Vision for a Global Registry of Anticipated Public Health Studies

In public health, the generation, management, and transfer of knowledge all need major improvement. Problems in generating knowledge include an imbalance in research funding, publication bias, unnecessary studies, adherence to fashion, and undue interest in novel and immediate issues.

Impaired generation of knowledge, combined with a dated and inadequate process for managing knowledge and an inefficient system for transferring knowledge, mean a distorted body of evidence available for decision-making in public health. This article hopes to stimulate discussion by proposing a Global Registry of Anticipated Public Health Studies.

This prospective, comprehensive system for tracking research in public health could help enhance collaboration and improve efficiency. Practical problems must be discussed before such a vision can be further developed. (Am J Public Health. 2007;97:S82–S87. doi:10.2105/AJPH.2005.081711)

IN 2004, THE INTERNATIONAL Committee of Medical Journal Editors announced that, from July 2005, researchers submitting articles to 11 medical journals would be asked to report the full results of clinical trials, both positive and negative, and that the journals would not publish studies unless they had been included in a public registry at their inception.1 This policy should guard against selective reporting of trials and the distortion of the body of evidence available for clinical decision-making.2 The International Committee of Medical Journal Editors has now specified the minimum registration data set.3,4

We believe that similar considerations and standards are needed for nontrial public health studies. Public health studies are studies related to the efforts organized by society to protect, promote, and restore the people’s health,5 many of which are observational and nonexperimental, or involve “natural experiments.”6 We examined the current problems in generating, managing, and transferring knowledge in public health and have described a vision for a future Global Registry of Anticipated Public Health Studies (GRAPHS).

Knowledge generation and use are a critical foundation of effective public health programs and policies, but many problems are evident in current practice. Because this article covers a broad scope, it can discuss neither all of the issues nor each issue in sufficient depth. Also, the proposed vision is not meant to address all of the numerous practical issues but to generate public discussion. We are describing a vision to encourage possible solutions to important problems; we are not making a concrete proposal. For the purpose of this article, the knowledge cycle is divided into 3 stages: (1) knowledge generation (also known as knowledge acquisition or creation); (2) knowledge management (exploitation and development of the knowledge assets); and (3) knowledge transfer (also known as knowledge exchange, dissemination, access, brokering, or translation).7

THE NEED

Knowledge Generation

The first problem in generating knowledge is the imbalance in the funding of health care versus health protection, which is mirrored in the funding of medical versus public health research. For example, in the United States, less than 1% of the US$1.9 trillion annually spent on health care is spent on health protection and prevention.8 In the United Kingdom, although there is a government commitment to improving population health and prevention,9 only 2% of cancer research funding10 and 0.4% of public health research11 are provided for prevention. The problem is exacerbated because few major journals are interested in publishing public health research.6 Thus, the Guide to Community Preventive Services,12 a major US effort to synthesize current evidence supporting health promotion and prevention programs, reveals significant gaps (lack of studies of reasonable quality) in the current knowledge base when reviewing evidence to support health promotion programs.14 Furthermore, these knowledge gaps are not random and are found to be greater for interventions developed by the public sector versus those funded by private interests, for interventions that are more complex, longer term, and focused on upstream versus downstream causes of ill health, and in the developing versus the developed world.15

The second problem is the accumulation of false-positive information, or the “false-positive research cycle.”16 It begins with publication of a false-positive study (possibly because of bias or chance), which then leads to new studies on the same topic (fictopic bias). At the conventional significance level of 0.05, 100 studies where the null hypothesis is true will, on average, yield 5
false-positive studies. Because positive results are more likely to be submitted to scientific journals and to be accepted by editors, a cycle can be generated that may convince readers of something that is not true.  

The third problem is continuing research themes when issues are largely settled, or “circular epidemiology.” True-positive (or true-negative) studies are repeated needlessly, wasting resources that could have been used to study other more pressing problems. For example, between 1987 and 2002, 64 studies were published on the effectiveness of aprotinin (to reduce perioperative blood loss). Because the effectiveness was clearly established after the 12th study in 1992, what followed were essentially 52 studies that did not really advance science.  

