

Communicating Community-Based Participatory Research Findings to Non-Scientific Communities: Lessons Learned from the Community Networks Program (CNP)

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One of the fundamental principles of community-based participatory research (CBPR) is that the quality of research is improved with the involvement of the community, and that the community directly benefits from the research that is conducted. This requires researchers to communicate scientific information to the lay communities they serve. In this paper we describe the communication techniques that have been used by researchers who are conducting cancer disparities research as part of the Community Networks Project. We focus on communicating findings of scientific research studies to two types of groups: community members and political decision-makers. Findings suggest a need for interdisciplinary collaboration to develop tools that will meet the unique needs of individual communities.

Keywords: Community-Based Participatory Research, Cancer Prevention, Public Health Policy

INTRODUCTION

Cancer Health Disparities

Racial and ethnic healthcare disparities occur when one or more racial or ethnic groups receives a lower quality of care relative to other racial or ethnic groups, after controlling for access-related factors and clinical need. The remaining disparity is the result of factors related to the legal and regulatory climate of healthcare operations and discrimination at the individual provider level. These disparities exist in a wide variety of disease areas, including cardiovascular disease, HIV/AIDS, diabetes, kidney disease, pediatric care, and many forms of cancer (Smedley, 2002).

The United States Government has identified the elimination of healthcare disparities as a top priority and has engaged in several initiatives to address the issue. In the National Institutes of Health's Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities, the NIH outlined current and planned efforts to address health disparities, including research to identify methods to prevent or delay diseases that are associated with disparities in healthcare quality in minority populations. (DHHS, 2000).

Selecting cancer health disparities as a model, the United States department of Health and Human Services (HHS) established the Trans-HHS Cancer Health Disparities Progress Review Group (PRG) and charged the group with developing an integrated set of recommendations to

be implemented by the Department and its agencies. One of the 14 priority recommendations in the PRG's Call to Action is to: "Establish partnerships for and support the development of sustainable community-based networks for participatory research in areas of high cancer disparities" (DHHS, 2004). This community-based participatory research (CBPR) approach is increasingly used in public health, nursing, social work, and related fields (Israel et al., 2001; Minkler and Wallerstein, 2003) because it encourages evaluators and grantee participants to work in partnership to identify and address issues that are unique to that community (Cousins and Whitmore, 1998; Green and McAllister, 2002; House and Howe, 2000).

In 2003, the Director of the National Cancer Institute (NCI) issued NCI's Challenge Goal to the Nation, which was to "eliminate the suffering and death due to cancer by 2015" (NCI, 2006). The ensuing NCI Strategic Plan presented eight objectives and a series of strategies to meet this challenge. One of these objectives calls for NCI to work to overcome cancer health disparities by "taking the lead in accelerating the dissemination and implementation of interventions to address cancer health disparities." The Community Networks Program is a result of NCI's response to that challenge.

Community Networks Program

The Community Networks to Reduce Cancer Health Disparities through Education, Research and Training program (CNP) is based on a collaborative and participatory approach that encourages community-based programs to include program personnel, researchers, and community stakeholders in the planning, development, and evaluation of each grantee’s efforts to reduce cancer health disparities.

In May 2005, NCI’s Center to Reduce Cancer Health Disparities (CRCHD) awarded a total of \$95 million to establish and support 25 CNP programs over the course of 5 years. The purpose of these 25 programs was to assist specific communities and populations that were experiencing a disproportionate share of the cancer burden. They did this by conducting community-based participatory education, training, and research with racial or ethnic minorities (e.g., African Americans, Hispanics, Asians, Pacific Islanders, or Native Americans/Alaska Natives) or underserved populations (e.g., Appalachian, rural, low socioeconomic status, and other underserved communities). Community participation is expected to increase the relevance, cultural appropriateness, and effectiveness of disparity reduction efforts.

The CNP was implemented in three phases:

- Phase I of the program established an infrastructure and systems to support community-based participatory education, research, and training to reduce cancer health disparities.
- Phase II focused on developing community-based participatory research and training programs to reduce cancer health disparities.
- In Phase III, the 25 Community Networks Programs (CNP) grantees were charged with implementing strategies to establish the credibility and sustainability of CNP activities. These strategies included publishing articles about CBPR and training researchers in the principles of CBPR.

