CONSUMER HEALTH INFORMATICS

Abstract

Author

Consumer Health Informatics (CHI) is an emerging area of study within the broader discipline of biomedical and health informatics. Consumers are increasingly turning to the internet for health-related information due to the rapid advancement of computers and information technology for health decision making and CHI has drawn the interest of more academics. CHI focuses on the analysis of consumers' information requirements, the creation of consumeraccessible information tools. and the facilitation of self-management promotion. The emergence of the concept of CHI is attributable to the patients' desire to assume responsibility for their own healthcare and to cultivate healthy habits, as well as the physicians' recognition of the patient's potential and commitment to educating them about their healthcare needs. The field of CHI is of utmost importance due to its significant contribution in providing valuable information to patients and consumers. This, in turn, facilitates the promotion of self-care, enables informed decision-making, encourages the adoption of healthy behaviours, and facilitates the exchange of information among peers.

Keywords: Informatics, Consumers, Health Informatics, Consumer Health Informatics, Electronic Health Records.

Dr. Rumi Deori

Professor & Head Department of Biochemistry Lakhimpur Medical College & Hospital North Lakhimpur, Assam, India. rumideori@rediffmail.com

Dr. Kumud Bordoloi

Senior Vice President Head- Accident & Health Underwriting Peak Reinsurance Company Ltd Kowloon, Hong Kong.

Mittul Mishra

Architect Montefiore Hospital Bronx, New York.

Dr. Bedanta Bhuyan

Consultant Pathologist and Managing Partner Bharat Laboratory Dibrugarh, Assam, India.

I. INTRODUCTION

With the fast-changing landscape of information technology (IT), the use of technology and the internet by humans has grown exponentially. Even health isn't spared from this trend. Consumers are increasingly turning to the internet for health-related information, and they prefer quick, concise answers to their questions rather than having to go through lists of articles given by search engines and read each one individually. As people learn more about the possibilities of information and communication technology, healthcare services are changed to meet the health needs of consumers.

Since 1965, the Consumer Health Informatics (CHI) has been a topic of conversation; however, it wasn't until Gustafson and his colleagues from the University of Wisconsin made a conference presentation in the 1990s titled "Consumer Health Informatics: Bringing the Patient Into the Loop" (CHI: Bringing the Patient Into the Loop), that the topic really took off. Warner Slack and Tom Ferguson conducted a half-day tutorial with the same title at the American Medical Informatics Association Annual Meeting in Washington DC later that year [1] The experts are confident that these new methods will become an essential component of our ongoing drive to reinvent health care by transforming individuals into providers and delivering individualized health information at the press of a button.

Eysenbach, defines consumer health informatics (CHI) as the branch of health informatics that analyses consumers' information needs, implements methods of making information accessible to consumers, and models and integrates consumers' preferences into medical information systems, making it one of the most challenging and rapidly expanding fields in health informatics [2]. The American Medical Informatics Association (AMIA) defines CHI as a subspecialty in medical informatics that examines the use of electronic information and communication from a patient/consumer perspective to improve medical outcomes and the healthcare decision making process [3].

In the field of medical informatics, CHI is arguably the most difficult and challenging discipline, but it is also one of the fastest growing; it is establishing the foundation for healthcare in the digital age. This expanding field is touted as the most effective application of information technology (IT) to enhance patient-centred healthcare delivery. Additionally, CHI supports healthcare services by assisting patients in providing and serving patients in a positive manner, emphasizing prevention, self-management, and giving consumers access to the technology and information they need to manage their health and lead healthy lifestyles [4-8]. CHI encompasses essential information systems insights and other disciplines, including nursing informatics, public health, information systems, psychology, health promotion, health education, library science, and communication science, among others [9].

A new generation of savvy computer-literature consumers is gradually redefining the doctor-patient relationship. The establishment of electronic health records that can be accessed via the internet is one of the most revolutionary advances towards the empowerment of consumers. The COVID epidemic was also largely responsible for driving consumer adoption of telehealth as a means of accessing healthcare. This was then helped and made even better when smartphones, social media, and personal tools came out and became more popular.

With growing number of consumers using the internet to access health-related information and internet of things (IoTs), and CHI has drawn the interest of more academics as a result of the quick growth of computer and information technology for health decision making. As a result of this trend, healthcare consumers are becoming more eager to actively participate in healthcare systems and have a greater desire for health information, which increases the demand for health information technologies to help patients and consumers obtain more information. By fully utilizing the patient's and their family's capacity for self-help, this has the potential to both improve the quality of patient treatment and save expenses [8].

