in the preconception and postpartum period compared with white non-Latine individuals (Daw et al., 2020). Lack of insurance leads to disruptions in physician care, increased usage of the emergency department, worsened self-report quality of care, and poor health outcomes (Daw et al., 2020). Social vulnerabilities such as poverty, structural racism, education, and stress may be exacerbated throughout the perinatal period, resulting in more adverse health outcomes (Baumgartel et al., 2023).

Continued medical care is vital throughout all stages of pregnancy. It is increasingly important that medical conditions that disproportionately affect Latine individuals be monitored throughout this time. According to the Centers for Disease Control and Prevention, the maternal mortality rate for Latine women in 2021 was 28 per 100,000 live births, which is a significant increase from previous years (Errisuriz et al., 2024; Hoyert, 2023). A recent study showed that Latine pregnant women have poor cardiovascular outcomes. The results projected that Latine women will overtake Black women as the population with the highest risk of adverse cardiovascular morbidity and mortality in the next few years (Gad et al., 2021). Several studies have looked into risk factors that are common among Latine women that increase the risk of cardiovascular disease, which include type 2 diabetes mellitus (Aguayo-Mazzucato et al., 2019), being overweight at the beginning of the pregnancy, as well as an increase in weight throughout the pregnancy (Hromi-Fiedler et al., 2016).

Studies on infant health outcomes have consistently highlighted the critical role of the gestational period in determining infant survival and health, with preterm birth (PTB) being the leading cause of infant mortality and morbidity globally and within the United States (Leonard et al., 2015; Reno et al., 2021). Defined as births occurring before 37 gestational weeks (Behrman and Butler, 2007), PTB includes both spontaneous and medically indicated deliveries (Stout et al., 2018), affecting 10.38 % of all US births in 2022 (Hamilton et al., 2023). Respective to race and ethnicity, 10.06 % of births for Hispanic mothers were preterm, compared to 9.44 % for non-Hispanic white mothers and 14.58 % for non-Hispanic black mothers in 2022 (Hamilton et al., 2023). Alarming, the prevalence of PTB among Hispanic mothers has surged by 12 % since 2014, surpassing rates among non-Hispanic white and black mothers (Martin et al., 2024). Unfortunately, governmental reports typically lack detailed statistics on nativity, ethnicity, generational status, and race within Hispanic subgroups, limiting our understanding of disparities in birth outcomes in this diverse population.

The disparities in PTB rates among Latine women in the United States are shaped by a multitude of sociodemographic factors and social determinants. Research indicates that certain factors heighten the risk within this population, such as poor socioeconomic conditions, adverse neighborhood environments, short inter-pregnancy intervals, low educational attainment (Behrman and Butler, 2007; Goldenberg et al., 2008; Kaufman et al., 2011; Leonard et al., 2015), perceived discrimination (Bediako et al., 2015), adverse prenatal occupational exposures (Von Ehrenstein et al., 2014), and young (Ruiz et al., 2008) as well as advanced maternal age (Leonard et al., 2015; Ruiz et al., 2008). Conversely, certain protective factors have been identified as significant in mitigating preterm birth risks among Latine women, including robust social support networks (Behrman and Butler, 2007; Tandon et al., 2012) and adherence to positive health behaviors (i.e. engaging in regular physical activity (Gollenberg et al., 2011), maintaining a balanced diet (Maldonado et al., 2022), and abstaining from smoking (Haskins et al., 2008), alongside access to culturally competent health-care characterized by adequate health insurance coverage and timely

access to prenatal care (Behrman and Butler, 2007; Castelló et al., 2012). Despite advancements in knowledge about birth outcomes, the intersectionality of risk and protective factors remains poorly understood (Goldenberg et al., 2008; Leonard et al., 2015).

