

New CDC Evaluation Program: Rube Goldberg Meets Big Brother

The CDC tightens its grip

Starting in January, the Centers for Disease Control and Prevention (CDC) will progressively implement its new system for evaluating the HIV prevention programs it directly and indirectly funds. Dubbed "PEMS," for Program Evaluation and Monitoring System, the effort mixes monitoring of the quantity and type of prevention services delivered with a detailed evaluation of the outcome of those services – the extent to which they changed behavior. In so doing, the Centers have created a scheme of enormous complexity and intrusiveness: Rube Goldberg combined with Big Brother.

PEMS centerpiece is its computerized, web-based data entry system that includes 25 "tables" of information. These tables cover various types of service, from counseling, testing and referral (CTR) to group prevention education to individualized prevention case management. They also cover various levels of organization. Agencies are obliged to provide information about their structure, programs, budget, plans and clients, up to and including specific details about individuals' HIV risk behaviors. The manual explaining all the PEMS "variables" runs to over 200 pages.

How many times have you had sex with an injection drug user?

Some of the required information is standard, or at least easily obtainable.

The detailed forms covering agency structure, staff, budget, contractual relationships with other agencies, programs and goals need to be filled out once and then updated as necessary. The real guts of the system lie in the oversight of staff-client relationships. Tables G1-3, H and I have to be filled out for every client and revised regularly -- in many cases at every client-staff interaction -- to follow how an "intervention" is affecting behavior. The recorded data includes some very personal information, such as how many times you had unprotected sex or shared syringes in the last 15 to 90 days – and what the gender and HIV status of your partners were. Of course, the client's own HIV status is one of the first details recorded, as is whether he or she exchanges sex for drugs or money.

One HIV prevention director commented, "Gathering PEMS-required fields is definitely going to interfere with and create a barrier to delivering client-centered prevention services, especially counseling services. We are going to have to gather so much info about folks that we will have slim time to problem-solve with them around issues that are actually affecting their lives. I think it will force a much more form-driven, clinical experience where folks feel like a number and totally kill the rapport with counselors."

One great issue is one of confidentiality – real and perceived. The information is all entered into a database accessible through the Internet. The CDC has

emphasized all along that it is employing the most advanced security features to protect the data. The PEMS security “summary” all by itself is 48 pages long. Supposedly, much of the most personal information, including client names and addresses, will remain hidden from the CDC.

It will be hard to convince clients that what they are telling the counselor really will not end up in somebody’s file. As an outreach program supervisor commented, “We already serve a vulnerable population that doesn’t want to give us their personal details. People walk away from us when asked for contact information. I have a hard time seeing an outreach worker getting a positive response from PEMS. It will cut down on the number of people willing to enter our program.”

Persons with HIV have special concerns for guarding their privacy. Aside from fears of discrimination, transmitting HIV, or even exposing others to HIV, is considered criminal activity under state public health laws even when no HIV-specific measure exists. At the very least, private agencies and public health departments will want to track down their partners in unsafe sex and bring them in for testing and counseling. Likewise, intravenous drug users will have concerns about admitting to possession of illicit drugs.

With the President claiming authority to wiretap Americans without a court order, such fears are not misplaced. The outreach director continued, “This could be the first step down a slippery slope. Next they might want to keep track of all Ryan White [Care Act] clients [receiving HIV treatment], including their names. Is

the information subpoenaable? In this atmosphere, who’s to say there will even be a subpoena?”

A black hole for gray data

A more immediate question is what is officially supposed to happen to all the data the CDC collects. That part is murky. In principle, someone will measure how well each prevention program reduce risky behavior. But such analyses are not straightforward. In the first place, the information will come from many different interviewers with no standard interviewing method. This is not the Kinsey Institute here. The degree to which interviewers collect complete and honest information is fundamentally affected by the manner, attitudes and personality of the interviewer. A bored, judgmental or rushed style is likely to end up with clients merely giving the answers that the program wants to hear. And then there’s the “refused to answer” box, which will be a frequent resort of the more annoyed clients (if they don’t get up and leave).

There are further inherent biases in the way the data is recorded that arise from interviewers’ and clients’ understanding of the questions. There is also the possibility that staff or clients consciously adjust interview responses to make themselves look more successful.

