H1N1 Influenza Pandemic and Racially and Ethnically Diverse Communities in the United States

Assessing the Evidence and Charting Opportunities for Advancing Health Equity

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EXECUTIVE SUMMARY

Background

Racially and ethnically diverse communities have historically been disproportionately affected by disasters and public health emergencies in the United States. Factors related to socioeconomic disadvantage, limited English proficiency, cultural differences, distrust in government, and a legacy of inattention to the distinct needs of diverse communities have repeatedly contributed to elevated rates of mortality, morbidity, injury, and economic loss for these populations. The complexity, and injustice, of these dynamics played out on a national stage in 2005 following Hurricane Katrina which prompted the U.S. Department of Health and Human Services' Office of Minority Health to establish the National Consensus Panel on Emergency Preparedness and Cultural Diversity.

The mission of this Panel is to provide guidance to national, state, territorial, tribal and local agencies and organizations on the development of effective strategies to advance emergency preparedness and eliminate disparities among racially and ethnically diverse communities. Since its inception, the Panel has worked within an all-hazards framework to explore the drivers of racial and ethnic disparities in disaster and public health emergency outcomes and identify opportunities for intervention. The H1N1 Pandemic of 2009-2010 provided an unfortunate opportunity to explore the applicability of the Panel's findings and recommendations within the context of a widespread outbreak of a novel and communicable disease.

Purpose

The purpose of this report is three-fold. First, it intends to offer a thorough synthesis of peer-review research, major reports and other publications documenting persistent, significant racial and ethnic disparities in morbidity and mortality associated with the 2009-2010 H1N1 pandemic. Second, the report explores reasons for the disparities observed in exposure, susceptibility and treatment. Finally, this document utilizes a unique and comprehensive framework—grounded in theory and practice, as developed by the National Consensus Panel on Emergency Preparedness for Cultural Diversity—to offer concrete recommendations for integrating diversity and equity into pandemic influenza planning and response. It, therefore, serves as a resource and reference on pandemic influenza and diverse communities. This report is intended for use by a broad audience, including public health agencies, health care organizations, community-based organizations, policymakers and others working to plan for, educate, treat and respond to diverse communities in an influenza pandemic.

Reviewing the Evidence: Racial and Ethnic Disparities in H1N1 Morbidity, Hospitalization, and Mortality

While existing research provides clear evidence of racial and ethnic disparities in H1N1 outcomes, these outcomes vary across geographic localities, highlighting the interplay of a complex set of dynamics related to exposure, susceptibility and resistance. In this section, we present the evidence highlighting the nature, scope and extent of racial and ethnic disparities in morbidity, hospitalization and mortality.

While patterns in the distribution of H1N1 morbidity, hospitalization, and mortality by race and ethnicity varied between geographic regions, national and local data generally confirm the presence of disparities. For example, analysis of Behavioral Risk Factor and Surveillance System data from 49 states found that rates of self-reported influenza-like illness (ILI) was substantially higher among American Indians and Alaska Natives (16.2%) than Non-Hispanic Whites (8.5%). A study from King County, Washington revealed that while African Americans and Asians comprised just 6% and 14% of King County's population, they accounted for 21% and 31%, respectively, of reported cases in emergency department settings. In terms of morbidity severity, data from the Emerging Infections Program revealed that American Indians and Alaska Natives (32.7), Hispanics (30.7), and African Americans (29.7) all had higher age-adjusted rates of H1N1 hospitalization than Non-Hispanic Whites (3.0 per 100,000) during the second wave of the pandemic. A similar trend was also evident during the first wave of the pandemic.

National data also suggest the presence of racial and ethnic disparities in H1N1 mortality—particularly among Hispanics and American Indians and Alaska Natives. Data reported to the Influenza-Associated Pediatric Mortality Surveillance System showed that nearly one-third of the confirmed 278 H1N1-associated deaths among individuals younger than 18 years of age occurred among Hispanics, despite the fact that they only accounted for 22% of the pediatric population. A 2009 review of H1N1 surveillance data from 12 states, representing 50% of the total American Indian and Alaska Native population, found that the H1N1 case-specific mortality rate for this group was four times that of all other racial and ethnic populations combined. This fourfold disparity in cause-specific mortality observed in 2009 mirrors estimates of the disparity in mortality between American Indians and all other racial and ethnic groups during the Great Pandemic of 1918—underscoring the enduring, and structural nature, of health disparities.

Putting the Pieces Together: Potential Reasons for Racial and Ethnic Disparities in H1N1 Morbidity and Mortality

A robust body of research conducted before, during, and after the pandemic suggests that these disparities in morbidity, hospitalization, and mortality were driven by socio-cultural and economic factors which lead to increased H1N1 exposure, greater H1N1

susceptibility, and delayed H1N1 treatment among racial and ethnic minorities. Regarding H1N1 exposure, linguistic barriers and cultural preferences for obtaining risk communication information are likely to have limited the extent to which some racial and ethnic groups were reached by, and understood, social distancing recommendations. Empirical evidence also suggests that the absence of paid sick leave policies, domestic and urban crowding, and reliance on public transportation all hindered these groups ability to comply with such recommendations.

Differences in rates of H1N1 vaccine uptake between racial and ethnic groups are likely to have contributed to disparities in H1N1 susceptibility. This was particularly the case among African Americans who were vaccinated against H1N1 at a rate approximately half that of Non-Hispanic whites. Research on attitudes towards seasonal and H1N1 influenza vaccination suggests that such disparities were, in part, the result of negative attitudes towards vaccine safety and efficacy. Long-standing racial and ethnic disparities in the prevalence of chronic conditions—such as asthma and diabetes—are also likely to have increased H1N1 susceptibility as these conditions were major risk factors for adverse H1N1-related outcomes.

Antiviral agents such as oseltamivir and zanamivir were the primary pharmaceutical countermeasures for H1N1, and barriers to health care access may have delayed treatment and contributed to racial and ethnic disparities in H1N1 hospitalization and mortality. Accounts of discrimination against Hispanics in some communities suggest that H1N1-related stigma may have dissuaded some from seeking treatment. Despite the widespread availability of free H1N1 vaccine and treatment during the pandemic, some studies suggest that racial and ethnic minorities had more difficulty accessing care than Non-Hispanic Whites.

Recommendations

Recommendation 1: Identify diverse communities and their needs, attitudes, and beliefs. Well before an outbreak, and on an ongoing basis, it is imperative that pandemic planning efforts incorporate an assessment of the characteristics, needs and assets of diverse communities. Knowing the community's racial, ethnic and linguistic composition, along with their attitudes, beliefs, and behaviors related to a wide array of health concerns and practices, is critical to fostering a deeper understanding of the factors that may serve as barriers to communication, prevention and treatment. In turn, this knowledge and understanding can inform the development of sound interventions and policies.

Recommendation 2: Build partnerships with communities to foster trust. Building and sustaining trust by partnering with community leaders and representatives is imperative

to ensuring that critical messages, resources and services are effectively delivered and received by diverse communities. Trusted, community sources should be leveraged to ensure that diverse populations receive critical information on social distancing, prevention and treatment, and can access vaccinations and antiviral treatment in settings they trust.

Recommendation 3: Develop clear, concise and culturally and linguistically appropriate messages. Tailoring information in a culturally and linguistically appropriate manner is a critical tool to bridging the gap in distributing timely and accurate information to diverse communities. In the case of the H1N1 pandemic, this information gap had profound effects: Non-White populations showed less knowledge about signs and symptoms of the virus and appropriate prevention and treatment. Public health professionals should use trusted avenues such as racial and ethnic media, community health workers or *promotores* and other ethnic networks to relay key public health messages. Translated materials, which are culturally tailored and provided through a range of mediums including print and online, should also be a part of this repertoire.

Recommendation 4: Develop training, drills and exercises that engage and reflect diverse communities. Public health professionals should seek to engage individuals from diverse racial and ethnic backgrounds to assist in integrating scenarios around race, culture, language, and trust into tabletop exercises. These scenarios should cover how to effectively reach diverse populations with messages, outreach and education around social distancing and other prevention actions, along with how to appropriately deliver services, such as administering vaccinations and antiviral medications to populations that may have low trust or be skeptical. Equally important is the need to ensure that public health workers and health care providers regularly receive cultural competency education and training.

Recommendation 5: Ensure the delivery of culturally and linguistically appropriate services. A culturally competent workforce, that is bi-lingual, reflective of diverse communities, and has knowledge on how to address cultural differences and limited English proficiency, is essential to effectively plan for and respond to the needs of diverse communities in a pandemic. In addition, services should be provided in a culturally and linguistically appropriate manner to ensure understanding, participation in and adherence to recommendations including social distancing, isolation and quarantine and administration of vaccinations and antiviral medications.

Recommendation 6: Engage community representatives and organizations in evaluation. An ongoing method for assessing program effectiveness is important in pandemic planning and response to determine if such programs both reach and meet the needs of the targeted communities. In carrying out this process, public health professionals should involve community members at multiple levels to evaluate actions such as communication, partnerships, education and training, and cultural/linguistic appropriateness of services.

Recommendation 7: Coordinate information and resources. Responsible pandemic influenza planning and response for racially and ethnically diverse communities requires effective coordination of information and resources among involved agencies and organizations. These groups should work to reduce duplication of efforts and open lines of communication by participation and resource sharing through neutral conveners such as interagency councils and planning committees. Examples of information that can be shared include best practices, lessons learned and inventories of medical interpreters, bilingual staff, and trusted points of distribution.

