Urgent Action Needed to Ensure Systematic, Inclusive and Comprehensive Data Collection across the COVID-19 Continuum of Care to Inform an Equitable COVID-19 Response for the Latinx Community

The COVID-19 Latinx Task Force is a national group of over 40 organizations. The mission of the COVID-19 Latinx Task Force is to strategically articulate, bridge, and connect Latinx/Hispanic serving organizations and build a repository and collective effort that provides authoritative public health information, resources, and leadership to Latinx communities, by delivering timely, life-saving information and health access during COVID-19, and beyond.

The goal of the statement is to call attention to the urgent need for complete and accurate data reporting for COVID-19 across the spectrum of data collection including symptoms, testing, infection rates, case reporting, hospitalizations and deaths.

On June 4th, 2020 the U.S. Department of Health and Human Services (HHS) announced new Guidance that specifies what additional data must be reported to HHS by laboratories along with Coronavirus Disease 2019 (COVID-19) test results. The Guidance standardizes reporting to ensure that public health officials have access to comprehensive and nearly real-time data to inform decision making in their response to COVID-19.

As the country grapples with reopening in a phased approach, engagement of Latinx communities in population health programs and access to clear and accurate data is essential to communities and leadership for making decisions critical to a phased reopening. We're very concerned about the lack of data if Latinx communities don't actually have access to COVID-19 programs (testing, prevention, symptom monitoring, access to clinical trials and vaccines, etc.) since that will impact how resources are directed.

The new reporting requirements advocate for the reporting of the following information when for testing:

- Patient age
- Patient race
- Patient ethnicity
- Patient sex
- Patient residence zip code
- Patient residence county

We recognize this is a major effort in using data to inform decision-making and urge the adoption of this reporting as soon as possible to ensure useful, accurate and actionable data.

In light of the recent national figures showing that Latinx communities are increasingly amongst the most impacted by COVID-19, we urge for more detailed and nuanced data collection and community engagement that accounts for the diverse racial/ethnic, national origin, and preferred language of those most impacted. According to the CDC, Latinx community now accounts for 34% of COVID-19 cases nationally, only slightly behind the proportion of White cases (35%). Given the variable access to testing within Latinx communities, this figure is also likely an undercount. This highlights a glaring disproportionate toll on Latinx community and is particularly high in the under 17 years of age group, where Latinx children and adolescents account for 53% of the COVID-19 cases within that age group.
Latinx communities also account for the highest proportion of COVID-19 infections amongst the 18-44 age group (42.5%).

Furthermore, Latinx individuals are more likely to report severe symptoms associated with COVID-19 despite demonstrating lower mortality as compared to Black people who experience the highest mortality rates. Recent data illustrates the inequitable severity and morbidity also impacting the Latinx community, especially now amongst the younger age groups. Latinx patients are hospitalized at a rate 4 times higher than their White counterparts. A recent study by US World News found that 1 in 12 Hispanic households said someone in their home experienced severe COVID-19 symptoms at least once from late March to late May, compared with 1 in 21 non-Hispanic households. Finally, the death rate of Latinx people with Covid-19 continues to increase over time. As of June 24th, 1 in 3,200 Latinx people has died (or 31.1 deaths per 100,000) a higher death rate than for White people (1 in 3,600 or 28.5 deaths per 100,000). This disparate death rate results in an additional 1,500 lives lost for Latinx community. Despite these alarming facts, there are concerns that this is an undercount for the Latinx community given that data is not consistently collected for all racial/ethnic demographics across all states and that there has been limited access to testing services geared towards the Latinx community.

There is still a large amount of missing data specific to race/ethnic data reporting for confirmed cases, hospitalizations and deaths. Many reasons exist for this missing data but amongst the Latinx community there is a deep level of mistrust between the community and the government which also extends to the healthcare and public health sector. These concerns are about the extent to which privacy and confidentiality will be maintained given the sensitivity of data provided. Furthermore, reports around misclassification of Latinx as White or other racial/ethnic groups may present an even greater undercount about the true impact of Covid-19 in the Latinx community. Finally, we also acknowledge that this dependence on lab reporting and case reporting as a marker of our nation’s progress in addressing the Covid-19 pandemic does not account for those who are unable to access testing.

