Published in final edited form as:

J Consum Health Internet. 2014 ; 18(4): 357–366. doi:10.1080/15398285.2014.952999.

NLM Workshop Marks 20 Years of Community Outreach and Capacity Building in HIV/AIDS

NICOLE DANCY-SCOTT, MPH, GALE A. DUTCHER, MS, MLS, AHIP, ALIA KESELMAN, PhD, MA, and ELLIOT R. SIEGEL, PhD, FACMI

National Library of Medicine, Bethesda, Maryland, USA

Abstract

The National Library of Medicine's (NLM) AIDS Community Information Outreach Program (ACIOP) was launched in 1994 to provide the HIV/AIDS affected community with access to vital health information resources increasingly becoming available on the Internet. Three hundred awards have been made mostly to community-based organizations. An evaluation in 2012 found that most program objectives are being met; a principal recommendation going forward was that NLM seek to enhance the capacity of community-based awardees to conduct evaluations of their own projects. This article reports on a workshop whose invitees were drawn from AIDS serving organizations, along with scientists, clinicians, and information technologists, to review the evaluation findings and recommendations. They considered alternatives for improving awardees' evaluation capabilities with the help of expert consultation, identified additional steps that could be taken to make individual project results more transparent and sharable, and looked at external influences ranging from mobile health devices to the latest HIV/AIDS scientific research findings that could be used to align future awards with unmet needs in the community. The paper identifies efforts subsequently made by ACIOP managers to prioritize and operationalize guidance from the evaluation and the workshop, and discusses the benefits of community engagement.

Keywords

AIDS; community-based organizations; community outreach; health information access; HIV; project evaluation

INTRODUCTION

The U.S. National Library of Medicine (NLM), a part of the National Institutes of Health, is the world's largest library in a single discipline. NLM offers at no charge an unrivaled array

Address correspondence to Nicole Dancy-Scott, Two Democracy Plaza, Suite 510, 6707 Democracy Blvd., MSC 5467, Bethesda, MD 20892-5467. nicole.scott@nih.gov.

ABOUT THE AUTHORS

Nicole Dancy-Scott, MPH (nicole.scott@nih.gov) is Technical Information Specialist; Gale A. Dutcher, MS, MLS, AHIP (dutcher@mail.nlm.nih.gov) is Deputy Associate Director for Specialized Information Services; Alla Keselman, PhD, MA (keselmana@mail.nlm.nih.gov) is Senior Social Science Analyst at the Division of Specialized Information Services, Two Democracy Plaza, Suite 510, 6707 Democracy Blvd., MSC 5467, Bethesda, MD 20892-5467. Elliot R. Siegel, PhD, FACMI (siegel.consulting@gmail.com) leads Elliot Siegel Consulting, P.O. Box 3095, Bluffton, SC 29910. Dr. Siegel is retired from the National Library of Medicine, National Institutes of Health in Bethesda, Md. where he served as Associate Director for Health Information Programs Development.

of general purpose (e.g., PubMed/Medline; MedlinePlus) and specialized (e.g., AIDSInfo) electronic health information resources for scientists, health professionals, and the general public. They are accessed and searched billions of times a day (National Institute of Health, National Library of Medicine 2012). But, this remarkable technology cannot reach its full potential utility if it is unknown or cannot be used by all who may benefit from it, including the underserved and underrepresented minority populations who are challenged by the existence of significant health disparities.

This report from the field highlights the central role that outreach has come to play in the mission and programs of the National Library of Medicine (NLM). It focuses on the Library's AIDS Community Information Outreach Program (ACIOP) that was launched in the earliest days of the Internet, and whose primary intent was to improve the capacity of the affected HIV/AIDS community to use vital health information resources online. A recently completed formal evaluation of the ACIOP by colleagues at Columbia University was the focal point of an invitational Workshop convened by NLM with key community and health leaders (Dancy 2014). The objectives of the Workshop were to validate the study's findings, and extend them to include an understanding of important external changes not addressed by the evaluation and which may further inform the future course of the ACIOP.

OUTREACH AND COMMUNITY ENGAGEMENT AT NLM

Famed heart surgeon Dr. Michael DeBakey prescribed for his patients the sound advice, "the more you know, the better you heal." Over the course of five decades of friendship and support for the NLM, Dr. DeBakey helped shape the vision and innovative programs of this remarkable public institution. He enabled an expansion of NLM's legislative authority so that access to its extensive array of paper-based and now ubiquitous electronic information resources could be brought to bear in making his goal a reality throughout the world for individual health professionals and their patients, especially among the underserved and underrepresented minority populations (DeBakey 1989).

