

## Biomedical science that the public can embrace

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For most of its existence, NIH has had two goals not always in concert. One is to gain fundamental knowledge about molecular and biological systems that can be well-established by the scientific community and the other is to improve people's health by clinically addressing their diseases and their physical, social, and mental challenges (NIH, 2014; Cook-Deegan, 2023; Sampat, 2023). At various times and in various corners of the NIH, one or the other of these seems to gain precedence.

The stated mission of the National Institutes of Health is to “seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability” (NIH, 2014). Compare this to the mission of NIH stated more than two decades ago: “to uncover new knowledge that will lead to better health for everyone (IOM, 1998).” The difference may be subtle, but it points toward a solution to some of the problems America faces in healthcare. As I read the first statement, the emphasis is on knowledge presumably gained in the laboratory, in contrast to the second, which as I read it, is on better health for all, drawing a thread out of the laboratory into society.

The two goals come together when research teams take their research all the way from fundamental processes, through simplified model systems, to physiological treatments, and finally to clinical application and social acceptance of those treatments. Scientifically valid research is needed at every stage of the process, and so is social awareness. To be complete and robust, research must include all stages. The various parts of the work can be undertaken by different groups of people, even in different institutions. One would hope the groups understand each other and coordinate their work.

Furthermore, the involvement of the public is invaluable at each stage. Public involvement (beyond oversight by the funders) provides continual reminders of the problem to be solved, checks on the relevance of the research findings to actual humans, understanding of the socially and psychologically acceptable risk and personal intrusion, and a gauge of public receptivity. Indeed, the continued involvement of the public is essential in both directions— as instigators and funders of the research and as the ultimate recipients and evaluators of the treatments.

Too often, research, whether at NIH or elsewhere, omits critical pieces of this tangled enterprise. The connection between one stage and the other— say, the study of model systems and development of clinical applications— is sometimes forgotten. Social attitudes and public acceptance of treatments, or vaccines, may be an afterthought for bench scientists. Efforts must be made to keep in mind members of the public, who are both sponsors of the research, as

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taxpayers, and beneficiaries as patients. At various times, programs in the scattered NIH institutes encourage interaction with the public. Often, interaction with the public involves informing them of the research in order to win their participation in clinical trials. Occasionally, programs are developed to learn how well the public would use the clinical applications of the research. Less frequently, researchers seek the engagement of the public in the design of research. (Burns et al., 2021; IOM, 2012).

It is an established pattern in any research, not only medical research, that the public and researchers do not work together. Scientists might say that their precise and controlled work would be impeded or ruined if buffeted by public whims or uninformed requests. Sociologists would say, perhaps cynically, that scientists enforce barriers to entry into their profession, developed over decades or even centuries, in order to preserve their privileges. Members of the public, for their part, intimidated by the technical methods and equipment of the researchers, in general keep their distance. For nearly a century, certainly since Vannever Bush laid out his blueprint for excellent research in America, it has been scientists, not the public or their political representatives, who have determined what research paths promise to be the most productive and where the research should be done, by whom, and how. In peer review of publications, grant award committees, or academic promotion, it has been the scientists who have judged what is excellent research, worthy of funding.

It is a troubling legacy of science at large that the general public, while very respectful of the skill and intelligence of the scientists and attracted by some of the advances, remains disconnected, even alienated, and wary. The disconnect between research science and the public has affected healthcare practice in many ways for many years. Public inability to distinguish between efficacious and bogus treatments has been the bane of all trained physicians. Public rejection of treatments that have been determined to have a good probability of success has vexed them too (Sparks et al., 2022). Scientific protocols that delay new medicines until every doubt about safety and efficacy is removed for the sake of future patients has left current patients feeling abandoned. The disconnect has been given sharpest focus and enormous poignancy by the COVID-19 pandemic. Vaccine rejection by large numbers of the public, inability or unwillingness of even educated people to recognize deliberate disinformation, and confusion about mechanisms of viral contagion have resulted in hundreds of thousands of needless deaths and a diminished trust in medicine and in science in general (Amin et al., 2022; Simmons-Duffin and Nakajima et al., 2022).

Scientists got the vaccine biochemistry right, but there were too many other pieces of the puzzle out of place. Biomedical science must go well beyond study of molecular and biomedical processes to achieve the goal of a healthy public. Making the scientific output useful to and used by patients is a necessary step, and the research process is not complete until the full process is accomplished. Of course, it does not help to blame the noncompliant public or malicious social media that manipulates them. Rather, the research enterprise must find a way to build trust in the medicine and overcome the impediments to public health, whether found in the chemistry of the treatment, the psychology of the doctor and patient, or the irrational herd behavior of some populations.

