A Review of International Consumer Health Informatics Research (Postprint)

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Abstract

[Purpose/Significance] To examine the evolution of consumer health informatics over the past two decades since its inception and propose recommendations based on literature review to provide reference for domestic research in this field.

[Method/Process] Foreign literature on consumer health informatics from recent years was systematically reviewed, investigating and analyzing research articles, review papers, and conference proceedings on relevant topics from four databases: Web of Science, Science Direct, Scopus, and PubMed.

[Results/Conclusion] Although research on consumer health informatics has yielded fruitful results, no consensus on its definition has yet been reached. Future efforts should strive to establish a unified definition of consumer health informatics, while the digital health divide also represents a key priority in this domain.

Full Text

A Review of Overseas Research on Consumer Health Informatics

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Abstract

[Purpose/Significance] This paper analyzes the development of consumer health informatics over the past two decades since its inception and proposes recommendations based on literature review to provide references for domestic research in this field. [**Method/Process**] This study surveys and analyzes recent overseas literature on consumer health informatics, focusing on research papers, review articles, and conference papers from four authoritative databases: Web of Science, ScienceDirect, Scopus, and PubMed. [**Result/Conclusion**] Although research on consumer health informatics has yielded fruitful results, a unified definition of the field has not yet been established. Future research needs to reach consensus on the definition of consumer health informatics, while the digital health divide also represents a key focus area for the field.

Keywords: consumer health informatics; health information literacy; health informatics education; health information service tools
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Introduction

With the advent of the big data era and rapid development of information technology, the general public has increasingly begun using the Internet to obtain health information for self-diagnosis and self-decision-making. Consequently, in the 1990s, patient-centered medical information gradually evolved into an emerging international discipline—Consumer Health Informatics (CHI). A 2014 literature survey showed that in the nearly 20 years since its birth, overseas scholars have published 142 journal articles and reviews addressing consumer health informatics issues. In addition to journal articles and reviews, international academic conferences have comprehensively explored the concepts, development, and challenges facing consumer health informatics [1].

Currently, many developed countries—including the United States, United Kingdom, Canada, Germany, and France—have produced extensive research on consumer health informatics. This paper examines 123 of the most relevant documents, covering four major research themes: definitions of consumer health informatics, consumer health information literacy, consumer health informatics education, and consumer health informatics tools. This review synthesizes these themes and proposes future research directions for the field to inform domestic research in China. Some Chinese scholars have introduced and studied consumer health informatics, primarily through academic reports and articles promoting the current status and vision of consumer health informatics in developed European and American countries [3-7].

The authors searched four authoritative databases (Web of Science, ScienceDirect, Scopus, and PubMed) using keywords including "Health Information," "Health Informatics," "Medical Informatics," "Consumer Health Information," and "Consumer Health Informatics," retrieving 411, 351, 376, and 452 relevant papers respectively. After manually screening titles and abstracts and removing duplicates, 123 articles were selected for analysis.

1. Definition of Consumer Health Informatics

1.1 Interpretation of Existing Definitions 1.1.1 Emphasis on Information Technology Scientific progress always builds upon previous achievements, and consumer health informatics emerged based on information technology [8]. Therefore, in the 1990s, most definitions of consumer health informatics resembled "using computer and communication technologies to support users in obtaining health information and helping them make relevant healthcare decisions."

Literature surveys reveal that the concept of consumer health informatics was first proposed by Dr. Ferguson from Harvard Medical School in 1995. In his paper "Consumer Health Informatics," he defined it as "the study, development, and application of computer and wireless communication technologies to establish interfaces for healthcare users" [9]. However, some scholars argue that Canadian scholar Thornton first introduced the CHI concept in 1994 at the Fifth International Health Informatics Association Workshop on Health/Medical Informatics Education, outlining CHI development directions such as health information Internet construction, automated patient records, health decision-making, and public health education [10]. The U.S. General Accounting Office also stated that "CHI is the integration of all healthcare disciplines that meet modern technological progress and development" [11]. Rhodes defined consumer informatics as "using computers to support consumers in accessing information, analyzing unique care needs, and helping make decisions about medical care and health promotion" [12].

1.1.2 Emphasis on Multidisciplinarity Consumer health informatics is an interdisciplinary field encompassing medical informatics, nursing informatics, social care, public health, health promotion, health education, and communication science [13]. Members of the American Medical Informatics Association also agree that CHI definitions should emphasize the field's multidisciplinary nature [14]. Notably, many published articles have identified the multidisciplinary nature of CHI but have not specifically delineated the contributing disciplines. Some scholars suggest that neglecting key contributing fields may hinder consensus on definitions [15-16].

