07-ID-08
Committee: Infectious Disease

Title: Use of HIV/AIDS surveillance data in future Ryan White HIV/AIDS Treatment Modernization Act funding formulas

Statement of Problem:

In 1997, CSTE recommended that all states and territories institute HIV reporting, specifically by name and not by unique identifier (CSTE Position statement 1997-ID-4). CSTE has consistently supported named HIV reporting since that time as the best way to get complete, unduplicated and comparable HIV data from all states and territories. In discussions around the 2006 reauthorization of the Ryan White CARE Act, CSTE supported adding HIV data from name-based HIV surveillance systems to AIDS case counts, as the most accurate measure of disease burden for calculating Ryan White funding formulas and determining eligibility. Barring that, CSTE supported CDC, the only federal agency with the required expertise, to certify the HIV surveillance data from states with non-named HIV reporting systems. The final reauthorized CARE Act (which was renamed the Ryan White HIV/AIDS Treatment Modernization Act of 2006 - RWHATMA) incorporated the use of reported living HIV and AIDS case data into allocation formulas. Further, it allowed counting of HIV infection reports that were reported by code and for these case counts to go directly from the states to HRSA with a 5% reduction applied to the totals to account for duplication. It also continued the use of *only* AIDS cases in determining eligibility for Part A (AKA Title I) Eligible Metropolitan Areas, Part A Transitional Grant Areas, and Part B (AKA Title II) Emerging Communities. Although the RWHATMA legislation requires areas to have begun name-based HIV reporting by April 1, 2008, it is assumed that, following the sunset date of September 30, 2009, some combination of named and non-named HIV surveillance data will be proposed to be used to determine future funding formulas, for some areas with less mature name-based HIV reporting systems. The purpose of this Position Statement is to confirm CSTE's position on the use of name based HIV/AIDS surveillance data for implementation of legislation used to fund care of HIV-infected persons that would go into effect after September 30, 2009.

CSTE reiterates its recommendation that HIV reporting by name is the most viable method for conducting HIV surveillance and deduplicating cases both within and between states. This ensures an equitable measure of HIV disease burden to be used as the basis for determining eligibility and allocating funds for care of HIV-infected persons and for other comparisons of HIV cases between reporting jurisdictions. This position statement reiterates that code based data should not be used as a part of formulas designed either for determining eligibility or for funding future HIV care programs

Statement of desired action(s) to be taken:

CSTE recommends that:

1. CDC, in collaboration with CSTE, determine the most scientifically valid method for combining data from states that are in various stages of implementing name-based HIV reporting for the purposes of the formulas used to fund care programs.
2. Any future eligibility and funding formulas should include name-based reported cases living with HIV infection (including AIDS), confirmed by CDC, as the basis of the formula(s).
3. CDC should provide technical support to ensure and require that by September 30, 2009 all project areas (states, cities and territories) : a) de-duplicate their HIV/AIDS cases both inside their state as well as with jurisdictions outside of their state within six months of receiving their list of potential interstate duplicates from CDC and, b) perform a match with their state death registry at least annually. Following the death match CDC should verify that the area uses the results of the match to update vital status of reported cases in the HIV/AIDS registry. They should assure that states have the necessary funding to perform these fundamental activities

and should be able to assure and verify that these activities are taking place.

4. Future legislation to determine formulas for funding the care of HIV-infected persons should reflect the input of CSTE HIV/AIDS surveillance experts who have experience with, and understand the complexities of HIV and AIDS data and can work to ensure a science-based approach to the use of these data for funding.

Public Health Impact:

Public health programs that provide care for persons infected with HIV will benefit from more equitable funding formulas. Use of HIV and AIDS surveillance data as the basis for both eligibility and funding formulas will result in the most equitable allocation of resources and maximize positive health outcomes for people living with HIV. Passage of this Position Statement will encourage the activities that need to be in place before the sunset date of the current legislation: reporting of prevalent cases of HIV infection, unduplicating HIV and AIDS cases and assuring that vital status information is current. These activities will allow the country to have, 25+ years after the beginning of the epidemic, a single integrated, national HIV/AIDS reporting system to provide high quality data to be used for planning prevention and care programs on both the local and national levels.

The authors acknowledge that hold harmless provisions have been helpful for minimizing large swings in funding that can disrupt the local infrastructure that is necessary for the continued care of HIV infected persons throughout the United States. However, they undermine the use of HIV/AIDS data in formulas. We believe that the hold harmless provisions should be re-evaluated when a fully mature integrated name-based HIV/AIDS reporting system has been implemented nationally.

Fiscal Impact on CSTE:

None.

References

CSTE Position statement 1997-ID-4

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