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April 21, 2006

By Email & First Class Mail
Dr. Robert S. Janssen, Director
Division of HIV/AIDS Prevention
Centers for Disease Control and Prevention
Corporate Square, MS D-21
8 Corporate Boulevard
Atlanta, GA 30329

Dear Dr. Janssen:

After reviewing draft documents regarding the Program Evaluation Management System ("PEMS") proposing increased data collection and reporting by community-based organizations providing HIV services, the undersigned organizations would like to express our deep concern that the approach taken in the draft documents does not appropriately protect the confidentiality and security of the clients of these agencies, and requires collection and reporting of information that risks interfering with provision of HIV services. We appreciate that a moratorium has been imposed on the implementation of PEMS, and that a Stakeholders Meeting is scheduled for April 25-26, 2006, to discuss these and other objections that have been raised about PEMS.

We understand that the purpose of the collection of PEMS data is to evaluate the success of various HIV prevention and counseling interventions. While we appreciate the need to evaluate CDC-funded programs, we have serious doubts about whether this type of detailed, personal data collection is necessary at all. However, if the CDC does require this level of data collection and retention, the law requires that any mandatory data collection scheme provide stringent protections to ensure that agencies hold in a secure manner any identifying medical and other personal information that they collect and track. The current PEMS proposals, including the draft documents regarding security, fail in a number of ways to provide this necessary protection. By requiring agencies to collect and share extensive, highly sensitive client information, including information about sexual behavior and drug use, PEMS unreasonably invades the privacy of clients, imposes significant burdens on agencies to protect the security of that data, and jeopardizes the client-provider relationship.

Under the current PEMS proposals, agencies will be required to develop far more extensive databases than they currently maintain, and will be recording and reporting highly-sensitive information along with individually identifiable client information. Mandating the collection of highly-sensitive and personally identifying information presents a serious and unavoidable risk that confidentiality will be breached. In addition, because the agencies will be maintaining databases with identifiable client information, even if steps are taken to prevent accidental breaches of confidentiality, we fear that aggressive law enforcement officials will be able to subpoena the agency to gather private information for possible use in criminal prosecutions. In short, the risk of inadvertent or compelled disclosure of this highly sensitive information is real, and the CDC and PEMS Stakeholders should reconsider whether requiring the collection of individually identifiable behavioral data is necessary to meet the goals of PEMS.

Of further concern, while the CDC apparently does not intend to require agencies to report client behavior data with individually identifiable information directly to the CDC, the draft PEMS documents indicate that the CDC will maintain two separate databases on its servers, one database that contains identifying information and one with de-identified information. We are deeply troubled about the possibility that the CDC will develop a national database of names of people with HIV that includes extensive private behavioral information about each of them, and see no reasonable public health justification for the CDC to collect identifiable information about individual clients.

We also note that the draft PEMS documents fail to give sufficient guidance to agencies about how to protect the security of the client data that is collected and reported. While the draft documents do express concerns about client privacy, statements regarding the importance of confidentiality lack teeth in the absence of an effective civil and criminal enforcement mechanism. Many agencies will not have the resources or experience to develop adequate procedures to protect the personal information that PEMS will require them to collect. To the extent that PEMS as ultimately implemented requires the collection and reporting of identifiable client information, the CDC and PEMS Stakeholders must develop a binding and enforceable privacy policy consistent with the most stringent state and federal protections of personal information with which all PEMS agencies must comply. As a starting point, the privacy provisions must ensure that there is no risk of disclosure to law enforcement, and that the information collected may be used only for the stated purpose of the collection. We note that the Model State Public Health Privacy Act, the development of which the undersigned organizations participated in, provides a strong model for protecting the privacy of public health information, and would encourage the CDC and PEMS Stakeholders to adopt the protections set forth in that Model Act. Relatedly, to the extent that agencies lack the resources, training or ability to protect the security of PEMS client data, they must not be required or allowed to collect that information.

Finally, because many people seeking HIV prevention services may be understandably concerned about the consequences of disclosing information regarding their sexual activity, drug use or other behaviors, especially where disclosing such information may result in criminal prosecutions, mandating collection and reporting of such data, while failing to ensure the absolute confidentiality of that information, will undermine the trust and confidence that is a necessary part of effective prevention and counseling interventions.

Our concerns about privacy are not merely speculative. We are aware of a number of potential breaches of confidentiality from agencies that lack the technological training to ensure that only encrypted data is reported, or that have failed to impose sufficient limitations on who has access to confidential client data.[1] As a result, any further implementation of PEMS requiring the reporting of any individually identifiable client data should be suspended unless and until client privacy can be adequately protected. Even if the CDC implements such protections, because of the highly-sensitive nature of the data required to be collected and reported, and the serious consequences that result from inadvertent or malicious disclosure, the broad and highly-invasive behavioral data collection contemplated by the draft PEMS documents is simply not warranted.

We believe it is crucial that the participants of the Stakeholders Meeting identify and discuss the appropriate goals for this project, and that those discussions focus on how to ensure that any implementation of PEMS adequately protects the confidentiality and privacy of people with HIV. A representative from our organizations will be attending the Stakeholders Meeting, and we look forward to working with you and the other stakeholders on this project.

Sincerely,

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EDUCATION FUND, INC.

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[1] Furthermore, the risk of inadvertent disclosure of highly sensitive client data is significantly increased because the draft PEMS documents allow agencies to release identifying information about individual clients to partner agencies, while providing no meaningful limits on the sharing of information with those partners. Thus, even those agencies with comprehensive privacy protections in place may jeopardize the confidentiality of client data if they share that data with partner agencies that lack adequate safeguards. The CDC should ensure that any data sharing is subject to the same stringent confidentiality provisions that should apply to all PEMS data.

cc: Janet Cleveland, CDC
Kevin Fenton, CDC
Julie Gerberding, CDC
Sean Griffiths, CDC
Craig Thomas, CDC
Attendees of the April 25-26, 2006 PEMS Stakeholders Meeting
(all via email)