A representative definition comes from Dr. G. Eysenbach, who pioneered the definition of CHI as "a branch of medical informatics that analyzes consumers' health information needs and changes, studies methods for consumers to access health information, establishes health information demand models, and integrates consumer perspectives and needs into medical information systems." This definition clearly identifies CHI as an applied interdisciplinary field intersecting with information science, cognitive science, education, sociology, behavioral medicine, and other disciplines [17]. As a founder and leading figure in the field who has published numerous influential articles and serves as editor-in-chief of the Journal of Medical Internet Research, Eysenbach's definition has gained widespread acceptance and has promoted further CHI development. However, his description of contributing disciplines omits other key areas such as software engineering, graphic design, and communication studies, which are also potential important contributors and components of consumer health informatics [18].

1.1.3 Emphasis on Personalization A crucial distinction between CHI and Public Health Informatics (PHI) is that PHI focuses on the public rather than individual consumers, whereas CHI should emphasize personalized consumer needs [19]. Without the “personalization” label, CHI would lose its meaning. Therefore, many scholars emphasize consumer-centered definitions. For example, D. Gustafson et al. stress that CHI should include consumer-centered, interactive computer-based programs that provide personalized health information and health decision-making [20]. The American Medical Informatics Association defines CHI as “the study of electronic information and communication technology applications from the consumer or patient perspective to improve medical outcomes and healthcare decision-making processes.” The American Medical Library Association also defines CHI from the consumer perspective as “health and medical information related to the public, patients, and their families” [21]. J. Arocha and L. Hoffman-Goetz believe the focus of consumer health informatics is analyzing consumer information needs, researching methods for consumer access to information, incorporating consumer health needs into information systems [22]. Dr. A. Amy from the University of Washington defines CHI as: (1) any electronic tool, technology, or system designed to interact with consumers; (2) customized personalized health information or medical advice; (3) requiring collaboration between consumers and healthcare professionals; and (4) disease management, lifestyle management, daily life tracking, self-care, and nursing [23].

1.2 Reasons for Disagreement on CHI Definitions Literature surveys show that researchers and professionals in the CHI field have not reached consensus on its definition. The authors identify at least two reasons:

(1) **CHI is a multidisciplinary field** where nursing informatics, public health, health promotion, health education, library science, and information science all play roles in its application and services. Reaching a consensus definition across so many disciplines is challenging because researchers and practitioners from each field view CHI from their own perspectives [24].

(2) **CHI is a technology-based field** where rapid technological changes make it difficult to define. The fast development of CHI and technology may overturn researchers’ previous ideas and concepts, making CHI a continuously evolving dynamic discipline [25].

Fundamentally, CHI aims to provide consumers with relevant, accurate, and accessible health information to enable them to make informed health decisions independently. Another potential goal is to promote patient empowerment and reduce uncertainty when consumers discuss health issues with physicians, as informed consumers become informed patients, potentially improving doctor-patient relationships—for example, physicians may spend less time explaining health problems or discussing treatment options [26].

2. Research Areas in Consumer Health Informatics

The International Medical Informatics Association (IMIA) considers CHI a branch of medical informatics that helps bridge the gap between patients and health information resources [27]. The American Medical Informatics Association (AMIA) believes CHI should focus on patient-centered health literacy and consumer education, using Internet-based strategies and health information resources to enable patients to manage their own health [28]. H. Edward and J. James mention in their book *Computers in Healthcare and Biomedicine* that CHI must focus on the primary technologies consumers use to access health information [29].

Based on the literature review and analysis, beyond definitional studies, the authors believe CHI research concentrates on consumer health information literacy, health informatics education, and consumer health information service tools. These research areas complement each other and jointly reveal the application process of consumer health informatics.

2.1 Consumer Health Information Literacy S. Ratzan and R. Parker define health information literacy as "the ability of individuals to obtain, process, and understand basic health information needed to make health decisions" [30]. In the modern health information environment, even in North America—the region with the highest Internet usage—many people lack the skills to effectively participate in online healthcare. The level of health information literacy determines the degree of health information utilization. For example, when receiving the same information, individuals with higher education and socioeconomic status may access information more quickly.

