The following is a set of recommendations sent to CDC by email on June 23, 2006. The ACLU AIDS Project and Lambda Legal sent these recommendations in response to a request from CDC staff for specific suggestions following our April 21, 2006 letter. We welcome feedback from the HIV community and look forward to further discussion about how we can ensure protections for individuals receiving prevention services and minimize the burden PEMS places on prevention providers.

June 23, 2006

Lambda Legal and ACLU suggest that CDC consider taking the following steps as a means toward correcting the significant privacy, confidentiality, and security concerns that we raised in our letter dated April 21, 2006. We set forth these suggestions in a good faith effort to assist you in correcting the serious problems with PEMS that we have identified. We would be happy to discuss these suggestions in more detail and to work with you to draft and implement policies. Because PEMS is under continual revision, we must of course reserve the right to supplement or modify these suggestions in the future.

1. PEMS should not facilitate the creation of any database at the agency, state, and/or federal level that links behavioral data to personally identifying information. Whether or not CDC plans to access or use such data for any particular purpose, the mere existence of this database is chilling and dangerous, and is likely to interfere with prevention efforts. Further, we believe that law enforcement will quickly become aware of the existence of PEMS databases and seek incriminating information about clients from directly-funded CBOs, health departments, and CDC. We are unaware of any law or privilege that would protect client-level data entered into the PEMS database. In addition, we are concerned that data could be accessed by government authorities in future data mining efforts.

   We also note that because of the risk of subpoena or other inquiry by law enforcement, prevention providers who are collecting identifying data should be informing their clients at the beginning of each PEMS session that information collected during the intervention may be subject to subpoena and inquiry by law enforcement. PEMS trainings should include meaningful instruction for prevention providers about privacy concerns for clients.

   Moreover, we are concerned that many PEMS users, particularly small, directly-funded CBOs, do not have adequate resources to ensure that adequate client confidentiality protections are in place and ensure the security of PEMS databases. We are concerned that some of the most successful prevention providers will stop seeking CDC funding because they are too small and too poor to handle PEMS and the security protections that it requires.

To remedy the above concerns, we suggest that CDC eliminate all PEMS variables that seek identifying information (name, address, SSN, etc). These variables should be replaced with a uniform code variable that will uniquely identify each client. One possible unique identifier code that permits anonymous identification is as follows:

Instructions: Put "x" if you don't know the answer to any question.

What is your middle initial (put "X" if you don't have a middle name)?
What are the first two letters of your mother's first name?
What are the first two letters of the city in which you were born?
What are the first two letters of your father's first name?
What month, day, and year were you born? MM/DD/YYYY

If you eliminate names (and other identifying variables) from the PEMS software, the recommendations and concerns discussed in paragraphs two to seven below become less significant.

Until CDC is able to eliminate the names field and other identifying variables, CDC should instruct PEMS users to stop collecting identifying data.

2. CDC should re-examine which CDC-required variables are truly critical to CDC's program of monitoring and evaluation in light of their highly intrusive nature and the concerns we have raised about the collection of incriminating information from people living with HIV. CDC should make public its evaluation questions and explain which variables relate to which questions.

3. CDC should not require the collection of any client-level data until CDC has formulated specific evaluation questions that justify that data collection and identify how data variables help to answer evaluation questions.

4. CDC should require all PEMS users to formulate evaluation questions and an analysis plan before they collect data on client behavior (when that data is not required by CDC).

5. PEMS currently requires agencies to develop written policies governing the disclosure of identifying data. We are concerned that CDC has not done enough to ensure that stringent confidentiality protocols are in place. To remedy this situation, CDC could do the following:

   Draft a specific confidentiality protocol consistent with the most stringent state and federal protections for personal information and require agencies to either:

   a) certify that their own confidentiality protocol is at least as protective of client confidentiality as the CDC protocol; or
   b) adopt the CDC protocol.

We are willing to help you draft such a protocol. The protocol must provide expressly that PEMS agencies and their partners shall not disclose any client information to federal or local law enforcement. This provision must be included in any confidentiality protocol used by a PEMS agency.

Again, we note that confidentiality protocols could be less stringent if CDC were to eliminate the collection of identifying data as recommended in paragraph one.

6. CDC should provide meaningful resources and technical assistance for agencies, particularly small providers, to ensure that they are able to comply with the confidentiality requirements suggested in paragraph five and that adequate security safeguards are in place.

7. We are concerned about the way the current PEMS documents describe the sharing of information among agencies and partner agencies. We understand that you are reviewing and revising PEMS, and we would like to know what kind of data sharing you anticipate between agencies. Our concern is that the current description of data sharing between agencies is vague and perhaps overbroad. The PEMS Security Summary currently allows agencies to "share limited information about specific clients" with "other agencies" to assist in "tracking referrals and other purposes." However, the document places no limitations on the type of information that may be shared, the purposes for which information may be shared, or which types of "partner" agencies may receive information. As you move forward, we suggest that CDC must narrowly constrain the parameters of this data sharing and place restrictions on the release of identifying data between agencies. Further, as part of the confidentiality protocol described in paragraph five, CDC should require that agencies may not share identifying information without specific, written client consent.

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