Recommendation 8: Ensure diversity and health equity are part of funding and program priorities for pandemic influenza. When outlining grant activities, funders should consider diversity and health equity as core objectives in order to address the disproportionate impact of public health emergencies on diverse communities. For example, in their grantmaking efforts, funding agencies should make community engagement and building community partnerships a funded deliverable. In addition, such agencies could make available pandemic planning and response funding directly to community-based organizations to achieve goals around defining roles and expectations, increasing accountability and capacity building.

Conclusion

The specific recommendations, tailored guidance, practices and results embedded in this report offer a body of knowledge that can inform, improve and fill gaps in influenza pandemic planning for diverse populations. Ensuring the inclusion of our nation's growing racially and ethnically diverse populations in pandemic planning is critical to protecting and safeguarding the health of all people in the United States.

INTRODUCTION

Racially and ethnically diverse populations often experience higher rates of injury, disease and death from disasters and other public health emergencies in the United States (U.S).[1] While this unequal impact is linked to community poverty and underlying socioeconomic inequalities, longstanding inattention to the profound influence of race, ethnicity and language—intimately related to, but extending far beyond emergency events—contribute significantly to this gap. As a result, failure to learn about and consider cultural beliefs and norms, limited English proficiency, legacies of distrust in government, and historic lack of access to health care, may greatly affect these communities' understanding of, participation in, and adherence to prevention, preparedness and protective actions that can make the difference between life, disability and death.

While the legacy of Hurricane Katrina prompted attention to this national priority, recent public health emergencies, including the 2009-2010 H1N1 Pandemic, reinforce the deep-rooted patterns of inequity that date at least as far back as the Great Pandemic of 1918, where American Indians experienced a disease-specific mortality rate four times that of other ethnic groups.[2] The H1N1 Pandemic also disproportionately impacted Non-White populations, who generally faced higher burden of illness, hospitalization and mortality. The Centers for Disease Control and Prevention acknowledged this disparity:

> *"[I]t's clear that minority groups have consistently had higher rates of serious 2009 H1N1 disease, including hospitalizations, than non-minority groups. In fact, hospitalization rates among minority groups have consistently been more than double those of White, non Hispanics".*[3]

Legacies of differential impact experienced by racially and ethnically diverse populations—which are quickly growing in the United States—raise the importance of understanding the complex roles that race, ethnicity, culture and language play in influencing public health preparedness, response and outcomes. They further point to the need and urgency for national policies to build infrastructure, programs and strategies that ultimately eliminate inequities. This priority will grow as the nation continues to become increasingly diverse—as Non-Hispanic whites are projected to comprise the minority of the United States population by 2050.[4]

The purpose of this report is three-fold. First, it intends to offer a thorough synthesis of peer-review research, major reports and other publications documenting persistent, significant racial and ethnic disparities in morbidity and mortality associated with the 2009-2010 H1N1 pandemic. Second, the report explores reasons for the disparities observed in exposure, susceptibility and treatment. Finally, this document utilizes a

unique and comprehensive framework—grounded in theory and practice, as developed by the National Consensus Panel on Emergency Preparedness for Cultural Diversity—to offer concrete recommendations for integrating diversity and equity into pandemic influenza planning and response. It, therefore, serves as a resource and reference on pandemic influenza and diverse communities.

This report is intended to complement other after action reports on the pandemic—such as those developed by the Association of State and Territorial Health Officials and the Government Accountability Office – as well as peer-review literature – offering a unique perspective that is specific to racially and ethnically diverse populations.[5,6]

Finally, this report is intended for use by a broad audience, including but not limited to:

- Public health agencies seeking guidance on concrete ways to integrate racial and ethnic health equity into pandemic influenza prevention and response;

- Community-based organizations needing assistance in identifying their potential role or opportunities for collaboration with public health and other agencies;

- Health care providers and organizations seeking guidance on collaborating with communities to provide appropriate education and outreach; and

- Policymakers seeking to understand how racial and ethnic disparities have historically played out in pandemic influenza and what opportunities exist for policy and action.

BACKGROUND

The National Consensus Panel on Emergency Preparedness and Cultural Diversity (referred to as 'the Panel') was established in 2007 with the mission of developing and issuing "guidance to national, state, territorial, tribal and local agencies and organizations on the development of effective strategies to advance emergency preparedness and eliminate disparities for racial and ethnic communities."[7] The Panel is comprised of nearly three dozen experts from leading national, state and local/community based public and private organizations, representing a broad spectrum of perspectives including public health, emergency management and response, hospital and health care, risk communication, and community-, ethnic-, and faith-based groups. Since its inception, the Panel has developed tools—including a Consensus Statement, Guiding Principles, and a Toolkit—to promote the integration of racially and ethnically diverse communities into public health preparedness, response, and recovery activities and ameliorate the disproportionately adverse outcomes they have consistently experienced in emergencies.

While Hurricane Katrina served as the primary impetus for the Panel's work, a number of prior events signaled the need for greater and more strategic investments in public health preparedness. The events of September 11, 2001, subsequent anthrax attacks, and Severe Acute Respiratory Syndrome outbreak of 2003, led to the *Pandemic and All-Hazards Preparedness Act*, which was signed into law in December 2006—stimulating a wave of Federal support to protect against the threat of a pandemic.

In 2008, the Centers for Disease Control and Prevention (CDC) hosted a number of stakeholder sessions to explore potential challenges to meeting the needs of diverse communities—such as immigrants and refugees, Native Americans and Alaska Natives, farmworkers, and racial/ethnic minorities— in a pandemic and develop recommendations tailored to their needs and circumstances.[8,9,10,11] Less than a year later—following the confirmation of Swine Influenza A (H1N1) cases in California, Texas, Kansas, and New York—the threat of a pandemic became a reality and Acting Secretary of the U.S. Department of Health and Human Services, Charles E. Johnson, officially declared a public health emergency in the United States on April 25, 2009.[12] Less than a year later, the CDC reported an estimated 60 million cases of H1N1, 270,000 H1N1-associated hospitalizations, and over 12,000 H1N1-associated deaths.[13]

REVIEWING THE EVIDENCE

Racial and Ethnic Disparities in H1N1 Morbidity, Hospitalization, and Mortality

Robust surveillance and reporting of H1N1-associated morbidity, hospitalization and mortality has afforded an opportunity to explore the impact of this pandemic on racially and ethnically diverse individuals and communities. While existing research provides clear evidence of racial and ethnic disparities in H1N1 outcomes, these outcomes vary across geographic localities, highlighting the interplay of a complex set of dynamics related to exposure, susceptibility and resistance. In this section, we present the evidence highlighting the nature, scope and extent of racial and ethnic disparities in morbidity, hospitalization and mortality. The next section explores the potential reasons for these disparities.

Morbidity

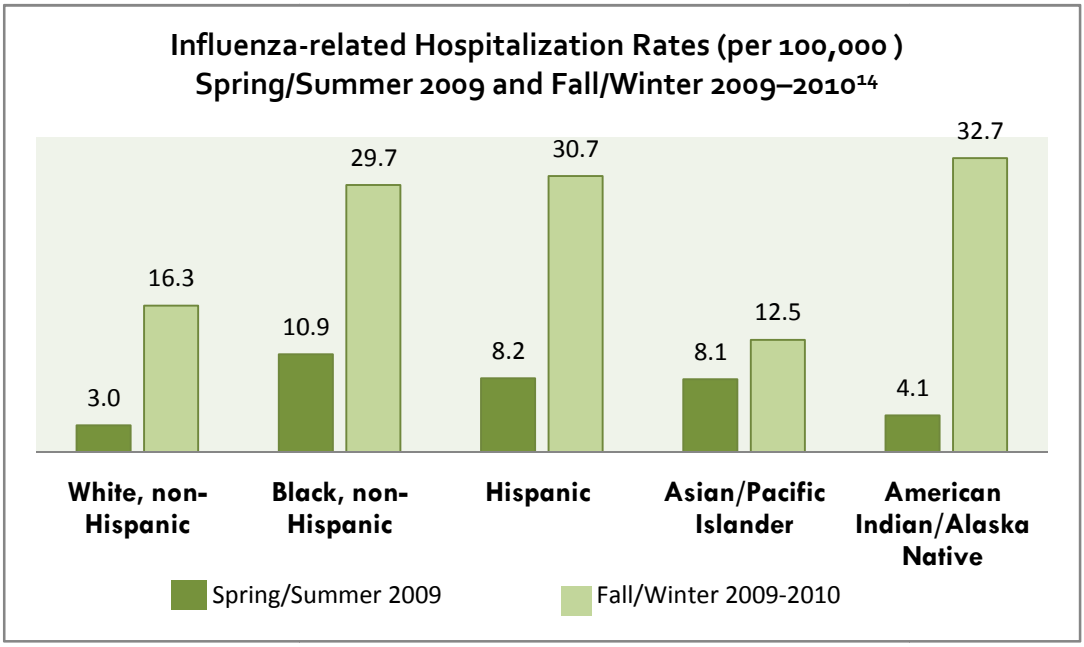
Review of national datasets provides robust estimates of the pandemic's impact on racially and ethnically diverse communities at the national level.[14] For example, analysis of Behavioral Risk Factor and Surveillance System (BRFSS) data from 49 states revealed substantially higher rates of self-reported influenza-like illness (ILI) among American Indians and Alaska Natives (16.2%) than Non-Hispanic Whites and African Americans (8.5% and 7.7%, respectfully); both of whom reported higher rates of ILI than Hispanics (6.5%).

