Focus on Agendas for Biomedical Informatics

JAMIA

Viewpoint ■

Toward a New Culture for Biomedical Informatics:

Report of the 2001 ACMI Symposium

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For those of us who have dedicated our careers to medical informatics, it is easy to feel over-stimulated in the current times. Moore's Law has seemingly been generalized, beyond the hardware we use, to embrace every aspect of our professional lives. Opportunities to apply our science seem to double annually, in ways unforeseeable as recently as five years ago. A field that once was clearly focused on systems to support the care of hospitalized and clinic patients has extended its reach to health information resources for consumers, systems to enhance and protect public health, and systems that support research in genomics and proteomics. We have spawned subfields denoted by prefixes or qualifying phrases, such as "public health informatics," to mark this trend. Moreover, a field that was solidly rooted in academic medical centers now finds professional representation in for-profit corporations both large and small, in government agencies, and in foundations and professional societies. The field has acquired a distinct entrepreneurial spirit, not at all unwelcome but somehow new and unfamiliar.

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Rationale for the Symposium

As our relatively small field engages new problems in new settings, these novel activities are accompanied by an inevitable sense of dilution reflected in specific concerns about our collective future. If we expand our representation into new and diverse environments—as informatics engages Big Science, Big Government, and Big Industry—will there be a sufficient number of us in each of these environments to be influential? Will we retain our own culture or will we dissolve into the cultures of these expanding work settings? Will the information technology deployed in these settings build on the generalizable solutions we have developed and the experience we have accrued, or will these solutions be reinvented? Reflecting this concern, our name—"informatics"—

has metamorphosed into something novel and unintended: in many circles "informatics" is coming to mean "anything one does with a computer" in contrast to the more specific research and development connotations that most readers of this journal would attach to the name. So, according to this novel conception, the authors of this manuscript are "doing informatics" as we compose the text using word processing software on our personal computers.

It is, indeed, a strange and unsettling time, as many in the field of informatics worry about becoming irrelevant and losing our identity, while the appropriation of our name by most of the rest of the world might suggest that we are more important than ever. Whatever path we take, the future of medical or health informatics is evidently not going to be a straightforward evolution from the past. Under such circumstances, one completely understandable response is a xenophobic circling of the professional wagons, consolidating our identity around a set of very familiar clinically oriented problems as they manifest themselves in academic environments. Another response sees these torsions and exertions as an extraordinary opportunity to take a prominent role in leading biomedicine to wherever it may be headed, wherever that requires us to work. Such concerns are the non-exclusive purview of the elected fellows of the American College of Medical Informatics and established the theme of the College's 2001 Symposium.

Symposium Theme and Process

The stated theme of the symposium was "ACMI.com: The 'Business' of Informatics in the 21st Century." This theme, from the outset, was intended to be more metaphoric than literal, above all capturing the spirit of the times in which we live and work. If interpreted literally, the theme captured only a few aspects of the multifaceted changes affecting the field. As discussions occurred during the symposium, scientific, sociologic, and professional issues in the evolution of informatics overtook the business focus implicit in the program title. The symposium's broader points of departure, as stated in the formal call for participation, spanned multiple interrelated trends currently influencing the field:

- The emergence of "dot coms," new information technology companies fueled by readily available venture capital that have attracted several prominent researchers from academe to the private sector
- An increased interest in information resources directly serving the needs of health care consumers
- The rapid development of the field of bioinformatics, applying information technology to computational problems in modern molecular biology
- The evolution of mega-systems of health care, and the corresponding emergence of the technologic challenge of integrating information systems across multi-billion-dollar businesses
- The appearance of a new generation of vendor products, including sophisticated electronic health record systems with intelligent features that had previously been available only to a small number of medical centers that had developed such systems locally
- The gradual emergence of new business procedures and policies governing health care, requiring care-providing organizations to acquire sophisticated information systems to support administrative and financial aspects of their operations
- The increasing interest in information systems addressing the health of identified populations, directing the development of information systems to monitor the health states of intact regions, and allowing early intervention in the event of disease outbreaks

The symposium activities were designed to acknowledge formally, describe crisply, and analyze insightfully the implications of these sweeping changes, for the College specifically but also for AMIA and the field of medical informatics as a whole. To this end, the symposium's 3 days were organized into a flexible sequence of activities to promote shared understanding of the theme and its importance; to develop a set of more specific topics, not specified in advance, for detailed exploration; and ultimately to allow the participants to explore these more detailed topics and develop conclusions.