Following adoption of the DeBakey report, NLM was awarded special funding by Congress to support outreach. The Library developed and put in place the beginnings of an ambitious and novel strategy that would ultimately enlist the participation of literally hundreds of health sciences libraries located at large medical centers and small community hospitals throughout the country, and encouraged them to collaborate with community-based organizations as equal partners. Together, they were in tune with the unmet needs for health information services at the local level, and could devise the best means for providing access to these information resources from the libraries directly, or from NLM as the Internet and World Wide Web began their roll out in the mid-1990s. Frequently, these outreach projects also had as a corollary goal the reduction and ultimate elimination of health disparities.

Over the ensuing years from 1991 to the present, literally thousands of NLM-sponsored outreach projects have included among their target populations African Americans, Hispanics, and Native Americans. For example, working with Historically Black Colleges and Universities (HBCU), NLM supported efforts at strengthening these institutions' capacity to promote environmental justice through access to a suite of toxicology and

environmental health databases (Dutcher, Spann, and Gaines 2007). Similarly, in the Lower Rio Grande Valley of Texas, promotoras trained residents of Colonias to use the consumer health website, MedlinePlus.gov (Olney et al. 2007); and helped enable magnet high school librarians to train their students in the use of information and computer technology and become peer tutors (Olney et al. 2011). The Native American community has been the focus of outreach projects throughout Alaska, Hawaii, and the Lower 48 states (Wood et al. 2005). Outreach projects have been subjected to formal and informal evaluations from the earliest days (Wallingford et al. 1996). Moreover, NLM has sponsored collaborative learning exercises for health science librarians with the community to foster a mutual understanding of best practices for reaching underserved populations (Dutcher and Hamasu 2005). NLM's institutional commitment to outreach was strongly reaffirmed in its current Long Range Plan for 2006–2016 (NLM Board of Regents 2006).

CAPACITY BUILDING FOR THE HIV/AIDS COMMUNITY

It was against this backdrop of community engagement and outreach that NLM was able to successfully embrace the challenge of supporting the HIV/AIDS affected community when, at an NIH-sponsored conference in 1993 (National Library of Medicine and the NIH Office of AIDS Research 1993), it became apparent that research scientists, clinicians, and health professionals at many academic institutions could now rapidly access the latest authoritative research and treatment information electronically over the Internet. A few community-based organizations could do so as well, but most lacked the knowledge and/or technical means to do so. The ACIOP was created by NLM in 1994 primarily to support at the community level the acquisition of computers, software, and Internet connections; training in the use of this modern information technology as a means to access HIV/AIDS databases available from NLM, Food and Drug Administration, the Centers for Disease Control and Prevention, and other sources; and the repurposing of these educational and informational materials to comply with locally specific cultural and linguistic preferences. Almost 300 projects have been funded in the 20 years since the start of the ACIOP. Throughout, there has been an emphasis on the centrality and principles of community engagement (Agency for Toxic Substances and Disease Registry 2011) in the Program's design, implementation, and evaluation. Awardees have included secular and faith-based community-based organizations, patient advocacy groups, clinics, public and health sciences libraries, public health departments, and academic institutions working in partnership with community groups.

A limited internal evaluation by NLM of ACIOP projects funded in 1994–2005 found that access to HIV/AIDS information led to improved communication between patients and their health care providers, and encouraged better health care decision-making (Dancy and Dutcher 2007). A comprehensive evaluation of the ACIOP's performance, impact and continued relevance was performed by NLM and Columbia University in 2011–2012. That study reported that project objectives were mostly met; high-risk populations were reached; low resource organizations were successfully funded; community involvement and partnerships were significant; projects built on existing efforts; information resources and training were tailored to local needs; and most projects successfully overcame barriers experienced (Dancy 2014). Now, in the latest effort by NLM at program improvement as called for in the report's recommendations, the Library responded positively and

aggressively to the call for increased capacity building at the community level, and once again sought to benefit from feedback offered by the community in an invitational Workshop convened at NLM in December 2012.

THE WORKSHOP

The Workshop brought together a diverse contingent of representative community organizations and several academic collaborators that were studied in the evaluation along with other HTV/AIDS community leaders. In attendance were representatives from non-profit community-based organizations such as Philadelphia Fight, Metro Teen/AIDS, Renz Addiction Counseling Center and PREL, the Pacific Resources for Education and Learning. Local government public health departments and universities were also represented.