While local area data reinforce the disparities in morbidity faced by diverse communities, the patterns that emerged were slightly different. For example, an epidemiological study from King County, Washington revealed that while African Americans and Asians comprised just 6% and 14% of King County's population, they accounted for 21% and 31%, respectively, of reported cases in emergency department settings.[15] Among the confirmed cases, 40% spoke a language other than English at home. While no racial or ethnic differences in ILI health care seeking behavior were found, the study suggested that those who spoke a foreign language faced longer average times between disease onset and antiviral treatment (3.1 days versus 2.3 days). In Oklahoma, among the 1,081 cases reported, the rates of ILI were highest for African Americans (55%) and Native Americans (37%) and lowest for Whites (26%).[16]

Hospitalization

The Emerging Infections Program collected extensive data which highlight national trends in H1N1 hospitalization by race and ethnicity.[17] An analysis of these data revealed that all major racial and ethnic groups had higher age-adjusted rates of H1N1 hospitalization than Non-Hispanic Whites (3.0 per 100,000) during the first wave of the pandemic (see Figure 1). African Americans fared the worst (10.9) followed by Hispanics (8.2), Asians (8.1), and American Indians and Alaska Natives (4.1). A similar trend emerged during the second wave of the pandemic, with the exception of Asians who had a slightly lower rate than Whites (12.5 versus 16.1) and American Indians and Alaska Natives who experienced a dramatic increase (32.7).

Figure 1.



Local area data generally reflect national trends in that major diverse population groups often experienced higher hospitalization rates than their White counterparts. For example, in Wisconsin, African Americans had a hospitalization rate of 36.3 compared to a rate of 16.8 among Asians, 13.6 among Hispanics and 1.4 among Whites.[18] In King County, Washington, those hospitalized with H1N1 were significantly more likely to be African American (O.R. 4.2) or Hispanic (O.R. 3.3) than White. In Chicago, African Americans (9.0) had the highest H1N1 hospitalization rate followed by Asian and Pacific Islanders (8.0), Hispanics (8.0), and Non-Hispanic Whites (2.0).[19]

Mortality

National data revealed variation by race and ethnicity in H1N1-associated deaths. For example, an analysis of data from the Influenza-Associated Pediatric Mortality Surveillance System showed that nearly one-third of the confirmed 278 H1N1-associated deaths among individuals younger than 18 years of age occurred among Hispanics, who only accounted for 22% of the pediatric population. Local area data on the severity of the illness may explain some of this trend. For example, a review of hospital data from Salt Lake County, Utah, found greater H1N1 severity among Hispanics; they were nearly three times more likely to be admitted to the intensive care unit than Non-Hispanic Whites.[20]

Hispanics accounted for 22% of the population under 18 years of age, but for 31% of pediatric H1N1 mortality

In addition to Hispanic children, evidence from a broad group of states revealed that American Indians and Alaska Natives were disproportionally impacted by the pandemic – a finding which was not as evident in many earlier studies given the population's relatively small size and concentration in certain geographic localities. In fact, it was after elevated H1N1 mortality and morbidity rates were observed among indigenous populations in Australia, Canada, and New Zealand, that a workgroup was developed to explore the potential of such a disparity in the United States.[21] A 2009 review of H1N1 surveillance data from 12 states, representing 50% of the total American Indian and Alaska Native population, found that the H1N1 case-specific mortality rate for this group was four times that of all other racial and ethnic populations combined.[22] This fourfold disparity in cause-specific mortality observed in 2009 mirrors estimates of the disparity in mortality between American Indians and all other diverse populations during the Great Pandemic of 1918.[23]

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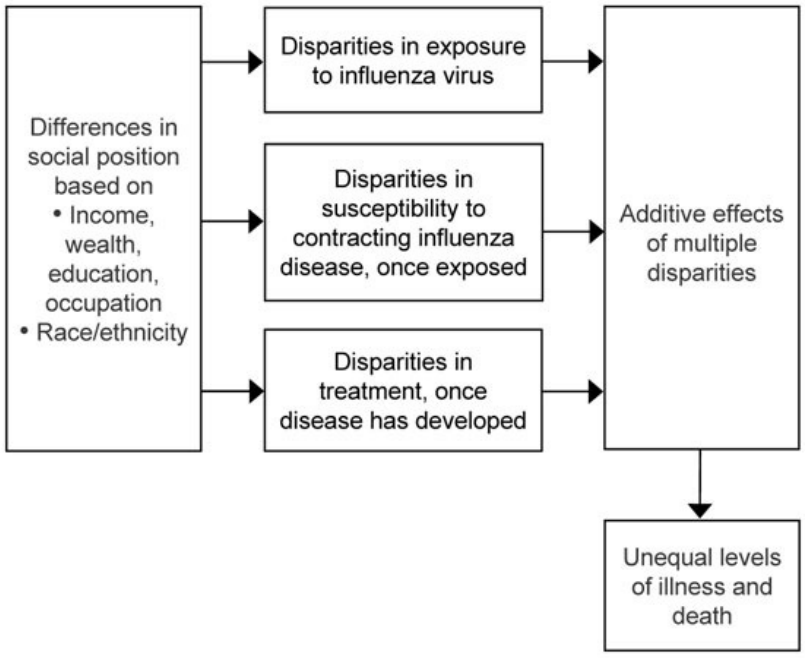
While inconsistencies and variability in disease surveillance systems, data collection and reporting procedures by race and ethnicity limit the ability to produce precise estimates, it is clear that racially and ethnically diverse populations suffered a disproportionate burden of morbidity, hospitalization, and mortality during the H1N1 pandemic. The variations observed between geographic locales are to be expected as they reflect the diversity of social, economic, political, cultural, and health care environments and differences in the magnitude of existing racial and ethnic health disparities in communities across the country. The empirical evidence presented above provides a foundation for exploring the potential causes of the disparities observed and developing prevention strategies accordingly.

PUTTING THE PIECES TOGETHER

Potential Reasons for Racial and Ethnic Disparities in H1N1 Morbidity and Mortality

A key question researchers have been pondering post-H1N1 is -- *why did racially and ethnically diverse communities fare worse than their White counterparts during the pandemic?* While the evidence presented in the previous section offers no clear explanation, prior research has identified potential contributing factors. In particular, a conceptual framework developed by Blumenshine and colleagues (2008) describes ways in which "different racial and ethnic groups might fare differently in an influenza pandemic, on the basis of current knowledge of social factors that shape exposure and vulnerability to influenza virus and that influence the timeliness and adequacy of treatment among those who become ill." [24] Post-H1N1, many researchers have explored potential reasons for the documented disparities utilizing this framework, which is also referenced in this report (Figure 2).

Figure 2.
Possible Sources of Disparities During a Pandemic Influenza Outbreak



Source: Blumenshine P, Reingold A, Egerter S, Mockenhaupt R, Braveman P, Marks J. Pandemic influenza planning in the United States from a health disparities perspective. Emerg Infect Dis [serial on the Internet]. 2008 May [*date cited*]. Available from http://wwwnc.cdc.gov/eid/article/14/5/07-1301.htm

In their framework, Blumenshine and colleagues suggest factors that influence disparities along three dimensions (see Figure 2):

- Those that may increase likelihood of *exposure to the virus*;
- Those that may increase *susceptibility to contracting the virus,* if exposed; and
- Those that may inhibit *treatment or access to care,* after the virus has been contracted.

The following sections use this framework to synthesize research that emerged post-H1N1, and identify potential causes leading to disparities by race and ethnicity.

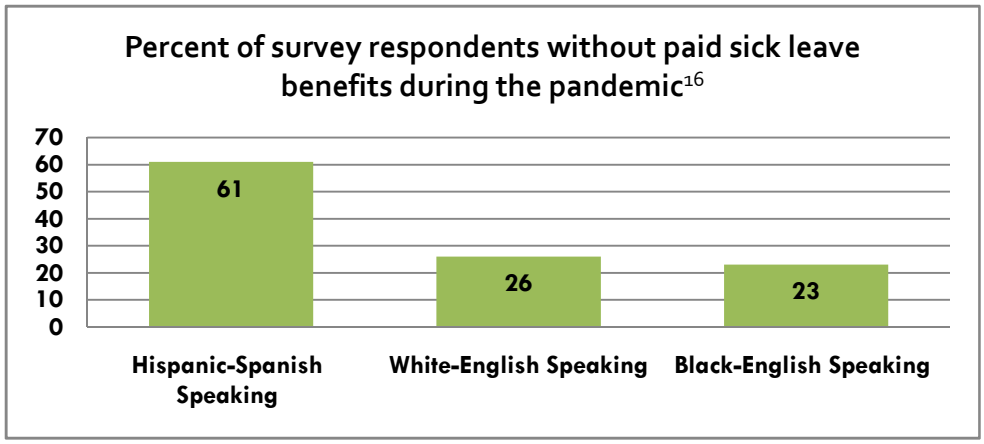
Disparities in H1N1 Exposure

Generally, any strain of an influenza virus is highly transmissible between humans. Often, transmission is airborne and occurs during coughing and sneezing (although other direct or indirect contact may result in transmission as well). Individuals are frequently exposed to viruses at settings where people gather, such as homes, health care facilities, schools, workplaces, and public transits. Therefore, factors such as household size, urban crowding, employer sick leave policies, health care seeking behaviors, as well as other economic and socio-cultural factors are likely to contribute to exposure, particularly if they inhibit an individual's ability to take necessary protective action, such as "social distancing"– an effective and cost-efficient non-pharmaceutical countermeasure for preventing the spread of communicable disease.[24]

In this section, we explore the economic and socio-cultural factors which may have served as barriers to diverse communities engaging in recommended social distancing practices during the H1N1 pandemic, and thus contributed to greater rates of exposure among these populations.[25]

Employment . Employment circumstances and concerns are potential contributors in differential exposure to H1N1 among diverse populations. A nationally representative survey conducted pre-H1N1, for example, found that African Americans were least likely (66%) to have someone to care for them if they were sick and that both Hispanics (68%) and African Americans (65%) were more likely than Whites (53%) to report foreseeing a serious financial problem if they had to stay home from work for one month.[26] The results on another study assessing social distancing practices during the first wave of the H1N1 pandemic suggest that Hispanics had significantly more difficulty staying home from work than Whites.[16] This was particularly the case among respondents of the Spanish language survey—75% of whom were not able to work from home, compared to 46% of Whites and 30% of African Americans. In addition, 61% of Spanish-language respondents did not have sick leave benefits at their job, compared to 26% of Whites and 23% of African Americans.