II. CONSUMER HEALTH INFORMATICS

As the recognition of the importance of individuals' active involvement in healthcare is increasing, there is a corresponding demand from consumers for consumer health resources that are both effective and easily understandable [10]. Consumer health informatics has the capacity to offer frameworks and strategies for the development of efficient health information communication tools that empower individuals and enhance their decisionmaking in healthcare.

In order to have a deeper understanding of CHI, we will now explain, step by step, the numerous components that make up CHI. The components are Informatics, Health informatics and then Consumer Health Informatics.

- **1. Informatics:** Informatics also known as the "science of information," is the study of the operation and structure of any system that creates, saves, processes, and then presents information.
- 2. Health Informatics: Health informatics is the study and observation of information acquisition, storage, analysis, retrieval, and dissemination. The utilization of information technology within healthcare environments is an additional domain of focus within the field of health informatics. Health informatics considerably improves the quality of the healthcare system and the communication between patients and their healthcare providers.

Health informatics is critical for the healthcare industry and its customers. For tracking health information and health issues, the healthcare industries have created technologies and a variety of programs (applications) for devices (mobile and smartphones). Apps are available to track exercise, dietary intake, taking the proper medicine at the right time, and so on. Health informatics facilitates information sharing between patients and their healthcare providers.

3. Consumer Health Informatics: CHI is a subfield of health informatics that uses information and communication technologies to assist patients and the general public in gathering health-related information and enhancing health education in order to manage and take care of their own health [11]. The emphasis is transferred from problem resolution to consumers' comprehension of the nature of the problems and the availability of multiple solutions to resolve them.

The consumer within the domain of health informatics encompasses both the individual seeking healthcare services (i.e., the patient) and the healthcare professional providing those services.

III. CONSUMER HEALTH INFORMATICS TOOLS AND TECHNOLOGIES

The integration of consumer health informatics and information technology into contemporary public health practice is gaining importance. New consumer health information technology applications are being developed for mobile phones, messaging systems, email, and the internet [3].

Consumer health informatics tools and technologies include the development of telehealth solutions utilizing data from clinical trials and in-home monitoring, the creation of electronic health records (EHRs), personal health records (PHRs), and patient portals, as well as the development of technically advanced mobile and smartphone applications, instruments that facilitate the delivery of high-quality healthcare to patients/consumers [12-18]. The various consumer health informatics tools and technologies are described below:

- 1. Home Monitoring: There are two different kinds of home monitoring that can be done from home: active monitoring and passive monitoring. Active monitoring occurs when patients are trained to use specific health information technology solutions that the patient is expected to begin as per the professional instructions of a healthcare provider. This type of monitoring is known as patient-initiated care (PIC). Installing an automated infrastructure within the patients' home environment to watch and monitor certain actions is an example of passive monitoring. The patient does not need to initiate any interaction with the health information technology solution in order for the patient to benefit from this type of monitoring [18].
- 2. Personal Health Records (PHRs): Personal health records, often known as PHRs, are a type of consumer technology that are thought to be useful in the process of sharing, tracking, and managing the personal health information of patients [3]. PHR is the compilation of an individual's medical data that is kept up to date either by the individual themselves or, in the event that the patient is unable to do so on their own, by a caregiver [19]. Patients can store electronic copies of information that they have received from their physicians in their personal health records[20].
- **3.** Electronic Health Records (EHRs): Electronic health records, also known as EHRs, make it possible for authorized healthcare professionals to exchange patient information with one another. A patient should be able to enter any health care environment, obtain authorisation, and then talk with a clinician who has ready access to the patient's complete health information after entering the facility. Electronic health records (EHRs) should be securely linked over the internet and should be integrated smoothly with medical information for the education of both healthcare providers and patients [21].
- **4. Patient Portals:** Over the past two decades, there has been a growing trend among healthcare organizations to incorporate patient portals into their electronic health record systems. Patient portals provide patients with the ability to access specific health information from their healthcare organization's electronic health record (EHR). This

includes details such as medications, laboratory results, immunization records, allergies, and discharge summaries. Patient portals have the potential to enhance patient-provider interactions, thereby facilitate shared decision-making and patient engagement. Consequently, these portals can contribute to improved communication and increased satisfaction with healthcare services [21,22].

5. Smartphones Applications: Applications designed for smartphones have made it possible to retrieve a great deal of information on one's health in an effective manner and in a very short amount of time. Prior to opting to make an appointment with a medical professional, customers have regular access to health information on the internet through their smartphones, and they exhibit interest in applications that offer advice and provide information [23].

