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## Making Sure Research Is Used: Community-Generated Recommendations for Disseminating Research

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### Abstract

Academic research, no matter how innovative, will never make a difference in the lives of people unless it is disseminated in an appropriate and timely manner to providers and organizations serving the public. Yet many researchers are not trained, rewarded, or supported to disseminate research findings. The Community Advisory Board (CAB) of the University of California, San Francisco, Center for AIDS Prevention Studies (CAPS) developed a set of guidelines to support researchers' intentions to disseminate their findings through nontraditional venues. These guidelines are unique because community members, many

of whom have struggled with accessing research in a timely way, generated them. In addition to developing the guidelines, the CAB also conceived and implemented a dissemination strategy for the guidelines. The purpose of this article is to present specific guidelines for disseminating research developed by the CAPS CAB.

### Keywords

Community advisory Board, community-based participatory research, dissemination guidelines, public health, HIV/AIDS

Effective and efficient information dissemination and exchange are important tools in the effort to control the HIV epidemic.<sup>1</sup> Effective dissemination strategies can impact programs, resources, and policies.<sup>2</sup> Over the years, ample research has been conducted to understand facilitators and barriers to using research in service settings, and increase the use of research in programs.<sup>3-5</sup> Most of the efforts and research focuses on helping service providers to use the research produced by scientists, yet there is little research on programs that help researchers disseminate science in non-traditional ways.

Relationships between service provider communities and academic research communities are often complicated. The lack of bilateral information streams contributes to misunderstanding/miscommunication. Service communities may

see themselves sought out as research subjects, but seldom share in the fruits of research. Academics, in turn, may intend to share their findings with the communities who made the research possible. However, the structures of academe often make this difficult or untenable. Funding rarely includes provisions for dissemination. Careers are built on peer-reviewed journal articles, not community forums. Preliminary findings, which might be useful for providers, are usually embargoed until more definitive announcements can be made. And many academics may feel like they have neither the language nor the skills to present their work to lay people.

In public health, this gap slows the process of effective prevention. Providers must wait until needed data get into journals, which they may or may not access or have the time to peruse. Given the delays in publication, academic journals'

reluctance to publish negative findings, and the massive quantity of data that is produced, it is difficult for providers to stay on top of the latest literature. In the absence of “provider-friendly” dissemination strategies, information that could strengthen programs and services is not used. This failure defeats the purpose of the efforts of both the providers and researchers.

Researcher barriers to successful dissemination include lack of time and money allocated to dissemination (traditional or nontraditional), little consideration of nontraditional dissemination as criteria for faculty promotions, and lack of knowledge or comfort regarding dissemination to service providers. Other barriers for researchers include an academic culture where community involvement is seen as being done by those “not good enough” for academic careers.<sup>6</sup>

Traditionally, researchers disseminate their work in peer-reviewed journals and academic conferences, yet we know that service providers do not use these resources in their program planning.<sup>7</sup> There is little understanding of how and why researchers do or do not disseminate their science in nontraditional ways or what types of training or support researchers might need to do this. To this end, the CAPS CAB developed “Recommendations for Research Dissemination,” a set of guidelines and best practices for getting research findings into the community. This paper presents the process for developing these recommendations and its outcome.

In the interests of remedying some of the issues between community and academia, the CAPS convened a CAB in 2000. The goals of the CAPS CAB are to maintain a channel for community input into CAPS’ research agenda, provide information about new community trends, concerns, and resources, and assist CAPS in developing effective methods for conducting research in and with communities. The CAPS CAB consists of 8 to 12 community members, representing a variety of stakeholders throughout the San Francisco Bay Area, including service agencies, activists, and teachers. Some CAB members have experience conducting research; others have been participants in research studies or helped in recruitment.

### PROCESS FOR DEVELOPING THE DISSEMINATION GUIDELINES

The process of developing the guidelines began with a specific concern of an HIV-positive CAB member who had participated in a research study where the researchers had not

published any of their findings. The entire CAB discussed this issue and decided that addressing dissemination issues was a priority. They convened two subcommittees, one to work on a set of guidelines, the other to work on a dissemination award.

The guidelines subcommittee conducted formative research to help inform their work. First, they developed a discussion guide to use with key informant interviews and focus groups. They began with their own CAB members’ experience both receiving (or not) and disseminating research findings. The subcommittee conducted informal key informant interviews with researchers at CAPS as well as outside of UCSF. They also conducted archival research to see if there were any other institutions that had similar guidelines for research dissemination. Finally, the subcommittee conducted a focus group with researchers and community members at CAPS’s 2004 conference. Based on these data, the subcommittee wrote a first draft of the guidelines.