Figure 3.



A similar survey conducted in January 2010 reinforced these findings and suggested that workplace policies were a significant determinant of H1N1 incidence among Hispanics.[27] The survey found that work-related policies which inhibited social distancing, such as the absence of paid sick leave, increased the odds of acquiring influenza-like-illness (ILI) by 8% during the pandemic. Given that 40% of Hispanics surveyed did not have access to paid sick leave, the 8% increase in risk observed translated into a population-attributable risk of 1.2 million cases of ILI among Hispanics.

***Domestic and Urban Crowding*.** It is well established that crowding, which is more common among certain racial and ethnic groups, increases the likelihood of exposure to communicable disease. Regardless of income, Hispanic and Asian households are relatively more crowded than African American and Non-Hispanic White households.[24] In fact, recent data indicate that the average household size for Hispanics is 3.5, compared to 2.5 for African Americans and Whites.[28] Spanish-speaking Hispanics are significantly more likely to live in larger households and with more children than Non-Hispanic Whites or African Americans.[16] A study by Kumar and colleagues investigated the social determinants of H1N1 exposure, including household size and crowding, among different races and ethnicities and their impact on the incidence of ILI using survey methods.[27] The authors found that Hispanics were more likely to have larger households and that the incidence of self-reported ILI was positively associated with household size during the H1N1 pandemic influenza.

Furthermore, diverse communities are growing in urban areas, which generally include more crowded housing and rental properties. An analysis of U.S. Census data found that Non-Whites accounted for 98% of population growth in large metropolitan areas between 2000 and 2010,[28] and data from a nationally representative survey revealed that during the H1N1 pandemic, Hispanics and African Americans—who generally faced higher ILI—were significantly more likely than Non-Hispanic Whites to reside in an urban setting and apartment buildings.[27]

Cultural and Linguistic Factors. Failure to consider culture, language, and information seeking behaviors can adversely impact the effectiveness of mainstream health communication campaigns among racially and ethnically diverse populations.[29] Specifically, these factors may have contributed to disparities in knowledge about H1N1—similar to how they have contributed to racial and ethnic disparities in past disasters and public health emergencies—resulting in greater exposure.

A recent study by Savoia and colleagues (2012) surveyed 1,569 respondents to investigate their knowledge regarding the H1N1 pandemic.[30] An analysis by race and ethnicity revealed that Blacks and Hispanics were less likely to be knowledgeable about H1N1 transmission than respondents in all other categories. Non-Whites, and in particular Hispanics and those who speak a language other than English at home, were found to be less likely to have "knowledge about signs and symptoms of H1N1 infection".

Spanish-speaking individuals were more likely to obtain information on H1N1 from local newspapers and preferred to receive information from Spanish language television stations

Anecdotal reports and experience from regions across the country offer insights into specific factors that may have affected the effectiveness of the risk communication strategies employed and knowledge among diverse communities. For example, The Association of State and Territorial Health Officials led a project to synthesize evidence on the barriers that health officials encountered when responding to the pandemic.[5] Health officials participating in the project expressed the need for more effective risk communication strategies to reach diverse populations—such as those addressing distrust in government, limited English proficiency, and alternative modes of communication; all of which were reported as barriers to effective health department response.

Researchers at the Dana-Farber Cancer Institute conducted a series of focus groups, both in English and Spanish, to explore how H1N1 information was obtained and processed during the pandemic.[31] They found that Spanish-speaking individuals were more likely to obtain H1N1 information from local newspapers than English-speakers and also preferred to receive information from Spanish language television stations such as *Univision* and *Telemundo*. These findings suggest that the inadequate distribution of timely and accurate information through these channels during the pandemic may have contributed to a lack of knowledge that inhibited the adoption of protective behaviors, such as vaccination and social distancing.

Public Transportation. Studies suggest that the likelihood of exposure to influenza could also be higher for individuals who regularly use, or are dependent upon, public transportation. For example, a study in the United Kingdom found recent use of public transit to be significantly associated with acute respiratory infection, but the magnitude

of this association was smaller among frequent users of public transit.[32] This could have important implications for different influenza scenarios (seasonal versus pandemic) as the authors suggest that persons who regularly travel via public transportation develop immunity to such viruses. Thus, during a novel, pandemic influenza, the authors suggest that this protective effect would be reduced. Research following the H1N1 pandemic supports this theory. A county-level analysis of factors associated with H1N1 hospitalization found that public transportation usage was positively correlated with H1N1 hospitalization rates.[33]

Rates of public transit usage are disproportionately high among Non-White populations, which account for 45% of the U.S. population, but nearly two-thirds of public transit riders.[34,35] Evidence suggests that the disproportionately high rates of public transit ridership among Non-Whites is not the result of cultural preference, but rather a matter of circumstance and lack of alternatives. In a nationally-representative survey conducted during the first wave of the pandemic, both Hispanic and African Americans respondents were more likely to report that it was "somewhat" or "very" difficult to avoid public transportation if it were recommended than White respondents.[16] These finding suggest that Non-Whites experienced disproportionately high rates of H1N1 exposure due to elevated rates of public transportation usage and determinants of this disparity—such as a lack of personal transportation.

Disparities in H1N1 Susceptibility

Among individuals who were exposed to H1N1, the likelihood of contracting the virus was influenced by a range of factors—particularly vaccine uptake and pre-existing health status. In this section, we explore these factors and how they may have contributed to the relatively high rates of H1N1 incidence among diverse communities.

Vaccination. Vaccination was a primary means of reducing host susceptibility to the H1N1 virus. Despite widespread availability, however, less than a quarter (23%) of the total U.S. population reported being vaccinated for H1N1 at the end of 2010—a proportion significantly less than typical seasonal vaccination rates.[36] Historical trends in seasonal influenza vaccination provide context for understanding differences in H1N1 vaccination rates for diverse communities.

Negative attitudes towards seasonal influenza vaccination among African Americans likely shaped attitudes toward the H1N1 vaccine and contributed to disparities in vaccine uptake

- Seasonal Influenza Vaccination. Racial and ethnic disparities in rates of seasonal influenza vaccination are well documented. While such disparities exist across different demographic and socioeconomic groups (e.g., sex, age, income, and education level), they are most pronounced and persistent by race and

ethnicity -- with estimates suggesting that disparities in influenza vaccination are responsible for 1,880 excess deaths annually among Hispanics and Non-Whites over the age of 65. [37,38,39,40,41,]

Generally, Whites are more likely to be vaccinated for seasonal influenza than their Non-White counterparts. An analysis of data from the Medicare Beneficiary Survey—which assesses factors associated with vaccination uptake such as resistant attitudes/beliefs, access to care, and provider discrimination--revealed that White beneficiaries (66.6%) were most likely to self-report being vaccinated for seasonal influenza, followed by Hispanics (53.5%), and African Americans (43.4%).[42] While provider discrimination and barriers to care appeared to have very little effect (less than 2%) on the observed disparities between African Americans and Whites, resistant attitudes/beliefs about vaccination were identified as a major factor. In fact, African Americans were significantly more likely to express a resistant attitude or belief toward vaccination than Whites (30.2% versus 18.4%). A similar analysis using data from the Medicare Consumer Assessment of Healthcare Providers and Systems Survey found that influenza immunization rates for both Spanish- and English-speaking Hispanics were significantly lower than those of Non-Hispanic Whites (64% and 68% versus 76%, respectively).[43]

- H1N1 Vaccination. An extensive body of research following the H1N1 pandemic identified significant differences in vaccine uptake between Non-Hispanic Whites and African Americans. In many cases, however, studies revealed that racial and ethnic groups other than African Americans were vaccinated against H1N1 at rates higher than even Whites. In this section, we therefore focus on research documenting disparities between African Americans and other racial and ethnic groups, exploring potential reasons. We emphasize, however, that, given the disproportionate impact of H1N1 mortality and morbidity on all Non-White racial and ethnic groups, there are likely a host of factors beyond vaccine uptake which contributed to the inequitable distribution of the pandemic's effects.