Suzanne Bakken, RN, DNSc, Columbia University, New York, N.Y., presented a summary of the evaluation study findings and recommendations. Workshop participants uniformly agreed that the findings were relevant and accurately reflected their own project experiences. They endorsed the study's key recommendation that remediating a lack of evaluation capacity at project awardee institutions would enhance local evaluation efforts and enable better project planning and documentation of impact. They agreed that this could be accomplished by means of providing expert consultation, and by advancing the capabilities of local project staff with limited evaluation experience. Additionally, they urged that means be explored to make awardees' project methods and results more transparent and sharable amongst all awardees by encouraging the use of external listservs and blogs.

Workshop participants were also asked to consider a wide range of external influences on the ACIOP, including the latest HIV/AIDS research on prevention and treatment options that may more closely align future project awards with unmet needs in the community. Victoria Cargill, MD from the NIH Office of AIDS Research, Bethesda, MD reviewed recent scientific advances in the United States and abroad, and Veronica Jenkins, MD, Family and Medical Counseling Services, Inc., Washington, D.C., commented on current trends in clinical practice. These presentations suggested potential benefits in targeting groups unaware that they are at high risk for infection (18–24 year olds), and also heterosexual men and discordant sexual partners. This is in keeping with new research findings and guidelines on the use of antiretroviral drugs for “treatment as prevention” (Cohen 2011; U.S. Public Health Service 2014) and “pre-exposure prophylaxis” (Grant et al. 2010) as promising strategies in an aggressive pursuit of the goal of ending AIDS.

From its earliest days, the ACIOP sought to narrow the digital divide by enabling community-based organizations and the people they serve to acquire broadband Internet capability. Today that access is increasingly moving from static desktop devices to powerful and versatile mobile platforms. Many of NLM's own resources are now available on a variety of smartphones and tablets.

Workshop participants were briefed by Susannah Fox on the Pew Research Center's Internet and American Life Project study findings (Fox and Duggan 2012), and learned that there are currently no widely accepted apps in the health domain generally and for HIV/AIDS in

particular. However, this technology is changing very rapidly, and it can be expected that with a current base of 81% of U.S. adults who use the Internet, and 59% who say they have looked online for health information in the past year (Fox and Duggan 2013), increasing migration to and use of mobile platforms awaits only the development and awareness by prospective users of apps with robust functionalities that enable convenient and easy access to high quality HIV/AIDS information resources. It was recommended that NLM should investigate and support the emergence of new uses of mobile apps for reaching HIV/AIDS affected populations and their caregivers, and specifically encourage new ACIOP proposals that use mobile technology. Such projects will also need to address technology integration issues surrounding the use of such apps with social networking tools, such as Facebook and Twitter that can provide another convenient gateway to HIV/AIDS information.

POST WORKSHOP ACTIVITIES AND PROGRAM IMPROVEMENTS

Feedback from the community at the Workshop was instrumental in prioritizing and operationalizing the recommendations that emerged from the Columbia study, and also those envisioned by NLM program staff and discussed with Workshop participants. Implementation began in September 2013 when seven new projects were funded in the 20th year of the ACIOP. Among these are three awards that explicitly focus on the use of mobile and smartphone technology by African Americans and Hispanics. One project, *YTH: HIV Access* in Oakland, Calif., will employ a multimedia hub-spoke model of online, social media and mobile platforms that builds on their previous work that created a mobile compatible version of its popular Web site and connected it to its Facebook page for young adults of color. The other two projects include *Comunidades Unidas* that deploys mobile technology by promotoras, Hispanic health workers, in community-based organizations in Utah that expands their text messaging system and social media campaigns. Similarly, *Project HIVE I* in Washington, DC will develop a “health information virtual exchange” that will serve as a one-stop HIV/AIDS resource for the growing use of smartphone technology by African Americans.

NLM made significant changes in awardee proposal preparation requirements, and also in the reporting, evaluation and documentation of individual project results. Perhaps most importantly, the Library’s expectations are now more clearly enumerated and three important steps have been taken to provide expert evaluation support and consultation to awardees that will lead to improved capacity by them to fulfill these new requirements, and achieve their project’s objectives.

