

Consumer Health Informatics: A Consensus Description and Commentary from the American Medical Informatics Association Members

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ABSTRACT:

Background: Although interest in Consumer Health Informatics (CHI) has increased, a consensus definition of CHI does not yet exist.

Purpose: To conduct a hypothesis-generating survey of AMIA members regarding definition and research agenda for CHI.

Methods: We solicited participation among AMIA members in an Internet-based survey focusing on issues related to a definition of CHI.

Results: One hundred thirty-five AMIA members responded. Participants indicated a broad spectrum of topics important to CHI including "self-help for disease management" and "patient access to their own medical records." CHI research was felt to rely heavily on public health methods such as epidemiology and outcomes research, a paradigm shift from traditional medical informatics. Responses indicated a perceived lack of funding and need for further research in CHI.

Conclusions: A working definition should emphasize the multidisciplinary nature of CHI, include consumer input into CHI design, and focus on public health approaches to evaluation.

INTRODUCTION:

Recently, health care professionals have begun to notice the increasing number of patients who use information technology for health education and communication.^{1,2} Emphasis on Consumer Health Informatics (CHI) within the American Medical Informatics Association has continued to strengthen. CHI has been previously defined as the study of "consumer interfaces in health care systems," "the branch of medical informatics that analyzes consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information

systems," or "information supplied to patients using advanced information and communication technologies."²⁻⁴ A keynote panel at the AMIA Spring Congress 2000, "Consumer Informatics Supporting Patients As Co-Producers of Quality," continued to generate expert opinions regarding the definition and scope of Consumer Health Informatics. The increasing interest in CHI may in part be due to the explosion of medical information for patients and consumers on the Internet.⁵

Consumer Health Informatics may be distinct from Medical Informatics in some aspects. First, because of its frequent patient-centered approach, CHI may have an even stronger overlap with public health.^{4,6} In addition, more frequent input from patients and consumers is required in the design of interventions. The AMIA task force on Consumer Health Informatics emphasizes "the changing roles of patients and providers" as an important theme.⁷

To promote the development of CHI within AMIA, the Consumer Health Informatics Working Group has attempted to further clarify the definition of Consumer Health Informatics. During a meeting at the AMIA 2000 Spring symposium, the working group proposed a survey of the AMIA membership. Our purpose for this survey was to solicit hypothesis-generating qualitative and quantitative feedback from AMIA members with interests in CHI to further define the components of CHI. Specific objectives included:

- Identify important components of a description of consumer health informatics.
- Identify important technical expertise related to CHI development and evaluation
- Identify the relative importance of specific issues for a research agenda in CHI.

- Solicit comments on important barriers and facilitating factors related to CHI.

METHODS:

Study Design: A survey was designed by the authors based on presentations at the AMIA 2000 Spring Congress, the medical literature, and discussion within the Consumer Health Informatics Working Group. The survey was pilot tested by physicians at the Johns Hopkins School of Medicine. The instrument was then implemented on the World Wide Web and was beta-tested with the help of a research assistant at the University of California, Los Angeles.

Study Sample and Data Collection: Participants were recruited from within the AMIA membership. In personal communication with others who have surveyed AMIA members, we did not expect a response that would be fully representative of the AMIA membership. (Personal communication, Bonnie Kaplan, PhD. 10/25/00) However, we hoped that by emphasizing the relevance of the survey to Consumer Health Informatics, we would generate responses from AMIA members with specific interest in CHI. A participation request was sent through the "AMIA Alert" listserve to all members. The e-mail request directed members to the Internet-based survey. A reminder was sent one month later.

Survey Content: To describe our respondents, individuals were asked their primary affiliation (academic, industry, government, or other) and their participation in AMIA working groups. In addition, individuals were asked if they had CHI activities (program development, research, education) currently at their institution. To confirm that responses were unique, we asked participants to indicate their e-mail address or their AMIA membership number.

Quantitative questions included:

1. Please indicate topic areas that should be incorporated in a description of CHI.
2. Please rate how important areas of expertise are to the development, implementation, and evaluation of CHI. Ratings were on a Likert scale from 1=very important, 2=unimportant, 3=neutral, 4=important, 5=very important.
3. Please indicate your opinion of the three most important issues to incorporate into CHI research. For questions 1 through 3, a list of potential answers was included with an additional space for "others, please specify."

Semi-structured questions, designed to collect qualitative responses asked what are the most

important facilitating factors and greatest barriers to the development of CHI interventions. Finally, we asked, "Would you recommend that Consumer Health Informatics be considered a separate discipline within Medical Informatics." Possible answers were: (a) no, I would not recommend; (b) yes, somewhat recommend; (c) yes, recommend; (d) yes, strongly recommend.