2.4. The Hispanic/Latine Paradox

The Hispanic/Latine Paradox is an epidemiological phenomenon that refers to the unexpected positive health outcomes observed in these disadvantaged populations despite facing socioeconomic challenges such as lower education levels, reduced income, reliance on government assistance, and lower prenatal care (Brown et al., 2007; McGlade et al., 2004; Montoya-Williams et al., 2021; Rosenberg et al., 2005). In 2008, Ruiz et al. investigated the Hispanic acculturation phenomenon, examining how varying degrees of acculturation affect the risk of preterm birth and key reproductive hormones (e.g., progesterone and estrogen levels) during the parturition process (Ruiz et al., 2008). Various definitions and applications of the concept of acculturation among Hispanics were identified in multidisciplinary research studies (Caplan, 2007; Siatkowski, 2007; Thomson and Hoffman-Goetz, 2009). Acculturation among Hispanics is understood as the interaction between two cultures, Hispanic and U.S., and encompasses learning new language skills (English) along with adopting new values, changes in cultural beliefs, and practices to align with those of the new culture, while retaining aspects of the original culture (De La Cruz et al., 2000; Siatkowski, 2007). It represents an adaptation to a new sociocultural context, where individuals of Hispanic origin adjust to the cultural and environmental norms encountered in the United States (Gandhi et al., 2022; Gibson, 2001; Landrine and Klonoff, 2004; Siatkowski, 2007; Velasco-Mondragon et al., 2016). Latine women with higher acculturation levels to American norms, cultural beliefs, and English proficiency faced a fourfold increase in the likelihood of preterm birth (Ruiz et al., 2008). One explanation for this decline in health advantage may arise from alterations in the physiological stress response triggered by heightened acculturative stress and exposure to stressful life events (Almeida et al., 2023; Ruiz et al., 2008). However, the precise timing of this detrimental response to maternal and fetal health within the acculturation process remains elusive (Ruiz et al., 2008). Understanding and addressing acculturation-related risks are essential to enhance clinical care and effectively mitigate the rising prevalence of preterm birth within the growing Latine population (Flores et al., 2012; Ruiz et al., 2008; Shaw and Pickett, 2013).

Moreover, Latine women are disproportionately underrepresented in preterm birth research and are often subsumed under a singular group, primarily because of a shared language (Bediako et al., 2015; Behrman and Butler, 2007; Schaaf et al., 2013). This oversimplification obfuscates racial and ethnic variations and disparities in birth outcomes within the diverse Latine population, characterized by multifaceted ethnicities, cultures, and socioeconomic as well as genetic backgrounds. This oversight underscores the need to identify distinct risk and protective factors across different ethnic and racial groups, offering valuable insights for targeted interventions to reduce disparities and improve maternal and child health outcomes (Leonard et al., 2015).

There are many limitations among studies on the Hispanic/Latine-paradox and Latine health. First, current studies mostly focus on preterm birth and low birth weight, a phenomenon known as the 'Immigrant Birth Weight Paradox' (Dyer et al., 2011; Fleuriet and Sunil, 2018; Flores et al., 2012; Fuentes-Afflick et al., 1999; Romero et al., 2012). More research is needed on other pregnancy, perinatal, and childhood outcomes to test the validity of this paradox throughout this sensitive period of development. Second, further studies may need to include larger sample sizes to be able to stratify many factors simultaneously (Flores et al., 2012), including social support, acculturation measures, substance use, health insurance, language preference, legal status among foreign-born Latine, and country of origin of foreign-born. Finally, many studies have used data predominantly from states with

very large Latine populations (such as California), making it difficult to generalize. Therefore, it is essential to conduct research that includes populations from different states in the U.S. to confirm or refute health patterns reported from other areas.

2.5. HBCD Spanish language and culture committee

To bridge these research gaps, longitudinal cohort studies such as HBCD can utilize a lens that is not only cognizant of but actively aims to reduce, health disparities and racial/ethnicity misrepresentation in science. Moreover, to be able to assist clinicians in modifying or preserving specific pregnancy/childhood health factors that may vary among different Latine subgroups in the country, the inclusion of Latine individuals is essential in HBCD, the largest nationwide longitudinal study on pregnancy and child outcomes.

