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Completeness of Reporting of Race and Ethnicity Data in the Nationally Notifiable Diseases Surveillance System, United States, 2006–2010

Dr. Nelson Adekoya, DrPH, Dr. Benedict I. Truman, MD, MPH, and Dr. Umed A. Ajani, MBBS, MPH

Division of Health Informatics and Surveillance, Center for Surveillance, Epidemiology and Laboratory Services, Office of Public Health Scientific Services (Drs Adekoya and Ajani), and Office of the Director, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (Dr Truman), Centers for Disease Control and Prevention, Atlanta, Georgia

Abstract

Context—During 1994–1997, approximately 70% and 60% of the cases of conditions reported to the National Notifiable Diseases Surveillance System included persons of known race and ethnicity, respectively. A major goal of the *Healthy People 2020* initiative is to eliminate health disparities.

Objective—To describe trends in the completeness of race and ethnicity in case reports of the National Notifiable Diseases Surveillance System during 2006–2010.

Methods—The National Notifiable Diseases Surveillance System is a public health surveillance system that aggregates case reports of infectious diseases and conditions that are designated nationally notifiable and are collected by US states and territories. The Centers for Disease Control and Prevention (Atlanta, Georgia) maintains this surveillance system in collaboration with the Council of State and Territorial Epidemiologists. We used Cochran-Armitage Trend Test (SAS, version 9.2) to test the hypothesis that the percentage of case reports with the completeness of race and ethnicity data increased or decreased linearly during 2006–2010.

Main Outcome Measure—Completeness of race and ethnicity variables.

Results—The 32 conditions reviewed included 1 030 804 case records. Seventy percent of records included a known value for race, and 49% of records included ethnicity during 2006–2010. During 2006–2010, race was known in 70% or more of records in 24 of 32 conditions and in 23 of 51 jurisdictions. During 2006–2010, the systemwide reporting of race remained at the same level of completeness (70%) but the reporting of ethnicity increased slightly from 48% in 2006 to

Correspondence: Nelson Adekoya, DrPH, Office of Public Health Scientific Services, Center for Surveillance, Epidemiology and Laboratory Services, 1600 Clifton Rd, NE, MS-E91, Atlanta, GA 30333 (nba7@cdc.gov).

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53% in 2010. In comparison with race, the proportions of records coded to ethnicity were less among all conditions.

Conclusions—Significant change has occurred in the completeness of reporting of ethnicity but not race during 2006–2010. However, the reporting of ethnicity still lags substantially behind the reporting of race. Jurisdictions that identify conditions with lower rates of completeness of race and ethnicity can assess the net benefits of efforts to improve the completeness of race and ethnicity data.

Keywords

completion rate; ethnic groups; NNDSS; race

Racial and ethnic disparities in health are well documented, and certain initiatives, including the *Healthy People 2020* objectives, highlight the need for programs and policies to address health disparities.¹ Several infectious diseases demonstrate disproportionately increased morbidity when rates are compared among racial and ethnic groups.² Although complete reporting of race and ethnicity data is desirable both in monitoring disease trends and in planning and evaluating disease prevention and control efforts, previous reports indicate that completeness of reporting for infectious diseases varied widely by condition.^{2,3} In 1993, the Centers for Disease Control and Prevention (CDC) convened a workshop among experts to address race and ethnicity data in surveillance systems.⁴ This workshop was organized because consensus was lacking when defining and measuring race and ethnicity in public health surveillance systems, and if the *Healthy People 2000* objectives were to be met, these limitations had to be addressed. Specifically, the workshop addressed concepts, measures, and uses of race and ethnicity in public health surveillance.⁴ Independently, in 1997, the Office of Management and Budget (OMB) issued revised standards for collecting and reporting of race and ethnicity data within the federal statistical system.⁵ Although the 1997 standards do not apply to state-based surveillance systems, many such systems use the same standards to maintain comparability with federal statistical systems. In 2005, the national committee on vital and health statistics called for greater efforts to enhance completeness of race and ethnicity data through leadership, coordination with health organizations, and fostering partnerships among stakeholders because these data are crucial in addressing health disparities.⁶ Similar efforts might be needed to achieve the same goals for the same reasons in the case of disease surveillance systems that are essential to effective public health practice.

