Recommendations for Research Dissemination

Revised October 2018 – Final

Community Advisory Board

Center for AIDS Prevention Studies (CAPS)

Prevention Research Center (PRC)

Center for AIDS Research (CFAR)

 University of California, San Francisco

 

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/PRC/CFAR Community Advisory Board (CAB) has encouraged and guided researchers in expanding their dissemination efforts to better reach community based organizations (CBOs), policymakers and community stakeholders. The CAB drew from their own experiences and interviewed researchers and CBOs to develop "Recommendations for Research Dissemination." two Two CAB members led the revision of the original guidelines, developed in 2013. All Board members had the opportunity to provide final comments.

The Recommendations for Research Dissemination are also available online:

<https://prevention.ucsf.edu/about/community-advisory-board/recommendations-for-research-dissemination>

## Current CAPS/PRC/CFAR CAB members:

## Jesse Brooks (Past Co-Chair)\*/\*\* Carolyn Kuali`i\*\*\*

## Nasheedah Bynes-Muhammad\*/\*\*\* Kevin Lo\*\*

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## \*Developed initial guidelines

## \*\*Lead role in revising guidelines

## \*\*\* Provided input to 2018 revision

# General Recommendations for Research Dissemination

## 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 into languages to reach non-English speakers (e.g., Spanish), 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/PRC/CFAR resources such as the centers’ websites, 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.

## 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.

## 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 practical implications of study results and how they inform HIV prevention and/or treatment interventions.

* Write articles about the study in newsletters or websites frequently used by service providers. (see Attachment D)

## Disseminate research findings to community

Use dissemination venues appropriate to the targeted community. (see Attachment D)

Present research results to local HIV/AIDS and Ryan White Planning Councils, specifically the San Francisco Eligible Metropolitan Area (EMA) HIV Community Planning Council (HCPC) and Oakland Transitional Geographical Area (OTGA) Planning Council.

* Make dissemination accessible, paying attention to days and times that community are available, language and literacy needs of audience (*e.g.,* immigrant communities).

 Be sure to avoid technical jargon that a lay audience will not understand.

## Disseminate research findings to policymakers.

* Involve CAPS’ Intervention and Implementation Core to evaluate if research results have a potential policy impact.
* Disseminate results to HIV/AIDS policy groups and local congressional representatives.

## Sample Recommendations by CAB to /PRC/CFAR Leadership

* Encourage researchers to use the CB 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/PRC/CFAR websites.
* 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** - Kinds of research data that should be disseminated

**Attachment F** - Resources for researchers

**Attachment G** - Examples of effective dissemination

# Attachment A - Sample grant language for dissemination plan

The sample text below can be included in grant proposals:

We will work with CAPS/PRC Community Engagement (CE) Core staff to develop effective dissemination strategies. The CE 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.

Innovative dissemination methods used by the CE Core include individual consultations, group trainings, conference workshops, e-newsletters, fact sheets, the website, and other social media (*e.g.*,Facebook, Twitter, LinkedIn).

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 research results at conferences that target researchers and conferences that are more community-based.
	3. Peer review all published products with CAPS/PRC/CFAR researchers and CBO staff.
	4. Include one (or more) of our community collaborators as author(s) on academic journal articles.
	5. Write an article for a local paper, magazine or newsletter in English or Spanish, highlighting research results.
	6. Present our project to the CAPS/PRC/CFAR 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) have meaningful access to our findings.
	8. Make study report or other articles 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 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** the research findings will be received

* + - 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** information will be disseminated. (see Attachment E)

**How** the information/results will be received (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/PRC and other websites
			* conferences
			* agency in-services
			* town halls
			* newsletters
			* emails
			* phone calls
			* mailings
			* 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 in which the study is conducted, and must be in the language accessible to the specific audience.
		- Electronic dissemination tools such as a slide share ([www.slideshare.net](http://www.slideshare.net/)) or YouTube can also be utilized

 Budget sufficient resources to ensure a successful dissemination plan.