The nature of the symposium theme led us to embellish the group, traditionally a self-selected set of ACMI fellows, with an experienced person from outside ACMI, to provide additional perspectives. We were fortunate that Dr. Bruce Hochstadt, a principal at Thomas Wiesel Partners, was able to join the 36 ACMI fellows in attendance. Dr. Hochstadt's primary professional concerns are health care information, services, and e-health companies. Dr. Hochstadt was a panelist in the symposium's opening session, contributed to the small-group discussions, and offered a summary perspective at the close of the proceedings. His participation enriched the discussions

and lent external validity to the conclusions that emerged from the event.

On the initial day of the symposium, an opening panel, moderated by Judy Ozbolt, explored the "changing milieu of informatics."* Judy's introductory remarks framed the presentations and discussions that followed:

> What events and developments that we already see will strongly shape the future of health care and medical informatics? How should we respond? What business opportunities hold real promise for bringing the benefits of medical informatics to consumers and clinicians? And what surprise development is lurking over the horizon that may revolutionize again what is possible, what is desirable, and what is necessary?

The panelists addressed these questions in the context of an initial set of four themes that had been identified in advance—modern biology, academic medical centers, e-health, and the business of health care. Subsequent deliberations in small groups addressed these same four themes. Following the group sessions, one member from each group prepared a summary on newsprint of the group's findings. These were on display as part of an informal poster session over breakfast the following morning.

The second day of the symposium began with an address by Dan Masys, "Beyond the EMR: The Problems Needing Us to Solve."† Dan's address spawned four themes that spanned and reorganized the ideas introduced on the first day. These themes subsequently became the organizing framework for further discussions and the presentation of the symposium's findings—1) genome-enabled science and health care, 2) education to reduce reliance on memory and opinion, 3) system-mindedness and error reduction, and 4) moving beyond the "guild mentality" in health care and education. Each theme was explored by small groups on the second day, with a poster session to report and share these deliberations on the morning of the symposium's third day. The third day was devoted to further exploration of these themes.

We offer as the symposium's central findings an explication of each theme along with some elements of an action agenda for the field of informatics, to include members of AMIA and ACMI. This report's focus on four principal themes, while eliminating many details and side issues that arose during the event, captures the core of what was discussed. The "acmi.com" metaphor became more implicit as the discussions unfolded. Implicit in this exposition is a rejection of wagon-circling in response to the excitement of the current times. Instead we suggest—as an antidote to over-stimulation, differentiation, and dilution—focused attention on a core mission that can be expressed in terms of themes. Such focus can preserve and consolidate the field's identity while promoting substantial research and development to advance the health of the public through direct clinical care, biomedical research, and programs of education. The four themes discussed at the symposium and explicated below are not an exhaustive list, but rather a starting point, and perhaps a rallying-point for a field in serious danger of losing its way. Inevitably, a new and different culture of informatics will emerge as action related to these themes occurs in new organizational contexts and diversified workplaces.

Symposium Findings

Genome-enabled Science and Health Care

Genomic science can be seen in two ways—as a structural component to map the genome and thus understand nature's blueprint for biological action, and, as we increasingly understand how these molecular signatures affect living systems in action, as a functional component. With the structural map of many organisms now complete, we are moving beyond a primary focus on molecular sequence and well into the era of functional genomics, which now makes it possible to identify molecular signatures of specific diseases. Microarray technology to measure gene expression, the primary scientific apparatus of functional genomics, generates data that are multi-dimensional and noisy.