2.1.1 Importance of Consumer Health Information Literacy CHI primarily serves consumers through computer network systems. While CHI applications enable consumers to obtain needed health information through health information platforms for self-diagnosis and self-decision-making, this assumes consumers possess adequate health information literacy and information processing capabilities. Scholars such as L. Thomas argue that individuals with low health information literacy cannot benefit from advances in consumer health informatics and network medicine because they lack access to and understanding of these technologies [31]. B. Nton and R. Nelson further explored the interrelationships among computer literacy, information literacy, health information literacy, and health literacy [32]. C. Michael et al., through systematic evaluation of existing health information tools, identified barriers affecting consumer use, such as lack of literacy, computer skills, information evaluation, and access capabilities. They noted that individuals with computer anxiety, limited contact with clinicians, and skepticism that health IT would improve health cannot benefit from these tools [33]. Therefore, healthcare professionals must consider potential real-world barriers in their consumer-facing Web applications to ensure accessibility for those with low health information literacy.

2.1.2 Core Skills Comprising Consumer Health Information Literacy Through content analysis, the authors identify six core skills: literacy, health literacy, information literacy, media literacy, computer literacy, and scientific literacy. Literacy is the most basic skill, including the ability to read health information, understand written meaning, and correctly speak and write a language [34]. Information literacy refers to consumers' and healthcare providers' ability to effectively organize, locate, and utilize health information [35]. Media literacy is the ability to critically accept and think about health information media content and make correct health choices through learning and reflection [36]. Health literacy refers to consumers' ability to appropriately make self-health decisions through interaction with health information tools or systems [37]. Computer literacy is the ability to use and adapt to computer technology and software to retrieve and access health information resources [38]. Scientific literacy means consumers fully understand the health research process, enrich their scientific experience, and effectively utilize science-based online health information to avoid incorrect medical decisions [39].

2.2 Consumer Health Informatics Education Current research shows that consumer health informatics education targets both consumers and healthcare professionals, with educational methods differing from traditional health education—for example, using information technology for online education instead of traditional face-to-face training.

2.2.1 Consumer Health Education Consumer health education cultivates consumers' ability to obtain correct health information and understand medical processes, helping them establish health concepts to make the wisest health decisions [40]. Current research indicates that due to limited ability to read and understand health information, most consumers can only passively accept information and may misinterpret it during utilization. Therefore, many scholars attempt to help patients with low health information literacy through enhanced doctor-patient communication, enabling patients to actively trust, understand, and participate in health decision-making processes through effective communication and exchange.

For example, German scholar M. Marschollek, through extensive research on CHI applications, found that intelligent tutoring technology based on natural language dialogue can improve the performance of consumer information retrieval systems and developed health education systems specifically for consumers and health professionals to help them understand difficult medical terminology [41-42]. South African scholars N. Mbananga and S. Mnikhi proposed a method for developing medical terminology in indigenous languages for consumer health education, encouraging consumers to participate in disease treatment and self-health management [43]. S. Wolpin et al. proposed using audio annotations in speech engines to supplement text content and create virtual agent readers to help vulnerable groups access health information [44]. J. Fabric et al. believe that empowering patients through appropriate consumer education can enhance consumer autonomy and encourage them to become medical partners [45].

2.2.2 Consumer Health Informatics Curriculum Foreign medical schools have launched consumer health informatics courses to train healthcare professionals in this emerging field. Foreign health information service platforms involve researchers with dual expertise in medicine and informatics throughout the design, construction, and operation processes.

The Canadian Association of Schools of Nursing and the Canadian Health Information Center have integrated consumer digital health solutions into undergraduate nursing education programs in Canada [46]. J. Arocha surveyed public health and consumer health informatics programs and courses in all Canadian universities and colleges, calling for consideration of skills and information literacy training for health professionals and patients in health informatics education [22]. The University of Manchester Medical School's consumer health informatics curriculum focuses on the impact of digital environment development on practical medical services and explores how to construct health information resources suitable for user needs [5]. Similarly, P. Staccini et al., by investigating existing telemedicine systems, emphasized the importance of training clinicians to guide patients in using telemedicine systems and adopting personal health records (PHRs) [47].

Core courses in consumer health informatics include: consumer care under the Internet, electronic medical records, information systems analysis and design, and information literacy. Undergraduate programs focus on foundational health informatics disciplines, where students learn disease prevention or medical insurance by developing and utilizing medical databases, with most courses requiring internships. Master's programs focus on how data systems collaborate with healthcare delivery systems, studying how to collect and manage consumer health information and learning how to optimize service processes to improve the overall medical experience.

