

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" (although if you can, that would be great). Community audiences appreciate being informed about ongoing studies in many ways.

- 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

For intervention studies

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

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

Examples of effective dissemination

CAPS products

- Annual Research Portfolio (www.caps.ucsf.edu/research/)
- CAPS website (www.caps.ucsf.edu)
- Science to Community reports (www.caps.ucsf.edu/pubs/reports/S2Cindex.php)
- CAPS Conference (www.caps.ucsf.edu/conference/)
- Policy monographs (www.caps.ucsf.edu/pubs/reports/)
- Survey instrument archive (www.caps.ucsf.edu/tools/surveys/)

Researcher-generated products

- Participant newsletter from the Gay Couples Study (www.caps.ucsf.edu/projects/GayCouples/pdf/Newsletter2005.pdf)
- Ryan White CARE Act Reauthorization Models (ari.ucsf.edu/programs/policy_reauthorization.aspx)
- Seroconversion Narratives for AIDS Prevention (The SNAP Project) presentation to CBOs (www.caps.ucsf.edu/pubs/reports/pdf/SNAPS2C.pdf)

Recommendations for Research Dissemination

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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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Suggested Minimum Requirements for each Dissemination Plan

- 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
- 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.
- 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

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 CAPS resources such as website, Research Portfolio, Newsletter, Science to Community reports, CAPS Conference.

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 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/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 the CAPS website.
- Advocate with faculty promotions committee on the value of research dissemination in the community.

Suggested Minimum Requirements for each Dissemination Plan (cont'd)

When they will receive research findings.

- 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 research findings they will receive.

How they will receive research findings.

- 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.