Race and ethnicity are among the most commonly used epidemiologic variables in public health,⁷ including for the quantification of health disparities.⁸ Within public health surveillance systems, race and ethnicity data can serve as risk markers for certain notifiable diseases.⁴ The National Notifiable Diseases Surveillance System (NNDSS) is the official source of reportable conditions data for the United States. Because the US population has become increasingly more diverse over time, a surveillance system that collects data regarding race and ethnicity should be continually evaluated^{9,10} to ensure that it is adequate in meeting the *Healthy People* objectives. Public health policies to support development of objectives and specific targets, determine priorities for the use of limited resources, and assess progress should be based on reliable data with optimal levels of completeness.¹¹

Given the importance of race and ethnicity data in public health surveillance, we sought to assess whether changes in the completeness (the percentage of known or nonmissing values) of reporting race and ethnicity to NNDSS have occurred during 2006–2010 and to examine variation in the completeness of race and ethnicity by events and geographic (jurisdictions) locations.

National Notifiable Diseases Surveillance System

The National Notifiable Diseases Surveillance System is a public health surveillance system that aggregates case report data on infectious diseases and conditions that are designated nationally notifiable in the United States and its territories. The Centers for Disease Control and Prevention maintains this surveillance system, in collaboration with the Council of State and Territorial Epidemiologists (CSTE), which determines nationally notifiable conditions and approves the use of national surveillance case definitions. Annually, state epidemiologists, other CSTE members, and CDC collaborate in determining which conditions are still of national importance and therefore should remain or otherwise be removed from the national list. Not all nationally notifiable conditions are reportable in all 51 jurisdictions (50 states, including the District of Columbia).

Material and Methods

Data analyses

In this study, we used data submitted to NNDSS by the reporting jurisdictions to calculate completeness (ie, the percentage of case reports with known values for race and ethnicity). We performed separate analyses to determine both the completeness of race by event and jurisdictions and the completeness of ethnicity by event and jurisdiction. We limited our analysis to case reports with selected attributes because the completeness of race and ethnicity is known to vary both by notifiable disease and by state.² For our inclusion criteria, (a) we applied the “print criteria” approved by CSTE,^{*} which were based on case confirmation status and whether the event is reportable in the jurisdiction each year; (b) we included influenza-associated pediatric mortality because of its high impact on persons younger than 18 years and on those with chronic conditions.¹²; (c) conditions must have been reported for 100 persons or more[†] during the study period or must have been reported for at least 10 persons[‡] each year during 2006–2010; and (d) conditions must have been notifiable throughout 2006–2010.^{*} In 2010, CSTE replaced Rocky Mountain spotted fever with spotted fever rickettsiosis. However, both names refer to the same condition. We used spotted fever rickettsiosis to display this condition in our tables. The following criteria were used to exclude notifiable diseases or health conditions for this study:

- a. We excluded sexually transmitted diseases,¹³ tuberculosis,^{14,15} and HIV/AIDS¹⁶ because these conditions publish annual reports with extensive data on race and

* Available at: <http://wwwn.cdc.gov/nndss>.

† Anthrax; rubella, congenital syndrome; trichinellosis; polio, paralytic; rabies, human; plague, psittacosis; cholera; novel influenza A virus infections; viral hemorrhagic fever; and vancomycin-resistant *Staphylococcus aureus* infection recorded fewer than 100 counts.

‡ Vancomycin-intermediate *Staphylococcus aureus* infection was excluded because fewer than 10 counts were recorded in 2006.

* Coccidioidomycosis and vibriosis were not notifiable throughout the study period.

ethnicity, including performance measures (ie, rate ratios) of selected conditions.¹⁷ In addition, these conditions were excluded in a prior race and ethnicity study.⁹

- a. Data from the US territories[†] were excluded because they are displayed differently in the annual *Morbidity and Mortality Weekly Report Summary of Notifiable Diseases* and are excluded when CDC displays US disease totals.²
- b. Because race and ethnicity are attributes of cases of human disease only, cases of animal rabies were excluded. Thirty-two diseases or health conditions met our inclusion criteria. For the conditions that met our criteria, we considered total case reports by serogroup as a separate condition[‡] and we reported total cases for botulism and measles.