Current analytic methodology, using statistical clustering algorithms and manual identification of gene loci, is crude but nonetheless has identified some important linkages between the approximately 10,000 known human genes, with 20,000 known expression patterns, and a small number of diseases such as large cell lymphoma for which gene expression is strongly predictive of prognosis.[1] A next generation of analytic tools for functional genomics envisions the simultaneous measurement of the expression patterns of all the approximately 35,000 genes that the human genome is expected to comprise. These tools would automatically find correlations between gene expression patterns and normal meta-

* Panelists included Drs. Russ Altman, Bruce Hochstadt, Dean Sittig, and William Stead.

† The slides from this talk are available at http://medicine.ucsd.edu/faculty/masys/.

bolic homeostasis, nonspecific reactions to disease stimuli, and specific disease states. These correlations, in turn, will enable a next phase of genomics, "personal genomics," whereby the gene maps of individuals can be used to diagnose risks and states of illness and to plan therapy.

With a few exceptions, the community of scientists traditionally associated with medical informatics has not played a significant role in the work of structural genomics. This can and should change as we proceed into the eras of functional and personal genomics, because these eras require linkage of molecular data with "person data," the traditional purview of our field. Moreover, the challenges to create ontologies that promote understanding of the problems to be solved, to build systems that are scalable to the magnitude of the computational challenges that the functional genomics problem creates, to identify new algorithms that offer efficient and creative solutions to the computational problems at hand, and to reconcile the various vocabularies used to represent information are challenges that medical informatics has successfully addressed in the past.

The question facing the field of medical informatics, the group historically identified with AMIA and ACMI, is whether to remain firmly planted on traditional turf or take aggressive steps to build collaborations with the communities of biologists who are extending their own expertise to include computational methods. The cost of not acting at all is to be left behind regarding many of the most exciting future developments in informatics and health care.

Education to Reduce Reliance on Memory and Opinion

Cognitive psychologists distinguish between the internal "knowledge in the head" of an individual completing a task and the external knowledge available to that individual "in the world."[2] How an individual—for example, a health care practitioner or biomedical researcher—completes a task will invariably be directed by knowledge in the head, but it can be amplified by appropriate integration of knowledge in the world. Whereas knowledge in the head is automatically available to practitioners, knowledge in the world must often be sought, understood, and integrated before it can play a helpful role. Too much reliance on either kind of knowledge inhibits effective professional practice. A practitioner too reliant on knowledge in the world will be overburdened by the relatively slow process of accessing external information sources; a practitioner too reliant on knowledge in the head can be misled by faulty recollection or guided by knowledge that is not valid.

In health care, the current problem is excessive dependency on knowledge in the head, leading to excessive reliance by practitioners on flawed memory and learned opinions that have become, for these persons, pseudo-facts. By no means the only cause of medical errors, acting in the belief that one's personal knowledge is correct, when in fact it is wrong, is certainly one of the major causes of suboptimal professional performance in health care.

A grand goal of medical informatics has always been the creation of knowledge resources that facilitate the incorporation of "knowledge in the world" into professional practice. Such tools would make the search for and integration of this knowledge sufficiently fluid that practitioners can be supported by external knowledge without bogging themselves down to the point of hopeless inefficiency. Making this vision into reality, however, poses numerous challenges. Although easily searchable sources of validated biomedical knowledge are now widely available at the bedside and in the examination room, this addresses only one piece of the problem. How to integrate this external knowledge into the practitioner's "thought flow" and work flow remains largely unsolved.

An external knowledge resource addressing the thought-flow problem would provide an answer matching the practitioner's question, since the practitioner framed the question. The external knowledge must be not only correct and relevant but also appropriately granular and specific. If the practitioner has to *think* too hard to recognize that the external resource is indeed providing potentially useful knowledge, the external resource will not be used. Similarly, an external knowledge resource addressing work flow should not add additional discrete tasks to the process of caring for patients. If the practitioner has to *work* too hard to recognize that the external resource is indeed providing potentially useful knowledge, the external resource will not be used.