The fourth problem is the funding of areas that are in fashion at the expense of others less in vogue but more important. Once a certain volume of research has been conducted in an area, a group of experts is formed whose vested interest in the topic influences future decisions on funding and publication.  

The fifth problem is nonpublication of unpopular or even politically incorrect studies, or “cul-de-sac epidemiology.” Findings are shunned by the medical community and the media because they are deemed inappropriate (e.g., modern obstetric anesthesia as a possible risk factor for autism). The original studies are not replicated, even by the original investigators, and they are rarely quoted after publication.  

The sixth problem relates to a novelty effect in research. Scientific journals, researchers, the media, and the public show a particular interest in “new” risk factors. Even very shaky evidence of possible new risk factors draws media and public attention that helps cast doubt on the known risk factors. Thus, researchers still go about searching for new risk factors for coronary heart disease after most are already known, as traditional risk factors for coronary heart disease have been found to explain 75% to 90% of new cases.  

The seventh problem is the preoccupation of health researchers and practitioners with immediate but not necessarily the most important health issues. Thus, to accentuate the first problem, the search for effective treatment often overshadows prevention, even though approximately half of all deaths in the United States in 2000 were driven by behavioral and social risk factors, with 40% attributable to tobacco, poor diet and physical inactivity, or excessive drinking of alcoholic beverages, all of them potentially preventable.  

The eighth problem involves sacrificing external validity for internal validity. The problem arises when control measures used to ensure greater internal validity create artificial and unnatural circumstances that limit external validity (generalizability). Thus, an efficacious intervention in a controlled environment fails to work when used in normal practice circumstances.  

Furthermore, many epidemiological biases affect the design, data collection, and analysis of public health research. At least 48 types of questionnaire biases have been identified. Other issues with public health research include the underfunding of upstream research addressing disease prevention, the quality of research, and the importance of research synthesis. Added to this list are translation of research into practice, cost-effectiveness analysis, and issues of false-negatives and multiple end points within a single study (data on many of which may not be published).  

Knowledge Management  

The current process for managing knowledge produces a dated, incomplete evidence base for decisions. First, it usually takes many years from conceptualization of a public health research idea to publication of findings in the scientific literature. Systems for managing knowledge may also lack the staffing or other resources needed to maintain currency.  

Second, search of the “gray” literature (e.g., unpublished and internal reports, technical documents), although improved by the Internet, remains notoriously difficult to conduct and replicate. Even when a search uncovers relevant work, obtaining a copy can be difficult. In addition, some studies may never be written up, because time or interest is lacking. In the case of government agency—or industry-funded research, clearance and official checks may limit what can be released as public information. These problems are not resolved by even the most comprehensive literature search and review strategies, and they are accentuated among researchers who are not native English speakers or who reside in countries with less-developed access to the literature.  

Knowledge Transfer  

The current process for transferring public health knowledge is hindered by the insufficient investment in directed research. In the end, the clear identification of priorities by decisionmakers and funders of research may mean relatively little. Research may be funded and conducted in a targeted area, but the findings produced do not necessarily answer the strategic questions that guide policy and practice. The result is that those who make decisions in public health are often frustrated by their inability to base those decisions on relevant research.  

Much of public health research focuses on the discovery and characterization of health problems, rather than on the effective interventions or possible solutions. Yet, policymakers are often looking for intervention studies. Community-based intervention studies are less easily located, not only because they are methodologically challenging and, therefore, more difficult to conduct and publish, but many policy and program evaluations may be commissioned by nonacademic sponsors and, therefore, may not be published or easily accessible because they have less incentive to publish. Even if community-based intervention studies are commissioned and published, there is still the challenge of how to apply the findings to the right population groups or community circumstances. There is a need for guidance for practitioners and decisionmakers on how best to assess external validity of studies and to apply the evidence in situ.  