To ensure equitable participation among Latine individuals, particularly those who were monolingual Spanish-speaking or Spanish-English bilingual, HBCD formed a Spanish Language and Culture Committee. Initially charged with ensuring that all participant-facing materials – from recruitment materials to assessments – would be available to Spanish-speaking participants, the role of the SLCC has been extended to considerations of recruitment/retention and diversity, equity, and inclusion (DEI) through cross-participation in subgroups on the HBCD Recruitment/Retention and DEI working groups (WGs), respectively. Our efforts have shown collaborative results that further HBCD’s mission of representing a diverse national population to inform child development. Hence, we strongly believe that integrating a Spanish Language and Culture Committee into all research studies is vital to ensuring diverse representation and effectiveness within scientific research.

3. HBCD-SLCC organization and integrative workflow

3.1. Presence in the HBCD

As mentioned, HBCD aims to characterize early development, beginning prenatally and extending through the first decade of life. The currently funded protocol includes visits 1 (prenatal) through 4 (9–15 months) as shown schematically in Fig. 1. For details about the protocol and each of the domains sampled (e.g., biospecimens, EEG, MRI, wearable sensors), please consult the additional papers in this Special

Issue (Cioffredi et al., 2024b, 2024a; Dean et al., 2024; Fox et al., 2024; Nelson et al., 2024; Pini et al., 2024; Sullivan et al., 2024). This paper aims to describe the role of the SLCC in the design and implementation of this protocol. The SLCC collaborates closely with other HBCD workgroups, study leadership, and stakeholders adhering to a unified approach while ensuring cultural sensitivity tailored to the Hispanic/Latine population it serves. Across 27 sites, the SLCC creates and oversees the all HBCD Spanish content, documents, and materials and carefully reviews submissions before granting approvals.

3.2. Operationalization and committee workflow

The SLCC was formed in the summer of 2022 at the request of one of the directors. The committee was initially tasked to comment on the “readability” of all professionally translated materials (recruitment, study measures, newsletters, etc.). This committee was modeled after the Spanish Language Committee in the Adolescent Brain Cognitive Development (ABCD) Study. The members of the SLCC are HBCD staff (e.g., clinical research coordinators, study navigators, recruiters, site monitors, program managers, clinical research supervisors) and researchers (e.g., research assistants, PhD students, Postdocs, Principal Investigators) already involved in the HBCD study, representing HBCD sites across the US that are engaging directly with the Spanish-speaking communities. The call for volunteers for the committee emphasized the importance of securing participation from a diverse array of Spanish speakers representing various countries and dialects of our HBCD Study population. There were not specific requirements of language proficiency. Members were encouraged to self-identify their proficiency levels in Spanish (Native Speaker, Heritage Speaker, Spanish as a Second Language, Experience working with Spanish-speaking individuals) and provide their strengths for reviewing, such as grammar, flow, cultural aspects, and other considerations.

The SLCC is also responsible for reviewing consortium-wide and site-specific materials that have been translated by translation companies, bilingual staff, and university translation services to ensure cultural accuracy and correct translation. The initial workflow was as follows: the committee chair would receive professionally translated documents, subsequently arranging them for distribution to the entire committee in both English and Spanish versions, thereby allowing members to provide feedback via an Excel spreadsheet. Once the comments were gathered the chair would review and edit the documents. If there was a



Fig. 1. HBCD Study timeline and assessments for visits 1–4, created as a recruitment resource to visually inform participants about the study and consent process.

discrepancy or several ways to state something the chair would choose the version that the most people would understand. For more details about the SLCC translation review workflow please see Fig. 2.

In some cases, committee members also provide translations for short documents, such as those requested by the Social Media HBCD WG, a subgroup of the Communications, Engagement, and Dissemination Committee (CED). This subgroup creates short texts for posting on the HBCD social media platforms and requests the SLCC to translate them into Spanish for the Spanish-speaking community (Cole et al., 2024). The chair of the Social Media subgroup selects about five posts per month for translation, those posts are then translated by two SLCC members who are also part of the Social Media group. The translated materials are then submitted to the Spanish Language and Culture Committee for review by the co-chairs and members. Feedback is provided, necessary changes are made, and the translations are finalized. Lastly, the co-chairs sign an attestation document and items are sent for IRB approval.