Data in NNDSS are not coded according to the revised OMB standard for race and ethnicity. In the NNDSS data set, the race variable is coded as follows: 1, Native American/Alaskan Native; 2, Asian/Pacific Islander; 3, Afro-American; 5, white; 8, other; and 9, unknown.[§] Values corresponding to 1, 2, 3, 5, and 8 were recoded “Yes, known race,” but 9 was coded “No, unknown race.” Similarly, ethnicity was coded as follows: 1, Yes, Hispanic; 2, No, not Hispanic; or 9, unknown. Values corresponding to 1 or 2 were recoded “Yes, known ethnicity,” but 9 was coded “No, unknown ethnicity.” We constructed 2-by-5 tables (stratified by state and disease) with race or ethnicity (coded = yes; coded = no) by year (2006, 2007, 2008, 2009, 2010), computing the percentage of case reports with known race or ethnicity (completed) in each year. We used Cochran-Armitage Trend test in SAS (version 9.2; SAS Institute Inc, Cary, North Carolina) to assess the statistical significance of year-to-year changes in the percentage of case reports with known race or ethnicity by each disease and geographic location. For this statistical test, the z tests were used for a linear trend in the proportions, by testing whether the slope is zero. Tests were 2-sided, with significance of P value established at less than .05.

Results

The 32 conditions reviewed included 1 030 804 case reports (Table), of which sex was complete for 97% of records. During 2006–2010 combined, CDC received case reports with known race for approximately 70% of cases (718 253) (range by condition: 88%–58%). In 7 conditions, race was known in 80% or more of case reports; in 17 conditions, race was known for 70% to 79% of case reports; and in 7 conditions, race was coded for 60% to 69% of case reports. Toxic shock syndrome (caused by *Streptococcus* species) was the condition with the highest percentage (88%) of case reports with known race, whereas giardiasis was the condition with the lowest percentage (58%) of case reports with known race. Altogether, in 24 of 32 conditions (75%), race was known in 70% or more of case records.

In each of 23 conditions, the percentage of case reports with known race increased from year to year during 2006–2010. Of these conditions, the year-to-year increase was significant for

[†]American Samoa, Guam, Puerto Rico, Commonwealth of the Northern Mariana Islands, and the US Virgin Islands.

[‡]For example, ehrlichiosis.

[§]Where race and ethnicity information are missing after data have been reconciled with the state epidemiologists, CDC codes all remaining missing race and ethnicity values to “unknown.” The proportion of missing values cannot be determined in the finalized NNDSS data set but might be available to jurisdictions that do not recode their missing values to “unknown.”

13 conditions[¶] ($P = < .05$) and not significant for the remaining 10 conditions. A detailed description of decreases and increases by conditions and their significant levels are provided in Appendix A (see Supplemental Digital Content, available at: <http://links.lww.com/JPHMP/A82>).

Overall, the percentage of case reports with known race varied widely by jurisdiction (range, 29%–95%). In 4 jurisdictions (Florida, North Carolina, Oklahoma, and South Dakota), race was known in 90% or more of case reports; but at the other extreme, in one jurisdiction (Delaware), race was known in only 29% of case reports. In 6 jurisdictions, the race variable was complete in 80% to 89% of case reports; and in 13 jurisdictions, the race variable was complete in 70% to 79% of case reports. A detailed description of decreases and increases by jurisdictions, including significance levels, is provided in Appendix B (see Supplemental Digital Content, available at: <http://links.lww.com/JPHMP/A83>).

During 2006–2010, approximately 49% of case reports were for persons of known ethnicity (501 735) (range, 28%–77%). Compared with race, the percentages of case reports with known ethnicity were lower than the percentages of case reports with known race in all conditions examined. In 28 of 32 conditions (88%) examined, the percentage of case reports with known ethnicity increased from year to year during 2006–2010, but, overall, the range of completeness for ethnicity was still considerably lower than the range of completeness for race. In 19 of the 28 conditions (68%), year-to-year increases were significant ($P < .05$).^{*} A detailed description of decreases or increases by conditions and their significance levels is provided in Appendix C (see Supplemental Digital Content, available at: <http://links.lww.com/JPHMP/A84>).

The percentage of case reports with known ethnicity increased in 35 jurisdictions; in 34 of 35 jurisdictions, the year-to-year increase was significant. In 23 states, race was known in 70% or more of case reports, but in only 6 jurisdictions, ethnicity was known in 70% or more of case reports. The percentage of case reports with known ethnicity by jurisdiction ranged from 91% to 15% during 2006–2010. A detailed description of decreases and increases by jurisdictions and their significance levels is provided in Appendix D (see Supplemental Digital Content, available at: <http://links.lww.com/JPHMP/A85>).