Tools that solve the work flow and thought flow problem are still sparse, but they are becoming palpably more prevalent. The technical side of this problem will be solved first, as ongoing research produces better information retrieval tools, and as dissemination of electronic health record systems provides a basis for integrating these resources into work flow and thought flow.

Culture and tradition—and, notably, the "guild mentality" addressed later in this report—pose addition-

al, and even more substantial, challenges to the integration of external knowledge into professional practice. The culture and tradition of the health professions value knowledge in the head. Traditional models of clinical teaching reward students who can, when asked, instantly recall pertinent facts about a patient or quote the classic differential diagnosis or treatment of choice. Attending physicians who "know a lot" are revered in the culture. Experienced nurses who accurately and almost instantaneously assess a patient's changing condition are respected by other nurses and physicians alike.

While the biomedical literature is valued as the source of authoritative knowledge, the legitimate model for using this external knowledge resource is to read and remember rather than to integrate it continuously. Continuing education programs that bombard a passive audience with facts, with the implied expectation that these facts will be remembered, both reflect and reinforce these values.

These values, instilled into the work habits of trainees in the teaching hospital and clinic, become enshrined in practice and perpetuated by the next generation of teachers. Although it is a relatively slow solution, changing the educational process is the most effective way of promoting the integration of external knowledge into practice. Attending physicians and expert nurses should be revered for their ability to find and integrate external information with their personal knowledge. This is the primary challenge facing medical informatics. A field that has largely ignored health professions education now has the opportunity to revolutionize it.

System-mindedness and Error Reduction

In the preface to *To Err Is Human: Building a Safer Health System*,[3] William Richardson wrote, "Human beings, in all lines of work, make errors. Errors can be prevented by designing systems that make it hard for people to do the wrong thing and easy for people to do the right thing." Estimating that errors in U.S. hospitals cause from 44,000 to 98,000 deaths per year, this report put medical errors, even at the more conservative estimate, above the eighth leading cause of death. Hundreds of thousands more Americans experience non-fatal medical errors each year. Resources consumed in treating the injuries caused by medical errors add to the cost of health care without improving the benefits.

In its second report, *Crossing the Quality Chasm: A New Health System for the 21st Century*,[4] the Committee on Quality of Health Care in America noted that "What is perhaps most disturbing is the absence of real progress toward restructuring health care systems to address both quality and cost concerns, or toward applying advances in information technology to improve administrative and clinical processes."

Most medical errors are not reckless. They occur because information that could prevent the error, information that exists somewhere, is not available when and where it is needed. The challenge to ACMI, AMIA, and the whole field of biomedical informatics is clear: We must integrate the delivery and use of knowledge and information into new and better systems of health care delivery.

As we strive to meet this challenge, problems of technology and information collide with problems of professional culture and tradition. Health care continues to depend on the decision-making capacity and reliability of autonomous individual practitioners to resolve problems that routinely exceed the bounds of human cognition. If we are to reduce errors, we must transform our culture to one in which caregivers exercise their unique human capacities within supportive systems that compensate for their inevitable human limitations. Achieving that vision, however, requires that we first build the systems and demonstrate their utility. Only then can we expect clinicians to integrate these new tools into their practices and to adopt system-oriented values.

How can the field of medical informatics promote rapid development of appropriate tools to transform the culture and systems of health care? In a few academic medical centers, informaticians have already developed and successfully implemented systems for order entry, care management, and quality improvement that provide both real-time decision support and long-term learning from clinical data for quality improvement. These sites should conduct systematic evaluations and demonstrations to show:

- The effects on error reduction of order sets and care plans based on current scientific knowledge and customized to the individual patient
- The additional effects on error reduction of decision support systems that reference both patient data and knowledge bases
- The additional effects on error reduction of quality improvement systems that reference patient data to produce knowledge for changing care and that provide specific decision support
- The responses of clinicians to the changes in cog-

nitive, psychomotor, and interpersonal processes of care that the information systems entail

