

Recommendations for Research Dissemination

Community Advisory Board
Center for AIDS Prevention Studies (CAPS),
University of California, San Francisco

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Why Dissemination Recommendations?

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 CAPS Community Advisory Board (CAB) has encouraged and guided CAPS researchers in expanding their dissemination efforts to better reach CBOs, policymakers and community stakeholders. The CAPS CAB drew from their own experiences and interviewed researchers and CBOs to develop "Recommendations for Research Dissemination."

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<http://caps.ucsf.edu/about/community-advisory-board/recommendation-for-research-dissemination/>

General Recommendations for Research Dissemination

CAPS Community Advisory Board

1. Create a dissemination plan for all studies.

- Include dissemination plan in grants. See Attachment A for sample grant language.
- 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. See Attachment B for guidelines.
- Get input from study participants and community representatives on the best methods to disseminate research findings.
- Make research results accessible to various audiences through CAPS resources such as the center's website, social media and electronic communications, Research Portfolio and Newsletter.
- Consider utilizing open access journals, institutional repositories or subject-based repositories for wider dissemination beyond proprietary peer reviewed academic journals.

2. Disseminate research progress and findings to study participants.

- Ask study participants how they would like to be informed of findings. See Attachment C for examples.
- Use multiple methods to disseminate findings to study participants including Q& A forums, articles in the lay media, newsletters, websites and listservs. See Attachment D for suggestions.
- 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. (Attachment D)

4. Disseminate research findings to community.

- Use dissemination venues appropriate to the targeted community. (Attachment D)
- Present research results to local HIV Prevention Planning Council (HPPC) and Ryan White Care Council.
- Be sure to avoid technical jargon that a lay audience will not understand.

5. Disseminate research findings to policymakers.

- Involve CAPS' Policy Core to evaluate if research results have a potential policy impact and disseminate results to HIV/AIDS policy groups and local congressional representatives.

Specific Recommendations to CAPS Leadership

- Encourage researchers to use the CAB for input on dissemination ideas/plans/grant language.
- 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 the CAPS website.
- Advocate with faculty promotions committee on the value of research dissemination in the community.

Attachment A- Sample grant language for dissemination plan

Attachment B- Guidelines for dissemination plan/timeline

Attachment C- Ideas for involving participants in dissemination

Attachment D- Local and national HIV/AIDS conferences, publications and websites used by service providers

Attachment E- What kinds of research data should be disseminated?

Attachment F- Resources for researchers

Attachment G- Examples of effective dissemination

Attachment A: Sample grant language for dissemination plan

Following is sample text that could be included in grant proposals:

We will work with the CAPS Technology and Information Exchange (TIE) Core to develop effective dissemination strategies. The TIE Core has extensive experience disseminating research materials and findings, as well as synthesizing and rewriting the data to make it understandable and useable for CBOs and other audiences. Some of the innovative dissemination methods the TIE Core uses are: individual consultations, group trainings, conference workshops, e-newsletters, Fact Sheets, the CAPS website and other social media (Facebook, Twitter, LinkedIn, etc), {?

To ensure that our results are used by researchers, policymakers and CBOs, we will:

1. Make the survey available to CAPS and other researchers through the CAPS Instrument Archive on the CAPS web page. Both English and Spanish versions will be available.
2. Report the results at conferences that target researchers and conferences that are more community-based.
3. Peer review all published products with CAPS researchers and CBO staff.
4. Write an academic journal article and include one (or more) of our community collaborators as author
5. Write an article for a local magazine or newsletter in English or Spanish.
6. Present our project to the CAPS Community Advisory Board for input and help with dissemination.
7. Host an informal seminar with refreshments for all research participants in San Francisco or other major relevant Bay Area cities (e.g. Oakland, Berkeley, Hayward, San Jose), where we discuss study findings. This will ensure that our interview and focus group participants and key informants (such as owners of venues where we recruited) hear our findings.
8. Make study report or other article available at the venues where we recruited.
9. Work with UCSF media department to strategize methods for disseminating findings through Spanish-language radio and television stations.