THE VISION  

Our vision for a future knowledge-based information system is GRAPHS. Public health researchers and practitioners will benefit from such a globally collaborative registry, of which the key
aim is to provide a platform for the following: (1) ensuring all of the relevant research data becomes publicly available, (2) the identification of research and researchers on specific topics, (3) the cross-validation of studies, (4) the prioritization of research funding for issues of national and international interest, (5) the advancement of research to the next level, and (6) the identification of knowledge gaps.

Research studies on human health, ecological and social studies (including economic evaluation and policy analysis), and other public health investigations would be entered in GRAPHs when they are commissioned or when they are funded by a granting agency. Research findings, whether positive or negative, will be tracked. The method of tracking would be similar to that used by the Cochrane Collaboration and Campbell Collaboration, global registries for evidence on controlled-trial interventions in health care and the social, behavioral, and educational arenas, respectively. To keep up to date, the registry will need an automated reminder system for researchers to submit ongoing project updates. A unique registration number and standardized format will also be needed. Results will be classified by study design and the type of data analysis. An effective search engine will be needed to retrieve information.

GRAPHs must be freely accessible to all interested parties, which raises the issue of protecting intellectual rights. Operational guidelines should strike a careful balance between open access and the privacy (personal information, ownership of data, and copyright) of the individual researchers. More detailed information could be accessed by researchers with an access code.

Ideally, GRAPHs should include studies as soon as the research process begins and, thus, well before any results are obtained or published. GRAPHs registration could be required by all funding bodies and as a condition of granting ethical approval. It will be fundamentally different from a meta-analysis or any current system for synthesizing research, such as Cochrane or Campbell, which are inherently retrospective.

GRAPHs needs not be built from scratch. For example, it could be based on a process similar to that used by the Cochrane Collaboration and Campbell Collaboration, global registries for evidence on controlled-trial interventions in health care and the social, behavioral, and educational arenas, respectively. To keep up to date, the registry will need an automated reminder system for researchers to submit ongoing project updates. A unique registration number and standardized format will also be needed. Results will be classified by study design and the type of data analysis. An effective search engine will be needed to retrieve information.

GRAPHs must be freely accessible to all interested parties, which raises the issue of protecting intellectual rights. Operational guidelines should strike a careful balance between open access and the privacy (personal information, ownership of data, and copyright) of the individual researchers. More detailed information could be accessed by researchers with an access code.

Fourth, “hierarchies of evidence” tables, indicating appropriate research designs to answer specific types of questions and their application frameworks, are available to guide the rating and use of evidence from research studies. Fifth, the science of “bibliometrics” (statistical bibliography) can help describe and analyze “information epidemics,” for example, by studying the numbers of papers published on a new idea and charting their spread. Sixth, efforts in the selective dissemination of information by academic libraries over the last 30 years have led to the development of “push” technologies touting for the Internet a few years ago. These technologies can provide a basis for systems to filter and distribute information, such as an automatic e-mail posting triggered by changes in a Web page and an Internet-based electronic table of contents service.

Seventh, there are existing methods of review, evaluation, and dissemination that can be integrated into GRAPHs. These include meta-analysis; systematic reviews of qualitative studies; translation of research into practice, such as the Reach, Effectiveness, Adoption, Implementation, and Maintenance framework; and reporting standards and rating scales using Consolidated Standards of Reporting Trials criteria. GRAPHs needs to resolve issues such as how criteria for methodologic quality in reporting (Consolidated Standards of Reporting Trials) could be applied to observational research. Progress has been made. For example, Reach, Effectiveness, Adoption, Implementation, and Maintenance has been used to structure a set of criteria for judging the external validity, generalizability, and relevance of a research study beyond the setting and circumstances in which it was conducted and in line with Consolidated Standards of Reporting Trials. Because both internal and external validity are important for population health studies, a final component of GRAPHs could be the incorporation of Reach, Effectiveness, Adoption, Implementation, and Maintenance principles. When studies are complete, authors could be asked to provide specification of the key components of an evidence-based program and the range of permissible adaptation that would still retain the essential elements of the original efficacy study. In this way, GRAPHs would help provide a platform for research transfer, with explicit

---

**TOWARD A PREPARED FUTURE FOR PUBLIC HEALTH**
Strengths and institutionalization of decisionmaking, maintenance, implementation, outcomes reach representativeness, pro-
critically evaluating all studies, overly studied (circular epidemi-
ment in topics that are being agencies avoid excessive invest-
will be replaced by more sophis-
mation here because they often fail to get their own researchers, with their busy schedules, to even complete their institutional pro-
files of research and expertise on the Internet.