2.3 Consumer Health Informatics Tools The primary purpose of CHI research is to use relevant technologies to develop information systems, tools, or other software that assist consumers in health decision-making, providing appropriate disease treatment and healthcare information. Johns Hopkins University defines consumer health information service tools as: any electronic tool, technology, or application software that interacts with consumers, provides customized or personalized information and health assistance tools, and helps consumers better manage their own health, with or without physician involvement [48].

2.3.1 Development of Consumer Health Informatics Tools Consumer health informatics aims to improve various diseases and health conditions by providing individuals with customized information applications (or electronic tools, systems, or technologies) [49].

In the 1990s, consumer health informatics tools primarily referred to consumer health information systems, created through two basic approaches: The first approach created health information systems that met needs. As early as 1989, the University of Wisconsin Health Research and Analysis Center conducted needs assessments among hundreds of patients and family members, establishing CHESS (Comprehensive Health Enhancement Support System), which provided information services, communication services, expert analysis, and logging to help AIDS, cancer, and coronary heart disease patients [50]. In the same year, P. Brennan et al. designed ComputerLink software to promote patient self-care and information exchange with healthcare providers through special computer services [51].

The second approach modified existing medical information systems that served physicians. For example, in 1998, O. Bouthaddou, S. Miller et al. proposed the HouseCall system, which constructed patient information systems from existing medical knowledge bases [52], aiming to improve doctor-patient communication and empower patients. However, at that time, most consumer health information tool research focused on specific medical patients (such as diabetes or AIDS patients), rarely addressing the health needs of general consumers (including healthy individuals).

Over the past 20 years, more professionals have researched and created innovative applications for consumers, popularizing the term "consumer health information tools." Personal Health Records (PHR) and Electronic Health Records (EHR), as key technologies and research hotspots in this field, have received continuous attention from researchers [53]. The population using PHRs in New York grew rapidly between 2012-2013 [54]. Software companies dedicated to improving public health also emerged during this period, such as Keas, which developed online health assistants providing important health advice and insurance information, and supporting consumers in preventing and managing lifestyle-related chronic diseases [23].

Most current consumer health information tools can be customized for consumers (considering target user needs, operational barriers, and preference requirements). For example, K. Alla and L. Robbert explored measures to solve patient electronic health communication barriers, arguing for personalized health information solutions based on consumer health information needs [55]. R. Misra, J. Mark et al. developed consumer-centered decision aids to customize "healthy lifestyles" for consumers, helping them understand behavioral risks to reduce cardiovascular disease risk [56]. Korean scholar M. Jung identified the key process for designing consumer health information tools as: first empowering consumers, then promoting self-management of disease and health to create resonance between healthcare providers and medical staff, and finally customizing personalized health information to prevent confusion or inappropriate decisions caused by excessive information [57].

2.3.2 Functional Evaluation of Consumer Health Informatics Tools With rapid information technology development, increasing numbers of CHI service tools have emerged. Whether these tools can effectively improve consumer health requires empirical research by professionals.

Consumer health information service tools can be classified into five categories based on functional characteristics: (1) Information assistance tools, providing consumers with functions to access, store, control, and disseminate personal health information [58]; (2) Decision assistance tools, customizing personal health information to help people make wise healthcare decisions [59]; (3) Education assistance tools, typically for improving consumer health literacy [60]; (4) Management assistance tools, supporting consumers' long-term chronic condition management, characterized by support group services and subscription information services [61]; (5) Rating service tools, enabling consumers to rank and share information about healthcare providers, treatment quality, interventions, consumer health applications, websites, or any other aspects of interest [62].

Current literature shows that empirical research on CHI service tool functionality primarily focuses on whether these tools can effectively improve patients' quality of life, disease management, and health needs. However, few studies evaluate CHI tool functions from perspectives such as doctor-patient relationships or patient economic impact [63]. Regarding research objects, most scholars focus on computer information systems, health information websites, and health education websites, with fewer assessments of health risks in social media [48]. Regarding study populations, few scholars research Asian Americans or Asians, with most studies focusing on Caucasians [64].

2.3.3 Cultural Factors Affecting Consumer Health Informatics Tool Design Although consumers can search for online health information globally, cultural differences mean that people with different cultural customs and values obtain information through different channels and methods, and evaluate and utilize information differently. Research shows that consumer health information tools capturing the potential richness and complexity of consumers' cultural backgrounds will achieve better performance [65].

