

The Practice of Informatics

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Viewpoint ■

Informatics at the National Institutes of Health:

A Call to Action

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Abstract Biomedical informatics, imaging, and engineering are major forces driving the knowledge revolutions that are shaping the agendas for biomedical research and clinical medicine in the 21st century. These disciplines produce the tools and techniques to advance biomedical research, and continually feed new technologies and procedures into clinical medicine. To sustain this force, an increased investment is needed in the physics, biomedical science, engineering, mathematics, information science, and computer science undergirding biomedical informatics, engineering, and imaging. This investment should be made primarily through the National Institutes of Health (NIH). However, the NIH is not structured to support such disciplines as biomedical informatics, engineering, and imaging that cross boundaries between disease- and organ-oriented institutes. The solution to this dilemma is the creation of a new institute or center at the NIH devoted to biomedical imaging, engineering, and informatics. Bills are being introduced into the 106th Congress to authorize such an entity. The pathway is long and arduous, from the introduction of bills in the House and Senate to the realization of new opportunities for biomedical informatics, engineering, and imaging at the NIH. There are many opportunities for medical informaticians to contribute to this realization.

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Three knowledge revolutions are shaping research agendas and clinical advances in medical science for the 21st century. These revolutions are in molecular biology and genetics; neurobiology; and digital electronics, computers, and communications. The first revolution is yielding a deeper understanding of the molecular and genetic basis of human health and disease and is leading to genetic diagnosis and screening,

gene therapy, and the engineering of new diagnostic and therapeutic agents. The neurobiology revolution is permitting researchers to unravel the mysteries of the human brain and its relation to attitude, behavior, and consciousness. Finally, the revolution in digital electronics, computers, and communications is setting the technical stage for more productive research, improved diagnostic and therapeutic devices, and more effective delivery of health care services worldwide. These revolutions affect our understanding of biologic systems at all levels, from genes and cells to organs and the whole body, and give rise to new clinical procedures to improve human health and alleviate pain and suffering.

Three intellectual disciplines are essential components of the engine driving the three knowledge revolu-

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tions. These disciplines are biomedical imaging, biomedical engineering, and biomedical informatics. They form the infrastructure on which many of the advances in medical science are built, including those in molecular biology and genetics, neurobiology, and digital computers and communications. Without biomedical imaging, engineering, and informatics, medical science and its diffusion into clinical medicine would not have evolved to their present state of sophistication, and the future of medical science and health care would be substantially less promising.

The intellectual disciplines of biomedical imaging, engineering, and informatics are grounded in basic physics and biomedical science, engineering concepts, and the foundations of mathematics, information science, and computer science. They use scientific knowledge, engineering principles, and mathematical algorithms to develop tools and techniques to increase understanding of disease and disability and to improve the diagnosis and treatment of illness and injury. Biomedical imaging, engineering, and informatics must be nurtured and supported so that they will continue to function as the foundation for the knowledge revolutions of the 21st century.

The Challenge

The National Institutes of Health (NIH) is the premier biomedical research center in the world. Through its intramural and extramural research programs, it is the principal force driving developments in medical science and growth of the knowledge base underlying clinical health care. However, the organization of the NIH into disease- and organ-specific institutes is ill-suited to intellectual disciplines that cut across institute priorities and apply to research programs in several institutes. Biomedical imaging, engineering, and informatics are the foremost examples of such disciplines. There is no home at the NIH for the basic research that is essential to growth of the intellectual capital of these disciplines.

Research supported by the NIH, and the resulting improvements in medical science and the clinical care of patients, have benefited immeasurably from the tools and techniques provided by biomedical imaging, engineering, and informatics. But these tools and techniques can continue to evolve only if a substantial investment is made in the physics, biomedical science, engineering, mathematics, information science, and computer science that lie at the core of these disciplines. This investment is a dilemma for the NIH in its present configuration, because biomedical imaging, engineering, and informatics are not confined to a particular organ or disease. Consequently, no specific

institute at the NIH takes responsibility for the continued viability and productivity of these disciplines. Some institutes do invest in imaging, engineering, and informatics tools and techniques applied to research problems specific to the institutes' priorities. But none feels obligated to support the underlying science, engineering, and mathematics that give rise to the tools and techniques.