This first draft was presented and discussed at the next full CAB meeting. CAB members discussed the viability and acceptability of the guidelines, and how to maintain minimum ethical standards of dissemination without alienating researchers. After this discussion, the subcommittee, working with CAPS staff, wrote a second draft of the guidelines. The second draft was distributed to four 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 again discussed the guidelines and agreed upon edits to a final version.

Three CAB members presented the final version of the guidelines to the Director of CAPS, who fully endorsed the guidelines. Several CAB members, including the CAB member who voiced the original concern that started the process, then presented the guidelines at a Town Hall meeting at CAPS.

### DISSEMINATION GUIDELINES

I used to think dissemination was just giving out my e-mail and phone number. I never really thought about it before, but now I see how important it is. —CAPS Researcher

The guidelines highlight several important considerations for dissemination of research. The first, and most important, is simply to think about dissemination in research studies. All

studies should have a written plan that is included in the grant proposal, along with a budget to these cover activities. The second point is to consider the different audiences who need to hear about the study. The CAB prioritized in this way: participants, agencies used for recruiting and similar agencies, the general community, and policymakers. The third point is that there are different types of data that should be disseminated, including research “failures” and null findings. To be most helpful, the recommendations also include sample grant language, examples of innovative dissemination products and community-friendly venues. Below is the text of the recommendations.

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 HPPC and Care Council.
  5. Disseminate research findings to policymakers.
    - Evaluate whether research results have a potential policy impact and disseminate results to HIV/AIDS policy groups and local congressional representatives.

In addition, the CAPS CAB developed a companion piece to the Guidelines, which included samples of good community dissemination models, a list of conferences frequently attended by HIV/AIDS service providers, community media that reaches various populations, and resources for other dissemination activities. This document includes the following.

#### **Sample Grant Language and Timeline for Dissemination Plan**

The grant language can be edited and added directly to grants. For example, for a community-based agency that aids in recruitment of participants, the grant language suggests the following activities: Have agency staff participate in peer review of any presentations or publications; include agency collaborators as co-authors of articles; host an informal meeting with refreshments at agency to report on findings; and make reports and other articles available at the agency. For a timeline, the Guidelines suggest that if a research study lasts longer than 2 years, participants should receive at least yearly updates. For intervention studies, curricula and data collection instruments should be made available to the public for a minimum of 10 years after the end of the study.

#### **Ideas for Involving Participants in Dissemination**

For example, research studies can include a question at the end of the baseline survey: “Would you like to know the results/be kept informed/find out more about this research study? If so, how can we contact you? (e-mail address, phone, snail mail)”

#### **Kinds of Research Data to Be Disseminated**

The Guidelines clarify that disseminating data does not require confidential, unanalyzed, or proprietary data to be

released to the public, but that community audiences appreciate being informed about ongoing studies in many ways. Data that can be disseminated include basic study description, recruitment plan and flyers, and baseline demographics; baseline risk behaviors; research instruments; follow-up data (retention, etc.); data analysis; and final research findings. Intervention studies can disseminate an outline of curricula, sample activities, handouts from intervention, intervention surveys, and complete curricula including facilitators manual and training manual.

### Examples of Effective Dissemination

These include the annual CAPS Research Portfolio, which gives a one-page description of all current research projects, including staff, end dates and interesting findings to date. There are also examples of newsletters for research study participants, an online archive of survey instruments and research studies with community pages on Facebook and MySpace. The dissemination guidelines and its companion piece can be found at <http://www.caps.ucsf.edu/projects/collaboration/dissemination.php>

### Experiences With the Use of the Dissemination Guidelines

To date, the CAPS CAB has:

- Posted the recommendations to the CAPS website.
- Presented them at a Town Hall for CAPS researchers.
- Given an oral presentation at the 2006 American Public Health Association Conference in Boston, Massachusetts.
- Disseminated copies at the 2006 International AIDS Conference in Toronto, Ontario, Canada.
- Published them in the 2006 International Conference on AIDS CD-ROM.
- Led a skills-building workshop on nontraditional dissemination at the 2007 Community–Campus Partnerships for Health (CCPH) Conference in Toronto, Canada.
- Led a roundtable at the 2007 U.S. Conference on AIDS in Palm Springs, California.
- Presented a poster at the 2007 National HIV Prevention Conference in Atlanta, Georgia.
- Submitted abstracts to other conferences.
- Used the TIE Core administrative staff to share them within UCSF and to other academic institutions.
- Developed plans to send guidelines to potential funders.

- Developed plans to send guidelines to instructors at MPH programs.