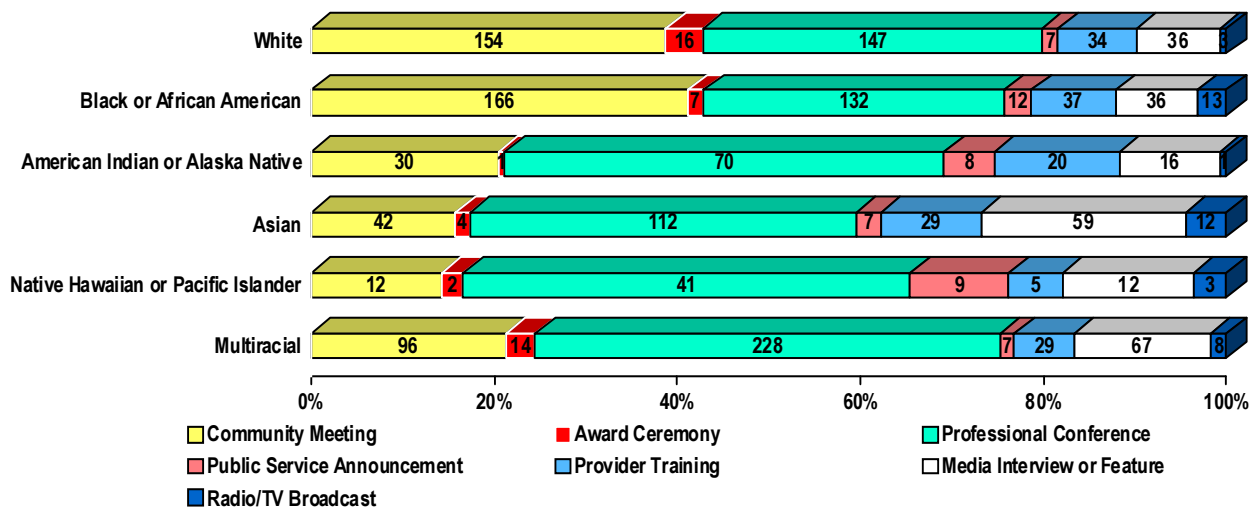
In this paper we explore the way CNP grantees communicate with disadvantaged populations about cancer prevention, and we review the techniques that they used to inform policy makers about health disparities. It is our hope that this information might contribute to a discussion of the current communication practices of community-based participatory researchers, and the identification of best practices for future researchers to follow when conducting this type of research.

METHOD

The CNP program is in its fifth and final year; this report presents descriptive data that was obtained during the first four years of the program. These data were reported semi-annually by each of the 25 CNP cooperative agreement

awardees (hereafter “grantees,”) using a Web-based reporting system that was developed as part of a national evaluation of the CNP initiative. The data presented here are a subset of those data.