Biomedical imaging, engineering, and informatics as intellectual disciplines are orphans at the NIH. A few years ago a similar challenge faced genetics research at the NIH. Genetics also cuts across all NIH institutes and affects the research programs of many of them. As a consequence, no single institute took ownership of genetics and accepted responsibility for its welfare. This shortcoming was addressed by congressional action that led to formation of the National Center for Human Genome Research and its subsequent elevation to the National Human Genome Research Institute in 1997.¹

The absence of a home for biomedical imaging, engineering, and informatics at the NIH causes problems in addition to inadequate investment in research underlying the disciplines. In its current configuration, the NIH has no centralized mechanism to orchestrate the applications of imaging, engineering, and informatics tools and techniques to specific research questions addressed in individual institutes. Often there is inadequate understanding of possibilities and limitations in the use of tools and techniques to resolve specific questions posed by disease- and organ-oriented investigators. These problems lead to duplicate efforts among institutes and to missed opportunities and ill-fated attempts to apply imaging, engineering, and informatics tools and techniques. The problems do not indicate weaknesses in the individual institutes or investigators funded by them. Rather, they reveal a fundamental flaw in the design of the NIH that excludes a home for the intellectual disciplines of biomedical imaging, engineering, and informatics.

The lack of coordination of research in biomedical imaging, engineering, and informatics is not confined to the NIH. Other federal agencies—such as the National Science Foundation, National Aeronautics and Space Administration, Food and Drug Administration, intelligence agencies, and the Departments of Defense, Commerce, and Energy—also support research in imaging, engineering, and informatics applied to biologic systems. The lack of research coordination among these agencies results in confusion and duplication. For example, the General Accounting Office (GAO) recently identified funded telemedicine

initiatives in more than 35 separate federal agencies.² Despite a federal investment of \$646 million over three years, the GAO found that “no formal mechanism or overall strategy exists to ensure that telemedicine development is fully coordinated among federal agencies to serve a common purpose.” According to the GAO, the Joint Working Group on Telemedicine, created in response to a directive from the Vice President, experienced great difficulty in even compiling an inventory of federal telemedicine programs.

The lack of research coordination among federal agencies impedes the transfer of tools and techniques among the agencies and into the public sector. In 1997, for example, images generated on Mars by an alpha proton x-ray spectrometer were transmitted to Earth for interpretation and analysis. The entire process depended on state-of-the-art imaging, engineering, and informatics. There is no mechanism, however, to ensure that technologies such as those employed by NASA are examined for potential applications to biomedical research or clinical medicine. Limited efforts to transfer technology, such as those invoked in digital breast imaging, occur today more by serendipity than by design. This author has heard scientists in defense and intelligence agencies boast that imaging in their agencies is 10 to 15 years ahead of medicine. Such statements may reveal an elitist posturing of defense and intelligence scientists, and perhaps a lack of diligence among medical scientists in keeping abreast of developments in other fields. But they also reveal the inadequacy of mechanisms for transferring potentially useful technologies from federal agencies to the public sector, including biomedical research and clinical care.

Addressing the Challenge

The NIH is not unaware of its deficiencies in supporting biomedical imaging, engineering, and informatics. The NIH Revitalization Act of 1993 directed the Secretary of Health and Human Services and the Director of NIH to conduct a study of support for research in biomedical engineering. In response, the NIH established an internal working group that in 1995 issued a report to Congress on support for bioengineering research.³ The NIH also convened an external consultants committee that met several times in 1994 and issued a report and recommendations on support for bioengineering research.⁴ In 1997, the National Cancer Institute elevated extramural imaging activities from a small branch to its new Diagnostic Imaging Program, with increased staff and resources. In the same year, the National Cancer Institute des-

ignated imaging as an “extraordinary opportunity for investment.” Also in 1997, the NIH created the Bioengineering Consortium (BECON), with representatives from every institute, to provide better coordination of biomedical engineering activities at the NIH. The consortium is an intramural NIH activity without policy, programmatic, or funding authority. The first BECON symposium, in March 1998, attracted more than 900 participants, and the second symposium, scheduled for June 1999, will address research in imaging.