As the group grew and we approached the beginning of recruitment for the main study, the SLCC evolved to focus not only on reviewing HBCD document translations but also on developing culturally sensitive recruitment and retention strategies for Hispanic/Latine participants. This included training staff involved in evaluating Spanish-speaking participants, ensuring that Spanish-speaking participant's feedback was incorporated into the study, and addressing broader cultural considerations. To support these efforts, we appointed two new co-chairs and added more members to address the linguistic nuances and cultural needs of these communities.

3.3. Challenges, best practices, and recommendations

We encountered several challenges during the creation and development of the SLCC that needed to be overcome to ensure the validity

and reliability of the HBCD Study's Spanish language protocol. These challenges were primarily due to the urgency to start the study in Spanish immediately after the English version was ready. This urgency, coupled with limited time for review of translated documents, posed significant hurdles for ensuring the reliability of the translations. Additionally, in some cases the responsibility to translate fell on individuals who were not professional translators, leading to concerns about accuracy and linguistic nuances. Finding an appropriate translation company to solve this problem proved to be another challenge, exacerbated by inconsistencies in translating words or phrases, among employees within the chosen company. Furthermore, initial surveys and questionnaires received for review that were supposedly validated by previous studies, were poorly translated, with grammatical errors, hindering the process further. The absence of a standardized assessment of language proficiency for all staff involved in the HBCD project added to the complexity we encountered in our SLCC creation and process. We highly recommend future research studies include a language proficiency assessment from a certified testing company of every staff member during the hiring process.

To address these challenges, the SLCC implemented innovative solutions and, what we considered, best practices (Fig. 2). One key decision was to select one translation company between many different companies that were being requested to translate all HBCD materials. It was also crucial to request the translation company to assign the same translators consistently for all HBCD documents and materials, ensuring continuity and adherence to specific vocabulary, especially for repetitive terms such as the study's name. Some recommendations for future studies would be starting the translation process simultaneously with the English version and involving Spanish speakers from the very beginning stages of the study, such as the grant writing phase. Drawing from experiences like the ABCD and HBCD studies, the committee proposes the inclusion of a Culture and Linguistic Associate Director role