FIGURE 1: INTENDED RECIPIENTS OF VARIOUS COMMUNICATION TECHNIQUES: FREQUENCY AND PERCENT, BY RACE



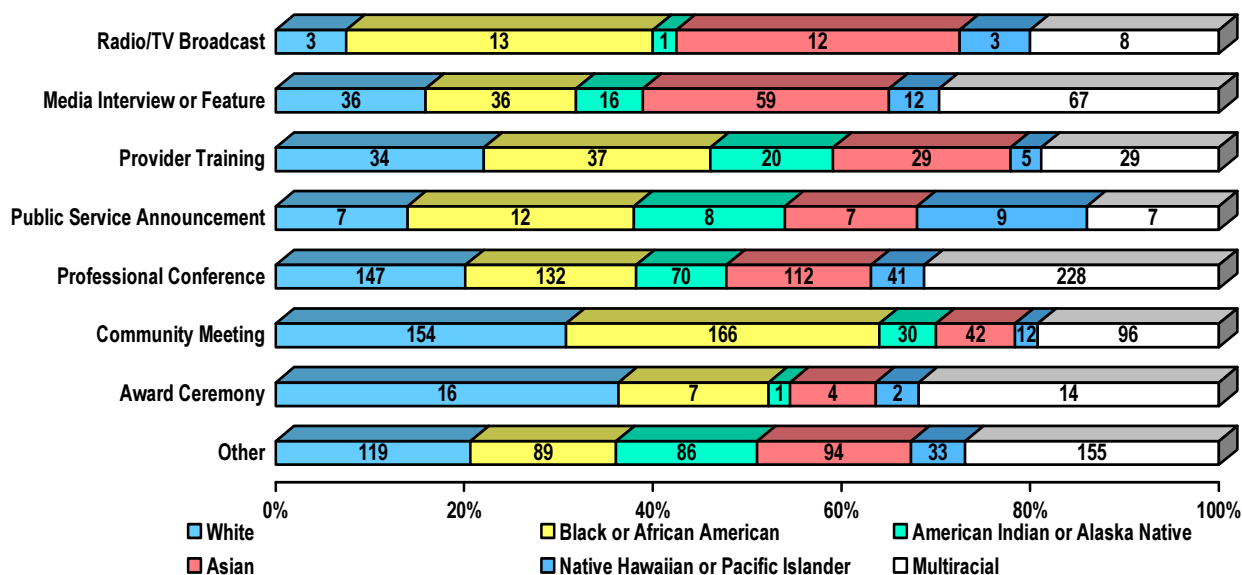
COMMUNICATING WITH COMMUNITIES

Grantees used a variety of methods to communicate cancer health information to the communities they serve, including educational information such as newsletters, websites, multimedia presentations, and informational brochures. They also produced educational events such as community meetings, award ceremonies, and professional conferences, and media messages such as radio and television broadcasts, media interviews, and public service announcements. Because each grantee produced these materials and planned these events in consideration of the unique makeup of their target population, the methods that they used needed to be targeted to the unique issues surrounding the racial, ethnic, and socio-economic demographic groups. The approach they chose should provide insight into the best practices for presenting technical research information in a format that is accessible to a lay audience. Figure 1 shows the

frequency with which these education materials were used by researchers for racial group they targeted. For each racial group, the frequency of use of each technique is indicated by the number in the bar, and the length of each segment shows the percent of total educational interventions that are accounted for by that method. Figure 2 emphasizes the communication technique used for each racial or ethnic group. Award ceremonies were used to reach whites more often than any other group, and radio and television broadcasts were more likely to be directed to African Americans or Asians.

Most CNP grantees (88%) reported having developed at least one website that was dedicated to communicating research findings to community members. Other methods included oral presentations including classroom lectures (60%), public service recordings (15%), and interviews on television or radio (9%).

FIGURE 2: INTENDED RECIPIENTS OF VARIOUS COMMUNICATION TECHNIQUES



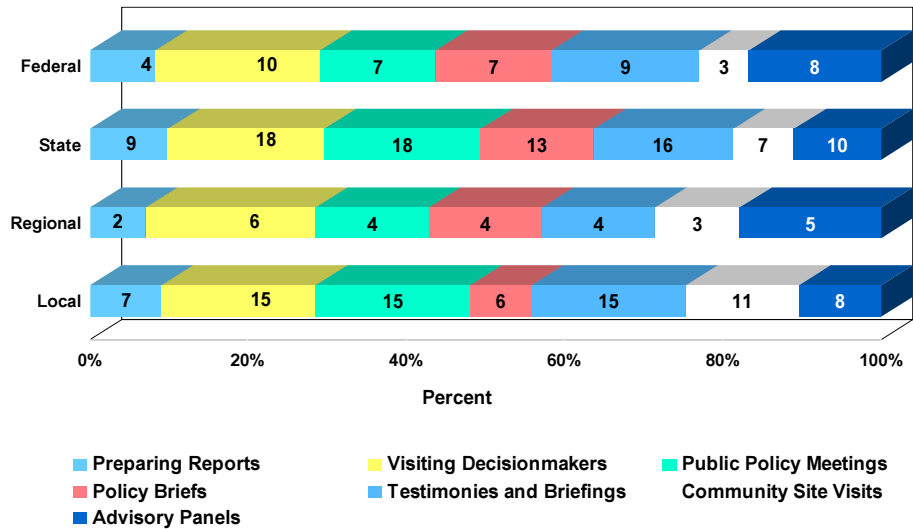
COMMUNICATING WITH POLICY-MAKERS

Grantees were charged with communicating with policy makers, and used a variety of techniques to do so. They were asked to report on their policy assessment activities, their methodologies for targeting decision-makers, and the impact of these activities on their policy agenda.

CNP grantees reported conducting policy assessments and studies aimed at informing state, local, and Federal policymakers. These findings indicate that grantees most

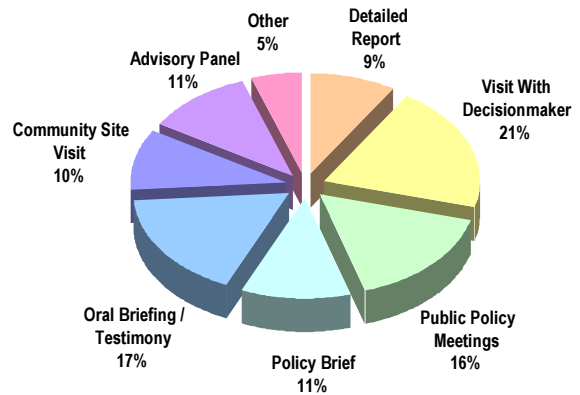
frequently geared their education and information work to assessing or evaluating existing policies, focusing primarily on examining policies that affect access to treatment or supported cancer-related programs. Further support for this observation can be found in the research methods used and the focus of studies by CNP grantees to learn about cancer-related policies (see Figure 3).

