



## **Bush Administration Imposes Sweeping Data Collection on U.S. HIV Prevention Programs**

*Activists warn that PEMS, the impending CDC reporting program, risks program effectiveness and participant privacy, and demand community-led program redesign, adequate resources for comprehensive monitoring and research, and assurances of privacy safeguards*

Providence, RI –

The Community HIV/AIDS Mobilization Project (CHAMP) is notifying the AIDS community about widely-held concerns about CDC's Program Evaluation and Monitoring System (PEMS), a massive and unprecedented set of new surveillance requirements for federally funded HIV prevention programs. They are calling for a postponement of deadlines for all programs to become PEMS-compliant, for fundamental changes in the program, and assurances that community providers who speak out will not be penalized with funding cuts.

"We are eager to collect necessary information that will help us continue to improve our prevention efforts but we share widespread public concern about government monitoring. PEMS prioritizes invasive data collection above the actual work of HIV prevention itself, threatening to turn educators into interrogators and overwhelm already understaffed HIV prevention agencies with paperwork," said Julie Davids, Executive Director of CHAMP. "Meanwhile, barely-monitored abstinence-only programs get funding increases, despite *no* evidence that they prevent HIV, and much documentation that they *do* spread misinformation."

CHAMP notes that many AIDS organizations have been facing cutbacks in funding and staff for multiple years, due to cuts for HIV prevention programs at the federal level and increased competition over limited resources at the community level. All programs will be required to dedicate a staff person as a PEMS coordinator, even though there is no additional funding being provided to support the position.

Many of the current CDC-funded prevention programs emphasize the importance of building rapport with people before entering into intensive discussions of stigmatized topics. However, PEMS requires that counselors ask a lengthy list of questions. This can be both invasive and time-consuming, alienating clients with intrusive questions while limiting the amount of time available for actual risk-reduction counseling.

Some community members have also noted that PEMS resembles behavioral research more than simple monitoring, and believe that it should be governed by the legal protections of research – such as informed consent and IRB approval – and providers should be compensated adequately for research expenses.

For prevention efforts targeting HIV positive people, questions include the date a client became aware of HIV status, subsequent risk-taking behaviors, and identifying information for their partner. This information can put the client at risk for criminal charges in certain states. CDC has refused to clarify the circumstances under which they would override the encryption key that safeguards this data.

"This program is not going to give us the answers we need," said Sean Barry, CHAMP Director of Prevention Policy. "Data collection that is too hard to do, and that conflicts with good and ethical prevention education, will not happen in a thorough way. We need to simplify monitoring, and then support real research to track the outcomes of prevention programs. PEMS will give us neither good monitoring, nor good information on outcomes. We demand a fundamental re-think of monitoring and evaluation that is shaped by full community involvement, not done on the cheap on the backs of community providers."

***CHAMP's recommendations for PEMS follow.***

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## Backgrounder: Program Evaluation and Monitoring System (PEMS)

### What is PEMS?

PEMS stands for “Program Evaluation and Monitoring System.” According to CDC, “PEMS is a prevention tool designed for monitoring and evaluating HIV prevention programs,” through a “standardized set of data variables to be collected by health departments and directly funded CBOs [community-based organizations].”

### What are the key problems with PEMS?

#### *Large, cumbersome and expensive:*

PEMS requires answering hundreds of questions, requiring many hours of data entry and complicated forms.

#### *Will interfere with actual prevention efforts:*

Prevention workers have to collect a lot of data for PEMS. One person involved in a pilot PEMS project cautioned that “PEMS is not going to evaluate our interventions. It is going to **be** our intervention,” because it requires not only time, but asking distinct and invasive questions about sexual behavior that might not ordinarily be broached in initial sessions while a counselor establishes rapport with a client.

#### *Could jeopardize privacy and have legal implications:*

CDC requires privacy and confidentiality statements and procedures from the grantees – but has not answered questions about how **they** will assure confidentiality of data. In addition, PEMS will track many interventions, including “prevention with positives” programs where HIV+ people talk about their date of diagnosis and then return to share information about their sexual practices, which some legal experts believe could be subpoenaed in states where there are laws that criminalize HIV transmission. This deters people from being frank in counseling, and can prevent people from accessing services and getting prevention support.

#### *Will not tell us how HIV prevention programs work:*

Although PEMS stands for “evaluation” and “monitoring,” it is unclear how PEMS will actually evaluate if these interventions are reducing HIV transmission. CDC currently spends far below the standard percentage recommended for outcomes evaluation. We need comprehensive, well-planned and adequately supported research on these programs that includes true community participation in the design, implementation and analysis and that factors in the impact of under-funding of programs.

#### *Can be considered research and need IRB (Institutional Review Board) approval:*

CDC has decided for itself that PEMS is not considered research and thus does not need to go through the legal safeguards that research does. But it may fit under some states’ definitions of research and need approval as such. Also, community providers are getting nothing near the costs of conducting research built into their contracts – just the requirements.

### CHAMP RECOMMENDATIONS FOR CORRECTIVE ACTION:

- CDC must convene and maintain a community-driven panel to address key concerns and make improvements to PEMS.
- CDC must encourage grantees to speak openly about impact of PEMS and to contribute to assessment and change of the program, and reassure them that to do so will in no way impact their funding.
- CDC must guarantee that full and permanent data safety, and that the encryption key protecting client data will never be overridden.
- CDC must separate out the monitoring from evaluation:
  - Simplify the monitoring data collection requirements. Less cumbersome data collection requirements that provide information already exist at the state and local level throughout the country, which can be considered as models to reform PEMS.
  - Limit evaluation and provide supplemental funding to fewer select areas where there is the capacity for quality outcomes research. Develop sentinel outcome evaluation programs in a range of locations and intervention models, provided with adequate funding, community oversight, and full compliance with research regulations.
- CDC must find non-programmatic offsets to dedicate more funding towards evaluation of prevention programs.
- President Bush and Congress must increase CDC funding for HIV prevention, surveillance, and DASH youth education by \$604 million to \$1.611 billion in FY07