HBCD Spanish Translation Workflow

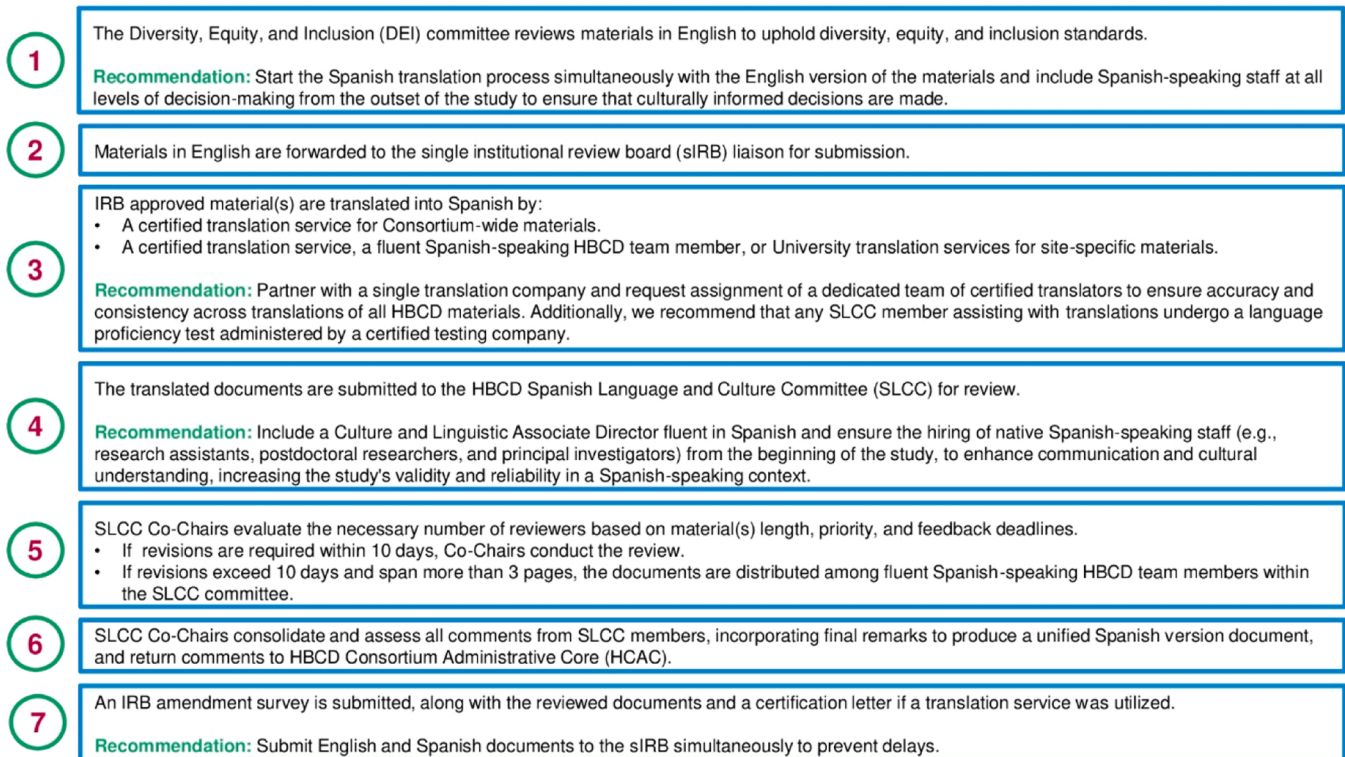


Fig. 2. Integrated Spanish Language Translation workflow and recommendations, outlining the collaboration between the SLCC committee, SLCC members, translation sources (i.e., certified translation companies, bilingual staff, University translation services), and the HCAC to disseminate sIRB approved Spanish-translated materials across the consortium and the general public.

who is fluent in Spanish, or other language being used in the study, and hiring native Spanish-speaking research assistants, postdoctoral researchers, PhD students and principal investigators. These individuals, embedded within participant and community engagement roles, would facilitate smoother communication and cultural understanding throughout the study, thereby enhancing its overall validity and reliability in the Spanish-speaking context.

4. Recruiting and retaining Hispanic/Latine individuals in science

Recruiting and retaining Hispanics/Latine in science continues to be challenging for researchers, citing Spanish as a complex language, combined with scarce resources, limited funds, few bilingual personnel, and other competing priorities. Researchers may frequently investigate what is familiar and of interest to them. Issues of ethnicity and culture are not usually central to mainstream investigators. Although deemed important, culture or racial/ethnic variation is frequently an afterthought or an addendum when included in research (Cwalina et al., 2022; Durán, 1998). Barriers contributing to low participation of Hispanics in research include stigma, low literacy, childcare, loss of wages, time, and disruption of family and work responsibilities, all which stage larger problems for underserved populations, higher incarceration rate, and unmet needs (Ellington et al., 2006; Jaramillo et al., 2023). Additional barriers include community beliefs/attitudes/knowledge, intrusiveness (time, routine, family), complexity of biospecimen collection, lack of access to resources, transportation, limited opportunities for screening education, and uncertainty of cost surrounding screening (Bonevski et al., 2014; Dreyfus et al., 2023; George et al., 2014; Shahghahi et al., 2011).

