

Focus on **An Agenda for Biomedical Informatics**

JAMIA

*White Paper* ■**Audacious Goals for Health and Biomedical Informatics in the New Millennium**

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**Abstract** The 1998 Scientific Symposium of the American College of Medical Informatics (ACMI) was devoted to developing visions for the future of health care and biomedicine and a strategic agenda for health and biomedical informatics in support of those visions. This symposium focus was prompted by the many major changes currently underway in health care delivery, education, and research, as well as in our health and biomedical enterprises, and by the constantly increasing role of information technology in both shaping and enabling these changes. The three audacious goals developed for 2008 are a virtual health care databank, a national health care knowledge base, and a personal clinical health record.

■ JAMIA. 1998;5:395–400.

Physicians and other health care professionals, health care institutions, and planners are facing many challenges in the wake of changes in health care delivery. These challenges are increasing constraints on the financing of health care education, the growing complexities of biomedical research, new relationships with industry, and advances in information technology. It is tempting to consider these as separate realms of turmoil; however, they share a number of features, which suggests that a predominant paradigm shift is occurring. Traditional entrepreneurial, task-driven approaches to health care practice, education, and research—in which the focus is on independent, com-

petitive solutions—are giving way to problem-oriented initiatives in which the focus is on interaction, collaboration, and resource sharing.

The 1998 Scientific Symposium of the American College of Medical Informatics (ACMI)\* was devoted to developing visions about the future of health care and biomedicine and a strategic agenda for health and biomedical informatics in support of those visions. This symposium topic was prompted by the many major changes currently underway in health care delivery, education, and research, as well as in health care and biomedical enterprises, and by the constantly increasing role of information technology in both shaping and enabling these changes. The target year of 2008 was chosen, as it will take us through the millennium but is not so far in the future as to be ungrounded in current realities.

Visions for 2008 were focused on biomedical and health care research, the enterprise, and clinical practice. This paper highlights the symposium content and

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\*Thirty-two ACMI Fellows participated in the 1998 Scientific Symposium, which was held in St. Petersburg, Florida, January 15–18, 1998.

presents three major 2008 health and biomedical informatics goals that emerged from the discussions there.

### **Health Care and Biomedicine in 1998**

Economies of scale are being sought throughout our health care and biomedical enterprises, along with the ability to provide services and capabilities in new ways. Many forces are altering health care. Among these are a growing recognition of the importance of health maintenance and preventive care, consumer information access, activism about health and health care issues, the shift from specialty-based to integrated, patient-centered care; and a growing ability to deliver certain aspects of care at a distance (telemedicine). Many health care practitioners are increasingly called on to be integrators, managers, and gatekeepers to health care resources, while others are becoming more niche-oriented, highly specialized providers of unique services. Health care practice is increasingly provided through integrated delivery networks that are intended to facilitate access to and more cost-effective use of resources by primary and specialty providers, patients, and the public, with planning and provision of these resources by health care managers.

With the rapidity of change and the plethora of health care information, the need for problem-based or “just-in-time” learning is acute, both as part of the formal education process and in practice. Technology assessment, critical thinking, improved decision making under uncertainty, and cost-effectiveness are all necessary components of today’s health care delivery process; education needs to include familiarity with these issues and with techniques for addressing them. Continuing education needs to be increasingly integrated with the care process, and distance-learning opportunities need to be made available. Consumer education needs to be an important part of the health care mission. At the same time, as financing of health care education is being threatened on numerous fronts, new ways of delivering education more effectively and new revenue sources need to be sought. Informed choice, enterprise management, clinical trials, and health care quality improvement all demand the ability to collect and analyze measurable, reproducible data.