Attachment B- Guidelines for dissemination plan/timeline

Suggested Minimum Requirements for each Dissemination Plan

- The plan must clearly state the following:
 - Who** will receive the research findings.
 - Study participants (to include opportunities for in-person Q&A with researchers)
 - Agencies that assist in research recruitment efforts
 - Service providers, including administrative and front-line staff (outreach workers, peer counselors, etc.)
 - Affected communities
 - Policy makers
 - Funders
 - When** they will receive them.
 - At the beginning of each research project, set a specific and firm timeline for releasing research findings to participants. It is suggested no more than two years after the final data are collected, whether the findings are positive, negative or null.
 - If the study lasts for more than two years, participants must be provided with at least yearly updates on the progress of the study.
 - For intervention studies, make available any intervention curricula and any data collection instruments for a minimum of ten years after the end of the study.
 - What** they will receive (see Attachment E)
 - How** they will receive them (see also Attachment D).
 - Research findings, whether positive, negative, or null, should be disseminated through any of the following methods including but not limited to peer reviewed journals, CAPS and other websites, conferences, agency in-services, town hall, newsletter, emails, phone calls, mailing, press releases, community forums, media including print, radio, television and internet media, presentations to various government bodies and policy makers, when appropriate.
 - Dissemination of research findings must be available in the language(s) in which the study is conducted, and must be in language accessible to the specific audience.
 - Electronic dissemination tools such a slide share (www.slideshare.net), YouTube and are also useful tools which can be utilized
- Sufficient resources must be budgeted to ensure a successful dissemination plan.
- Research findings, whether positive, negative, or null, must be published on CAPS' website, and remain on the website for a minimum of ten years; these findings must be readily searchable by at least the following fields: Study population(s), Research topic(s), Geographic area(s), Researcher(s), Date(s) of Study, Type of study

Attachment C- Ideas for involving participants in dissemination

Some ideas discussed at the CAB meetings are as follows:

- Include a question at the end of 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, snail mail)
- When appropriate, hand out cards to all participants with dissemination info:
 - Set a time 6 months later when participants can come back and get a newsletter/flyer, see a poster, hear a presentation
 - Give link to CAPS web site (if applicable) so participants can check in with status (www.caps.ucsf.edu/projects/mystudy/ -- this web address says “Not Found”)

Attachment D- Sample of local and national HIV/AIDS conferences, publications and websites used by service providers

Conferences/Meetings

HIV Prevention Leadership Summit (HPLS)

APHA Conference

STD Control Branch/HIV Prevention Training Center in Oakland (training)

Harm Reduction Coalition (training)

US Conference on AIDS

National Commission on Correctional Health Care (NCCHC) - conference

American Correctional Health Care Association (ACHCA) - conference

National AIDS Education & Services for Minorities (NAESM) - conference

Publications

American Journal of Public Health

STD

STI

Bay Area Reporter

CHAMP

AIDS Education and Prevention

HIV Counselor Perspectives

Websites/Listserve

Google- www.google.com

Kaiser Family Foundation daily AIDS update - www.kaisernetwork.org/daily_reports/rep_hiv.cfm

CDC daily update - www.cdcnpi.org/scripts/News/NewsList.asp?strTempOrLive=Live#0

CDC DEBI – www.effectiveinterventions.org

CDC National Prevention Information Network – www.cdcnpi.org

CAPS – www.caps.ucsf.edu

Google news - <http://news.google.com/nwshp?hl=en&gl=us>

The Body – thebody.com

CBPR Listserv (www.mailman2.u.washington.edu/mailman/listinfo/cbpr)

National AIDS Treatment Advocacy Project (www.natap.org)

Attachment E- What kinds of research data should be disseminated?

We'd like to make it clear that 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" (although if you can, that would be great). In general, community audiences appreciate being informed about ongoing studies in many ways.

Dissemination is for any information about the research study, from basic descriptive studies to intervention trials in peer reviewed journals.

- Basic study description (as in the annual CAPS Research Portfolio)
- Recruitment plan, recruitment flyers
- Baseline data—who we've recruited (basic demographics)
- Baseline risk behaviors, any interesting findings
- Research instruments
- Follow-up data (retention, etc)
- Data analysis
- Final research findings

Also, for intervention studies

- Outline of curricula
- Sample activities, handouts from intervention
- Intervention surveys
- Complete curricula (facilitators manual, training manual)

In addition, materials that are disseminated through traditional research venues should also be made available to lay audiences:

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

Attachment F- Resources for researchers

- **CAPS CAB**- Please come to us and we'll give input for dissemination plans and help with dissemination.
- **TIE Core** – Can help with grant language, dissemination plans, project-specific sites on the CAPS website, etc.
- **Policy Core** – Can help with policy analysis and dissemination to policy stakeholders.

Attachment G- Examples of effective dissemination

CAPS products

- Research Portfolio (www.caps.ucsf.edu/research/)
- CAPS website (www.caps.ucsf.edu)
- CAPS social media: Facebook page: www.facebook.com/CAPS.UCSF
Twitter: @UCSFCAPS and LinkedIn: <http://www.linkedin.com/groups/Center-AIDS-Prevention-Studies-UCSF-4602438>
- Policy monographs (www.caps.ucsf.edu/pubs/reports/)
- Survey instrument archive (www.caps.ucsf.edu/resources/survey-instruments/)

Researcher-generated products

- Participant newsletters from the Gay Couples Study (<http://caps.ucsf.edu/gay-couples-study/news-and-updates/>)
- Ryan White CARE Act Reauthorization Models (ari.ucsf.edu/programs/policy_reauthorization.aspx)
- Seroconversion Narratives for AIDS Prevention (The SNAP Project) Science to Community Report (<http://caps.ucsf.edu/uploads/pubs/reports/pdf/SNAPS2C.pdf>)