The CAB recognizes that changing behaviors can be a long process, and has made a commitment to continue disseminating the recommendations. CAPS' TIE Core continues to use the recommendations when consulting with researchers and providing training to junior and visiting scientists at CAPS. Researchers have used the recommendations in the following ways.

*Developing Dissemination Plans for Grants.* Several researchers have consulted with the TIE Core and used the recommendations to write dissemination plans for new grants, including specific nontraditional methods for getting their research into the community. Two grants received strong scores for their plans and have since been funded.

*Disseminating Preliminary Research Findings.* According to the recommendations, the TIE Core has helped two CAPS research projects report on preliminary findings of their research and get feedback from community members and service providers. One researcher held a lunchtime meeting for service providers who helped with recruitment for her study, giving baseline demographic data of participants and getting input on how they wanted to receive further data as the research progressed.

*Broadening the Audience for Dissemination.* A research project came to the CAPS CAB for help brainstorming how to access and report to the various audiences mentioned in the recommendations. They developed a list of non-HIV-specific service agencies who also worked with a similar population, who were eager to hear about the study.

The CAB has also established an annual award, The CAPS Innovative Dissemination Award, in the effort to reward researchers who engage in nontraditional dissemination and who follow the guidelines established by the CAB. This award was given for the second time in 2007; the Center intends to continue this as an annual award.

The goal of disseminating the guidelines is ongoing. Future plans include getting buy-in from academic department tenure and promotion committees, and getting evaluation data from researchers and providers on the usefulness of these guidelines and how they might be modified. The CAPS CAB hopes that the guidelines can be modified and used in any setting where health or social research is taking place.

## MONITORING AND EVALUATION OF GUIDELINES

While disseminating the guidelines, the TIE Core has instituted channels for process and outcome evaluation. First, the TIE Core documents the dissemination process, including when and where the guidelines are distributed, as noted above. All of the dissemination activities are logged in a database, along with all consultations with researchers based on the guidelines (examples given above). The database is programmed to send out a brief satisfaction survey to individuals using TIE Core services. Users note high satisfaction and usefulness of the guidelines, as the following quote illustrates:

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, and it's now been funded. —Researcher

Second, when the guidelines are presented at a formal training or workshop, we use SurveyMonkey to conduct follow-up surveys of participants. In the most recent evaluation of a workshop presented at the CCPH Conference, 13 participants responded (two thirds researchers, one third service providers). When asked what they had done with the materials from the workshop, over half noted they had read the guidelines and shared them with colleagues. When asked how the workshop affected their dissemination activities, one respondent developed a dissemination plan, one developed new materials, and three collaborated with a researcher or community agency. Three participants reported that the guidelines gave them ideas and audiences for future work. One workshop participant noted, "I shared with our journal team when we discussed plans for promoting dissemination of articles published by our journal." Another participant told the following story about how the guidelines impacted her work:

I attended a workshop on how to apply for a particular Knowledge Translation grant from the Canadian Institute of Health Research. During the workshop, I mentioned that the CAPS dissemination guidelines could be useful for applicants to the fund. The host of the workshop agreed that it was a relevant resource, and she e-mailed it to the attendees at the event. —Researcher

## APPLICABILITY OF GUIDELINES

We have consistently received positive feedback on the guidelines and have seen concrete results when researchers implement them. As the TIE Core and the CAB continue to disseminate the guidelines, we realize that the guidelines can be useful in other fields besides HIV prevention. We therefore produced a version of the guidelines that are not CAPS specific, but applicable to any academic institution conducting research. These guidelines can be used to train junior researchers, both in Masters of Public Health and doctoral programs, as well as fellowship programs. The TIE Core gives a presentation to all new CAPS fellows on the dissemination guidelines. The guidelines are also useful for grant applications, for developing dissemination plans, and for helping brainstorm ideas for disseminating data with research studies currently under way.

Researchers continue to cite barriers such as the lack of professional incentives to do dissemination, as well as the lack of time and money. Some researchers need on-going training and support to improve their skills in presenting science to lay people. And perhaps the most important barrier is the lack of funding available for dissemination. In the meantime, we laud the efforts of researchers who have used these guidelines and others who have used other methods to facilitate communication of research to communities. The CAPS CAB created one model. Other models should be brought out and debated, not just with researchers, but with funders and community members until we all have the best tools to improve the health of the public.

## ACKNOWLEDGMENTS

### CAPS CAB

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**Co-Chair.** Alix Lutnick.

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### TIE Core

*CAB Co-Chair.* Carolyn Hunt.

*Past Co-Chair.* Ellen Goldstein

### TIE Core Staff

Olga Grinstead, Director, and Pamela DeCarlo, Dissemination Manager.

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