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Health Research Philanthropy In A Time Of Plenty: A Strategic Agenda

The fruits of the nation’s investment in biomedical research can be damaged by too narrow a focus on specific diseases.

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ABSTRACT: Generous public investment in the National Institutes of Health (NIH) provides research foundations with a unique opportunity to more closely connect investments in basic research to a payoff in improved health. Foundations can support efforts to integrate what is known from the biological, behavioral, and social sciences to solve the nation’s most pressing health problems. In doing so, they will help to build the scientific capacity to conduct high-quality integrative research in anticipation of a more robust public investment in translating what is known about health into what is done to improve and maintain it.

In this new era of genetic discovery and bioterror doomsaying, basic health science enjoys a historically high level of public support. At the same time, philanthropies that fund research have a unique opportunity to magnify the impact of the federal investment in health science by using their authority, flexibility, and autonomy to support research that public agencies are ill equipped to fund—research that integrates what is known from the biological, behavioral, and social sciences to provide answers that are critical to solving the nation’s most pressing health problems.

The doubling of the National Institutes of Health (NIH) budget from $13.6 billion to $27.3 billion over the past five years has led to breathtaking advances in identifying, treating, and curing disease. Much of this knowledge is intended to be translated into products but rather has implications for changes in physicians’ practices, health policy, and individual behavior. The nation could realize far greater gains in population health if the full range of research findings were used to develop more effective policies and practices.

These goals traditionally have been paramount among behavioral and social science researchers, who have long recognized that most health problems are the products of powerful forces working in combination—genetic makeup, environmental conditions, social and economic circumstances, family background, cultural norms, infectious agents, geographic location, and medical care. Increases in the incidence of Type 2 diabetes in children, the growing epidemic of asthma in poor neighborhoods, and the challenges of preventing HIV infection and treating AIDS as a chronic condition vividly illustrate this complexity. Effective
solutions will need to draw not only on a solid understanding of the biology of the disease but also on what is known about how human behavior, environmental conditions, and social forces contribute to these conditions.

**Why Is Using Knowledge From Multiple Disciplines Important?**

The fruits of the nation's investment in biomedical research can be damaged by too narrow a focus on specific diseases or conditions (including terrorism) that are dressed up in political garb. Increased support for basic research throughout the NIH has led to an explosion of knowledge about biological processes and their relation to disease. These funding increases provide powerful incentives, both directly and indirectly, for young scientists to train as basic researchers. Although a small portion of each institute's budget is allocated to specific topics, the strength of the NIH is in its support of basic science, which means that the vast majority of funds are generally distributed through investigator-initiated, peer-reviewed grants to support the exploration of narrow research questions.

Growth in support for basic science at the NIH has not, however, been matched by an equivalent investment in research to synthesize findings across disciplines and accelerate their application. The contrast between the fiscal year 2002 appropriation of $23.6 billion for the NIH and those of the Agency for Healthcare Research and Quality (AHRQ) ($300.4 million) and the Centers for Disease Control and Prevention (CDC) ($4.1 billion for non-bioterrorism-related programs), of which a modest portion is directed toward outcomes and community-based research, on the other, reflects a disconcerting neglect of this essential aspect of the research process.

The disparity is even more stark in President George W. Bush's request for a nearly 16 percent increase in the NIH budget for FY 2003 and a 16.2 percent decrease in AHRQ's budget.3

But such neglect is not new: Efforts to more effectively integrate research findings into health care practice and policy have long been met by a litany of objections, mainly having to do with the nature of biomedical research itself. Three of these objections, in particular, represent commonly accepted myths that are major barriers to making full use of the knowledge generated by current health research.

- **Myth 1:** The marketplace takes care of applying research findings to practice. Health researchers disseminate the findings of their research through the scientific literature, where their principal audience is other scientists, who depend on this route of communication for presenting new findings in their fields, for verifying previously published results, and for demonstrating the effectiveness of new research methods. The pharmaceutical and biotechnology industries make good use of new findings, but with the exception of independently produced clinical practice guidelines, there are seldom any direct attempts to reach other audiences—for example, individuals, health care professionals, or policymakers—with new clinical findings.