These studies aim to understand cultural contexts from the consumer perspective, including race, ethnicity, nationality, religion, and socioeconomic status. However, most research has limited itself to mapping consumer health information tool solutions or attributes to certain cultural backgrounds, with few scholars advocating embedding consumer health informatics into the individual needs of multicultural environments [66]. For example, M. Anne and G. Judith, considering that cultural differences may affect the design and use of health information systems or tools, identified cross-cultural factors needing consideration to tailor health information tools for users and promote normal use of new health systems in different international contexts [67-70]. H. Song, J. Kim et al. found cultural differences in online health information search patterns, particularly regarding perceptions of online health information sources. For instance, compared to Americans, Koreans and Hong Kong Chinese are more likely to trust and use experience-based health information shared on social networking sites, while Americans value physicians' expertise more [71].

3. Future Research Trends in CHI

Numerous documents have extensively examined CHI definitions, empirical research, application tools, and patient health information education from various perspectives. However, to truly improve consumers' healthcare quality through CHI applications, the authors believe two issues require urgent resolution or full recognition:

3.1 Consistency in CHI Definitions In 2015, Canada's D. Flaherty et al. systematically evaluated published CHI definitions, concluding that CHI is an evolving multi-attribute discipline without unified conceptual standards at this stage [72]. The authors identify two reasons why CHI definition should be a future research priority:

(1) **A unified CHI definition drives development and progress in the field.** J. Arocha et al. note that given CHI's rapid development and disciplinary diversity, researchers must clarify what CHI covers to distinguish it from other informatics specialties [22]. T. Houston et al. surveyed AMIA members about CHI research topics and found these topics lacked clear definition [15]. D. Flaherty also pointed out that CHI's definition depends on professionals' clear understanding of its development mechanisms, and without a consistent definition, CHI cannot address client-centered health decision-making problems [73-74].

(2) **A consistent CHI definition can help professionals develop core competencies.** J. Arocha and L. Hoffman-Goetz note that the lack of a CHI core curriculum may relate to lack of clarity about what knowledge best suits CHI professionals and how to develop CHI development plans [15, 75]. For example, S. Fox et al. indicate that without a clear field definition, it may be difficult to cultivate core competencies for consumer health information professionals [15, 76-78]. The U.S. Centers for Disease Control and Prevention state that without agreement on disciplinary composition, it is difficult to reach consensus on core competencies and specific skills for medical and public health informaticians, and that clear definitions are the starting point for developing these core competencies [75].

3.2 The Digital Health Divide To date, existing literature lacks empirical research on the digital health divide between older adults and other adults. Although Internet usage among older adults continues to increase, the digital divide between them and other new media users persists, yet these individuals may be those who most need to benefit from CHI applications. The digital divide is defined as the gap between those with access to information and communication technologies and those without. The gap between those who can access and use health information technology and those who cannot is called the digital health divide [79].

Numerous factors cause the digital health divide. Surveys show that 26% of American adults lack Internet access, and these individuals generally have low income, are older, and live in rural areas—yet these are the people who may most need medical assistance. How to overcome these inequalities in digital resource utilization is an urgent problem [80]. Q. Moore et al. state that only people with stable income who can access digital health technology have opportunities to improve their health quality. For example, low-income diabetics may not afford technology or tools to improve blood glucose control. He emphasizes the need to understand the size of the divide to learn how to narrow it, calling on product developers to design low-cost health devices that could help more patients with chronic disease treatment and reduce the digital health gap [81]. A. Hall et al.'s 2015 empirical study demonstrated the existence of digital health differences among older adults and between users, arguing that with rapid health information technology development, research on the digital divide must receive increasing attention and effort to better understand and address it, preventing unlimited expansion of the digital health divide that could hinder older adults from benefiting from these technologies [82]. Measures must be taken to eliminate the digital divide; otherwise, older adults or others may not fully benefit from health information technology. For example, when designing consumer health information tools, consideration should be given to whether new tools will isolate populations with low health literacy, limited technical resources, and financial constraints, preventing expansion of the existing digital health divide [83].

Conclusion

Through this literature review, the authors found that most research focuses on consumer informatics technology and empirical studies. While some scholars are actively exploring theoretical definitions of this new discipline, existing research still has gaps in certain areas. For example, the discipline's theoretical framework model has not yet formed, and most technical research remains limited to specific medical patients (such as diabetes or AIDS patients) without addressing health and sub-health populations' health needs, potential personal economic impacts, or digital health divide issues. Future research should integrate theory with practical technology, consider every ordinary person globally as research subjects, and establish universal disciplinary models.

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Tang Feng: Collected literature, wrote and revised the manuscript.
Fang Xiangming: Conceived the topic, proposed research ideas, framework, and provided guidance and revision.

Note: Figure translations are in progress. See original paper for figures.