Health care and biomedical research requires access to expensive and unique resources, whether the research is based in the medical school, in affiliated institutions, or externally, and the resources need to be available on a shared basis. Individual laboratories and investigators frequently do not possess all the

necessary capabilities internally, and many institutions do not even have them within their walls. With respect to informatics, the breaking down of institutional and geographic boundaries and the formation of new collaborative relationships among researchers are stimulated by the need to access specialized information resources, skills, techniques, and tools that are widely distributed. As we increasingly stratify our data and refine our research methodologies, it is difficult to identify salient characteristics or trends without the ability to pool data from diverse sites. In clinical research, integration with the health care delivery process for the timely collection of useful data and the ability to assimilate the data collected at diverse points in the process are essential. Protection of patient confidentiality and mechanisms to ensure adequate institutional supervision and review are required. Students and faculty need to be able to identify other colleagues, laboratories, tools, and educational resources pertinent to their interest. Approaches to the use of information technology include establishing infrastructure and methodology for access to distributed databases, information resources, and analytic tools; providing electronic training in specialized techniques; and establishing “virtual laboratories,” remote collaboratories, and interactions with industry—i.e., evolution to universities “without walls.”

A common theme of these considerations is that information technology is a cornerstone for providing “point of need” access to information resources, integrating diverse information resources, providing methods of guidance and decision support, monitoring and measuring the health care process, conducting aspects of care at a distance, and providing education and training in specific skills. All these give rise to the possibility of a wide variety of creative new relationships, facilitating technology transfer as well as expansion of educational and research venues.

### **Symposium Process**

Developing the 2008 visions<sup>1-3</sup> required presymposium input by the ACMI fellows by means of a questionnaire (Figure 1). Topic coordinators were selected to focus individually on research, the enterprise, and clinical practice. One of these topics was addressed each day, beginning with the presentation of potential visions for that topic.

Symposium participants identified the major health and biomedical informatics issues of the projected visions. Small groups were formed to focus on one or more medical informatics issues, with the aims of

more clearly defining the scope of the issues and determining the key activities or initiatives required to attain the vision. The final step was to identify strategic goals for health and biomedical informatics and suggest approaches for attaining these goals.

## 2008 Visions

The key visions are summarized here and discussed in more detail in the other articles in this section of the Journal.

### Biomedical and Health Care Research

The 2008 biomedical and health care research vision projects the deep integration and dissemination of information technologies throughout the fields of health care and biomedicine. The collaboration and synthesis were fueled by rapid advances in understanding of the biomolecular basis of life and disease processes. All research and collaboration are mediated through ever more powerful digital information resources and communications and computation tools.

### The Enterprise

The 2008 enterprise is fully networked. This allows health care providers and biomedical researchers ready access to information for health care and biomedical research activities. Outside the enterprise people learn about health issues early in life (K–12) with the aid of a digital teacher that adapts to their level of understanding. The primary health provider plays the role of mentor and coach. At the annual checkup, the provider and the patient review the health logs and the record of use, discuss the patient's understanding of health-related information re-

sources, and model alternative health and disease management strategies for the coming year.

### Health Care Delivery

Health care is delivered in the context of some form of managed care, through health maintenance organizations or through integrated delivery networks in which systemic cost-effectiveness is a constant focus. It is within this context that individual needs and unique requirements will be addressed. The trend is toward delivery of care in an ambulatory setting or by interaction with a patient directly at home, and telemedicine services and information systems provide the necessary communication links. Health care delivery is increasingly patient-centered, with the patient and the provider utilizing resources as needed.

### Audacious Goals

As a powerful way to stimulate progress, visionary organizations often use bold missions that Collins and Porras<sup>4</sup> call BHAGs (pronounced "BEE-hags"), an acronym for "big, hairy, audacious goals." There is a difference between merely having a goal and being firmly committed to a huge, daunting challenge. A true BHAG is clear and compelling, serves as a unifying focal point of effort, and acts as a catalyst for team spirit.

In addressing the 2008 visions, ACMI developed three audacious goals: a virtual health care databank (clinical trials and clinical practice), a national health care knowledge base, and a personal clinical health record. The following discussion for each of these includes an explanation as well as a list of the informatics challenges and actions needed.

**Figure 1** A summary of the vision questionnaire distributed to all fellows of the American College of Medical Informatics prior to the 1998 symposium.

