Forging Alliances to Bridge the Research-policy Gap

Sana Loue, JD, PhD, MPH

ABSTRACT

It is critical that research findings be translated into policy if the research is to be beneficial. Researchers can play a role in bridging the research-policy gap by participating in the drafting of legislation and regulations, by testifying before lawmakers, and by building collaborations with key entities, including non-profit and governmental bodies outside of the health arena. Advocacy is inherent in the responsibilities of a researcher. A distinction must be made between researchers who serve as educators and advocates of change based on our current state of knowledge, and "scientific advocates" who rely on science only when it supports their political position. It is critical that researchers identify appropriate collaborators to bridge the research-policy gap and that the communities be involved in this process.

It is critical that research findings be translated into policy if the research is ultimately to be of benefit. This is unlikely to occur without input from those who conducted the studies and who are best able to explain the research findings, their significance, and their limitations. Several preliminary decisions must be made to bridge this research-policy gap in a specific context. First, the level at which policy is to be developed and implemented must be identified. Policy is implemented at all levels including, for example, institutional, local, state or provincial, and national. Second, policy may be formal, such as that embodied in written regulations and policies, or it may be informal, such as in the discretionary and often unwritten decisions of administrators.

STATE OF KNOWLEDGE

Various mechanisms can be used to bridge the research-policy gap. These include participating in the formulation or refinement of legislation and/or regulations; testifying before a legislative, judicial, or other law-making body; and forming collaborations and coalitions with a variety of organizations, including non-profit and professional organizations.

Formulating regulations

Researchers and policymakers have attempted to use findings from health research to formulate regulations, although such efforts have not always been successful. One of the best examples of this process occurred in conjunction with efforts by advocacy groups for immigrants to reform the legal provisions used to exclude immigrants from the United States for health-related reasons.

Prior to 1990, the immigration laws of the United States excluded individuals wishing to travel to the United States if they were found to have a "dangerous and contagious disease."¹ According to regulations that were promulgated by the Public Health Service to implement this law, this provision encompassed diseases such as leprosy, tuberculosis, and various sexually transmitted diseases. The passage of the Immigration Act of 1990 changed this basis of exclusion to that of "communicable disease of public health significance."

In an effort to reconcile immigration practice with the state of public health

La traduction du résumé se trouve à la fin de l'article.

Associate Professor, Case Western Reserve University, School of Medicine, Cleveland, OH

Correspondence: Dr. Sana Loue, Department of Epidemiology and Biostatistics, Case Western Reserve University, School of Medicine, 10900 Euclid Avenue, Cleveland, OH 44106-4945 USA, Tel: 216-368-3743, Fax: 216-368-3970, E-mail: Sana.Loue@cwru.edu

knowledge, researchers and legal advocates worked with the Public Health Service to remove from the regulations all diseases other than active tuberculosis. The supporters of this revision argued that, in contrast to the other diseases that were listed, tuberculosis was transmitted relatively easily and a susceptible individual could not prevent its transmission. However, the transmission of diseases such as syphilis and HIV could be prevented by utilizing strategies such as abstinence and condoms.

These efforts led to the elimination by the Public Health Service of all diseases from the list with the exception of active tuberculosis. However, the success was short-lived. Following extensive congressional debate, a statutory amendment was passed prohibiting the entry into the United States of immigrants who were infected with HIV.² The other diseases were also restored to the list.

Testifying before lawmakers

In 1993, the Alliance Healthcare Foundation (AHF) undertook a comprehensive needs assessment of injection drug users (IDUs) in San Diego County.³ Research indicates that the sharing of injection equipment for vitamin injection is particularly notable among some immigrant groups.⁴

The AHF established a study group, composed of individuals with direct experience working with the target population and/or expertise in HIV/AIDS and substance abuse, to provide direction to the design and implementation of the needs assessment. The needs assessment included five components: a review of the scientific literature and epidemiological data on HIV/AIDS and hepatitis B; a survey of health and social service agencies in San Diego County; semi-structured interviews with IDUs (both in and out of treatment); a medical records review of HIV-positive and IDU-identified inmates in county detention facilities to assess health needs and cost to the public sector; and an estimate of the costs of HIV infection among IDUs with and without a syringe exchange program. The needs assessment was intended to 1) assess the culture and patterns of injection drug use, including ethnicity and geographic distribution; 2) identify groups not traditionally associated with injection behaviours, such as vitamin,

steroid, and hormone injectors; 3) estimate the size and geographic spread of the IDU population of San Diego County; and 4) provide recommendations for the Injection Drug Use Study Group on appropriate prevention strategies for HIV and other blood-borne diseases, and service needs of the IDU population.⁵