One of the more challenging barriers to address is the mistrust of research and researchers in the Hispanic community. George et al. (2014), published that mistrust included fear of purposeful mistreatment, fear of unknown research procedures, and a fear of unintended consequences. Signing the informed consent, for example, was cited as a fear for participants signing away their rights or “free will”. The fear of unknown research procedures can be mitigated by having translated materials and bilingual/bicultural staff to review each step in the study process (George et al., 2014). However, the fear of purposeful mistreatment and unintended consequences stems from a history of unethical treatment. Latina women and their reproductive health have been targets for mistreatment in the medical field. Between 1920 and 1945 under the California Eugenics Law, doctors told women in labor that their welfare would be terminated if they did not agree to sterilization, doctors did not provide information regarding the procedures’ permanence, they cited sterilization is necessary, and in some cases proceeded with sterilization without any consent (Novak et al., 2018). These authors, analyzed over 17,000 forms recommending patients for sterilization and found that Latina women were at 59 % greater risk of sterilization than non-Latinas. In the 1950s poor and uneducated Puerto Rican women were given the pill, Enovid, with minimal information on potential side effects and risks. Six women died in this study presumably due to the extremely high doses of hormones the pill contained (Shamoo, 2023). Then again, from 1961 to 1976, ten thousand Puerto Rican women were enrolled in a study about oral contraception with no information about potential risks (Shamoo, 2023). Instances like these within the United States, and globally, serve to underscore the factors contributing to mistrust within the Hispanic community.

Acculturation is commonly cited as a barrier to research participation. A literature review by Hunt et al. (2004) concluded that the variable acculturation in health research may be based more on ethnic stereotyping than objective representations of cultural differences, 66 % of the articles provided no definition of acculturation, while the other 33 % provided vague definitions. Further suggesting that interest in US health research on racial/ethnic categories did not properly acknowledge the impact of socio-economic inequalities of people living in the US

(Hunt et al., 2004). A recent review article (Dreyfus et al., 2023) found that only 44 studies discussed barriers to participation for any minority group and of those 3 were exclusively with a Latine population. Furthermore, most studies group Hispanic/Latine together as a monolithic population without examining the heterogeneity within this category relating to aspects such as historical and geographical background, immigration status, language, and generational differences (Enid Zambrana et al., 2021).

Dreyfus et al., (2023), also looked at strategies that were effective in recruitment, participation, retention, or adherence of Hispanics in research. Effective strategies use community based participatory research approaches (using community partners, engagement of community and communication), bilingual bicultural clinical research assistants (Ragavan and Cowden, 2020), building on special relationships, involving a Community Advisory Board and community partners. Bilingual flyers, announcement, presentation at churches, recruitment materials at community events, communication strategies, digital marketing (Ashford et al., 2023). For example, the collaboration and engagement of *promotoras* in research studies. *Promotoras* are lay Hispanic/Latine community members who have been trained to educate the community on basic health principles and who serve as a liaison between the community and health professionals (Rangel et al., 2019; Vincent et al., 2013)(Rangel et al., 2019).

This highlights the importance of providing a clear explanation of the risks associated with each research study and establishing rapport between the research staff and participants. Medical mistrust and perceived discrimination can be diminished by consistently improving health research literacy. Participants need to be assured of their rights and protections for human participation in research, and that there is a safe space to learn and inquire about the research at any time of the study. For this, concordance of spoken language with the physician or research staff, appropriate tone and nonverbal communication when interacting with participants, provision of study materials in different languages at an appropriate literacy level, and inclusion of culturally relevant terms and images, will dramatically improve participation in research (Andrulis and Brach, 2007; Hernandez et al., 2020; Rangel et al., 2019).

In sum, improving recruitment, participation, retention of Hispanics/Latine subjects in clinical trials or observational studies is a multifaceted issue. There is no universal strategy; however, using a combination of elements that have been used and proved to be effective ways can be tailored to the population being studied.