- The changes in organizational processes that occur when health care systems become cybernetic—that is, when clinicians and managers use information derived from patient care data and current knowledge to adjust and improve care processes and outcomes
- The ethical values and issues that arise when responsibility for patient welfare is viewed not as the sole province of the individual clinician but as a shared responsibility in a system of care

A multi-site study using common research methods and data definitions would facilitate the aggregation of data across sites, where appropriate, and comparisons among sites and systems. Unique aspects of particular sites and systems would, of course, have to be evaluated in ways suited to their own objectives and impact. Results of these evaluations and demonstrations should be the subject of meta-analyses to differentiate generalizable from particularized knowledge. From such findings could come detailed recommendations for using information systems to reduce medical errors. Review and critique at each stage, from design to conclusions, by an independent advisory panel—perhaps even the Committee on Quality of Health Care in America itself—would ensure the rigor of the investigation and the validity of the findings.

Undertaking such a comprehensive evaluation of the most successful information systems designed to reduce medical errors will require a significant commitment of resources. Informatics leaders, institutions, and funding agencies would have to make this assessment of the state of the science a top priority. Not acting, however, would provide the archetypal example of allowing relevant knowledge to lie unused while (uninformed) humans decide how to respond to the crisis.

Moving Beyond the Guild Mentality

If a cultural change were required for health care practitioners to use information resources to integrate knowledge and information from "outside the head" into their clinical "thought flow," nothing short of revolution would be required to overturn a guild mentality that views health professional practitioners as an estate externalized from general society and responsible more to its own norms and values than to society as a whole. Moving "beyond the guild" requires viewing care recipients and all other social agencies relating to health as partners in an effort to attain a shared goal of maximizing public health and welfare. The "guilds" of health care professions defined by discipline-specific bodies of knowledge (medicine, nursing, social work, etc.) would yield to an array of certifications determined by societal need and practitioners' interests, abilities, and preferred mix of life-long learning and practice. In 1998, Stead[5] described a "beyond the guild" vision for health professions and the training required to move in that direction:

> Duplication and competition between health disciplines would be eliminated as competency became the sole credential for providing services. The make-up of the work force would adapt rapidly to changes in needs. … Learning would be built directly into practice, and portfolio careers would be supported. Experience and performance would be used to monitor competency. Extended science training would be concentrated where it was most needed. A lifelong interaction would be created between the learner and their learning infrastructure. The advanced expert would be allowed to practice worldwide in a focused area. Mentors would have a global market.

For all those advantages, moving beyond the guild mentality will not be easy. The group that addressed this issue during the ACMI symposium noted that the guild model is inefficient, expensive, and transient—that is, the knowledge required for each health profession is always changing—but the professional identities embodied in the guild are stable and self-perpetuating. Members agreed that the real goal was an "accepted, informatics-enabled, quality care system." Moving beyond the guild was nothing more or less than a necessary step to achieve the goal. The group identified concepts related to each aspect of the goal and actions that would be necessary to move toward the goal.

For example, to achieve acceptance of the "beyond the guild" model would require identifying what the recipients of health care want and need from professional health care providers and examining the myths and values held by clinicians and the lay public. A new social contract would have to be negotiated to redefine the roles of health care professionals and of individuals, families, and communities in providing health care.

Because in the new model lay persons would take greater responsibility for their own health, it is necessary to explore how these individuals use information and what kinds of information are available. The evolving role of genomics information in professional care and self-care must be considered. The medical informatics community has a major role to play in

developing health information for use by the lay public and making it accessible, understandable, useful, and verifiable. Medical informaticians must also examine how human interactions among clinicians and between clinicians and patients affect decisions, actions, and health outcomes. The redesign of health care systems must provide for effective collegial and therapeutic relationships. Only through such efforts will we enable lay persons to take effective responsibility for their own health and develop flexible partnerships with the appropriate professionals.