 Research findings, whether positive, negative, or null, must be published on CAPS/PRC’ 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, social media handles, 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/PRC web site (if applicable) so participants can check in with status <https://prevention.ucsf.edu/contribute/join-study>

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

**Conferences/Meetings**

* HIV Prevention Leadership Summit (HPLS)
* American Public Health Association (APHA) <https://www.apha.org/>
* STD Control Branch/HIV Prevention Training Center in Oakland (training)
* International Conference on Sexually Transmitted Diseases, Infections & AIDS
* International Conference on HIV/AIDS, STDs & STIs
* Harm Reduction Coalition <https://harmreduction.org/>
* US Conference on AIDS (USCA), National Minority AIDS Council (NMAC) <http://www.nmac.org/>
* National Commission on Correctional Health Care (NCCHC) - conference <https://www.ncchc.org/>
* American Correctional Health Care Association (ACHCA) - conference <http://www.achsa.org/>
* National AIDS Education & Services for Minorities (NAESM) – conference <https://naesm.org/>
* Pacific AIDS Education Training Center (PAETC), East Bay HIV Update Conference, <http://paetc.org/>
* California STD/HIV Controllers Association (CSHCA), <https://www.cdph.ca.gov/Programs/CID/DOA/Pages/OA_cstdhivca.aspx>

**Publications**

* American Journal of Public Health, <https://ajph.aphapublications.org/>
* STD/STI journals
* Bay Area Reporter <http://www.ebar.com/>
* Community HIV/AIDS Mobilization Project (CHAMP)
* AIDS Education and Prevention Interdisciplinary Journal
* HIV Counselor Perspectives, https://ahppublications.wordpress.com/perspectives/

**Websites/Listserves**

* Google, <https://www.google.com/>
* Kaiser Family Foundation Daily AIDS Update, www.kaisernetwork.org/daily\_reports/rep\_hiv.cfm
* CDC daily update - www.cdcnpin.org/scripts/News/NewsList.asp?strTempOrLive=Live#0
* CDC DEBI – [www.effectiveinterventions.org](http://www.effectiveinterventions.org)
* CDC National Prevention Information Network – www.cdcnpin.org
* CAPS/PRC – <https://prevention.ucsf.edu/>
* Google news - <http://news.google.com/nwshp?hl=en&gl=us>
* The Body – <http://www.thebody.com/>
* Community Based Participatory Research (CBPR) Listserv, <http://mailman13.u.washington.edu/mailman/listinfo/CBPR>
* National AIDS Treatment Advocacy Project - [www.natap.org](http://www.natap.org)

# Attachment E – Kinds of research data that should be disseminated

We would 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 are also not asking to prove that the research 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 have 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 surveys
	+ Complete curricula (facilitator’s 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

**CAB** – Please come to us and we can give input for dissemination plans and help with dissemination.

**CE Core** – This core works to improve the translation of high-impact HIV prevention science into practice in the community by building capacity among researchers and communities to effectively address HIV through technical assistance, skills-building, and dissemination. It can help with grant language, dissemination plans, project-specific sites on the website, etc.

**Intervention and Implementation Core –** This core is evolved from CAPS research on social-behavioral questions, interventions, and implementation science including policy and effectiveness trials. It galvanizes interdisciplinary advances in HIV prevention science by leveraging the latest science and fostering synergy and collaboration across research disciplines. It can help with policy analysis and dissemination to policy stakeholders.

**Attachment G - Examples of effective dissemination**

**CAPS/PRC products**

* Research Portfolio <https://prevention.ucsf.edu/library>
* Website <https://prevention.ucsf.edu/>
* Social media:
	+ Facebook pages:
		- Center for AIDS Prevention Studies: <http://facebook.com/CAPS.UCSF>
		- Prevention Research Center: <http://facebook.com/PRC.UCSF>
	+ Twitter handles:
		- @UCSFCAPS: <https://twitter.com/ucsfcaps>
		- @UCSFPRC: <https://twitter.com/ucsfprc>
	+ LinkedIn: https://www.linkedin.com/groups/4602438/
* Policy monographs <https://prevention.ucsf.edu/resources/reports-monographs>
* Survey instruments <https://prevention.ucsf.edu/resources/survey-instruments-and-scales>

**Researcher-generated products**

* Participant newsletters from the Gay Couples study [http://caps.ucsf.edu/gay-couples-study/news and updates/](http://caps.ucsf.edu/gay-couples-study/news%20and%20updates/)
* Ryan White CARE Act Reauthorization Models <http://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>