The NIH Center for Scientific Review has appointed a “blue-ribbon” working group on Review of Bioengineering and Technology and Instrumentation Development Research to make recommendations to improve the receptivity of NIH study sections to proposals for research support in biomedical imaging, engineering, and informatics. The National Library of Medicine has supported informatics projects through its R01 research grant program, the Integrated Advanced Information Management Systems (IAIMS) initiative, the compilation and distribution of databases such as GENBANK, ENTREZ, and PUBMED, and other application-oriented programs such as the Unified Medical Language Systems, the Visible Human, the electronic patient record, and clinical information systems.

Increased support of biomedical imaging, engineering, and informatics attracted considerable attention in the last (105th) Congress. In his March 1998 address to the American Institute of Medical and Biological Engineering, Senator William Frist (R., Tenn.) concluded that congressional action is required to address the needs of these disciplines. Legislation was introduced in the 105th Congress to create an institute for biomedical imaging [H.R.1715; S.990] and a center for bioengineering research [H.R.4120, S.10303]. Neither of these bills reached the Senate or House floor.

Efforts by the NIH and Congress are positive steps, and the NIH and congressional leadership deserve credit for taking them. As a solution, however, they are inadequate individually and collectively, because they do not address the fundamental dilemma of biomedical imaging, engineering, and informatics at the NIH. The intractable problem of the current NIH structure is that these disciplines do not have a home where resources can be invested to support the basic science, engineering, and mathematics essential to their growth and productivity. Without such a home, biomedical imaging, engineering, and informatics will continue to be considered utilities whose purpose is to produce tools and techniques useful to the research missions of the individual NIH institutes. This utilitarian approach does not encourage investments in

the infrastructure underlying the disciplines, and consequently is not a nurturing environment for biomedical imaging, engineering, or informatics. It is, in fact, impossible to conceive of an adequate solution for these disciplines within the current NIH structure of disease- and organ-oriented institutes.

The Solution

The solution to the current dilemma of biomedical imaging, engineering, and informatics at the NIH is the creation of an independent, funded, free-standing entity such as an Institute or Center. The mission of this freestanding entity would be to advance the basic physics and biomedical science, engineering concepts, and foundations of mathematics, information science, and computer science that form the infrastructure for the intellectual disciplines of biomedical imaging, engineering, and informatics. The institute or center would support fundamental research in the disciplines but would not draw resources from applications of imaging, engineering, and informatics to research questions centered in disease- and organ-oriented institutes. The institute or center should coordinate these applications across NIH institutes and identify and publicize similar developments in other federal agencies. It should help educate and train young investigators in biomedical imaging, engineering, and informatics and explore ways to diffuse its products—its tools and techniques—into research in other institutes.

In the past, the disciplines of biomedical imaging, engineering, and informatics have been separate and quite distinct. Today they are experiencing a remarkable convergence spurred by several factors, including digital electronics and computers, molecular imaging, engineering advances, and recognition that images and engineering models are simply physical representations of information databases. This convergence, the importance of the disciplines to sustaining advances in medical sciences and clinical medicine, and their shared need for identity and support in the NIH, all support the merging of biomedical imaging, engineering, and informatics into a freestanding institute or center in the NIH.