The AHF and the Study Group determined that the continuing transmission of HIV and hepatitis among IDUs and the lack of services for this marginalized population was a high priority for prevention and treatment efforts. However, there were little reliable data on the needs of IDUs in San Diego, the effectiveness of services designed to help IDUs and their sexual and needle-sharing partners reduce their risk of infectious diseases, as well as on the effectiveness of different program modalities. The AHF used the needs assessment to develop a public education campaign to educate elected officials and the general public on the benefits of comprehensive harm-reduction strategies that include syringe exchange.⁵

Building coalitions and developing collaborations

The development of collaborative relationships with non-profit and governmental entities may be critical in translating research findings into actual policy. The development of the Asian Pacific Islander Community AIDS Project (APICAP) is an example of how such a collaboration with an agency and its larger constituent community may develop. APICAP has now been in existence as a non-profit organization for 10 years. The organization grew out of what was initially a research study of risk behaviours for sexually transmitted diseases among nine Asian and Pacific Islander communities in San Diego, California.⁶ Following a period of investigation and the implementation of various community-based intervention strategies to reduce HIV risk, the study was legally incorporated as a non-profit organization to assure the continued provision of services to the Asian and Pacific Islander communities.^{6,7} APICAP now provides case management services to HIV-infected Asian and Pacific Islander individuals and their friends and families, in addition to providing HIV prevention services to the larger community. The organization is a

member of various coalitions that are responsible for the development of recommendations relating to the provision of HIV-related care and the determination of priorities for the distribution of local governmental funds for AIDS-related services. In addition, APICAP has input into policy through its participation in various county- and state-level advisory committees and its collaborations with departments of public health. Notably, the agency has assumed a tripartite strategy of research, program, and evaluation in the pursuit of its goals and the fulfillment of its mission.

Prison-based HIV education programs serve as one example of a partnership between health professionals and governmental agencies that has been successful in translating research findings into local institutional policy and practice. Case Western Reserve University has implemented a detention center-based HIV peer education program in collaboration with several detention facilities of what was formerly the United States Immigration and Naturalization Service.⁸ (This agency is now a part of the newly formed US Bureau of Homeland Security.) The program was developed and approved following preliminary research that found that individuals in detention had high levels of HIV risk behaviours and relatively low levels of knowledge regarding prevention strategies.⁹ In addition to providing needed information to prevent the transmission of HIV and other infections, the program provides an opportunity for detainees to use their time constructively.

The participation of the American Immigration Lawyers Association was critical in the effort to revise the health-related provisions of the US immigration laws. Due in large part to the efforts of this organization, US immigration laws were amended in 1990 to eliminate homosexuality as a basis of inadmissibility to the US and to provide for a more enlightened approach to the evaluation for admission of individuals suffering from mental illness.

KEY ISSUES

The role of the researcher in the formulation of health policy has been the subject of significant debate. One view posits that scientists bear no exceptional responsibility

to participate in the development and refinement of policy. This perspective is founded on the belief that scientific objectivity is threatened by participation in policymaking, especially advocacy,¹⁰⁻¹² and that researchers lack sufficient expertise in policy.^{11,12} Researchers in the role of advocates have been the target of particularly vociferous criticism, having been accused of ignoring facts,¹³ abandoning impartiality¹⁴ and critical self-examination,¹¹ refusing to adhere to the best scientific standards,¹³ and mistakenly believing that they can prove causation.¹⁵

Others have asserted that researchers' participation in advocacy is not only not inimical to the role of the researcher, but may actually be inherent to his or her responsibilities. Advocacy has been defined as "taking a position on an issue, and initiating actions in a deliberate way to influence private and public policy choices."¹⁶ Numerous functions relating to advocacy are within the usual scope of activity for researchers: making public statements at scientific conferences; participating in government-sponsored advisory meetings; serving as an expert in litigation; and presenting recommendations in review articles, statements to media representatives, and testimony to legislators and other governmental bodies and entities.¹⁷ Indeed, professional codes of ethics and various international documents recognize the researcher's responsibility to communicate his or her findings to the relevant communities and public health authorities.

Clearly, the researcher's approach to policy formulation must necessarily be one of balance. The researcher may be asked to comment publicly on issues that remain unsettled in the scientific arena. Those responsible for policy, such as legislators and other government authorities, may be required to make decisions in the absence of either complete information or a complete understanding of a situation and its various implications.¹⁸ It is critical that the researcher communicate adequately the extent to which scientific uncertainty exists and the implications of that uncertainty for policy. However, the existence of uncertainty does not mean that action is unnecessary or should not be taken.¹⁹

A distinction must be drawn between researchers who advocate for policy change and those who have been termed "scientific advocates."¹⁸ Scientific advocates have been defined as "people or organizations that use scientific arguments in support of policy positions during the course of public debate."¹⁸ Unlike scientists, scientific advocates do not consider themselves to be bound by any code of ethics and may rely on scientific knowledge only when it supports the cause to be advocated.

