TRIP REPORT: CDC HIV/AIDS CASE OWNERSHIP CONSULTATION
October 28-29, 2003
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Eve Mokotoff and Eve Mokotoff represented CSTE at this consultation. CDC had invited five HIV program directors, five surveillance coordinators, and representatives of CSTE (two) and NASTAD (one) to this consultation, along with two senior HRSA staff and a large number of CDC/DHAP staff. The consultation's goals were to decide:
a) how state ownership of a HIV/AIDS case should be determined in the future,
b) how best to find and remove duplicated HIV as well as AIDS cases between state case registries (to "deduplicate" cases) and whether this can be done reliably when one or both of the states with apparently duplicate HIV cases are "coded identifier' states/cities (16 of those in the USA),
c) based on the above, whether it will be feasible to assign unduplicated HIV cases as well as AIDS cases unequivocally to state "ownership" so that both can be used to allocate Ryan White Care Act dollars fairly among states.

Rob Janssen pointed out in his opening talk that these issues, and the deliberations of the Institute of Medicine on them, are of such enormous interest because HIV/AIDS data means so much. Not only is such data vital to track the epidemic, plan and evaluate programs and learn about risk factors, but it is also used to allocate 1.3 billion dollars each year, based currently on the number of unduplicated AIDS cases each state "owns." CDC and HRSA are committed, he said, to assuring that such allocation is absolutely equitable; to have equitable funds allocation we must be able to remove duplicate cases between (and within, but that is thought to be a lesser problem) state registries with equal accuracy in all states. The "elephant in the room" was the question of whether "coded identifier" states could remove duplicates as completely as confidential named reporting states. The financial incentive is unfortunately to not remove duplicates, since they increase the number of cases "owned" and therefore the federal dollars.

At present a case is "owned" by the state in which the person resides at their first AIDS diagnosis. Thus reporting date at AIDS diagnosis is key. Because a relatively high proportion (exact proportion was hotly debated) of cases change residence between states during their clinical course, and because a steadily increasing stream of diagnostic data flows in to be linked to cases, there is substantial duplication of apparent "first" diagnoses of AIDS between different state registries. Analyses of the Interstate Duplication Evaluation Project (IDEP) show that about 22% of HIV and AIDS cases in the CDC registry appeared identical (same Soundex, gender, DOB) but about 55% of those proved to be truly different people. Also, it was not possible to determine duplication status for a number of cases. The state average rate of "true" duplicates detected was under the target 5%, but with enormous variation between states. In general duplication was significantly lower for AIDS than HIV (as expected), and was clearly negatively associated with the size (amount of total HIV morbidity) in the state. That is, higher-morbidity states had a lower percentage of duplicates.

After much debate the consensus was to recommend that, in the future, state ownership of cases be the state of residence at first HIV diagnosis, changing to state of residency at first AIDS diagnosis when AIDS is diagnosed. In the future, as electronic information systems improve and as, hopefully, more states move to confidential named reporting, the best determinant of ownership would be current residence of the case. CDC registered concerns about the inconsistent quality of the variable "first HIV diagnosis" (that would include the state where this diagnosis took place) and the need for this to be used more consistently if state at first HIV diagnosis is to be used to assign "ownership". The concern that follows from this is that CDC has been unable to provide funding based on HIV cases to states as they add HIV to their AIDS reporting systems. Consequently the focus has been on AIDS.

Representatives from California and Maryland were able to provide somewhat convincing arguments that their coded systems (in which names are retained at the provider level only) might be able to remove duplicates as well as named states, and the consensus was that we had to make that assumption, and then gather data to test it.

The consensus was that data on HIV cases would be good enough in the future to move to funding on the basis of "location of first HIV diagnosis changing to location of first AIDS diagnosis." The funding to accomplish the rapid implementation of eHARS and electronic lab reporting would be essential.

The timeline of activities will be to: a) complete analysis of all apparent duplicates (Phase II of the IDEP) by July 2004, b) write a new CDC Guidance on HIV/AIDS surveillance definitions and processes (not done since 1996), c) then develop a process for acceptance of unduplicated HIV case data from all states including coded reporting states. Finally, we will have to collaborate with HRSA on their modifications of the Ryan White Care Act funding formula, as urged by the Institute of Medicine committee. All this progress will depend on continued steady progress on rolling out a usable eHARS to all states as soon as possible, and on maintaining or increasing federal resources for HIV/AIDS surveillance.

Note: Dr. McKenna asked the CSTE representatives if CSTE would be willing to accept new funding in the umbrella cooperative agreement to bring together state representatives to write a new CDC Guidance on rules, variable definitions and standard processes for conducting HIV/AIDS surveillance. I said that the Executive Committee would make that decision, but that I thought it likely that CSTE would want to accept that task.