An analysis of limitations for demographic data reporting on State COVID-19 dashboards

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Introduction

Demographic data is key to understanding health disparities among marginalized and minority populations. It helps identify trends and risk factors for groups based on age, sex/gender and race/ethnicity. This data can help improve the quality of care for all patients because it helps the healthcare industry identify the populations they serve, address the needs of these populations, and monitor improvements over time. [7] In essence, demographic data collection and analysis is necessary for improving health equity and reducing disparities within healthcare systems.

Historically, when it comes to disease and illness, specific populations face medical implications and predispositions far more than others because of their demographic makeup.[2] Ethnic minorities or communities of color are subject to systematic and structural discriminations causing this population to be more socioeconomically disadvantaged and ultimately less likely to be able to seek healthcare when they need it. Additionally, the physical makeup of sexes vary greatly and can lead to differences in display of symptoms, experience of pain, and more. Understanding the differences is sexes and genders is necessary to provide more precise and appropriate treatment and address different needs.[7] Furthermore, a shift in population growth has now led to a larger aging population in America. Therefore, hospitals will need more healthcare specialists trained in diseases and conditions of aging, including chronic disease and palliative and hospice care to better treat the aging cohort.

As the country gets bigger, older, and more diverse, the ever-evolving composition of the population will have profound effects on the U.S. health-care system and the people in its care.[10] Thus, collecting data on demographic risk factors is important to understand in order better address the health of the community. Regarding the raging wave of the COVID-19 cases in the US, gathering demographic data is crucial, as connections between demographic risk factors and COVID-19 could be beneficial to the general public as well as healthcare professionals in their course of treatment and care. Therefore, the purpose of this poster included gathering and analyzing demographic data on age, sex/gender, and race/ethnicity throughout all 50 states and the District of Columbia, to better understand the impact COVID-19 has on the US population.

Methodology

To begin, each team member investigated a different region of states and collected demographic data in the period of June 1-June 16. The regions were divided into Northwest, West, South, Midwest, and Northeast. Data was collected on three categories of demographic data, race and ethnicity, age groups, and sex and gender. Information was gathered from each state department website and saved on a google spreadsheet. After collecting demographic data, the goal was to identify trends and disparities apparent across state demographic dashboards. During this process, however, it was realized that each state created its own unique reporting structure and categorization, therefore limiting the process of finding demographic trends and risk factors within the US population. Thus, the poster focuses primarily on the limitations of state dashboard reporting and how that impacts COVID-19 research and community health response.

Discussion: Demographic Limitations

There are many limitations in the way that data is presented on state dashboards. These limitations not only draw from the overall understanding of demographics, they also fail to represent the data accurately.

One of the main limitations for this study is how sex or gender is reported on states websites. The limitation is that states have no uniformity on which term they are using, some states are using gender and some are using sex. In addition, if states are using gender, they are reporting only male or female, which is not an accurate representation of all genders. In many states, there are also no clear definitions of either gender nor sex. The US Census Bureau refers to sex as one's physical attributes (anatomy or chromosomes), while gender is defined by social constructs assigned by societies or cultures. Ambiguity of the two concepts results in inconsistent and inaccurate measuring. [4,5,9]

Another limitation of this study is that there is no standardized definition of races and ethnicities. This varies from state to state, and can present a problem for comparing racial and ethnic groups across different locations. The U.S. census bureau uses five main categories to classify races (White/Caucasian, Black, Asian, Native American/Alaskan Native, and Native Hawaiian/Pacific Islander) but most states do not use these five main categories, instead, they display various different racial and ethnic groupings. Some states even combine "Other", "Missing" and "Unknown" together, which is not accurate. "Other" could mean someone who is multi-racial or someone that does not fit into the other categories. "Unknown" means that it is missing or someone refused to answer that question and "Missing" means missing data. In addition, another limitation is that some states label "Hispanic" or "Latino" as a race and not an ethnicity. This creates concern as Hispanic or Latino are technically an ethnicity and it cannot be a mutually exclusive race. These limitations within reporting race and ethnicity limit the ability of drawing conclusions and can lead to misrepresentation of data.[3]