Analysis: Descriptive statistics of the quantitative questions were summarized. The authors then performed an ethnographic analysis of the open-ended questions to develop common themes. Finally, we used the Fisher's exact test to assess the association of participation in the Consumer Health Informatics Working Group and reported recommendation for CHI to be a subspecialty.

RESULTS:

Characteristics of Respondents: We were successful in recruiting 135 unique responses to the survey from among the AMIA membership. The actual response rate is difficult to assess because we are not sure how many AMIA members actually viewed to participation request. The majority of respondents (50%) were from academic institutions. An additional 15% indicated that their primary affiliation was industry, and 7% were in government. Other affiliations included hospitals, private practice groups, and medical societies.

Members of 16 of the 19 AMIA working groups participated. Nursing Informatics (24%), Consumer Health Informatics (16%), Policy and Organizational Issues (8%), Student (8%), and Internet (7%) were the most common affiliations reported. As expected, many respondents reported a specific interest in CHI. In addition to the high percentage of CHI Working Group members, 50% of participants reported ongoing CHI activities at their institution.

Important topic areas for CHI: Respondents indicated a broad range of topic areas that should be incorporated in a CHI description (Table 1). All but one category was included by over 50% of respondents. The most common topics were general methods for providing and evaluating CHI, patient decision-support, and patient access to their own electronic medical records. The least commonly included were topic areas related to consumer health commerce and social marketing of health communications. Additional comments entered by respondents included "assessment of existing CHI interventions," "Content/structure of patient content

contribution portals into the medical records,” and

“Liability issues.”

	Percent
Methodologies for providing and evaluating consumer health information and education through the application of technology	93
Patient decision support to facilitate self-help for disease management or behavior change	89
Issues related to patient access to their own electronic medical records	81
Outcomes evaluation of strategies involving technology delivery of health care decision support, information, or communication	79
Consumer involvement in designing consumer oriented health information systems.	77
Evaluation of patient-health care provider communication	76
Evaluation of issues related to confidentiality	74
Design of information portals for consumers.	72
Evaluating the quality assessment of CHI.	67
Structured language content tagging for consumer health information.	65
Patient-to-Patient communication for social support	54
Consumer health commerce advertising	51
Social marketing of healthcare communications and health information libraries	47

I. Expertise for CHI:

A broad range of expertise were felt to be important for CHI. Participants were quite inclusive regarding the relative importance of areas of expertise to the development, implementation, and evaluation of Consumer Health Informatics (Table 2).

	Mean Likert Scale Rating*
Health education sciences	4.3
Health sciences (medicine, nursing, public health, etc.)	4.3
Evaluation sciences (health services research, quality assessment, etc.)	4.3
Library sciences	4.0
Computer science	3.9
Medical illustration	3.5

* 1=very unimportant, 2=unimportant, 3=neutral, 4=important, 5=very important

Additional expertise were suggested including “Website usability experts,” “Human-computer interface design,” “Behavioral Science,” and “Consumer Input.”

II. Research Agenda for CHI:

CHI Epidemiology, Needs Assessment and Outcomes research were the most important research issues

identified (Table 3). We defined CHI Epidemiology and Needs Assessment as “understanding who uses the technology, what individuals want, and how they want the information presented” and Outcomes research for CHI as “the impact of CHI on health outcomes including symptom management, behavior change, need for professional visit or other service utilization.”

	%
CHI Epidemiology and Needs Assessment	75
Outcomes research for CHI	64
CHI Quality Assessment/Quality Assurance (evaluating, creating industry standards)	46
Evaluation of Consumer Health Satisfaction (understanding the perceived value of CHI interventions)	44
CHI program design/ implementation	34

Additional issues suggested for inclusion in a CHI research agenda included: “Development of strategies to increase consumers’ information literacy,” “Process--How consumers get to the information--motivation and utilization,” and “CHI knowledge modeling.”

III. Facilitators and Barriers to CHI:

Ninety participants reported facilitators to CHI and ninety-eight reported barriers. The authors identified seven major qualitative themes for potential “facilitators.” Important themes and example comments are listed below. The number of individual comments is listed in parentheses.

- 1) Developing an identity for CHI (24)
- 2) Increasing funding of CHI (13)
- 3) Increasing research and evaluation (11)
- 4) Increasing consumer access / demand (11)
- 5) Increasing multidisciplinary collaboration (5)
- 6) Education and training of health professionals, consumers, and CHI experts (4)
- 7) Maintaining Privacy (3)

Example comments for these themes are:

Theme 1) "Perception of CHI as a valid and important part of medical informatics;" and "Further elevation of CHI as a nationally important activity."

Theme 2) "Continued funding streams for Consumer Health Informatics."

Theme 3) "Establishment of research paradigms that would support assessment of impact on consumer's well-being of CHI information systems."

Theme 4) "Evidence of consumer perception of value;" "Growing access to the Internet;" and "Consumer group lobbying."