We can find a lesson of the pandemic that molecular biology and virology, however excellent they may be, are no substitute for public engagement. Vaccines, however effective they may be, cannot control a pandemic if a critical segment of the population rejects them. A person may find difficulty in trusting a vaccine or a drug she or he does not understand, from a lab whose motives cannot be checked, by a scientist who may be more interested in gaining a patent than in a patient's well-being. It should not be surprising that trust fails to take hold in the usual research

framework. In developing a vaccine, therapeutic, or treatment regime it is an appropriate part of the research to understand if and how the product will be used by the patient. Without that, the research is incomplete. The public engagement that is needed is more than colorful explanation of the science or clear directions for the applications or informed participation in clinical trials. There must be consultation and collaboration throughout the research.

In communications with the public, two-way communications, although usually difficult and awkward to accomplish, can lead to public trust, whereas top-down explanations of the science and health directives, however clear and accessible, require trust and are not effective for breeding that trust (Hyland-Wood et al., 2021). The public seeks to be involved as more than an audience. The public is always warmer to medicines or policies that they feel they have had a hand in developing, at least indirectly.

The public and their representatives put not only money, but also hope into NIH to give the country cures for disease and healthy lives. Those hopes may be overly optimistic. Nevertheless, NIH researchers and administrators surely remain aware that their sponsors want not simply breakthroughs in research but actual better health in people. So, too, researchers are aware at some level that the ultimate success of their research is affected by societal factors, public health considerations, and patient understanding of their own roles in illness and cure. Should sociology, psychology, epidemiology, and communication science— all areas of empirical research— be regarded as the purview of NIH on a par with virology, pharmacology, biophysics, and other disciplines? Can NIH handle a more extensive research role than has usually been assigned to the Institutes?

There are several reasons why NIH should fund and oversee such wide-ranging and comprehensive research. No other organization is like NIH: huge, multifaceted, well-endowed, and with a well-established reputation for excellent research. No other organization has the capabilities and reputation of NIH. The public and the congressional funders see NIH as the epitome of research-based healthcare, and true to its name, they see NIH as the primary source and repository of knowledge about health.

Conducting the research under one organizational roof would help ensure that the parts fit together. Research that is bench-to-bedside or petri dish-to-public adoption should not have to overcome organizational disconnects in addition to the normal cultural and social ones. NIH has achieved excellence in managing many disparate units. NIH can manage extensive research programs with its usual excellence not only, for example, on mRNA vaccines, but also on psychological and social factors leading to different rates of acceptance for different kinds of vaccines. NIH should be the organization that develops a comprehensive goal of good health in America. No one else is doing comprehensive research as described. If not NIH, who will?

Scientists often argue for support of curiosity-based, fundamental research where the application of the research findings is not yet imagined. There certainly is a place for this. Examples abound of beneficial applications found after the research has been started or thought to be completed. Of course, NIH could support research called fundamental or unapplied with no patient or public benefit in mind, even as such research is undertaken by the National Science Foundation and other organizations. Such research can be complemented with other more applied, clinical, or social research.

Research programs like those described here, translation of molecular and physiological understanding to actual patient care and public health, are not completely foreign to NIH. Wall

Street Journal writer Amy Dockser Marcus recounts a situation in NIH when beginning in 2007 some parents of children with a rare disease began collaborating as equals with scientists on experiments (Marcus, 2023). The collaboration produced positive results. The parents began the collaboration out of desperation. The scientists came to appreciate the collaboration, and it broadened their view of the research and made it more effective. The collaboration reflects well on NIH. It is good to recognize such a positive example of public engagement in research. It is worth remembering, though, that the experience warranted a book because of the rarity of that view of research.

NIH has drawn lessons from the COVID-19 national experience that indicate the need for some redirection of research and more comprehensive research in all aspects of vaccine delivery and uptake, healthcare delivery, and public communication (Collins et al., 2023). For years, NIH has been aware of impediments to public embrace of certain vaccines. However, the understanding, for example, of the phenomenon of vaccine uptake at a sufficient level to act to overcome the hesitancy and rejection clearly has been insufficient. NIH needs at least a rebalancing of the research that is being done, giving greater emphasis to comprehensive beginning-to-use research.

The implications permeate all activities of NIH. For NIH to do research on scales ranging from molecular to clinical to societal, research should be designed with an appreciation for cross-boundary interactions. Each project should be designed, in effect, by molecular biologists who understand the large-scale environment reflected epigenetically in gene expression, epidemiologists from minority communities who understand clinical patient compliance, psychologists who understand the range of human lifestyles, virologists who understand how international health organizations distribute vaccines, and so forth, all in concert with members of the public, patients, and families.

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