  Indeed, there really isn't much market demand. Clinicians and policymakers often do not base their decisions on findings reported in the scientific literature because they lack the time and skills to adequately track and evaluate the plethora of relevant journals.4 Responsibility for translating health research into practice and policy is distributed across a number of government agencies with limited resources and little mandate for coordination.5 If progress is to be made in making maximum use of the products of basic health research, new strategies must be developed to strengthen systematic links between research and its application.

- **Myth 2:** Insurmountable institutional barriers prevent the integration of behavioral, social, and biological research perspectives. Discussion of efforts to promote such research inevitably turns to enumeration of barriers related to the structures and incentives of academe (for example, tenure, promotion, publications) and the practices and norms of public funding agencies.6 But these barriers are upheld by scientists, who—as peer reviewers, editors, departmental committee members, and administrators—enforce
traditions that are hostile to interdisciplinary collaboration and regard applied research as second rate. As Pogo said, “We have met the enemy and he is us.” Progress toward applying knowledge to health improvement depends on incentives to train a skilled scientific workforce that is not punished for conducting transdisciplinary applied research.

Myth 3: Patients, clinicians, and policymakers have no role in the research process. Until recently it has been an article of faith among researchers that nonscientists should neither influence nor participate in the scientific process. This stance is based on the claim that such persons have little to contribute and will interfere with objective inquiry. More recently, AIDS, breast cancer, and mental health activists have played key roles in establishing research funding priorities, although not without much resistance from the scientific community. These efforts have sharpened the urgency with which research on these topics has been directed toward new solutions. Also, identifying research priorities and questions in collaboration with decisionmakers who are accountable for public health and health care in their states and communities helps to ensure that findings are used to develop policy. It is critical to define and institutionalize stakeholders’ role in identifying problems and setting applied research priorities.

What Can Foundations Do, And Why?

The combined resources of U.S. health research philanthropies are dwarfed by the federal dollars available for both research and application. But the deployment of private funds can be directed to accelerate progress on specific applied research questions; to provide incentives for senior scientists to overcome individual and institutional barriers and collaborate among disciplines, thus paving the way for junior colleagues; and to model new research and training methods that will build the scientific capacity to directly address the needs of policymakers, clinicians, and the public so that the full benefit of the nation’s investment in health research is realized.

Why philanthropy should take this on. Public and private funders all are interested in accelerating the pace at which the nation’s health improves. While philanthropy cannot shoulder the entire burden of building the scientific capacity to conduct applied transdisciplinary research, it can be instrumental in jump-starting its growth, in a variety of ways.

First, many foundations and voluntary health organizations have a commitment to addressing the specific health problems named in their mission and program guidelines. Foundations are being called upon to be more accountable for the outcomes of projects in which they invest and are discussing evaluation, assessment, and benchmarking. Creating a transparent link between philanthropy-funded research and its intended outcomes addresses this concern.

Second, unlike the NIH, philanthropies are not necessarily bound by a single disease focus. Many critical health problems—addiction, obesity, stress—are implicated in multiple diseases. Foundations can identify and convene the best scientists working on different diseases from within different disciplines to apply their expertise to the problem at hand.

Third, unlike the NIH, which spends the majority of its budget on basic, investigator-initiated research, foundations can direct research toward issues that are vital to their mission. They can identify key questions, can respond opportunistically to new scientific findings and secular events, and have the flexibility to make long-term commitments.

Fourth, unlike public research funders, which have few incentives or tools by which to test a seamless interchange between the laboratory and the community, foundations have the ability to serve as a neutral convener and a public laboratory. Foundations can invite advocates, researchers, government officials, academics, and other users of new knowledge to participate in identifying critical questions and testing methods to answer them.