Discussion

During 1994–1997, race and ethnicity data were complete for 70% and 60% of race and ethnicity records⁹ on average, compared with 70% and 49% for race and ethnicity during 2006–2010 discovered in our study. These percentages varied widely by jurisdictions and disease (condition). In comparison, sex, another demographic data, was recorded for 97% of cases.

[¶]Acute hepatitis A (viral), acute hepatitis B (viral), acute hepatitis C (viral), chickenpox, cryptosporidiosis, ehrlichiosis, hemolytic uremic syndrome (postdiarrheal), influenza-associated pediatric mortality, Lyme disease, mumps, salmonellosis, shigellosis and typhoid fever.

^{*}Acute hepatitis A (viral), acute hepatitis B (viral), acute hepatitis C (viral), chickenpox, cryptosporidiosis, ehrlichiosis, giardiasis, *Haemophilus influenzae*, influenza-associated pediatric mortality, legionellosis, listeriosis, Lyme disease, malaria, mumps, salmonellosis, shigellosis, toxic shock syndrome (streptococcal), tularemia, and typhoid fever.

The findings in this report demonstrate that, with limited exceptions by jurisdiction and by disease (condition), the average percentage of case reports with known race has remained approximately 70% overall from 1994–1997 to 2006–2010 in NNDSS but has decreased from 60% in 1994–1997 to 49% in 2006–2010 for ethnicity. Only 13 of 32 conditions demonstrated significant increases in completeness of the race variable, whereas 19 conditions demonstrated increases in completeness of the ethnicity variable. Although certain jurisdictions have implemented the OMB race and ethnicity standards, CDC[†] mapped these values to the National Electronic Telecommunications Systems for Surveillance race and ethnicity standards, which are based on the previous 1977 OMB race and ethnicity standards. Although changes have occurred in the way that race and ethnicity values are collected and forwarded to CDC, the changes in the standards for collecting and reporting such data in the federal statistical system would not affect our interpretation of results.

Because 75% of diseases (conditions) were reported for persons with known race in 70% or more of case reports but only 6% of diseases (conditions) achieved a comparable level of completeness for the ethnicity variable in case reports, inferring that substantially more emphasis has been placed on the completion of the race variable than on the ethnicity variable is reasonable. The analysis of temporal trends in racial and ethnic disparities in nationally notifiable diseases becomes unreliable when race and ethnicity data vary in the level of completeness from year to year and across longer periods.^{13,18,19}

Providing information for guiding actions and policies to improve population health is an essential public health function. Whenever surveillance data have high proportions of case reports with unknown race or ethnicity, those missing values can introduce measurement errors into estimates of racial and ethnic disparities produced from those data.²⁰ All health and health care entities (ie, hospitals, health care providers, community health centers, physician practices, and local and state agencies) have roles and responsibilities for collecting these data.^{16,21,22} High proportions of case reports with missing values on race and ethnicity in NNDSS^{2,10} are indicative of a long-standing problem. Salmonellosis is the most common foodborne illness in the United States and has been reported to have high proportions of missing values for both race and ethnicity.⁹ However, salmonellosis case reports demonstrated increasing levels of completeness for both race and ethnicity data during 2006–2010. Reasons for the increasing levels of completeness in the reporting of race and ethnicity in salmonellosis case reports are unclear. Potential reasons include increased awareness of the importance of accurately monitoring racial and ethnic health disparities¹ and acceleration of the adoption of new standards for collecting and reporting such data during 2006–2010.⁵ The pattern exhibited by Lyme disease is distinctive in that the percentage of case reports with known race and ethnicity has increased over time. During 2006–2010, the annual number of Lyme disease cases reported to CDC increased substantially. The increase is attributable in part to changes in the Lyme disease case definition and the implementation of an electronic laboratory reporting. These changes* created an additional reporting burden on the states because they had to go back to the

[†]The National Notifiable Diseases Surveillance System has been temporarily exempted from implementing the revised OMB guideline because of its transition to the National Electronic Diseases Surveillance System.

provider to obtain race and ethnicity data.^{23,24} Although the percentages of case reports completed for race and ethnicity are still low, increased attention and effort in collecting and reporting race and ethnicity of Lyme disease cases might have resulted in more complete data being reported to NNDSS.

