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January 6, 2006

Robert S. Janssen, M.D.
Director
Division of HIV/AIDS Prevention
CDC
1600 Clifton Road, NE
Atlanta, GA 30329

Dear Dr. Janssen,

On behalf of the National Alliance of State and Territorial AIDS Directors (NASTAD), I am writing to describe ongoing challenges that AIDS directors are encountering with the development and implementation of the Program Evaluation Monitoring System (PEMS). We recognize the value and need to evaluate HIV prevention programs and believe that successful implementation of PEMS is important for CDC and health departments. However, we have serious concerns with the implementation process. We urge CDC to examine the way that this project is being implemented and the impact that it has on prevention programs. NASTAD remains committed to working with CDC to ensure that a successful system is developed and implemented. Throughout the development of PEMS, NASTAD has worked with CDC and health departments to identify key issues and enhance communication between partners. Our concerns focus on four key areas: timelines/readiness, communication, security, and technical support.

Timelines/Readiness

According to the formal communication from CDC on December 19, 2005, health departments are responsible for collecting data on health department delivered client and aggregate level services beginning January 1, 2006, for the following: Counseling Testing and Referral (CTR), Partner Counseling and Referral Services (PCRS), Comprehensive Risk Counseling Services (CRCS), Diffusion of Effective Behavioral Interventions (DEBIs)/Procedural Guidance, Health Communication/Public Information (HC/PI), Health Education/Risk Reduction (HE/RR), and Outreach. Data collected during the first quarter of 2006 is then scheduled to be submitted to CDC on May 15, 2006.

Previous information from PERB had indicated that PEMS would be phased in to allow health departments time to develop the infrastructure necessary to collect and report high quality data. Since target dates for PEMS have not been met by CDC as they relate to the development of software, variables, and data collection tools, it is unreasonable to expect health departments to begin

collection of all the modules on January 1, 2006. The current deadline requires health departments to initiate a number of programs at one time. The timelines do not provide adequate time for health departments to revise their data collection tools, develop training modules, initiate trainings for their staff and provider agencies' staff, or validate data collection.

The adherence to articulated deadlines for deliverables from CDC has consistently been an issue for the implementation of PEMS. The development and roll out of the CTR module serves as an example of the lack of readiness. CDC developed and released a scan-able form in late 2005 that several health departments will use for collecting CTR data. This form was released as an electronic document to health departments. However, hardcopies of the form have not yet been provided. Without the forms health departments cannot begin to collect data on January 1, 2006.

As another example, the December 19, 2005 communication indicated that "selected PEMS software screen shots and DEBI specific data variables requirements will be forwarded by separate email in early 2006 to assist grantees in developing data collection forms for the above program models/interventions". However, the timeline clearly states that all health departments are expected to begin data collection on January 1, 2006 for health department delivered client and aggregate level services. Health departments cannot be expected to begin data collection when the relevant tools have not been provided by CDC.

Additional issues raised by health departments regarding PEMS have not been fully addressed. Collecting PCRS data in jurisdictions that use the Sexually Transmitted Disease Management Information System (STD*MIS) remains a concern. Currently data cannot be exported from STD*MIS to PEMS. PERB's requirement for assembling and reporting PCRS data prior to creating a method for data transfer, places an undue burden on health departments by requiring them to perform dual data entry in order to fulfill the PEMS requirements. This increases the likelihood of errors and reduces data quality.

As a second example, jurisdictions that are required under local regulations to submit data collection tools for review by Institutional Review Boards (IRB) need to have the variables, values, and guidance on data collection in final form. In addition, details regarding data linkages, storage, access, intended use, and public release must be available as well. Data collection cannot be initiated until receipt of IRB approval is obtained in these jurisdictions. Without these elements of the system being fully articulated, submissions to IRBs may be delayed. IRBs may reject submissions without this information or severely restrict data collection activities.

XPEMS jurisdictions are uniquely impacted by timelines and readiness. The responsiveness to PEMS is dependent upon modifying existing health department HIV data management systems, beta testing, and validating the data transfers. PERB has been unable to provide the technical specifications that have been requested by the XPEMS jurisdictions. The specifications are required by the XPEMS areas to begin making modifications and to estimate the amount of time and resources needed to meet PEMS requirements. It is unreasonable to expect these jurisdictions to respond with the speed needed to meet deadlines that have been established in absence of critical information. It should be noted that XPEMS jurisdictions already have experience gathering client level data and will likely provide the most accurate data in the early stages.

The communication to grantees from PERB on December 19, 2006 provides jurisdictions with the option of filing for a one time extension for up to 90 days for one or more of the modules. It is unreasonable to ask health departments to make a commitment for the collection of data without having final variables, values, guidance and technical information or without firm commitments as to the dates of delivery of these products. These items are critical for determining the amount of time and resources health departments will need to expend to meet PEMS requirements.