4.1. Recruitment strategies in the HBCD study

Recruitment of Spanish-speaking, Hispanic, or Latine populations for longitudinal studies requires culturally sensitive and inclusive practices to ensure the representation and validity of research findings. Key strategies currently implemented within the HBCD Study for recruitment include the employment of bilingual staff, provision of translated documentation (Fig. 3), and targeted interactive engagement materials via community engagement platforms and events tailored to the demographic (Harden et al., 2024)).

Establishing trust and rapport needs skillful cultural navigation and acknowledgment of societal norms and values. To build trust within the community, the HBCD consortium employs a hybrid approach integrating community outreach initiatives, collaboration with established community partners to cultivate trust, and the creation of the Spanish Language and Culture Committee to support and guide sites that may not have a lot of expertise with the recruitment of the target population (Harden et al., 2024). Methodologies incorporate active participation by staff in community events such as resource fairs, community events, parent meetings, food pantries, and baby showers. Multiple sites have also partnered with clinics in their areas that mainly cater to Latine or Spanish-speaking populations. Supplementary tactics involve the dissemination of translated recruitment materials within the community

Fig. 3. Dual language HBCD study recruitment poster.

that are provided by the consortium. While some sites prioritize in-person recruitment endeavors, others resort to remote techniques such as cold calling (Harden et al., 2024). However, the consortium faces several barriers, notably staffing limitations hindering direct community engagement efforts. Additionally, challenges encompass inadequate technological access and language proficiency among the target population, hindering communication and follow-up processes. Skepticism towards longitudinal studies and mistrust of scientific endeavors further pose significant hurdles, exacerbated by the insufficiency of translated recruitment materials tailored to the specific demographic. Though there are different barriers faced by sites across the consortium to the recruitment of this population, many have successfully recruited Hispanic or Latine participants. We also see the mix of overrepresentation of Hispanic participants for some sites; however, they may not always be monolingual Spanish speakers.

4.2. Retention strategies in the HBCD study

On the retention front, the HBCD Study employs a comprehensive strategy to mitigate attrition among Spanish-speaking participants. This involves prioritizing cultural competency through the translation of study materials into Spanish, engaging in social media outreach, and recruiting bilingual staff to facilitate creating and maintaining close relationships with participants across time and different visits (Feldstein Ewing et al., 2022). The HBCD Study enhances participant engagement by incorporating various light touches throughout the study, including

providing culturally appropriate incentives (e.g., bilingual children's books), sending friendly visit reminders, giving thank you cards (Fig. 4) and delivering personalized birthday and holiday cards. Additionally, supportive measures such as flexible scheduling, transportation assistance, childcare, and meals are provided to minimize participation barriers. Participants are connected with a study peer navigator (Harden et al., 2024; Nelson et al., 2024) who offers resource referrals and links them to essential social services like legal and immigrant assistance, English as a Second Language classes, and access to food pantries. Some recruitment sites have organized community drives to collect maternal and child essentials (e.g., formula, clothes, car seats, etc.), while others have partnered with nonprofits to ensure a steady supply of diapers and feminine hygiene products for interested participants. Additionally, certain recruitment sites collaborate with community organizations, including Latine agencies, to stock family closets where participants can access essential items as needed. As the study progresses, the HBCD staff recognize participants' evolving needs and remain committed to adapting retention strategies based on community feedback, thereby fostering trust among our diverse Spanish-speaking participants.

5. Diversity, equity, and inclusion

The HBCD Study is open to people of every race, ethnicity, religion, gender, and sexual orientation, regardless of national origin, education or income level, or health insurance status. This is essential to ensuring the study objectives, namely, developing a diverse cohort that is representative of pregnancy and early childhood in the US. The HBCD DEI working group is responsible for establishing effective approaches to promote diversity, equity, and inclusion across all facets of the study; however, it is the responsibility of each working group, including the SLCC, to ensure that these efforts are carried out across the consortium (Murray and Slopen, 2024). DEI has established workflows for reviewing each protocol and measure by independent reviewers to identify any



Estimado

¡Ha sido un placer verlo/a!

Nuestro equipo del estudio HBCD está muy agradecido por todo su tiempo y apoyo a esta investigación. ¡Nos queda tanto por descubrir sobre cómo crecen y aprenden los bebés!