NLM Hosted Two Webinars

The first webinar that NLM hosted addressed the importance of program evaluation and building capacity, the latter to be accomplished by providing the services of an independent evaluation consultant funded by NLM and made available to awardee organizations throughout the funding period. Support includes one-on-one consultation on how best to evaluate their project, and advice on questions/problems encountered, and facilitating access to web-based resources suitable for such needs as utilization tracking, satisfaction surveys, and skills assessments. The second webinar was intended to familiarize participants with the

most up-to-date and accurate HIV/AIDS prevention and treatment information resources that will meet the needs of AIDS service organizations, as well as those that need this information to manage HIV and AIDS. Included were specific pointers to information about clinical trials, HIV/AIDS drugs, treatment guidelines and medical literature.

Peer-to-peer Information Sharing and Exchange of Evaluation Materials

In addressing peer-to-peer information sharing, NLM launched the ACIOP Blog (<<http://aciopblog.wordpress.com>>) and an ACIOP listserv is now hosted by two participating community-based organizations at the Workshop that volunteered to take on this responsibility. Both the blog and the listserv are focal points for sharing project information and resources, exchanging ideas and building connections. Many projects are achieving great successes locally, and there are unrealized benefits by sharing their experiences nationally.

Tools Development

In terms of tool development, NLM and the evaluation consultant now assist awardee organizations in the development of specific tools to measure impact and/or other project outcome benchmarks. Consultation is customized to the four categories of projects currently funded by the ACIOP: Information Retrieval; Skills Development; Resource Development; and Equipment Acquisition. For example, projects developing staff and/or clients' skills in accessing or using HIV/AIDS-related information, including online databases and mobile devices, are given access to training templates that provide sample pre/post assessments, tips for writing measurable learning objectives, and evaluating outcomes. The evaluation consultant can assist the awardee organization to tailor each to meet their local needs. *Measuring the Difference* (Burroughs and Wood 2000), an NLM planning and evaluation resource that was developed many years ago to support NLM's community-based outreach efforts will be used by the evaluation consultant with ACIOP projects.

CONCLUSION

The AIDS Community Information Outreach Program has consistently benefited from community engagement, and in no small measure owes its longevity and continued success to a willingness to learn from the community while at the same time enhancing the community's capacity to achieve its own self-defined project objectives. Typically, when seeking government funding, community-based organizations are at a relative disadvantage to academic institutions that have well-staffed grants and contracts offices. The NLM has sought to level the playing field by creating in the ACIOP a funding opportunity that is tailored to and within reach of the community. While evaluation can be challenging for organizations large and small, with these program improvements now in place, NLM has raised the bar while enhancing the capacity of the community to succeed. Ultimately, time will tell how well we have succeeded with these program improvements, especially those requiring the expenditure of additional resources to support the provision of hosted webinars, a blog, and expert consultation. These efforts are currently being evaluated and the results will be reported in a subsequent article that may prove valuable as well to other groups and program funders involved in community outreach.

Acknowledgments

The authors gratefully acknowledge the following individuals from the community who participated in the HIV/AIDS Community Information Outreach Program Workshop which was held on December 10, 2012. The objectives of the Workshop were to validate the study's findings, and extend them to include an understanding of important external changes not addressed by the evaluation and which may further inform the future course of the ACIOP. Participants included: Jane Barnwell, AMLS, Pacific Resources for Education and Learning, Honolulu, HI; Carlos Chavez, Renz Addiction Counseling Center, Elgin, IL.; Stephanie Craig Rushing, Ph.D., MPH., Northwest Portland Area Indian Health Board, Portland, OR; Dazon Dixon Diallo, MPH, SisterLove, Inc., Atlanta, GA; Lorece Edwards, Dr.PH, MHS, Morgan State University, Baltimore, MD; Juliet Fink, EdM, Philadelphia FIGHT, Philadelphia, PA; Leandrea Gilliam, Metro Teen/AIDS, Washington, DC; Cary Goodman, The Balm in Gilead, Inc., Richmond, VA; Hana Hinkle, MPH, Lee County Health Department, Dixon, IL; Danielle Houston, MSPH, Legacy Community Health Services, Houston, TX; Robert Monk, PhD, AIDS InfoNet, Arroyo Seco, NM; Debra Murphy, PhD, MPH, Huston-Tillotson University, Austin, TX; Vicki Peterson, National Native American AIDS Prevention Center, Denver, CO; Karyn Pomerantz, MLS, MPH, George Washington University, Washington, DC; Bhupendra Sheoran, MD, MBA, Internet Sexuality Information services, Inc., Oakland, CA; Adam Tenner, Metro TeenAIDS, Washington, DC.