The new model of health care would thus continue to integrate human and informatics components, but with different definitions and modes of operation. To bring about radical change, leaders would have to recognize the bases and loci of resistance. They must then appeal to superordinate values—the production of good and affordable health outcomes for individuals, families, and populations through appropriate care informed by relevant knowledge and information. In seeking acceptance for their revolutionary proposals, the leaders would do well to look for the "tipping point" in public opinion and consider how to tilt events and attitudes in the desired direction. Informing and enlisting opinion leaders from the general public and from clinician communities would be necessary. The economic and social drive to achieve good health at affordable cost would be an important lever, since the guild model has been unable to produce an acceptable response.

If sufficient positive interest can be generated among the public and health care professionals, it will still be necessary to develop detailed, concrete proposals for "beyond the guild" health care systems. The proposals should describe the various roles of health care professionals and the public and how these players would do the work of health care. The proposals must address the training (perhaps life-long learning) required to fulfill each role, including educating the public about health through the K–12 school system. Such differences in health care delivery would entail changes in administrative structure, which must also be described. The proposals must lay out, too, the anticipated costs and benefits of the new systems, as well as the strategies for change from the status quo. They should base their projections on real data from primary and secondary sources.

In summary, to address the prospect of using informatics to facilitate revolutionary change in health care, leaders in the field of medical informatics should endorse an impact evaluation of changing the model of health professional education and practice. As part of that evaluation, investigators will develop understanding of the design of the new model, the beneficiaries, and the gains and losses entailed in the change; increase understanding of the concerns of health care professionals and executives; and demonstrate or explain how an accepted informatics-enabled quality care system can reduce errors and improve practice.

Conclusion

The four themes emerging from the 2001 ACMI symposium offer an action agenda that runs diagonally across the multi-axial categories used traditionally to subdivide and make sense of the field of informatics. These themes emerged de novo from a deliberation focused on a field endangered by its own success, or at least the successful connotation attached to its name. The themes emerged from the paradox of a field that could, if things run completely amok, differentiate itself into oblivion, reaching in the limit the point where each individual is his or her own sub-field and the only informatics that remains is "my Informatics," whatever, for each person, that happens to be.

These themes jointly raise a plea to reverse the trend to hyper-differentiation and replace it with a renewed integration, by which we join together around pressing problems in which there is profound social need and scientific challenge. The themes presented here represent an initial logical candidate set to rally us together; it may be that additional themes are needed to broaden the set, and thus the appeal, of this different approach to how we think about our field.

The pace of the changes affecting us requires immediate attention and suggests expeditious action. Perhaps this pace is seen most clearly in the "acmi.com" theme used to call initial attention to the event. Between the time this concept was identified, in the summer of 2000, and the actual symposium the following winter, the weakness of many Internet ventures in health became apparent, and it became evident that "WebMD" and "Dr. Koop" were not going to immediately revolutionize health care or informatics. So discussions related to e-health became less prominent and concepts related to business aspects of informatics more implicit as the symposium unfolded. What survived of the "acmi.com" theme was an awareness, permeating all deliberations, that the landscape will continue shifting in the future at least as rapidly as it has in the past, and the importance that we be supple and open to change.

Reintegrating the field of informatics around an action agenda itself requires a cultural change in the

field. Our values must shift, for example, from affinity among those who share specific professional backgrounds to affinity among those who share interest in a particular theme, whatever their professional backgrounds may be. The kind of institution in which one works would be much less important than what one actually does in that institution.

Informatics would be measured by its ability to solve problems it has visibly and proactively staked out for itself. Informatics' continuing claim to these problems as part of its domain would be justified by its continuing success in solving them. The success of medical informatics would be tied to the part we collectively play in promoting genome-enabled health care, reducing memory- and opinion-based education, inducing system-mindedness, diluting the guild mentality, and addressing whatever other issues might embellish this theme-driven agenda. The required change in the field is in some ways subtle and may not affect what most of us do in our day-to-day professional lives, but it could change profoundly how we think about what we do, with whom we do it, the meaning we give to our results, and how and to whom we communicate them.

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