Accessibility to demographic data is a major limitation when gathering demographic data. First considering is whether the state includes this demographic data in their public COVID-19 dashboards, many states are not (For example Utah). The second consideration is whether the state is consistently updating their demographic data and if the data they are publicly reporting is representing real time data. The third consideration is the number of "clicks" that is required to access publicly reported demographic data. For some states the data is located in a central location with the majority/rest of the COVID-19 information, while other states have the demographic data located on another page on the state website, making it difficult to discover the data. The final consideration we acknowledged is the reasoning behind not public reporting the demographic data. Due to the demographics of a states population as a whole, publicly reporting demographic data can identify members of the state without consent of the individual. Accessibility to demographic information allows for all people to have access to the same information, which can lead to an increase in health literacy. Strong health literacy enables people, especially those most affected, to develop skills and education to make informed decisions about their health.[8,12]

Lastly, there are limitations with how the age groups are stratified. Again, there is no standardization of groups across state dashboards. While some states stratify by 10 years, others combine a mixture of strata width, of 15 years, 20 years, etc, making it extremely difficult to gage specifics in data. The major limitation is that these strata may be broadly lumping ages together that do not act the same way. Additionally, some states also extend up to 95 years old or stop at 80+ which makes it less specific and difficult to compare across states. Overall, the age group stratifications need to be presented in a uniform manner across state dashboards to limit broad generalization.

State Data

Texas:
Sex/Gender reported as: Gender-Male, Female, Unknown/Missing
Age groups listed as: <1, 1-9, 10-19, 20-29, 30-39, 40-49, 50-59, 60-64, 65-69, 70-74, 75-79, 80+
Race/Ethnicity categorized as: White, Black, Asian, Hispanic, Other.

Minnesota:
Sex/Gender reported as: Gender-Male, Female, Other, Unknown/Missing
Age Groups listed as: 0-5, 6-19, 20-29, 30-29, 40-49, 50-59, 60-69, 70-79, 80-89, 90-99, 100+, Unknown.
Race/Ethnicity categorized as: White, Black, Asian, Native Hawaiian/Pacific Islander, American Indian/Alaska Native, Multiple Races, Other, Unknown/Missing.

Virginia:
Sex/Gender reported as: Gender-Male, Female. or Not reported
Age groups listed as: 0-9, 10-19, 20-29, 30-39, 40-49, 50-59, 60-64, 65-69, 70-74, 75-79, 80+
Race/Ethnicity categorized as: Black, Latino, Native American, Asian/Pacific Islander, White, Not reported, Two or more races, Other.

California:
Sex/Gender reported as: Gender-Male, Female, Other
Age groups listed as: 0-17, 18-49, 50-64, 65+, Unknown/missing
Race/Ethnicity categorized as: Latino, Asian, Black, White, American Indian/Alaska Native, Native Hawaiian/Pacific Islander, Multi-race, Other.

Conclusion

The goal of this poster is to inform about the discrepancies in categorization and defining demographic data. No one state had clear categorizations that matched one another, nor fully defined their demographic data within a standard census format. The lack of these connections limited data analysis greatly as trends and generalizations could not be made. The need to create a more uniform reporting structure for this information is imperative, as it reduces health inequities in research and healthcare treatments for specific populations. In addition, proper data can provide greater accountability and better treatment in healthcare settings so that when it comes to disease and illness, patients of different sexes, racial and ethnic backgrounds, or age groups, are treated with the specific demographic risk factors in mind. Furthermore, the more accessible demographic information is, the higher capacity for health literacy in the general population. Increasing the populations health literacy allows individuals to make sense of health information and services available to them, understand their choices, and communicate their needs.

Ultimately we urge state dashboards to incorporate reliable demographic data in their webpages on a more accessible format with accurate definitions and clear categorizations so to better serve the community during the current COVID-19 pandemic. The ability to reach a data transparent world is evident, however, further research and competency training is required to best determine a clear reporting format that is representative and standardized.

Acknowledgements

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