Examples. MacArthur Network. Foundations have experimented with this role over the past fifteen years. For example, the MacArthur Network on Mental Health and the
Law, funded by the John D. and Catherine T. MacArthur Foundation, brought together legal scholars, psychologists, forensic psychiatrists, judges, and patient advocates, who together posed questions that could be answered through quantitative research on competence, risk of violence, and coercion. There has been broad acceptance of the network’s methods of assessing competence and coercion, and its finding that the risk of violence is related to the use of alcohol and drugs—and not to mental illness itself—has shifted policy and practice perspectives.

RWJF. In 1998 the Robert Wood Johnson Foundation (RWJF) formed a research network to increase understanding of the etiology of tobacco dependence. Consistent with the RWJF’s goal to decrease harm resulting from substance abuse, this effort grew out of the recognition that development of interventions to prevent tobacco use and treat its effects is hampered by a lack of understanding of the causes and natural course of tobacco dependence.

The RWJF used the network approach to bring multiple perspectives, disciplines, and methodologies to bear on the problem; provide intellectual and financial support for developing new conceptual approaches and methods; and attract leading researchers to work in this area. Besides greatly increasing understanding of the development of tobacco dependence, scientists’ increased capacity to conduct this research has already begun to pave the way for more productive studies on this question.

A Strategic Agenda For Philanthropy

While funding for basic health research is at an all-time high, there is no particular need for philanthropy to supplement this investment. There is, however, an opportunity for foundation leadership, vision, and resources to ensure that the wealth of knowledge available about health is used to develop policies, practices, and programs that will improve the future health of the population. Specifically, philanthropies that fund health research can consider the following activities as a means to contribute to improved health.

- Focus on urgent public health needs. The long-term goal is directing philanthropy-funded research toward the solution of specific health problems. Toward this goal, private funders can (1) clearly specify the problem that is to be the focus of the research funding; (2) develop key questions that must be answered to solve the problem; (3) identify the barriers to progress in answering the questions, including gaps in knowledge, public policies, individual behavior, practices of health professionals, and community characteristics; (4) specify goals for the funder’s efforts to reduce barriers to progress, to describe the role of research in achieving those goals, and to identify the outcomes that are to result from the research; and (5) involve appropriate stakeholders—laypersons, clinicians, and policymakers—in every phase of this effort.

- Develop and support applied transdisciplinary research. The long-term goal is philanthropy-funded research integrating the full range of disciplines required to address complex health problems. Toward this goal, private funders can (1) support the development of sustained collaborations among scientists and stakeholders to develop common frameworks for understanding how biological, behavioral, social, and environmental influences interact in specific health problems; and (2) fund research that addresses questions posed within such frameworks.

- Contribute to increased flexibility in the research environment. The long-term goal is making academic environments more conducive to conducting applied research that transcends disciplinary and organizational boundaries. Toward this goal, private funders can (1) support alternative institutional models for promoting, sustaining, and rewarding the conduct of integrative research (such as research networks, consortia, and centers of excellence); (2) support graduate training programs that demonstrate an emphasis on applied research, appreciate the perspectives and methods of other disciplines, and model transdisciplinary collaboration among faculty and inclusion of stakeholders throughout the research process; (3) assess and disseminate
the results of these efforts; and (4) advocate for expansion of successful approaches among public and private funders.

■ Work to broaden the focus of federal research funding. The long-term goal is balancing federally funded basic research with funding based on measures of the burden of disease and disability on individuals, families, communities, and society; on gaps in the knowledge and technology needed to reduce those burdens; and on the degree to which research has the potential to fill those gaps. Toward this goal, private funders can (1) convene nonprofits, advocates, and others to clearly represent their interests as stakeholders in the research process; (2) support the collection and analysis of data that track the burden of illness and of disability and the quality of life; and (3) disseminate those data in reports that decisionmakers can readily use.

Philanthropy has an opportunity to help both the government and academic health science to more closely connect their investments in research with their payoff in improved health. The approaches described above will strengthen these relationships and build the scientific capacity to conduct high-quality, integrative research in anticipation of a more robust public investment in translating what is known about health into what is done to improve and maintain it.

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NOTES
5. Frist, “Federal Funding for Biomedical Research.”