  A fairly robust and consistent body of research suggests the presence of disparities in H1N1 vaccination between African Americans and other racial and ethnic groups. A review of the demographic characteristics of 163,087 Los Angeles County residents who received free H1N1 vaccine revealed such a disparity.[44] African Americans were half as likely to receive the H1N1 vaccine than Non-Hispanic Whites. A nationally representative survey also found that vaccine uptake was significantly higher among Non-Hispanic Whites than African Americans (20.4% versus 13.8%).[45] Results of the National 2009 H1N1 Flu Survey, a random-digit-dial telephone survey conducted in all 50 states by the Centers for Disease

Findings suggest that African Americans were vaccinated against H1N1 at a rate approximately half that of Whites

Control and Prevention (CDC), revealed statistically significant differences in H1N1 vaccination between Non-Hispanic Whites and African Americans, who were 25-64 years of age, and had pre-existing "high risk" conditions (13% versus 5%) or were health care workers (26% versus 8%).[36] Negative attitudes about seasonal influenza vaccination among African Americans may have contributed to these disparities. A 2010 nationally representative survey found that African Americans were significantly less likely to perceive the H1N1 vaccine as being safe than Non-Hispanic Whites (O.R. 0.65). [46]

- Access to Care. Even when vaccinations are accepted as a viable prevention strategy in diverse communities, logistical barriers can serve as impediments to uptake. While the H1N1 vaccine was available in a variety of settings—such as physicians' offices, health centers, retail pharmacies, and health departments—the utilization of these venues across racial and ethnic groups was not uniform. A survey of vaccination behaviors suggested that African Americans and Hispanics were more likely to be vaccinated in physician offices, while Whites were vaccinated across a more diverse range of locations.[45] It is possible that some racial and ethnic groups felt uncomfortable receiving vaccinations in non-clinical settings. Thus, constraining factors, such as physician office hours, could have contributed, in part, to disparities in H1N1 vaccine uptake. Quinn and colleagues (2009) also described barriers in access to health care that are likely to contribute to disparities in vaccine uptake. In an analysis of 1,479 survey respondents of various racial and ethnic backgrounds, authors found that Spanish-speaking Hispanics were significantly more likely to lack a regular healthcare provider and were more likely to report that lack of money or insurance would impede their ability to get an influenza vaccine compared to Whites, Blacks, and English-speaking Hispanics.[16]

Pre-Existing Health Conditions. Disparities between the health status of diverse populations and Non-Hispanic Whites are well documented and likely contributed to disparities in H1N1-associated mortality and morbidity. Chronic conditions such as diabetes, asthma, and cardiovascular disease were all associated with increased H1N1 risk and are disproportionally prevalent in diverse communities. For example, results from the 2010 BRFSS data indicated that 14% of African Americans have been diagnosed with diabetes compared to 8% of Whites. This disparity is likely to have contributed to racial disparities in H1N1 outcomes as diabetes was found to triple the risk of H1N1 hospitalization and increase the risk of ICU admission by a factor of seven.[47]

Chronic conditions, such as diabetes and asthma, which are disproportionately prevalent among minorities were risk factors for H1N1 complications

Asthma was the most common chronic condition among H1N1 patients admitted to hospitals and is more prevalent among African Americans (11%) than Whites (8.5%) or Hispanics (7%).[48] Among Native Americans and Alaska Natives, a substantially greater proportion of H1N1 decedents had high-risk conditions, such as diabetes and asthma, compared to decedents of other racial and ethnic groups (45% versus 24%; and 31% versus 14%, respectively).[22] A range of factors related to socioeconomic status could also suppress immune system function and increase susceptibility to infectious disease. Inadequate nutrition, deleterious health behaviors (e.g., sedentary lifestyle, smoking), and psychological stress associated with low socioeconomic position all inhibit immune system function and increase infectious disease risk.[49]

Disparities in H1N1 Treatment

Antiviral agents, such as oseltamivir and zanamivir, were the primary pharmaceutical treatments for H1N1.[50] If administered in a timely fashion, these antivirals served to reduce the severity of the virus among those infected and prevent spread of the virus to others. Longstanding racial and ethnic disparities in access to health care suggest that inequitable access to antivirals could have contributed to increased H1N1 incidence and severity in diverse communities. In addition to typical barriers to care—such as lack of health insurance and geographic isolation—social stigma associated with disease may have been a determinant of health care seeking behavior during the H1N1 outbreak, as it has in past epidemics, and contributed to elevated rates of infection among specific communities.

Social Stigma. Foreign born individuals are often stigmatized as etiologic agents of infectious disease.[51] The practice of ascribing etiological blame to a distinct racial or ethnic group is not uncommon and often emerges out of existing social prejudices, not scientific fact.[52] The initial identification of H1N1 cases in Mexico and coinage of the term "Mexican flu," may have been compounded by existing anti-immigrant sentiment and promoted the stigmatization of many Spanish speakers—regardless of their country of origin. Such stigmatization could have forced some Hispanics and Latinos to go "underground" and avoid care.

A series of key informant interviews explored how such issues may have affected the care seeking behaviors of Hispanic migrant and seasonal farm workers (MSFW) during the Spring 2009 wave of the pandemic.[53] While interview respondents from predominantly Hispanic communities did not report an increase in MSFW prejudice, a rise in anti-Hispanic sentiment was evident in areas where they comprised a small proportion of the local population. For example, in one community, shop vendors were unwilling to serve Mexicans, while a MSFW and her child in another community were publicly chastised for bringing H1N1 to the U.S. Although these interviews revealed sporadic, not pervasive, accounts of discrimination and scapegoating, such incidents

may cast a broader shadow as the general community may learn of the encounters. Moreover, this anecdotal evidence, combined with similar accounts from past outbreaks of infectious disease, provide support for the notion that the stigmatization of ethnic and foreign born populations may have served as a barrier to H1N1 treatment.

Barriers to Health Care. Racial and ethnic disparities in access to health care are well documented.[54,55] While cultural and linguistic differences, geographic isolation, cost, and under/uninsurance are all known to contribute to these disparities, it is less clear how they played out during the H1N1 pandemic. For example a study of a low-income, predominantly African American pediatric population found that those without health insurance were three times more likely to accept H1N1 vaccination than those with insurance.[56] The authors posited that this observation was due to fear of future H1N1-related medical care and bills. Disparities in workplace sick leave policies, as previously discussed, may have also served as a barrier to care among Hispanics as they may have been hesitant to take unpaid leave from work to seek treatment for ILI. Quinn and colleagues (2011) found that experiences with discrimination in a health care setting differed by race and ethnicity. All three minority groups surveyed were significantly more likely to report having been discriminated against when accessing health care. The authors suggested that this past experience with discrimination likely contributed to mistrust as well as hindered the readiness of diverse communities--which is key during a pandemic situation--to seek health care services.[16]

Spanish-speaking Hispanics and Latinos had more difficulty accessing care during the pandemic than Whites

RECOMMENDATIONS

Context

Empirical research, anecdotal accounts, and a robust body of evidence on longstanding racial and ethnic disparities in health and health care suggest that factors relating to disproportionate exposure, susceptibility, and treatment all contributed to the disparities in mortality and morbidity described above. While a synthesis of these findings reveals variability across regions and leaves many questions regarding why and how the H1N1 pandemic disproportionately affected racially and ethnically diverse communities, this review offers direction for refining existing influenza epidemic and pandemic planning guidance to reduce such disparities in future public health emergencies.

Unfavorable attitudes toward the H1N1 vaccine and poor pre-existing health status largely contributed to increased H1N1 susceptibility in racially and ethnically diverse communities. These findings highlight the need to openly confront past, and current, injustices and reinforce the imperative to improve the health of diverse communities—lest these disparities become magnified in a public health emergency. These findings also suggest that many of the root causes for disparities in H1N1 exposure, susceptibility, and treatment reflect social inequities and the legacy of past injustices. For example, the absence of paid sick leave policies among Hispanic workers was associated with higher risk of H1N1 exposure. Distrust in government and the medical establishment among African Americans contributed to increased H1N1 susceptibility as the population was vaccinated at approximately half the rate of Whites.

While such factors reflect persistent and pervasive inequities with origins beyond the health care sector, they need not be determinants of increased pandemic risk. Such issues can be addressed through informed pandemic preparedness planning and response procedures which reflect the range of social, economic, cultural, and linguistic circumstances of diverse communities.

The work of the National Consensus Panel on Emergency Preparedness and Cultural Diversity (referred to as the 'Panel') provides an important foundation and framework for integrating diversity and equity priorities into effectively planning for and responding to diverse communities in a pandemic. Established in 2007 with support from the Office of Minority Health at the U.S. Department of Health and Human Services, the mission of the Panel is "to develop and issue guidance to national, state, territorial, tribal and local agencies and organizations on the development of effective strategies to advance emergency preparedness and eliminate disparities for racial and ethnic communities."[57], [7] In 2008, the Panel issued a National Consensus Statement—with virtually unanimous

approval by Panel members—which established the first-ever national agenda on emergency preparedness for diverse communities. Endorsed and embedded by the Institute of Medicine in 2009 in its *Guidance for Establishing Crisis Standards of Care*, the National Consensus Statement states that:

> *The integration of racially and ethnically diverse communities into public health emergency preparedness is essential to a comprehensive, coordinated federal, state, tribal, territorial and local strategy to protect the health and safety of all persons in the United States. Such a strategy must recognize and emphasize the importance of distinctive individual and community characteristics such as culture, language, literacy and trust, and promote the active involvement and engagement of diverse communities to influence understanding of, participation in and adherence to public health emergency preparedness actions. Additionally, this strategy must acknowledge the critical commitment to developing effective and sustainable services, programs and policies and building mutual accountability. Only through these comprehensive, unified efforts can we work to counter the legacy of racial and ethnic disparities and ensure that quality and equality for all communities form the foundation of the Nation's planning for any and all public health emergencies.*[58]

Accompanying the statement, were eight Guiding Principles, which represented a novel effort at the national level to provide a set of key priorities and cohesive guidance for incorporating diverse communities in emergency planning (see Figure 4).