**It Is the Year 2008! What will the health and biomedical enterprise look like? How is information technology supporting the enterprise? This includes health care practice, biomedical research, and health/health care education.**

How is health care being delivered?

How are future health professionals being educated?

How is research being accomplished?

What significant changes in the above have occurred in the past decade?

How will information technology support your overall 2008 vision?

### Virtual Health Care Databank (Clinical Trials and Clinical Practice)

A virtual health care databank (VHCD) will link information from clinical practice with data from clinical trials to enable clinicians to ask, “What is the collective experience with patients like mine?” Such a resource is needed to relate evidence to decisions about individual patients and to monitor variance and outcome. Consistency in the use of terminology, the representation of protocols, and documentation will be a prerequisite to achieving a VHCD and will provide early paybacks in increased efficiency of care and clinical trial processes.

More clinical practices will be based on clinical trials and evidence-based guidelines, and these practices will recognize and adapt to variations in patient preferences. Quality of care will be electronically monitored for more consistent practice, and statistical analyses will identify outliers for appropriate educational or other interventions.

For this vision to become reality, funding agencies and other stakeholders must support this direction. The current clinical trials process is coordinated and monitored largely offline, rather than dynamically, requiring duplicate data entry and resulting in inconsistencies, increased errors, and delays in reporting and analysis. Documentation of protocols is nonstandard, and there is no consistent means of locating them or determining eligibility for them. The VHCD must be able to translate to and from any electronic medical record system to allow data to be collected at the point of use in a structured form to facilitate outcome analysis.

#### Informatics Challenges

- Develop usable standards for protocol representation, data definition, and coding.
- Use cognitive and social-psychological studies to improve interface design (more principled development of systems and human-computer interfaces).
- Design improved workflow systems within health care settings.
- Simplify the data collection process in clinical trials, and reduce the steps and delays involved. Increase the use of broader sensory modalities for collecting health care information to include speech, video, and audio means as needed.
- Develop ways of modeling diversity.
- Evolve “system” standards, i.e., standards for infra-

structure architecture for distributed, network-based design, development, conduct, and analysis of clinical trials.

- Become early adopters of emerging technologies (e.g., in authentication and security).
- Develop appropriate coding schemes.
- Design experimental and usability studies to measure what people need and want from a system.

#### Actions

- Establish a public-private partnership to develop a national effort.
- Benchmark successes in other markets (i.e., concurrent engineering<sup>5-9</sup>).
- Link and leverage federal activities, especially the National Institutes of Health and the National Science Foundation.
- Develop demonstrations to model the 2008 vision and to educate opinion leaders.
- Create an enterprise for clinical trials that will work collaboratively with the research community to establish national clinical trial norms.
- Work with health care agencies and with the legislature to ensure that sufficient funding is provided for system redesign to enable the future vision.
- Build security monitoring and detectors into our information-based systems.

### National Health Care Knowledge Base

A national health care knowledge base will contain collective, basic health-related knowledge, organized in an easy-to-use and almost intuitive framework that will meet the knowledge needs of its many daily users, particularly by methods aimed at supporting problem-based access to it. It will consist of both static knowledge and knowledge embodied in procedures and tools.

Recognizing the lack of coordination and inefficiencies among activities, whether in biomedical research, clinical practice, or education, the need for repositories of shared knowledge content, tools, methods of interchange and standardization, and other infrastructure resources is recognized. The Human Genome Project has clearly demonstrated the potential benefits to be accrued from a shared repository and an incentive structure by which all participants are motivated to contribute to it. This has also been done for the biomedical literature. Similar capabilities are desired

in clinical vocabulary, clinical protocols and practice guidelines, anatomic libraries, and a host of other content areas. The goal goes beyond merely sharing content and extends to sharing tools for searching, organizing, editing, building databases, integrating with local environments, and otherwise manipulating such content.