DIRECTIONS FOR RESEARCH AND POLICY

Several guidelines may be helpful in developing collaborations to assist in bridging the research-policy gap. First, it is critical that appropriate partners be identified. In fact, it may ultimately prove to be counterproductive if, for instance, researchers align themselves with individuals or organizations who have no regard for science other than as a tool for their own political purposes. Second, efforts to work with entities responsible for the development and implementation of policy will be greatly facilitated if the issue at hand is one of mutual interest and if the persons approached are those with responsibility for those issues. Third, it is critical to the success of research, and to efforts to bridge the research-policy gap, that the communities involved in the research also have an opportunity to participate in a meaningful way in discussions related to implementing the findings.

REFERENCES

1. 8 U.S.C. § 1182.
2. H.R. Conf. Rep. No. 100, 103d Cong., 1st Sess. 118 (1993).

RÉSUMÉ

Pour que la recherche ait un effet bénéfique, il faut absolument que les résultats de recherche se traduisent dans les politiques. Les chercheurs ont un rôle à jouer pour combler l'écart entre la recherche et les politiques en participant à l'élaboration des lois et règlements, en témoignant devant les législateurs et en tissant des liens de collaboration avec les entités clés, y compris les organismes gouvernementaux et sans but lucratif hors de la sphère de la santé. La défense des intérêts fait partie intégrante des responsabilités du chercheur. Il faut faire une distinction entre les chercheurs qui font office d'éducateurs et qui plaident pour le changement à la lumière de l'état actuel des connaissances, et les « défenseurs de la science » qui ne se fient à la science que lorsqu'elle appuie leur position politique. Il est impératif que les chercheurs trouvent des collaborateurs appropriés pour combler l'écart entre la recherche et les politiques, et que les collectivités participent au processus.

3. Alliance Healthcare Foundation. *Injection Drug Use in San Diego County: A Needs Assessment. October 1994*. San Diego, CA: Author, 1994.
4. Loue S, Oppenheim S. Immigration and HIV: A pilot study. *AIDS Educ Prev* 1994;6(1):74-80.
5. Loue S, Lloyd LS, O'Shea DP. *Community Health Advocacy*. New York: Kluwer Academic/Plenum Press, 2003.
6. Loue S, Lloyd LS, Phoombour E. Organizing Asian Pacific Islanders in an urban community to reduce HIV risk: A case study. *AIDS Educ Prev* 1996;8:381-93.
7. Loue S, Lloyd LS, Loh L. HIV prevention in US Asian Pacific Islander communities: An innovative approach. *J Health Care Poor Underserved* 1996;7:364-76.
8. Loue S, Lloyd LS. HIV prevention among detained immigrants: Report of a program of the Immigration and Naturalization Service. *J Immigr Health* 2001;3:157-63.
9. Loue S. HIV knowledge and risk behaviors among undocumented immigrants in San Diego: Preliminary findings. In: *Abstracts of the 127th American Public Health Association Annual Meeting and Exposition*, November 7-11, 1999. Chicago, IL: American Public Health Association, 1999.
10. Rothman KJ, Poole C. Science and policymaking. *Am J Public Health* 1985;75:340-41.
11. Poole C, Rothman KJ. Epidemiologic science and public health policy (letter). *J Clin Epidemiol* 1990;43:1270.
12. Savitz DA, Poole C, Miller WC. Reassessing the role of epidemiology in public health. *Am J Public Health* 1999;89(8):1158-61.
13. Feinstein AR. Scientific news and epidemiologic editorials: A reply to the critics. *Epidemiol* 1990;1:170-80.
14. Last JM. Epidemiology and ethics. *Law Med Health Care* 1991;19:166-74.
15. Savitz DA, Greenland S, Stolley PD, Kelsey JL. Scientific standards of criticism: A reaction to "scientific standards in epidemiologic studies of the menace of daily life" by A.R. Feinstein. *Epidemiol* 1990;1:78-83.
16. Labonte R. Health promotion and empowerment: Reflections on professional practice. *Health Educ Q* 1994;21:253-68.
17. Weed DL. Science, ethics guidelines, and advocacy in epidemiology. *Ann Epidemiol* 1994;4:166-71.
18. Weiss C. Scientific uncertainty in advising and advocacy. *Technology in Society* 2002;24:375-86.
19. Jamieson D. Scientific uncertainty: How do we know when to communicate research findings to the public? *Sci Total Environ* 1996;184:103-7.