In light of all these issues, we propose that mandated agencies and all sectors responsible for data collection adopt the following:

1. Standardize collection and reporting of race and ethnicity in health data that utilizes local, state, federal and territorial funds.
   
   a. Comprehensive and expanded data collection for Latinx and other racial/ethnic populations is urgently needed.
   
   b. Disaggregated ethnic categories (e.g., Mexican, Puerto Rican) and country of birth data is necessary for appropriate tailoring and public health messaging.
   
   c. Utilize or, if missing, develop best practices for sociodemographic data collection inclusive of racial/ethnic categories, socioeconomic status, educational level, and sex/gender to promote consistent use of these tools in healthcare settings.

2. Standardize collection and reporting of preferred language in health data that utilizes federal funding, in support of state, local and territorial efforts.

   a. Preferred language or primary language is sorely needed to inform public health messaging and to ensure that the demographics of the healthcare workforce reflect the needs of the various populations.

   b. We advocate for the systematic use of top 20 languages spoken in the US which requires public investment in sustained and accessible translation and interpreter services.
3. Standardize collection and reporting of workforce and occupation to inform potential emerging outbreaks and create rapid response efforts. At a minimum, we request that the CDC extends the workforce and occupation data collection beyond healthcare workers to include all essential workers including those in the farmwork, food packaging and distribution, restaurant and retail, transportation and maintenance industries.
   a. Add fields to collect name/type of lab and lab zipcode to inform where tests are performed
   b. Provide best practices, training, and technical assistance for mandated agencies and all sectors responsible for data collection to record accurate demographic data and to rigorously maintain testing, hospitalization, morbidity, and mortality records.

4. Ensure that data collection and reporting tools are multicultural and multilingual when they are developed to meet the needs of the communities they serve.
   a. Tools in other languages, especially Spanish, should be launched in conjunction with English-language tools and should undergo rigorous bicultural development process of translation and back-translation by native or fluent Spanish-speaking professionals with content area expertise.
   b. Tools developed should undergo cognitive testing when adapted for use with diverse Latinx ethnic communities to ensure conceptual equivalence of any instrument regardless of how well validated it appears to be.

5. Provide a plan for classifying Latinos and other racial/ethnic minority groups that are not being properly categorized with respect to COVID-19 testing, morbidity, and mortality.

6. Ensure the utmost privacy and confidentiality of the data collected for all public health and healthcare efforts and initiatives similar to the NIH Certificates of Confidentiality that offers extended privacy protection and limited access for any identifiable and sensitive data collected.

7. Invest in a multilingual and multicultural communication campaign to ensure that people are aware of the need for the collection of this sociodemographic data and that highlights the privacy and confidentiality protections afforded to healthcare, research and public health institutions.

8. Ensure the use of community-based resources to fill the gaps with appropriate data collection and access to services among Latinx communities.

9. Encourage research institutions and agencies to use community solutions to bridge the gap in data collection and lack of access to services, for example by using Promotoras or Community Health Workers to conduct community needs assessments in their communities and with their networks.

10. Expand upon and invest in the data infrastructure that informs public health to include data assets from other sources such as EMT, market scans, research studies and ensure these data assets are coordinated at the national level.

11. Where there is missing data because of lack of access to services, we propose directing funding towards the Latinx community to ensure that services are accessible. Public health responses should be culturally-specific to address concerns regarding trust and confidentiality such as increased access to mobile testing in communities.
12. Develop and fund a strong public health and research infrastructure to train and equip Promotoras, or community health workers, to collect data within their networks and communities.

13. Develop qualitative research agenda and Latinx focused story-telling campaign to gather more in-depth understanding of the challenges, strengths and opportunities to address the urgent and detrimental impact of Covid-19 that is uniquely attuned to the diversity of the Latinx community.