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NEW CDC DATA COLLECTION SYSTEM (PEMS) CALLED INTRUSIVE AND TROUBLESOME BY COMMUNITY ACTIVISTS – BACKLASH DELAYS IMPLEMENTATION – STEAMWORKS TAKES A STAND

The Center for Disease Control (CDC), the federal government agency in charge of HIV epidemiology and prevention program funding, is in the process of implementing a data collection system called PEMS, which will require all federally funded HIV prevention programs to gather highly personal information on the clients they serve.

If PEMS protocol goes forward as planned, people attending a prevention workshop, peer support group, "prevention for positives" program, or even just getting an HIV test will be asked detailed questions concerning their sex practices and drug use. CDC is proposing that this sensitive information be entered into a national on-line database. There are minimal security requirements for how agencies handle this data, which could expose people living with HIV to discrimination or criminal prosecution. This new data collection process also threatens to disrupt the delicate provider-client relationships that are key to effective HIV prevention interventions.

Due to community pressure, the CDC has delayed implementation of this system, and has convened a workgroup to fix it. Steamworks applauds this effort to reexamine protocol - in order to help inform their deliberations, CHAMP, a national HIV prevention advocacy group circulated a community sign-on letter which endorsed four core recommendations (summarized below).

*Restrict required data collection to routine program and contract monitoring. Simplify program and client-level data collection, including designating all Table I variables in version 2.0 as optional or non-required, and do not require CBOs to collect more program or client-level variables than health departments.

*Reduce the average time burden PEMS adds for CBOs in half, or no more than 33 hours per quarter. This must be verified through a documented piloting process that includes a range of different types and sizes of directly-funded CBOs.

*Provide a thorough explanation of how CDC and other Federal entities will use data collected by PEMS. This explanation must also include when and how data will be available for the use of CBOs that collect it, and additional guidance on how data collected can specifically inform program improvement.

*Do not require or encourage CBOs to record or report sensitive information on sexual behavior and/or drug use that could put people living with HIV at risk for discrimination or criminal prosecution, especially if CBOs also record client names or other identifying information. PEMS security guidelines are not currently requirements and are inadequate to provide the necessary level of protection for clients. Providing the necessary level of protection to safeguard longitudinal behavioral variables and HIV status also may present an undue burden for some organizations. In light of the significant concerns about data

security and client relationship-building, it is unsafe and unwise to require universal reporting for variables that present these concerns.

Steamworks has signed on to the CHAMP community letter along with hundreds of other concerned community organizations and individuals committed to improving ongoing HIV prevention efforts and treatment options within our local communities. Steamworks, along with CHAMP, strongly encourage our patrons and other community members to show your support by petitioning the CDC and the working group to embrace the outlined policy recommendations that we feel will better address the issues of data collection, privacy, and security surrounding HIV Prevention and Intervention strategies. An attached letter will make it easy to forward your support to CHAMP (and the CDC).

Over the past 3 decades Steamworks has worked closely with key community based organizations, Public Health Departments, and often times in collaboration with the CDC, to create and development on site in house HIV and STD Testing and Outreach programs at our bathhouses. These efforts have helped to make Steamworks a national model for prevention “Best Practices” and have in effect made Steamworks one of the safest and most proactive venues for men to meet men.

Our community partnerships and collaborations have enabled our patrons to have free and confidential access to HIV and STD Testing Programs along with risk reductive outreach and counseling initiatives. It has taken Steamworks years of diligent work thru our HIEP offices to create the types of community bonds and civic partnerships that have resulted in cutting edge prevention programs that our patrons have come to expect and trust. Each year, thousands of folks are able to take advantage of Steamwork’s in house programs – patron and community trust and accessibility are at the core and the heart of our program’s successes. Privacy, confidentiality, and an emphasis on maintaining consistent and nonjudgmental ethics have been key in our ability to expand our services and build patron support and community equity.

Steamworks believes that the new proposed PEMS data collection system could potentially derail our years of efforts to build patron comfort and trust in our services. The clear possibility that the PEMS system could handicap the agencies that provide prevention and intervention programs at Steamworks to our patrons is too important to ignore. Therefore, in solidarity with our communities we ask the CDC to rethink and retool the PEMS guidelines. In this age of illegal government phone surveillance programs and the ongoing assault on our personal liberties it is prudent for all of us to look closely at the erosion of our rights to personal privacy and the seemingly good intentions of our government and it’s agencies.

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STEAMWORKS has been providing men 18 years & older with a clean, comfortable and stylish place to meet other men, relax, workout and play 24 hours a day, 7 days a week for 30 years. Steamworks is located in Berkeley, Chicago, San Juan and Toronto. To learn more visit us online www.STEAMWORKSONline.com