There is also the issue of intelle-
structural funding or other em-
and ethical concerns included? Are there public policy, 

tional planning? Who decides with the use of such data for cen-

tial funding or other em-
phases? Do we lose opportunities to allow paradigm shifts?

Threats and challenges

The most critical challenge to GRAPHS involves a relative lack of incentives for individual re-
searchers to submit information on current or planned studies, let alone keep it updated. The ex-
perience of universities and other research institutions is instructive here. Because they often fail to get their own researchers, with their busy schedules, to even complete their institutional profiles of research and expertise on the Internet.

There is also the issue of intellectual property rights and the fear of having one’s ideas stolen. Only on publication do investigators believe their intellectual property rights can be defended. This challenge is even more formidable in basic science, where commercial applications or patents may be at stake.

OPPORTUNITIES

We believe that, in the short term, the incentives for GRAPHS most probably lie with the fund-
ers of research in each country who could keep a better log of what they fund and then link these logs internationally. In addition, major users of research, such as governments, may wish to pay for registries of current or forthcoming evidence on key public policy issues.

Some current barriers to GRAPHS, such as lack of incentives (for investigators to partici-
pate in GRAPHS), probable disincentives, research traditions, funding, and copyrights, may change in the future. For exam-
ple, there are ongoing initiatives on “portals” to link existing data-
bases or new databases, such as the entire “open access” (Public Library of Science, BioMed Central) and “open source” move-
ments (e.g., Tropical Disease Initiative). The Centers for Disease Control and Prevention have made available, free of charge, an online e-journal (Preventing Chronic Disease), of which the articles are not copyright protected.

At least in government, many scientists and other researchers conduct studies according to per-
ceived policy needs. Shared information, collaborative efforts, and wide consultation are en-
couraged during the whole re-
search process. This culture may one day be extended to aca-
ademic research. Systems for public health research may then be re-engineered to link more closely with policy and practice. GRAPHS should have, at minimum, the capacity to actively monitor research outcomes and perform basic knowledge transfer functions. It should document dissemination of research to date, including citation in policy documents. Because policymakers are not likely to read primary research papers or project proposals or even full structured reviews, 1- or 2-page policy briefs or lay summaries would be necessary.

In the future, granting agencies may become more assertive with journals, and in turn journals with researchers, in pushing the case that negative studies (of sufficient
methodologic quality, including statistical power) are important to publish. In addition, GRAPHs may establish global standards to assist journals and granting agencies in prioritizing research for publication and funding, perhaps even addressing the issue of when the evidence for a finding is sufficient to obviate the need for further studies in that area. In return, scientific journals may establish guidelines that studies are to be published only if they had been initially registered with GRAPHs at inception.

With widespread computer and communication technology, GRAPHs may one day become a virtual database of all studies in public health, readily accessible to all researchers and decision-makers in every country, subject to suitable anonymization and data safeguards. With good decision aids and access to either raw data or aggregated data, research users could evaluate the research objectively. This would be perceived by some as risky, but scrutiny can only improve an investigator’s work.

CONCLUSIONS

GRAPHs, for all its potential value, would be a major challenge to implement. The need to allocate formidable resources and overcome sociopolitical considerations may keep such a global registry from being born. Conversely, progress in technology and informatics, as well as a rethinking of the research enterprise, may soon make implementation much easier to achieve. This article is a call for public discussion to improve the way new public health scientific knowledge is produced, managed, and transferred.