References

- Agency for Toxic Substances and Disease Registry. Principles of community engagement. Bethesda, MD: U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health; 2011. NIH Publication No. 11-7782, <http://www.atsdr.cdc.gov/communityengagement/>
- Burroughs, CM.; Wood, FB. Measuring the difference: Guide to planning and evaluating health information outreach. Seattle, WA: National Network of Libraries of Medicine Pacific Northwest Region; 2000.
- Cohen J. HIV treatment as prevention. Science. 2011; 23(334 6063):1628.10.1126/science.334.6063.1628 [PubMed: 22194547]
- Dancy NC, Dutcher GA. HIV/AIDS information outreach: A community-based approach. Journal of the Medical Library Association. 2007; 95(3):323-9. [PubMed: 17641768]
- Dancy NC, Rockoff ML, Dutcher GA, Keselman A, Schnall R, Siegel ER, Bakken S. Empowering patients and community online: Evaluation of the AIDS community information outreach program. Information Services and Use. in press.
- DeBaakey, ME. Improving health professionals' access to information: Report of the board of regents. Bethesda, MD: U.S. Dept. of Health and Human Services, Public Health Service, National Institutes of Health; 1989.
- Dutcher GA, Hamasu C. Community-based organizations' perspective on health information outreach: A panel discussion. Journal of the Medical Library Association. 2005; 93(4 Suppl):S35-42. [PubMed: 16239956]
- Dutcher GA, Spann ML, Gaines C. Addressing health disparities and environmental justice: the National Library of Medicine's Environmental Health Information Outreach Program. Journal of Medical Library Association. 2007; 95(3):330-6.
- Fox, S.; Duggan, M. Mobile health 2012. Pew Research Center's Internet & American life project report. 2012. http://www.pewinternet.org/~media/Files/Reports/2012/PIP_MobileHealth2012_FINAL.pdf
- Fox, S.; Duggan, M. Health Online, 2013. Pew Research Center's Internet & American life project report. 2013. http://www.pewinternet.org/~media/Files/Reports/PIP_HealthOnline.pdf
- Grant, Robert M.; Lama, Javier R.; Anderson, Peter L.; McMahan, Vanessa; Liu, Albert Y.; Vargas, Lorena; ... Glidden, David V. Pre-exposure chemoprophylaxis for HIV prevention in men who have sex with men. New England Journal of Medicine. 2010; 363:2587-99.10.1056/NEJMoa1011205 [PubMed: 21091279]
- National Institutes of Health, National Library of Medicine. Programs and services, fiscal year 2012. Bethesda, MD: US Department of Health and Human Services, Public Health Service; 2012.
- National Library of Medicine and the NIH Office of AIDS Research. Information services for HIV/AIDS: Recommendations to the NIH. Report of a conference co-sponsored by the National Library of Medicine and the NIH Office of AIDS Research. Bethesda, MD: U.S. Department of

Health and Human Services, Public Health Service, National Institutes of Health; 1993.
Publication No. 94p3730 <ftp://nlmpubs.nlm.nih.gov/aidsets/nihrpt.txt>

NLM Board of Regents. Charting the course for the 21st century: NLM's long range plan 2006–2016.
Bethesda, MD: U.S. Dept. of Health and Human Services, Public Health Service, National
Institutes of Health, National Library of Medicine; 2006.

Olney CA, Warner DG, Wood FB, Siegel ER. MedlinePlus and the challenge of low health literacy:
Findings from the Colonias project. *Journal of Medical Library Association*. 2007; 95(1):31–9.

Olney CA, Hansen L, Vickman A, Reibma S, Wood FB, Siegel E. Long-term outcomes of the ¡VIVA!
peer tutor project: Use of MedlinePlus by former peer tutors and the adults they taught. *Journal of
Medical Library Association*. 2011; 99(4):317–20.10.3163/1536-5050.99.4.012

U.S. Public Health Service. Preexposure prophylaxis for the prevention of HIV infection - 2014: a
clinical practice guideline. US Public Health Service, Centers for Disease Control and Prevention,
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention; 2014. [http://
stacks.cdc.gov/view/cdc/23109](http://stacks.cdc.gov/view/cdc/23109)

Wallingford KT, Ruffin AB, Ginter KA, et al. Outreach activities of the National Library of Medicine:
A five-year review. *Bulletin of the Medical Library Association*. 1996; 84(2, Suppl):1–60.
[PubMed: 8826638]

Wood FB, Siegel ER, Dutcher GA, Ruffin A, Logan RA, Scott JC. The National Library of Medicine's
Native American outreach portfolio: A descriptive overview. *Journal of Medical Library
Association*. 2005; 93(4 Suppl):S21–34.