In the first half of 1999, bills will be introduced into the U.S. House of Representatives and in the U.S. Senate to establish an NIH institute or center in support of biomedical imaging, engineering, and informatics. These bills are supported strongly by imaging scientists and increasingly by biomedical engineers and informaticians. Supporters of the bills recognize that

creation of a new freestanding entity at the NIH is a bold step, but have concluded that only a new institute or center can provide the climate necessary for essential growth in biomedical imaging, engineering and informatics.

Only with a new institute or center at the NIH can the following major objectives be fulfilled: 1) a policy position at the level of an institute or center director that represents the interests of biomedical imaging, engineering, and informatics; 2) grant-making authority in support of basic research in biomedical imaging, engineering, and informatics; and 3) appropriation of sufficient funds to support this research.

In 1984, the National Academy of Sciences' Institute of Medicine⁵ concluded that a new institute should be created at the NIH only under unique circumstances in which the following criteria are satisfied:

- The activity of the new institute is compatible with the mission of the NIH.
- It can be demonstrated that the research area in question (defined either as a disease or health problem or as a biomedical or behavioral process related to a health problem) is not receiving adequate attention.
- There are reasonable prospects for scientific growth in the research area.
- There are reasonable prospects of sufficient funding for the new organization.
- The proposed structural change will improve communication, management, priority setting, and accountability.

The proposed freestanding National Institute of Biomedical Imaging and Engineering satisfies all but one of these criteria. Efforts to enhance the identity of biomedical imaging, engineering, and informatics at the NIH through the actions of the National Cancer Institute, BECON, and the National Library of Medicine demonstrate that NIH's leadership values the disciplines and recognizes their importance to its mission. With the fast pace of developments in fields such as molecular biology and genetics, neurobiology, and digital electronics, computers, and communications, the disciplines have excellent prospects for scientific growth, and greater resources should be allocated to them. Authorization to appropriate new funds for the proposed institute or center is an integral part of the bills to be introduced in the Senate and House. The proposed freestanding entity, which will include the

responsibility to coordinate imaging, engineering, and informatics research in the NIH, will greatly improve communication, management, priority setting, and accountability. Only the second criterion is open to question, because of its inappropriately restrictive definition. Limiting the NIH structure to specific diseases or health problems is exactly the reason that development of biomedical imaging, engineering, and informatics has been impeded at the NIH.

The proposal to create a new institute or center in support of biomedical imaging, engineering, and informatics at the NIH is entirely consistent with the rationale for creating the National Human Genome Research Institute (NHGRI), stated as follows: "As an institute, NHGRI can more appropriately interact with other federal agencies, and develop collaborations with industry, academia, and international organizations."¹ One of the principal missions of the proposed freestanding entity is interaction with other federal agencies in biomedical imaging, engineering, and informatics. Collaborations between industry and government are particularly important in these disciplines, because many technologic innovations occur in industry. The new institute or center will actively participate in the establishment of priorities for development of new tools and techniques and in the evaluation of these products for biomedical research and clinical use.

Conclusion

Attainment of a critical goal—continued and enhanced advances in biomedical imaging, engineering, and informatics—requires the establishment of an institute or center in support of these disciplines at the NIH. This freestanding entity would provide, for the first time, a home for basic research in imaging, engineering, and informatics. This research is essential to fulfillment of NIH's mission to improve the health and well-being of people worldwide in the 21st century.

There are many things individuals can do now to help attain the critical goal. They include:

- Promote central orchestration of tool- and technique-oriented research in biomedical imaging, engineering, and informatics that is funded in separate institutes at the NIH.
- Advocate new centralized funding for basic research in biomedical imaging, engineering, and informatics that supports the research missions of multiple institutes at the NIH.
- Recognize that biomedical imaging, engineering, and informatics share common goals at the NIH and that they command greater attention by working together compared with acting alone.
- Speak out on the need for legislation to establish a freestanding institute or center at the NIH in support of basic research in biomedical engineering and informatics.
- Encourage congressional leaders to actively support bills to establish a freestanding institute or center.
- Join forces with other biomedical engineers, imagers, and informaticians to strengthen support for basic research in each of the disciplines.

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