Thirdly, there’s the effect that the intrusive PEMS evaluation process has on the intervention. If it is true that “PEMS becomes the intervention,” disrupting communications and rapport between counselors and their clients, then it will diminish or destroy the effectiveness of prevention programs. This is the most fundamental introduced bias of all.

The ever-increasing power of computers has greatly facilitated the manipulation of large datasets, but major headaches remain. A standard glitch is duplication of files. Clients frequently hop from one agency to another. If not fully identified, they will end up with a new record each time they appear at a new site. This could occur even within one agency due to errors in identification or data entry. Multiple records will make follow-up difficult, if not impossible, as each record will record a different part of the client's history.

Officials from state agencies and community organizations report that they have not been given enough training to manage PEMS properly at the planned January start-up. The training that has occurred has focused on one person per organization, the PEMS "coordinator." The coordinator is supposed to train and direct the other staff members involved, including those overseeing data collection, software application, counseling and testing, and administration. Many details have been elusive. For example, it is not clear to agencies what personal information is mandatory and what is optional – it all appears the same on data collection forms.

A major lapse is the failure to provide the promised interface (known as "XPEMS") to feed data already required by states into PEMS. New York, California and several other states already have computerized performance-reporting systems, though not nearly as extensive as PEMS. Without XPEMS, all this information will have to be entered twice.

Hiding under the covers

This flailing bespeaks a lack of funding. The CDC's Division of HIV/AIDS Prevention (DHAP) has seen its budget slowly decrease since 2000. Agencies are spending their own money preparing for PEMS since their CDC grants are not covering all the costs. Everyone is moving slowly, and often resentfully. Said the outreach supervisor, "People feel like the CDC is never ready when it says it will be. They count on CDC incompetence in meeting deadlines. But they may get burnt if they take a wait-and-see attitude."

Indeed they may. It is difficult to discount the pressure on the CDC to move forward with PEMS. Said a former DHAP staffer, "With this administration, it took a while to come down. But then the OMB [the White House's Office of Management of the Budget] and [HHS deputy secretary] Claude Allen exerted pressure. They sent a passel of young conservatives to do an audit of all CDC programs. They kept asking DHAP, in particular, 'we give you 700 million a year and what do you have to show for it? There are still 40,000 a year infected -- and by the way how do you know its only 40,000?'" CDC officials have had no good answers, either for the Bush administration or congressional critics such as Rep. Mark Souder (R-IN) and Sen. Tom Coburn (R-OK).

At the same time, according to a Union of Concerned Scientists report issued a year ago, "[T]he Bush administration [distorted] the US Center for Disease Control's science-based performance measures to test whether abstinence-only programs were proving effective, such as charting the birth rate of female program participants. In place of such established

measures, the Bush administration has required the CDC to track only participants' program attendance and attitudes, measures designed to obscure the lack of efficacy of abstinence-only programs."

What does work, anyway?

PEMS threatens to come up with completely unreliable results that tip the balance in favor of abstinence promotion. PEMS' technical errors, introduced biases and direct interference heighten the chances that it may lead to a finding that the historically funded, community-level intervention programs accomplish little.

Still, it is critical to know accurately what HIV prevention efforts are effective. Rather than try to gather enormous

amounts of information with a broad sweep, a focused approach might well provide greater accuracy. Monitoring of quantity of service delivered could be universal, but a set of representative sites utilizing different methods would be chosen for intensive evaluation. Those sites would have to be sufficiently funded and trained to accomplish the goals of evaluation. The totalitarian aspects would be absent, further inducing cooperation with the evaluation effort. The CDC wouldn't be able to evaluate every program – which is any case is impractical. It would produce high quality, respectable results that make possible an accurate comparison of different prevention methods.

This issue of HHS Watch was written by David Gilden

HHSWatch, a watchdog newsletter from CHAMP, monitors and reports on activities related to HIV prevention at Health and Human Services agencies, including CDC, NIH, HRSA and SAMHSA. HHSWatch is a resource for community members, policy advocates, researchers and anyone interested in more fully understanding and tracking the committees, panels and administrators whose recommendations and decisions affect our work. HHSWatch is committed to providing an outlet for those concerned about infringements upon science-based HIV prevention and treatment, and will respect your wishes for confidentiality. If you are interested in contributing information or suggesting a story, please contact champ@champnetwork.org.



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