A primary informatics challenge will be to provide an infrastructure that facilitates problem-specific, task-specific integration of disparate information resources—clinical data, images, reminders, possible actions, decision aids, educational materials, etc.—assembled on a “just-in-time” basis as needed. The results of such analyses plus learning models based on actions found useful in similar situations will continually improve the problem-specific resource integration process.

#### Informatics Challenges

- For each kind of resource, consider both the content and the issues of update, maintenance, and local adaptation. For example, the knowledge base might contain a model for guidelines that are based on evidence, built on vocabularies, and computable. Guidelines today are often developed without such rigor. Effort needs to be devoted to adapting guidelines to these requirements. Guidelines must be usable in diverse local settings, with version control and with context links to local data elements and actions.
- Develop strategies to recognize the increasingly tight connections among knowledge, internal representation, and external form for human–computer interaction and the need for standardized formats for representation and for transport.
- Develop intelligent agents and other ways to both actively disseminate as well as search for relevant knowledge.

#### Actions

- Conceptualize the scope and domain coverage of a national health care knowledge base.
- Develop a clear definition of the roles of the wide variety of informatics professionals (e.g., clinicians, researchers, system developers, and librarians) who will support the achievement of the goals.
- Develop a broader consensus-building process regarding the informatics activities needed to implement the visions.
- Convene consortia to focus on specific resources.

- Convene consortia to focus on global implementation.
- Identify constituencies and put together public–private initiatives to sponsor development of resource collections.
- Choose initial focus areas and develop informatics demonstrations to model the 2008 vision.
- Identify resources needed to support the vision.

#### Personal Clinical Health Record

A personal clinical health record will allow individuals to be more in control of their health through easy access to health-related information. This includes access to health-related literature as well as to their personal medical information. This record will allow medical information about the patient to be recorded, e.g., all immunization, disease states, prescription or over-the-counter medications, and preventive measures. It will be created at birth and updated by the patient and care providers throughout a person’s life.

The access to health-related literature could be through the Internet or educational center, or both. Educational centers could be located in individual homes, schools, libraries, or public shopping centers. Given the empowerment of individuals by 2008, they will demand a personal clinical health care record. Empowering individuals to take responsibility for their own health care means that they would not have to rely on memory but would instead have access to lifelong health-related information through a personal clinical health record.

#### Informatics Challenges

- Address important issues in authentication and security to protect the patient.
- Develop sensors and other reliable methods of identification so that authentication will happen automatically and unambiguously.
- Monitor the developments in emerging wearable computers and sensors—possibly even implantable ones—for their potential contribution to a personal health record and status monitoring.
- Adapt current health care information systems to incorporate a component to interact with and update the personal health record.
- Create a new generation of intelligent agents to assemble, record, and update individuals’ data.
- Develop usable standards for interfaces and updates.

- Develop educational programs to help individuals better understand their health care data.

#### Actions

- Develop educational programs that can simulate the effects of new healthy behaviors as part of the educational process for individuals.
- Work in conjunction with health educators to develop educational strategies regarding the consequences of unhealthy behaviors, risk factors, and genetic predisposition.
- Develop a consensus-building process regarding informatics activities needed to implement this vision.
- Develop informatics demonstrations of the 2008 vision.
- Apply workflow, cognitive, and social-psychology studies to the task of interface design.
- Facilitate joint planning by including clinicians and patients in the development process

### Summary

While there are many ways to move forward in meeting the many grand millennial challenges, the following six global action items are a strategic beginning:

- Appoint an interdisciplinary task force to develop further the 2008 visions and to develop a consensus-building process for an agenda for the medical informatics community.
- Benchmark successes in other markets that will fa-

ilitate the medical informatics community's pursuit of the visions.

- Develop a public-private partnership to create a national blueprint.
- Work with health care agencies and legislatures to ensure that sufficient funds are available for system redesign to enable the visions.
- Develop demonstrations to model the projected 2008 vision, and use these models to help educate opinion leaders about what medical informatics can do to support the visions.
- Support the convergence on standards and coding schemes by accelerating current initiatives.

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