Through continued support from the Office of Minority Health and engagement of Panel members, along with synthesis of leading research, publications and evidence-based practices in the field, the statement and principles formed the foundation of a toolkit, entitled, *Guidance for Integrating Culturally Diverse Communities into Planning for and Responding to Emergencies*.[7] The toolkit offers a practical framework and recommendations for engaging and integrating issues of race, culture and language across all phases of a public health emergency or disaster event.

Since the release of the toolkit in 2011, the framework established by the Panel has been applied at various levels (federal, state and local) as well as across a range of settings. For example, the National Council of La Raza's guidance on how to plan for and prepare Latino communities builds on the Panel's statement and principles.[59] In addition, state and local government agencies are utilizing the Panel's recommendations and framework to address and tailor their planning for diverse communities. For example, the Whatcom County Public Health Department in the State of Washington applied the Panel's framework to develop emergency communication and outreach for the county's large Slavic immigrant and Latino migrant communities. [60] Finally, the Panel's recommendations continue to remain at the forefront of federal priorities. Most recently, this work was referenced in the *National Prevention Strategy* – as was created and mandated by the *Patient Protection and Affordable Care Act of 2010* – in context of addressing racial and ethnic disparities broadly in public health and prevention.[61]

Figure 4. Guiding Principles for Integrating Racially and Ethnically Diverse Populations in Public Health Emergency Preparedness

PRINCIPLE 1: Identifying, locating, and maintaining a profile of diverse racial/ethnic, immigrant, and limited English proficiency populations within the community.

PRINCIPLE 2: Establishing sustainable partnerships between community representatives and the public health preparedness system to assess, build, and sustain trust with diverse racial/ethnic, immigrant and limited English proficiency populations.

PRINCIPLE 3: Engaging community representatives to design, implement, and evaluate emergency risk communication strategies, ensuring that they are culturally and linguistically appropriate.

PRINCIPLE 4: Developing and testing drills and exercises that reflect the community and incorporate scenarios that explicitly involve culturally and linguistically diverse populations.

PRINCIPLE 5: Building capacity within the public health preparedness system to respond to the unique needs of diverse communities.

PRINCIPLE 6: Measuring and evaluating emergency plans and actions from preparedness to recovery, ensuring the active involvement of participants from the public health preparedness system and the community in a continual process of review.

PRINCIPLE 7: Coordinating information, resources, and actions across organizations and diverse communities to maximize compliance and adherence to preparedness practices.

PRINCIPLE 8: Ensuring the availability of funds to develop and sustain activities that strengthen diverse communities' ability to prepare, respond to, and recover from emergency events.

In 2010, the Panel convened in Washington, D.C., to consider the consensus statement and deliberate on the application of the toolkit for influenza pandemic planning. The related recommendations that follow in this section reflect a reaffirmation of the statement and the relevance of the toolkit, as well as the Panel members' knowledge, experience and expertise.

This section utilizes the framework established by the Panel to provide a set of practical recommendations to better plan for and respond to diverse communities in a pandemic.

These recommendations directly build on the Toolkit and highlight its primary cross-cutting theme: the importance of engaging and collaborating with trusted community representatives and organizations across the continuum of planning and response. The recommendations that follow closely align with the eight guiding principles issued by the Panel. Each recommendation includes a discussion of why it is important, what steps might be taken to achieve the intended outcomes, along with examples of promising initiatives that can further guide and inform implementation.

Recommendation 1: Identify diverse communities and their needs, attitudes, and beliefs

A number of economic and socio-cultural factors contributed to higher rates of H1N1 exposure and susceptibility and lower rates of, or delayed, treatment among diverse communities. Contributing factors included a lack of workplace paid sick leave policies, reliance on public transportation, domestic crowding, absence of a usual source of health care, limited English proficiency, preference for information through non-mainstream sources, in addition to many others.

Guiding Principle 1 emphasizes the critical need for pandemic planning to involve an assessment of community needs, characteristics, assets and challenges, well before an outbreak occurs. This requires understanding the racial and ethnic groups that reside within a community as well as the languages they speak and their attitudes, beliefs, and behaviors related to health, prevention, public health preparedness, and issues that may impact vaccine uptake, social distancing, and adherence to other recommended actions. Understanding these intricacies is key to dispelling myths or stereotypes that often hinder effective planning.

Data on many relevant characteristics of racially and ethnically diverse populations is publicly available through national, state and local data sets—such as the U.S. Census Bureau's American Community Survey and the CDC's Behavioral Risk Factor Surveillance System and National Immunization Survey. However, estimates for smaller groups, including immigrant and foreign born populations, are often not as readily available through these resources. Information on cultural beliefs and attitudes towards health care treatment and preventive actions—such as immunization, voluntary social distancing, isolation, and quarantine—are also not captured in these datasets.

As daunting as it sounds, primary data collection—ranging from more resource intensive methods such as surveys to those that are comparatively less intensive, but meaningful, including interviews, focus groups or community engagement sessions with representatives and leaders of diverse cultural, linguistic and faith populations—are important for understanding communities. Often times this information is already available through secondary resources– such as reports, peer-review research, and other publications issued by state/local government agencies, universities, nonprofits or think tanks—so reinventing the wheel may not be necessary. At the same time, ensuring well established relationships with representatives of diverse communities is critical to the process to prevent any social stigma or fear of "being identified."

The Public Engagement Project on Medical Services Prioritization during Influenza Pandemic conducted by the Seattle & King County Department of Public Health provides an example of community-driven pandemic planning.[62] Over the course of four public engagement sessions, a racially, ethnically and socioeconomically diverse group of 153 participants offered recommendations and guidance to the Department on how to

prioritize medical services for these communities during a pandemic. Spanish-speaking focus group participants shared experiences of perceived discrimination during the first wave of the H1N1 outbreak. Among the findings was a consensus that access to treatment should not hinge on factors such as legal status, nationality or outstanding hospital bills. The resulting report, which described the values and priorities of community members regarding the delivery of services during a pandemic influenza, was shared with national, state and local policymakers.

The San Francisco Bay Area Advanced Practice Center developed a toolkit entitled the *Seasonal and Pandemic Influenza Vaccination Assessment Tool* for local health departments on the topic of seasonal and pandemic influenza in which community assessment is the central planning tool: key informant interviews, focus groups and surveys are outlined as critical methods for data collection. [63] The comprehensive resource includes strategies on engaging special populations and utilizing data derived from community assessment methods. The toolkit's purpose is to augment vaccination planning among several partners including private health care providers and community-based organizations. In addition, the toolkit aims to raise awareness of potential gaps in preparedness planning.

Recommendation 2: Build partnerships with communities to foster trust

A common theme underlying lessons learned and promising practices for meeting the needs of diverse communities in the H1N1 pandemic was assuring, building and sustaining trust with communities, including their leaders and representatives. As discussed under Guiding Principle 2 in the *Toolkit*, working through trusted entities is especially critical to ensuring communication and information is received by and adhered to among diverse populations. In the case of the H1N1 pandemic, trust was critical not only for communication but also for distribution and acceptance of vaccinations and antiviral medication.

Community Engagement and Partnership. Partnering with community leaders, representatives and organizations requires shared priority setting and decision making, as well as developing and sustaining effective working relationships that address the communities' needs well before an emergency strikes. It is also essential that partnerships between health officials and community stakeholders be mutually beneficial for both parties. This may require direct, tangible incentives for community participation. While health officials are often paid for the time they spend working in local communities, community members are not, and thus could benefit from tangible or financial incentives.

A promising model for community engagement and cross-sector collaboration is the Los Angeles County Community Disaster Resilience Project.[64] With federal support, the project brought local community-based organizations (CBOs) together with the Los Angeles Department of Public Health and Emergency Network of Los Angeles to establish a common understanding of community resilience and how communities and government entities can effectively work together in emergencies. This objective is achieved through surveys, community meetings and discussion groups that provide participants with the opportunity to network, develop improved leadership skills and train partnering agencies in the fundamentals of community resilience. Such knowledge and engagement can be especially critical in planning for and responding to pandemic influenza in that it builds and reinforces upon the relationship between community agencies and local public health agencies to create effective strategies that are based on improved community resilience.

Building Trust. Distrust in the H1N1 vaccine was a significant barrier to vaccine uptake across all racial and ethnic groups, including Whites, but was particularly evident among African Americans. In addition, social stigma and fear of deportation among undocumented immigrants contributed to non-compliance with preventive actions as well as delayed treatment. Engaging trusted community leaders to serve as effective spokespersons can mitigate distrust, dispel myths and rumors, and assist in improving

understanding and acceptance of pandemic health information, while promoting preventive behaviors—such as social distancing and vaccination uptake.