About the Authors

Bernard C.K. Choi is with the Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada, Ottawa, Ontario: Department of Public Health Sciences, University of Toronto, Toronto, Ontario; and the Department of Epidemiology and Community Medicine, University of Ottawa, Ottawa. John Frank is with the Institute of Population and Public Health, Canadian Institutes of Health Research, Toronto; Department of Public Health Sciences, University of Toronto, Toronto; and Institute for Work and Health, Toronto. Jennifer S. Mindell is with the Department of Epidemiology and Public Health, University College, London, England. Anna Orlova is with the Division of Health Sciences Informatics, Johns Hopkins School of Medicine; Public Health Data Standards Consortium; and the Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore. Vinh T. Lin is with the School of Public Health, La Trobe University, Bend- doora, Australia. Alain D.M. G. Vaillancourt is with the Office of Public Health Practice, Public Health Agency of Canada, Ottawa. Pekhu Parkash is with the National Public Health Institute, Helsinki, Finland. Tikh Fung is with Research Policy and Cooperation, World Health Organization, Geneva, Switzerland. Harvey A. Skinner is with the Faculty of Health, York University, Toronto. Marsha Marsh is with the Environmental Science Center, US Environmental Protection Agency, Fort Meade, Md. Ali H. Mohlad is with the Behavioral Surveillance Branch, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, Ga. Shu-Zhang Yu is with the School of Public Health, Fudan University, Shanghai, China; and the Shanghai Preventive Medical Association, Shanghai. M. Cristina Lindner is with the Hospital de Clinicas, Universidad de la Republica del Uruguay, Montevideo. Gregory Sherman is with the Office of Public Health Practice, Public Health Agency of Canada, Ottawa. Sandhi M. Barreto is with the Federal University of Minas Gerais, Belo Horizonte, Brazil. Lawrence W. Green is with the Department of Epidemiology and Biostatistics, University of California, San Francisco. Laurence W. Svenson is with the Public Health Surveillance and Environmental Health Branch, Alberta Ministry of Health and Wellness, Calgary. Department of Public Health Sciences, University of Alberta, Calgary, and the Department of Community Health Sciences, University of Calgary, Calgary. Peter Sainsbury is with Population Health, Sydney South West Area Health Service, Campbelltown, Australia; and the School of Public Health, University of Sydney, Sydney, Australia. Yongrung Yan is with the Department of Epidemiology, Fourth Military Medical University, Xian, China.

Zuo-Feng Zhang is with the Department of Epidemiology, University of California School of Public Health, Los Angeles. Juan C. Zevaillos is with the National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta. Suzanne C. Ho is with the Department of Community and Family Medicine, and the School of Public Health, Chinese University of Hong Kong, Hong Kong, China. Ligna M. de Salazar is with the Public Health Evaluation Centre, University of Valle, Cali, Colombia.

Requests for reprints should be sent to Bernard C.K. Choi, Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada, Government of Canada, AL#8701A, Ottawa, Ontario K1A 1B4, Canada (e-mail: Bernard... Choi@phac-aspc.gc.ca). This analytic essay was accepted September 24, 2006.

Note. Opinions expressed in this article are solely those of the authors and do not necessarily represent the views of any agencies, organizations, or countries.

Contributors

B.C.K. Choi conceived and designed the study and acquired the data. B.C.K. Choi, J. Frank, J.S. Mindell, A. Orlova, V. Lin, A.D.M.C. Vaillancourt, P. Parkash, T. Fung, H.A. Skinner, M. Marsh, A.H. Mohlad, S.Z. Yu, M.C. Lindner, G. Sherman, S.M. Barreto, L.W. Green, L.W. Svenson, P. Sainsbury, Y. Yan, Z-F. Zhang, J.C. Zevallos, S.C. Ho, and L.M. de Salazar were responsible for analysis and interpretation of data, drafting of the article, critical revision of the article for important intellectual content, and final approval of the version to be published.

Acknowledgments

The authors would like to thank Peter L. Taylor for the editorial contribution made to an early version.

Human Participant Protection

No approval was required.

References


19. Odent M. Between circular and...