The National Notifiable Diseases Surveillance System uses a passive data collection method and cannot provide all the information required for understanding infectious diseases. In addition to NNDSS, active surveillance systems have been developed to collect additional information needed for management and prevention of infectious diseases. Because completeness in the reporting of race has increased in some jurisdictions, decreased in some jurisdictions, and remained steady in other jurisdictions, reasons for this variation in the completion of race in case reports among jurisdictions should be explored in future studies. For example, Florida, North Carolina, Oklahoma, and South Dakota achieved 90% or more completeness on known race in their case reports, whereas Alaska, California, Delaware, Hawaii, Maine, Nebraska, New Jersey, North Dakota, Rhode Island, and West Virginia achieved 50% or less completeness on known race in their case reports. A review of policies and procedures in states where 70% or more of case reports included known race or ethnicity could assist states where less than 70% of case reports were complete. Also, with progressive increase in the number of case reports for pertussis but a decreasing trend in level of completeness of race and ethnicity, program officials should explore reasons for decreasing completeness in the face of an increasing caseload. Public health officials can examine the net benefits, if any, of continuing efforts to increase the percentage of case reports with known race and ethnicity for each condition and in each jurisdiction in terms of progress toward eliminating racial and ethnic health disparities.

Limitations

The findings in this report are subject to certain limitations. This report did not estimate the size or precision of racial disparities in notifiable diseases,^{2,9} nor did we determine the extent of racial disparities between pairs of populations. To reduce health disparities (eg, nationally, statewide, locally) while improving overall health status of the population, public health surveillance systems must be accurate, reliable, and complete. This assessment considered the levels of completeness of race and ethnicity data in case reports at the national and jurisdictional levels and identified where improvements are needed. Because NNDSS data are voluntarily reported by the states, identifying jurisdictions with lower percentages of case reports with known race or ethnicity is crucial, as high-quality data are needed to develop prevention policy and programs. In addition, laws and regulations that require public health reporting are under the authority of each reporting jurisdiction and further research is needed to ascertain the value of efforts to increase the completeness of race and ethnicity variables. We did not assess the extent to which state and local reporting sources are using the 1997 OMB standards for collection and reporting of race and ethnicity data within the federal statistical system.^{5,25,26} However, NNDSS could decide to conduct such an assessment and to accelerate the transition toward full implementation of the 1997

*Under the National Biosurveillance Strategy for Human Health, Lyme disease is aligned under the Electronic Laboratory Information Exchange and race is among its variables of interest (<http://www.cdc.gov/osels/phsipo/pdf/NBSHHv2.pdf>).

OMB standards, to increase completeness of race and ethnicity variables, and to enable better characterization of disease distribution. Finally, NNDSS data are reported from several sources and completeness of reporting may be different for these sources. Jurisdictions may adopt a new surveillance system that can also lead to issues in the collection of some variables. These issues could partly explain the experience with Alabama where completeness in the ethnicity variable ranged from 0% of case reports with known ethnicity in 2006 to 82% of case reports with known ethnicity in 2010. Notwithstanding, we did not assess completeness of reporting by different sources in this study. Because reporting of race is unchanged while reporting of ethnicity is still less than 50%, future research will examine the contributions of these sources to our findings.

Practice Implications

Public health surveillance is increasingly being transformed by technology, and implementation of the electronic surveillance system has improved case reporting of notifiable conditions.²⁷ Since 2001, NNDSS has been transitioning from the National Electronic Telecommunication Surveillance System to the National Electronic Diseases Surveillance System. The National Electronic Diseases Surveillance System promotes data usage and information system standards, especially interoperability of systems at the federal, state, and local levels. Monitoring and reporting the completeness of NNDSS data on race and ethnicity by reporting jurisdictions and by conditions can identify areas where additional efforts are needed to improve our reporting system to guide public health policy and programs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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TABLE

Summary of Completeness of Reporting Race, Ethnicity and Combined Race and Ethnicity in the National Notifiable Diseases Surveillance System, 2006–2010

Variable	No. Records	No. Records Coded	% Records Coded
Race	1 030 804	718 253	70
Ethnicity	1 030 804	501 735	49
Race and ethnicity	1 030 804	481 728	47
Sex	1 030 804	1 003 100	97

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