The outreach efforts of numerous health departments across the country provide examples of strategies to engage trusted community leaders in the dissemination of health information. The Massachusetts State Department of Public Health allocated over $1 million in funding to trusted community entities—such as CBOs and community health centers—to conduct H1N1 outreach activities in African American and Latino communities.[65] Funded organizations focused their objectives around breaking down barriers to vaccination uptake in these communities through new commercials and expansion of the "Flu Facts" media campaign. The Ohio Department of Health reviewed seasonal influenza data to identify high-risk communities and then hosted a series of conference calls with African American and Hispanic community leaders to create a forum for bi-directional dialogue and information exchange.[66] Ohio health officials provided H1N1 information to community leaders to disseminate among their stakeholders, and community leaders provided health officials with advice on how they could better communicate H1N1 information in a way that promotes trust in messaging. The Ohio Department of Health also collaborated with faith-based leaders in African American communities to disseminate health information. The Rhode Island Department of Health made presentations before professional associations representing diverse communities and utilized translators to present information to audiences with limited-English proficiency.[67]

Establishing Convenient and Trusted Points of Distribution. Health officials should seek information about alternative locations that could be both convenient and trusted sources of vaccination and medical countermeasure distribution in diverse communities. It is quite possible, however, that trusted locations for vaccination and medical countermeasures may differ from trusted sources of health information. For example, churches may be a trusted source of health information in African American communities, but not a trusted venue for vaccinations. Thus, it is critical that such information is obtained from primary sources, working through trusted, community representatives.

Approaches should also consider multiple modes of intervention tailored to maximize acceptability and reach. For example, mobile clinics offer a promising strategy to improve vaccine access and uptake in diverse communities during a pandemic. The Los Angeles County Department of Public Health partnered with community health clinics and CBOs to offer no-cost H1N1 vaccination through mobile clinics in African American communities.[68] The mobile clinic activities were coordinated so that the clinic was present at community events with strong community turnout.

Recommendation 3: Develop clear, concise and culturally and linguistically appropriate messages

Studies conducted in the wake of the H1N1 pandemic revealed that Non-White populations generally had less knowledge about the H1N1 pandemic, including knowledge of the signs and symptoms of the virus, and its prevention and treatment. An important contributing factor to this finding was the inadequate distribution of timely and accurate information.

Guiding Principle 3 highlights the importance of developing information and messages that utilize trusted messengers and multiple modes of communication, while also being culturally and linguistically tailored. Translated materials, which are culturally appropriate, as well as racial and ethnic media sources, offer important outlets for such communication, particularly in a pandemic situation.

Culturally Appropriate, Translated Materials. Developing risk communication materials in multiple languages is critical to providing linguistically diverse communities with the information they need to make informed decisions in an emergency. This is particularly important in a pandemic scenario when there is often misinformation surrounding a novel disease. Messages should be clear, concise, and emphasize simple steps that people can take to prevent infection. Translated materials should be developed and disseminated quickly, but not at the cost of sacrificing quality. As pandemics often involve a disease for which translated materials do not already exist, developing materials in collaboration with community and ethnic representatives, as well as providing community members with an opportunity to vet materials before they are disseminated, can serve as critical quality control measures.

Translated materials, however, are typically costly to develop and produce, with limited resources taxed by a host of circumstances specific to the localities. For example, faced with the challenge presented by a geographic region with significant linguistic diversity, the Minnesota Department of Health developed "The Grid" to systematically prioritize the languages into which H1N1 materials were translated.[69] The Grid is a decision making tool that weighs factors like population size, length of time residing in the United States, level of English proficiency, and literacy when determining the order in which Non-English language materials should be translated. The Grid was successful in increasing the number of languages for which H1N1 materials were available from 10 to 18—allowing the Minnesota Department of Health to better serve its diverse resident populations, who speak 123 languages other than English.

Racial and Ethnic Media. Racial and ethnic media outlets—such as non-English radio stations, television programs, and newspapers—were a primary source of H1N1 information for many communities with limited-English proficiency during the pandemic. A promising practice that emerged from the pandemic was a series of H1N1

information sessions for members of the ethnic media hosted by New America Media and the CDC. In major cities across the U.S., representatives of ethnic media outlets were invited to roundtable sessions where health officials provided updates about the virus and answered questions. Similar strategies should be employed to reach diverse communities with health information in emergency, and non-emergency, contexts.

Recommendation 4: Develop drills and exercises that engage and reflect diverse communities

Ensuring a knowledgeable, culturally competent and diverse workforce is just as important as ensuring that communities are informed and educated about the risks, preventive strategies and treatments associated with a novel communicable disease. Guiding Principle 4 stresses the need for public health professionals to involve and engage individuals from diverse backgrounds to inform the development, testing of, and participation in drills and exercises that incorporate scenarios around race, culture, language, religion and trust into influenza planning and response. Such activities can be focused explicitly on special issues facing these communities, such as challenges in reaching individuals with little understanding of English or low trust in government.

To improve its training for pandemic influenza and promote community involvement, the Harris County Public Health and Environmental Services in Houston, Texas hosted a series of *Harris County Pandemic Influenza Partner Workshops.*[70] Convened in partnership with a wide range of community stakeholders, the project's objective was to identify strengths, gaps and potential solutions in the event of a pandemic influenza. The workshop, held over two days in four languages (English, Spanish, Mandarin Chinese and Vietnamese), stimulated discussion related to a hypothetical outbreak of influenza, considering a variety of legal, ethical and operational dilemmas that may occur in the region. The workshops intended to respond to important ethical questions, such as:

- If vaccines are in short supply, who should be vaccinated first?
- If we have a limited amount of antiviral medications, who should get them?
- If there aren't enough ventilators (breathing machines), who should get them?

Additionally, as part of the county's disaster response plan to provide human services after a disaster, officials host table top exercises twice yearly. The county has recently invited other social service agencies to participate, including the Asian Community Center, with the goal that each organization will provide their constituents with the relevant information in a culturally sensitive manner.

Also in Texas, the El Paso City-County Health and Environmental District expanded pandemic influenza education to its diverse communities by training community health workers and *promotores* to reach out to Hispanic/Latino residents.[71] The program utilizes culturally sensitive workers to reach individuals with limited English proficiency as well as those who, due to social and economic circumstances, may be isolated from the mainstream health system.

Recommendation 5: Ensure culturally and linguistically appropriate services

As was seen in the H1N1 pandemic, factors relating to language and culture can shape the attitudes, behaviors and actions of individuals in an outbreak of communicable disease--and potentially contribute to excess morbidity and mortality among racially and ethnically diverse communities, if not considered in planning and outreach efforts by public health professionals. Ensuring diverse communities receive important public health information and services in a culturally and linguistically appropriate manner is critical to their understanding of and adherence to recommended actions to prevent the onset and spread of ILI.

Guiding Principle 5 in the Toolkit discusses the importance of cultural competence in the context of public health preparedness. Cultural competence is defined as "a set of attitudes, skills, behaviors, and policies that enable organizations and staff to work effectively in cross-cultural situations. It reflects the ability to acquire and use knowledge of the health related beliefs, attitudes, practices and communication patterns of clients and their families to improve services, strengthen programs, increase community participation, and close the gaps in health status among diverse population groups."[72] Integrating cultural competence into pandemic influenza planning and response will involve, at least:

- Ensuring that information on the signs, symptoms, prevention and treatment options (including vaccination, social distancing, isolation and quarantine), as discussed under Recommendation 3, is accurately translated and presented appropriately within different cultural contexts.
- Ensuring that the public health workforce, including for example, health educators, community health workers, and clinical staff and volunteers at distributing sites for vaccinations and antiviral drugs reflect the diversity of their communities and/or are knowledgeable about their cultural attitudes, preferences and belief.
- Offering cultural competence training for providers and volunteers likely to be involved with pandemic preparation and response.
- Developing a plan to address language needs—including understanding how to access medical interpreter resources, how to work with medical interpreters, knowing language interpretation capacity and limits, and assuring access to other sources such as language hotlines.

Given the heightened attention and importance of addressing cultural competence in public health and health care, a number of key resources have emerged to guide providers in achieving this objective. The *National Standards for Culturally and Linguistically Appropriate Services* (CLAS), first issued in 2001 and updated in 2012 by the U.S. Department of Health and Human Services' Office of Minority , provide

guidance to health care organizations on specific actions to improve cultural competence, language access and organizational support. Building on this initiative is an online learning tool entitled, *Cultural Competency Curriculum for Disaster Preparedness and Crisis Response*, also supported by the Office of Minority Health. This series of online training modules is intended to educate public health and emergency personnel on the concept of cultural competence and its relevance to readiness, response and recovery. Topics covered include working with interpreters, locating translated materials, negotiating cultural differences and implementing the CLAS standards.

In addition to federal efforts, many state and local public health efforts have emerged to improve cultural and linguistic competence. The Midwest Asian Health Association, a CBO, provides culturally and linguistically appropriate outreach to Chicago's Asian communities related to a variety of health topics, including influenza. [73] The group aims to reduce barriers toward influenza vaccination including doubts around vaccination efficacy, lack of knowledge about immunizations and challenges to accessing health care. Furthermore, cultural and linguistic barriers are addressed by utilizing bi-lingual staff, ensuring both cultural sensitivity and convenience as well as cultivating trusting relationships. Services are implemented through community partnerships where "natural helpers" are identified. These individuals, in essence, serve as lay health advisors and are chosen due to their role as trusted resources that others seek out for various types of support and guidance. The Health Initiative of the Americas' *Promotores* program was developed in 2003 to train community health workers in both the U.S. and Mexico. [74] The program dedicated resources toward developing culturally and linguistically appropriate flyers and other materials related to H1N1 influenza for outreach in Latino communities which have been distributed through over 300 *promotores* in these two countries.

Recommendation 6: Engage community representatives and organizations in evaluation

A continual process of review and evaluation is critical to ensure that programs and interventions intended to reach and meet the needs of specific populations are, in fact, effective. There were numerous programs and lessons learned that emerged following the H1N1 pandemic. These include those tailored specifically for racially and ethnically diverse populations, such as the previously mentioned *promotores* and community health worker programs, as well as other initiatives that aimed to break down barriers in vaccination uptake, social isolation and other recommended actions.