Theme 5) "Being able to link, integrate, and have all of the domains and subspecialties communicate and work cooperatively;" and "Collaboration of consumers, health care providers, the insurance industry, and employer groups regarding consumer information needs."

Theme 6) "Education of potential investigators regarding opportunities for research, funding, publication, etc.;" "Education of health care professionals about CHI;" and "Education of students in informatics programs."

Theme 7) "Security and confidentiality issues."

Interestingly, AMIA member "barrier" comments mirrored the facilitating factors. Major "barrier" themes included:

- 1) Lack of funding for CHI (22)
- 2) Lack of a common definition for CHI (21)
- 3) Lack of access for some, Digital Divide (13)
- 4) Lack of quality control /research evidence (6)
- 5) Lack of cooperation and support (5)
- 6) Lack of consumer privacy (3)

The AMIA members also added additional qualitative comments that did not fit directly into the themes above. Unique comments reported under "barriers" are listed below.

- "Fragmentation of resources on the Web... Too many web sites with too little useful information."
- "The field is moving so fast it's hard for evaluators to hit the "moving target."

- "Consumers are being bombarded with information of varying quality which is perhaps in conflict with health care provider recommendations. Leads to confusion as opposed to facilitating informed decision-making."
- "Professionally-centered bias of most Medical Informatics professionals... and their failure to understand that the end-users are now beginning to call the shots."

IV. CHI as a separate discipline:

The majority of respondents indicated that CHI should be considered a separate discipline (Table 4). Overall, only 35% of respondents would not recommend. A stepwise association was seen between participation in the CHI Working Group, and the strength of recommendation that CHI should be a separate discipline, with 25% of CHI working group members strongly recommending, compared with 5% of non-members. (Fisher's exact $p = 0.027$)

Table 4: Would you recommend that Consumer Health Informatics be considered a separate discipline within Medical Informatics?

	Overall (n=127) Percent	CHI-WG Participant?	
		No (n=107) Percent	Yes (n=20) Percent
Yes, Strongly	8	5	25
Yes	18	18	20
Yes, Somewhat	39	40	35
No, I would not recommend	35	37	20

DISCUSSION:

We were successful in recruiting individuals from the AMIA membership; many with specific interest in Consumer Health Informatics, to help us further describe the field. Quantitative questions regarding the topic areas and expertise related reflect the multidisciplinary nature of CHI. Our findings support and expand previous expert opinions of Ferguson and Houston and a clinical review by Eysenbach regarding the broad nature of CHI.^{2,4,5}

We were unable to narrow the definition of CHI by the consensus of our survey. One respondent wrote "It is such a broad area covering all aspects of wellness and illness and numerous variables of teaching and learning strategies." The issue may be whether it is even desirable at this point to narrow the definition. A "working" definition for CHI may be "a

subspecialty of medical informatics which studies from a patient/consumer perspective the use of electronic information and communication to improve medical outcomes and the health care decision-making process.” This working definition adds to previous definitions by emphasizing the patient-centered nature of CHI research, practice and policy.

A narrower consensus was achieved in identifying a research focus for CHI including epidemiology, needs assessment, and outcomes research. The difficulties in evaluating this rapidly changing field and the importance of adapting research paradigms from the public health sciences to CHI were evident within the research theme of our barriers question. The recent report Networking Health: Prescriptions for the Internet, describes CHI as:

“The set of activities aimed at giving consumers a more pronounced role in their own health and health care, ranging from the development of tools for self assessment of health risks and management of chronic diseases, to home based monitoring of health status and delivery of care. This area is similar to public health in that it aims to provide consumers with the information and tools needed to improve their health.”⁶

The focus of our respondents on epidemiology and outcomes assessment within a recommended research agenda reinforces the overlap of CHI and public health. The importance of outcomes research was even stronger among participants in the CHI working group, with 83% of working group members indicating outcomes research as a priority, compared with 62% of non-participants ($p = 0.037$).

As expected, we experienced some self-selection in our survey response with a high percentage of respondents being CHI working group members. CHI working group members ($n=21$) were also more in favor of creating CHI as a separate discipline. Thus, due to this participation bias and the overall low response rate, our results may not be generalizable to the total AMIA membership. Our survey also is weighted toward academic interests and has less input from industry, government, managed care, and consumer perspectives.

In conclusion, we recommend that any further efforts to define Consumer Health Informatics reflect the patient-centered, multidisciplinary nature of this developing field. We also recommend that the leadership of CHI focus on funding and adoption of research techniques from public health and other

disciplines. We hope the commentary summarized in this report will continue to further the development of CHI by stimulating discussion among the AMIA membership. Seventy-three of our respondents have asked to participate in an online forum to continue our discussion of the description and future directions of CHI.

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