

Making sure research is used: Community-generated recommendations for disseminating research

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Issue

HIV research, no matter how innovative, will never make a difference in the epidemic unless it is disseminated in an appropriate and timely manner to the people and organizations providing HIV services. Yet many researchers are not trained, rewarded or supported to disseminate research findings beyond academic journals. The Community Advisory Board (CAB) of the Center for AIDS Prevention Studies (CAPS), University of California San Francisco, has encouraged and guided CAPS researchers in expanding their dissemination efforts to better reach CBOs, policymakers and community stakeholders. As a part of this, they developed “Recommendations for Research Dissemination.”

The CAPS CAB consists of 8-12 community members, representing a variety of stakeholders throughout the San Francisco Bay Area, including service agencies, activists and teachers.

Developing the Recommendations

An HIV+ CAB member expressed concern about participating in a research study where the researchers had not published findings. The CAB decided that addressing dissemination issues was a priority. They convened subcommittees to work on guidelines and an award.

The guidelines subcommittee conducted formative research. First, they developed a discussion guide to use with key informant interviews and focus groups. They began with the CAB members’ own experiences receiving and disseminating research findings. They conducted informal key informant interviews with a few researchers at CAPS as well as outside of UCSF. They conducted archival research to see if there were any other institutions that had similar guidelines. Finally, they conducted a focus group at CAPS conference with researchers and community members. Based on this data, they drafted the Recommendations.

The CAB reviewed the first draft at the next full CAB meeting. They discussed the viability and acceptability of the Recommendations, and how to maintain minimum ethical standards of dissemination without alienating researchers. After this discussion, the subcommittee, working with the CAPS Technology and Information Exchange (TIE) Core, wrote a second draft. The second draft was given to three junior researchers at CAPS, who then attended the next CAB meeting and discussed potential barriers and what they thought was possible in a research context. After the researchers left the CAB meeting, CAB members agreed upon a final version.

Three CAB members presented the final version to the Director of CAPS, who thanked them for their work and fully endorsed the Recommendations. Several CAB members, including the one who voiced the concern, presented the Recommendations at a Town Hall at CAPS.

“I have given you my blood, my semen, my saliva and my urine. I have spent hours with you answering intimate question about my sex life, my drug use, my health and my partners and friends.



In return, I ask that you simply tell me what you learned.”

-Hank Wilson, Activist, San Francisco

Recommendations for Research Dissemination - CAPS Community Advisory Board

- 1. Create a dissemination plan for all studies.**
 - Include dissemination plan in grants.
 - Develop a budget that supports dissemination efforts. This may include translation, printing, mailing and/or community forum costs.
 - Develop a timeline for dissemination efforts. Long-term studies can do annual updates to key stakeholders such as study participants, agencies assisting in recruitment and targeted communities.
 - Get input from study participants and community representatives on the best methods to disseminate research findings.
 - Make research results accessible to various audiences through institutional resources such as websites, newsletters, reports and conferences.
- 2. Disseminate research progress and findings to study participants.**
 - Ask study participants how they would like to be informed of findings.
 - Use multiple methods to disseminate findings to study participants including Q&A forums, articles in the lay media, newsletters and websites.
 - Disseminate positive, negative and null results.
 - Make dissemination accessible paying attention to language and literacy needs of audience as was done during the outreach/recruitment study phase.
- 3. Disseminate research progress and findings to agencies and service providers.**
 - Prioritize dissemination of results for agencies that assisted with recruitment and/or serve the target population.
 - Emphasize the practical implications of the study results and how it informs HIV prevention or treatment interventions.
 - Write articles about the study in newsletters or websites frequently used by service providers.
- 4. Disseminate research findings to community.**
 - Use dissemination venues appropriate to the targeted community.
 - Present research results to Planning Councils.
- 5. Disseminate research findings to policymakers.**
 - Evaluate if research results have a potential policy impact and disseminate results to HIV/AIDS policy groups and local congressional representatives.

Recommendations for Academic Leadership

- Encourage researchers to use the CAB for input on dissemination ideas/plans/grants.
- Monitor and evaluate dissemination efforts.
- Provide training on dissemination of research findings to project directors, fellows and faculty.
- Provide public access to all research dissemination efforts, including progress and final reports to funders, through your website.
- Advocate with faculty promotions committee on the value of research dissemination in the community.

These Recommendations are available online at: www.caps.ucsf.edu/projects/collaboration/dissemination.php



“Wow, the CAB’s document (Recommendations for Research Dissemination) is wonderful! I especially appreciate learning about various things I should budget in and having a timeline to consider. Terrific. Also, thanks for your consultation and providing sample grant language. I wrote a dissemination section for my grant based on what you provided. My grant, ‘Gender Role Norms, Sexual Scripts and Black Men’s Heterosexual Risk Behaviors’ has now been funded.”

-Lisa Bowleg, Associate Professor, Drexel University School of Public Health and CAPS Visiting Professor

What kinds of research data should be disseminated?

When we talk about dissemination, we are not asking for confidential, unanalyzed or proprietary data to be released to the public. We’re also not asking to “prove that it worked.” Community audiences appreciate being informed about ongoing studies.

- Basic study description
- Recruitment plan and flyers
- Baseline data- demographics
- Baseline data- risk behaviors
- Research instruments
- Follow-up data (retention, etc)
- Data analysis
- Final research findings

- For intervention studies:
- Outline of curricula
 - Sample activities, handouts from intervention
 - Intervention surveys
 - Complete curricula (facilitator and training manuals)

Materials that are disseminated through traditional research venues should also be made available to lay audiences:

- Posters and slides presented at conferences
- Talks given to peers
- Yearly reports to funders (perhaps with some editing)
- Journal articles

Annual Innovative Dissemination Award

The CAB established an annual award, the CAPS Innovative Dissemination Award, in the effort to reward researchers at CAPS who engage in non-traditional dissemination and who follow the Recommendations established by the CAB. In 2006, the Award was presented to Héctor Carrillo. In 2007, the Award was presented to the Translating Research into Practice (TRiP) team: Susan Kegeles, Greg Rebchook, John Hamiga, David Sweeney, Scott Tebbetts and Ben Zovod.