As Guiding Principle 6 strongly suggests in the *Toolkit*, efforts to evaluate processes and outcomes for public health preparedness must include diverse community input at many levels. Thus, community representatives and organizations should be active participants in the evaluation of: community needs and assets; collaborations and partnerships; communication; training and education; culturally and linguistically appropriate services; coordination of information and resources; and program development. In this section, we provide examples of the kinds of questions that should be asked to evaluate pandemic influenza plans and actions for diverse communities, as discussed in the aforementioned Recommendations 1 – 5, as well as Recommendations 7 -8:

- **Recommendation 1: Community Needs Assessment**
    - How has the racial, ethnic and linguistic composition of the community changed since the last assessment?
    - Are there new assets within the community to serve diverse populations?
    - Are there potentially new pandemic vulnerabilities related to changes in populations?

- **Recommendation 2: Partnership Building**
    - Based on population dynamics, are there new racial, ethnic or religious partners that should be invited and involved?
    - Are there potential new, trusted and non-traditional sites that can serve as points of distribution for vaccines, antivirals and other resources?

- **Recommendation 3: Communication**
    - Are trusted channels of communication being utilized?
    - Is there a history of effective communication or miscommunication around previous influenza outbreaks that should be considered in planning for future communication strategies?
    - Are messages accurately translated and culturally appropriate?
    - How effective are current messages and channels of communication in ensuring critical messages are understood, accepted and adhered to?

- **Recommendation 4: Training and Drills**
  - Do current training, drills and exercises sufficiently address community nuances – such as cultural barriers or limited English proficiency?
  - Have previous outbreaks of influenza or other infectious diseases brought to light new challenges for culturally and linguistically diverse communities that should be incorporated into current trainings, drills and exercises?

- **Recommendation 5: Culturally and Linguistically Appropriate Services**
  - Is there sufficient capacity to meet the linguistic requirements of the community – e.g., languages offered through translated materials, medical interpreters, and hotlines?
  - Does the public health and medical staff sufficiently reflect diversity in the community?
  - Do translated materials and medical interpreters portray influenza prevention and treatment in a culturally and linguistically appropriate manner – i.e. vaccination of priority populations, limited availability of antiviral medications, and live, attenuated vaccines?

- **Recommendation 7: Information and Resource Coordination**
  - How effective are current coordination efforts in reducing redundancies and waste in the system?
  - Are resource inventories up-to-date—for bi-lingual staff and volunteers; medical interpreters; and culturally appropriate, trusted points of distribution—and appropriately shared across organizations?

- **Recommendation 8: Funding and Program Development**
  - Is equity/diversity integrated into currently funded programs with components related to education, outreach, communication, and collaboration?
  - Have broader public health grant opportunities been tapped into to address this priority, particularly through the health care reform law of 2010 which appropriates dollars through various programs –e.g., Public Health and Prevention Fund, Community Transformation Grant, support for Community Health Workers, support for primary care providers in underserved areas, and others?

Recommendation 7: Coordinate information and resources

Effective coordination of resources and information within and across organizations and agencies is critical for responsible and responsive pandemic influenza planning and response for racially and ethnically diverse communities. As Guiding Principle 7 highlights in the *Toolkit*, organizations can develop effective coordination and resource sharing through neutral conveners such as interagency councils and planning committees – entities that facilitate open communication as well as work to reduce duplication of efforts.

Responsible planning for pandemic influenza includes spreading best practices, lessons learned and effective tools and trainings employed for reaching out to and engaging these communities. While communities have distinct identities, the experiences and lessons that shape them, and the resources and assets they use are often quite similar. For example, the cultural experiences and attitudes that shape a particular racial or ethnic community may be quite similar regardless of where they are located in the U.S.--such as Vietnamese, Somali or Lao immigrants in Minnesota or Texas. Thus, translated materials, public service announcements, outreach efforts, and interpreter/translation services developed or offered by a particular organization can be shared and coordinated across organizations regardless of organizational or geographic boundaries. Other resources that should be catalogued within an organization and can be coordinated across organizations in a locality to better serve racial and ethnic sub-populations are: bi-lingual staff and volunteers; medical interpreters; and culturally appropriate, trusted points of distribution.

Emergency Community Health Outreach (ECHO) Minnesota represents a promising initiative for cataloguing and coordinating culturally and linguistically appropriate information resources. The organization specializes in multi-language health, safety and emergency readiness communication which is provided through ethnic community leaders and spokespersons through multiple mediums including television and radio broadcasts, phone, print, web, DVD and in-person venues. ECHO Minnesota provided information on H1N1 as well as seasonal vaccinations in nearly twelve foreign languages, including English, Khmer, Somali, Vietnamese, Lao, Spanish, Hmong and others. As such, entities across the country can use ECHO's materials as a resource to coordinate and relay important messages to the local communities they serve.

Recommendation 8: Ensure diversity and health equity are part of funding and program priorities for pandemic influenza

Given the unequal impact of the H1N1 pandemic, and other public health emergencies, on racially and ethnically diverse populations, it is important that funders consider diversity and health equity as core objectives of their activities. In particular, agencies responsible for disbursing grants and funds should consider making community engagement and partnership with community-based organizations a funded deliverable.

During the H1N1 pandemic, federal entities issued specific guidance to community-based organizations on how to effectively protect the health of the communities they serve—such as the USDHHS' Center for Faith-based and Neighborhood Partnerships document *H1N1 Flu: A Guide for Community and Faith-based Organizations* and the CDC's *Preparing for the Flu: A Communication Toolkit for Community and Faith-based Organizations*.[75,76] While these documents indicate that Federal officials recognize CBOs as critical partners with great potential to mitigate pandemic outcomes, they fall short of establishing meaningful, sustainable partnerships. Offering pandemic preparedness funding directly to CBOs could help define roles and expectations, increase accountability, and build capacity to effectively meet the needs of diverse communities in times of public health emergency.

Agencies and organizations receiving funding for pandemic influenza planning and response can also find innovative ways to integrate objectives specific to addressing diversity and advancing health equity. The level of focus on these objectives may vary depending on the funding agency and the extent to which they are aligned with their mandates and goals. At the broad level, addressing this priority may involve engaging and building partnerships with "community stakeholders" or representatives of diverse, immigrant and limited English proficiency populations. More specifically, this may involve building in programs that, for example, increase the cultural and linguistic diversity of staff, particularly those who provide direct services at points of dispensing (PODs); utilize and tailor existing or develop new culturally appropriate translated messages using multiple modes of communication; and offer cultural competency training for planners as well as providers at PODs.

In addition, public health agencies and health care organizations can seek funds to integrate health equity into pandemic influenza planning through new, and emerging federal opportunities, such as those emanating from the health care reform law of 2010. In particular, appropriations for the Public Health and Prevention Fund, Community Transformation Grants, Community Health Workers, and others can be used to advance objectives to improve education, communication and prevention of influenza among diverse communities.

State and local opportunities have also emerged around pandemic influenza planning for diverse communities. Whatcom County Health Department incorporated objectives related to improved outreach in Slavic and Latino communities after deficiencies in communication were identified during the 2009 H1N1 pandemic. County public health officials worked to establish community partnerships as well as engage representatives from such communities throughout all stages of risk communication planning. By identifying CBOs in both the Latino and Slavic communities, county officials cultivated relationships with previously established partners who were trusted by target populations. The department began engaging community members through interviews to develop an understanding of their specific needs and beliefs. Several lessons learned emerged from the interviews and provided the foundation for tailoring pandemic preparedness to culturally and linguistically diverse groups. For example, public health officials established the creation of a Spanish-language radio station in the county as a goal after learning that the Hispanic community preferred and trusted this method of communication. They further discovered that many of the migrant workers did not speak Spanish as assumed, but spoke indigenous languages from Mexico. Findings from the Slavic community differed. Religious leaders were identified as important sources of communication and distrust in government and mainstream medicine was found to be pervasive. All of these findings fed into new objectives to update the pandemic influenza plan to increase sensitivity to the needs of these diverse populations.[60]

CONCLUSION

Nearly a century following the Great Pandemic of 1918, racially and ethnically diverse communities continue to face a disproportionate burden of adverse outcomes from public health emergencies in the United States. This was evident in the H1N1 Pandemic of 2009-2010, where racial and ethnic minorities generally experienced higher rates of morbidity, hospitalization and mortality across many regions of the country. The reasons for these disparities are varied and complex, but stem from a number of economic and socio-cultural factors which contributed to higher rates of exposure and greater susceptibility to H1N1 and lower rates of treatment among many diverse communities.

The unique framework presented in this report – based on the recommendations of the National Consensus Panel on Emergency Preparedness and Cultural Diversity – is intended to promote integration of actions for addressing distinct characteristics, circumstances and needs of diverse communities into pandemic planning and to encourage engagement and integration of these communities across eight essential actions for emergency preparedness:

1. Community Health Assessments;
2. Partnership Building;
3. Risk Communication;
4. Training and Education;
5. Culturally and Linguistically Appropriate Services;
6. Measurement and Evaluation;
7. Information Coordination;
8. Funding and Program Development.

The specific recommendations, tailored guidance, practices and results embedded in this report offer a body of knowledge that can inform, improve and fill gaps in influenza pandemic planning for diverse populations. Ensuring the inclusion of our nation's growing racially and ethnically diverse populations in pandemic planning is critical to protecting and safeguarding the health of all people in the U.S.

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