Communication

Communication has been an ongoing challenge between PERB and health departments. Health departments receive an array of information from various sources regarding PEMS including the PERB managed email helpdesk, PERB designated regional leads, along with individual staff at PERB. However, health departments have reported that there is often conflicting information from these various sources. During regional implementation calls hosted by CDC there has been a lack of technical understanding by the regional leads to address the technical issues raised by health departments. While we commend CDC for providing health departments with various sources to access PEMS information, the messages sent by PERB need to be clear, timely, and well informed in order to minimize confusion and frustration.

Poor communication has made the job of the Prevention Program Branch (PPB) project officers more difficult. Confusing information creates significant barriers in their role of providing guidance to jurisdictions on CDC expectations and priorities. Health departments appreciate the leadership that PPB has shown in trying to negotiate this challenge and provide health departments accurate information about CDC expectations. However, jurisdictions recognize the challenges faced when clear information is not available.

Security

Currently, CDC expects every grantee of a health department to sign a memorandum of understanding (MOU) and every person who collects, enters, or manages data to sign the rules of behavior (ROB) agreement on an annual basis. For some jurisdictions this means that literally thousands of individuals will need to annually sign a ROB agreement. In addition, hundreds of organizations will need to have MOUs updated and monitored annually. This creates a substantial burden that health departments will need to manage and monitor.

Technical Support

CDC has not articulated a plan for providing long term technical assistance and training for support of PEMS. Ongoing support is needed by grantees to address issues of staff turnover, capacity changes, and evolving program needs. While long term technical support is important to all jurisdictions, those using XPEMS have critical needs for support in both the near and long term. Many of these jurisdictions have integrated information systems with unique technical specifications that must be modified to work with PEMS. Information technology staff within each health department can only do so much without support from CDC. As noted above, these jurisdictions have the greatest experience in collecting client level data and will provide the most accurate information in the early stages.

During a recent PEMS training, participants from XPEMS areas requested a dedicated "technical consultant" or team of consultants to work with them and assist in problem solving as XPEMS areas modify systems to meet requirements. One of the key areas of concern is transferring data. It is imperative that staff from health departments and CDC work together to insure that transferred data is relevant and of the highest quality.

Recommendations

- Additional time is required for CDC and health departments to successfully implement the PEMS modules. A new timeline should be developed in collaboration with health departments that reflects the additional time CDC will need to provide final variables, values, and guidance for PEMS. CDC should collaborate directly with health departments to determine individual readiness and appropriate timelines for when each jurisdiction will have PEMS deployed. The timelines for health departments need to reflect the amount of time needed to revise their data collection tools, obtain clearances, develop training modules, initiate trainings for staff, and validate data collection.
- CDC needs to consult with health departments on a regular basis for the ongoing development of PEMS. The consultations should address the support needs of grantees and develop strategies for addressing support concerns. The consultations will also serve as a venue for addressing policy concerns that cannot be addressed by current technical leads.
- CDC needs to ensure that timely and accurate communication across jurisdictions occurs. Regular calls with PERB, PPB, and NASTAD can be used to help ensure jurisdictions receive accurate communication. In addition to ensuring accurate and timely communication, the calls can serve as a venue for developing collaborative solutions to key issues raised by health departments and PERB. The involvement of PPB will be critical to ensure that project officers have the information they need to provide appropriate guidance to jurisdictions.
- Establish a CDC website to post all PEMS related communications, timelines, and materials to help streamline communication and ensure a single point of reference for grantees.
- CDC should develop alternatives to MOUs and ROBs in collaboration with health departments that ensure that security measures are met and maintained. CDC needs to clarify MOUs and ROBs for jurisdictions using XPEMS and work with them to develop mutually acceptable alternatives.
- CDC needs to develop and articulate their long term plan for providing technical assistance and training to grantees. The technical support needs of XPEMS jurisdictions should be explicitly addressed in the plan.
- CDC needs to address the use of data as it relates to program evaluation and monitoring. Plans for data use should be developed in collaboration with health departments. CDC also should address the overarching issue of how health departments evaluate programs and how PEMS data supports such evaluation. PEMS is not an end in itself, but a tool to identify and support more extensive evaluation activities.

In closing, NASTAD supports CDC's efforts to develop an evaluation system for HIV prevention programs. However, we feel strongly that the system needs to be developed and implemented as a collaborative effort between health departments and CDC, and the system needs to take into account the needs of both health departments and CDC. NASTAD would like to partner with CDC leadership in hosting a series of conference calls or other forums to address the

above recommendations. The discussions would serve to review the current status of PEMS and develop strategies for collaboratively implementing PEMS with grantees and CDC.

I will be happy to discuss our recommendations in greater detail and look forward to hearing from you.

Sincerely,



Julie M. Scofield
Executive Director

CC:

Julie Gerberding – CDC
Mitch Cohen – CDC
Kevin Fenton - CDC
Ron Valdiserri – CDC
Robert Kohmescher- CDC
Linda Wright-Deaguero -CDC
H. “Mac” McCraw -CDC
NASTAD Members