FIGURE 3: USE OF INFORMATION TECHNIQUES FOR POLICY-MAKERS



The grantees use a variety of techniques to communicate with policymakers (see Figure 4). The most common methods were in-person visits (21%), oral testimonies or briefings (17%), and public policy meetings (16%). Grantees used community site visits and advisory panels around 10% to 11%, respectively. Grantees used written techniques such as detailed reports and policy briefs approximately 20% of the time.

FIGURE 4: METHODS USED TO COMMUNICATE WITH DECISION-MAKERS AT VARIOUS LEVELS.



CONCLUSION

This paper provides a first look at some of the methods that CBPR researchers are using to convey scientific information to non-scientists. These data show that there is substantial variation in the methods that community-based participatory researchers use to convey their scientific findings, and is largely a function of the characteristics of the community. The audience for this type of research is perhaps less likely to have been exposed to scientific writing, and yet will have a vested interest in the results of the research that has been conducted in their community. This presents some special challenges to researchers and educators in these areas. More research is needed to better understand the interaction between population characteristics and information delivery techniques. Because CBPR research (ideally) involves many people in the research process it

tends to be relatively visible to legislative bodies. It is therefore very important that CBPR researchers have the ability to communicate effectively with decision-makers at all levels of government. One of the interesting findings of this study was that the most (75%) of the communication that grantees have with decision-makers is conducted face-to-face, at all levels of government. This study also suggests an opportunity for designers of communication technology to collaborate with community researchers to develop tools that are accessible to lay audiences and meet the unique needs of their communities. Additional studies will demonstrate the relative efficacy of each of these modes of communication by racial and ethnic group, and may serve to guide future community-based research to eliminate health care disparities.

REFERENCES

- Cousins, J., and Whitmore, E. 1998. Framing participatory evaluation. In: *Understanding and Practicing Participatory Evaluation: New Directions for Evaluation*. San Francisco, CA: Jossey-Bass.
- Green, B.L., & McAllister, C. (2002). Theory-based, participatory evaluation: A powerful tool for evaluating family support programs. *Bulletin of the National Center for Zero to Three*. p.30-36. <http://www.npcresearch.com/Files/SRCDZ3.pdf>
- House, E. R., & Howe, K. R. (2000). Deliberative democratic evaluation. *New Directions for Evaluation*, 85, 3-12.
- Israel, B. A., Eng, E., Schulz, A. J. & Parker, E. A. (2005). Introduction to methods in community-based participatory research for health. In B. A. Israel, E. Eng, A. J. Schulz, & E. A. Parker (Eds.), *Methods in Community-Based Participatory Research for Health*. San Francisco: Jossey-Bass.
- Israel, B. A., Lichtenstein, R., Lantz, P., McGranaghan, R., Allen, A., Guzman, J. R., Softley, D., & Maciak, B. (2001). The Detroit community-academic urban research center: Development, implementation, and evaluation. *Journal of Public Health Management and Practice*, 7(5), 1-19.
- Minkler, M., & Wallerstein, N. (2003). *Community based participatory research for health* Jossey-Bass San Francisco.
- National Cancer Institute (NCI). 2006. The NCI Strategic Plan for Leading the Nation to Eliminate the Suffering and Death Due to Cancer. Bethesda (MD): National Cancer Institute, NIH Publication No. 06-5773
- Smedley, B. D., Stith, A. Y., & Nelson, A. R. (2002). *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, DC: National Academy Press.
- U.S. Department of Health and Human Services (DHHS). 2004. Making Cancer Health Disparities History: Report of the Trans-HHS Cancer Health Disparities Progress Review Group. Bethesda, MD: U.S. Department of Health and Human Services. <http://www.chdprg.omhrc.gov/pdf/chdprg.pdf>
- U.S. Department of Health and Human Services (DHHS). 2000. National Institutes of Health. Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities. Fiscal Years 2002–2006. Bethesda, MD: U.S. Department of Health and Human Services. <http://www.nih.gov/about/hd/strategicplan.pdf>