No podríamos hacerlo sin personas como usted.

Atentamente,

Fig. 4. Thank you card designed as a light touch to keep participants engaged with the HBCD Study and study staff.

occurrence of bias along the following dimensions: gender, heteronormative or nuclear family assumptions, ableism assumptions, racial bias, cultural bias, and coded language (Murray and Slopen, 2024). Members of the SLCC participate in these reviews. Additionally, the SLCC has worked collectively, and sought input from external consultants, to determine how best to address challenges such as gender-neutral language in Spanish, given that gendered language is not only central to Spanish but also that perspectives on gender neutral language within the Latine population are highly varied.

Central to DEI is the support, inclusion, and training of underrepresented populations in health research. As discussed above, ensuring that underrepresented populations are represented among the staff and the leadership of HBCD is vital to these efforts. The DEI administers surveys consortium wide with the intent to capture and follow staff diversity characteristics, growth, dimensions diversity, differentiation of staff, co-investigator status, and other language capacity (fluency in Spanish, multi-lingual) (Murray and Slopen, 2024). Additionally, the SLCC has set forth guidelines for determining fluency in Spanish and for staffing considerations across the consortium. The effects of these efforts, in turn, are monitored through participant feedback, with the SLCC playing a key role in reviewing feedback from Spanish language participants and addressing concerns.

The inclusion of primarily Spanish-speaking Latine participants in the HBCD Study will offer valuable knowledge in how we can improve care for children and families in the United States in a more diverse, equitable, and inclusive way. To appropriately navigate the diversity of this demographic, the majority of SLCC members are fluent or native heritage Spanish-speakers. These members work hard to ensure cultural competency and inclusive language are at the forefront of every participant interaction. Given how racial and ethnic minorities often lack representation in research (Adynski et al., 2023; Cwalina et al., 2022; Lopez et al., 2017), the SLCC's role as a resource for study sites to better support Hispanic and Latine families is critical in promoting equity.

6. Conclusion

The HBCD Study is the largest longitudinal study of early brain and child development across the United States. The inclusion of the Spanish Language and Culture Committee within the HBCD framework signifies a crucial step towards fostering demographic representation, inclusivity, and equity within health research. By addressing linguistic and cultural barriers, and embracing diverse identities within the Latine individuals co-existing in different states of the country, the HBCD initiative is poised to uncover groundbreaking scientific discoveries. The SLCC aims to access, engage, and represent HBCD Latine families, ensuring their inclusion in research studies from the beginning, paving the way for improved health outcomes not only within Latine communities but also for society at large. Through these efforts, the HBCD Study will create a comprehensive high-dimensional dataset and will inform public policy to improve developmental trajectories and health disparities, ultimately benefiting all children and families across the nation.

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CRedit authorship contribution statement

Florencia Anunziata: Writing – review & editing, Writing – original draft, Visualization, Supervision, Methodology, Investigation, Conceptualization. **Cynthia Cisneros:** Writing – review & editing, Writing – original draft, Conceptualization. **Maria Isabella Natale Castillo:** Writing – original draft. **Alexandra Perez:** Writing – original draft. **Valeria Rodriguez:** Writing – original draft. **Sheila De La Cruz:** Writing – original draft, Conceptualization. **Karla Estrada:** Writing – original draft, Project administration. **Abigale Durbal:** Writing – original draft. **Mishaska Jaramillo:** Writing – original draft. **Lidia Enriquez Marquez:** Writing – original draft. **Janet Nuñez:** Writing – original draft, Conceptualization. **Myriam Peralta-Carcelen:** Writing – original draft, Supervision, Investigation, Funding acquisition, Conceptualization. **Jessica Lee Wisnowski:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Funding acquisition, Conceptualization.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Jessica Lee Wisnowski reports financial support was provided by National Institutes of Health. Myriam Peralta-Carcelen reports financial support was provided by National Institutes of Health. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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