In the systems that are in use today, there are two different ways that data can be produced: either the user enters the information into a specific interface on their smartphone or tablet (for example, the Health apps on an iPhone or android phone, which includes dozens of parameters); or the data are harvested automatically by onboard sensors, with the results being compared to a "standard benchmarks," or at least to a socalled optimal state, or else to track the data over time. Certain programs will also make recommendations for remedial actions, with the goal of assisting the user in modifying their behaviour in order to more closely comply to the standard that has been created.

6. Telehealth and Telemedicine: Telehealth and telemedicine assist in delivering healthcare services from healthcare providers to patients in remote locations via the internet, without the patient having to visit the doctor's clinic. Telehealth is a method of delivering healthcare that expands access to health care services and may facilitate and support patient-centred care. With the aid of information technologies and telecommunications devices, telehealth facilitates the delivery of healthcare outside of the traditional in-person medical encounter. A patient receiving care via telehealth may receive a combination of a medical history, a modified physical examination, diagnostic testing, an evaluation, and management. Active decision-making and medical care may be provided synchronously (real-time face-to-face interaction) or asynchronously (communication between a patient and provider occurs at various times) [24].

Telehealth has a favourable effect on consumer health conditions, especially in isolated places far from medical facilities. With the aid of communication and electronic information technology, telemedicine refers to a range of medical services. It comprises a wide range of applications, such as remote physical and mental health rehabilitation, telehealth nursing, and online patient consultations. By streamlining clinical processes and reducing hospital travel costs, it is affordable for both doctors and patients. Telemedicine can effectively manage some non-emergent conditions and the follow-up of instances that have already been treated. Telemedicine enhances the quality of medical practice because it enables physicians to devote less time to the treatment of patients whose conditions do not require immediate attention. As a result, they are able to devote more time and attention to the treatment of patients whose conditions do require immediate attention, as well as to the improvement of health care facilities. Additionally, it enables medical professionals to access patient information in a more expedient and effective manner through the use of electronic files and patient portals [25-27].

7. Self-Management Systems: Self-management systems encompass a diverse range of functionalities that leverage multiple platforms to provide timely and efficient responses to user-generated information pertaining to their current status. The provision of feedback to patients regarding their health status can be contingent upon the design of the system, with the possibility of receiving such feedback either directly from the system or through the healthcare provider who obtains the information from the system. The implementation of comprehensive health informatics (CHI) tools, specifically designed for self-management systems, facilitates the transfer of care responsibilities from healthcare providers to patients. This transfer empowers patients to actively participate as genuine partners in the care process. Consequently, healthcare providers are able to allocate their attention towards the treatment of more severe and critical health conditions[23].

IV. BENEFITS OF CHI

The utilization of Consumer Health Informatics (CHI) tools can yield advantages for both patients and healthcare providers[28]. The level of trust and confidence experienced by both patients and physicians exhibits a significant increase. Consumer health information technology (IT) applications enable the collection and integration of data from diverse healthcare sources, thereby functioning as a comprehensive repository of information for patients and their healthcare providers. The utilization of CHI tools holds great importance in emergency situations as they facilitate the dissemination of crucial health information to healthcare professionals. Additionally, the utilization of messaging or smartphone applications could facilitate prompt and efficient communication between patients and healthcare providers, thereby aiding in timely interactions [23,29].

The utilization of Electronic Health Records (EHRs) plays a crucial role in mitigating medical errors, minimizing the occurrence of misplaced or duplicated paperwork, and facilitating the process of reimbursement [21]. Another advantage of CHI is that it improves the effectiveness of health education-based approaches by adapting them to the audience's specific needs, incorporating multiple dimensions, and placing an emphasis on practicality. It also improves the efficiency of comprehensive assessment by using adaptive testing techniques [30].

V. ETHICAL ISSUES OF CONSUMER HEALTH INFORMATICS

Many individuals who are seeking health information frequently utilize the internet as a means of gathering relevant data. The utilization of computers and the internet has witnessed a notable surge among both healthcare providers and patients, primarily driven by the widespread adoption of digital medical record systems in healthcare institutions. Ensuring the confidentiality of patient medical information and safeguarding patient privacy pose significant challenges due to the widespread accessibility of medical records among healthcare providers, information technology personnel, insurance personnel, government entities, coders, managers, and patients themselves [31,32].

Although health as a subject is essential and the stakes are significant, patients/consumers are not qualified to evaluate value and safeguard themselves. Due to the vast number of Web sites and the dynamic nature of Web content, it is difficult for experts to regulate and verify web content, despite the fact that almost anyone can create a website

quickly and affordably. Moreover, technologies are continuously evolving, producing new capabilities with additional ethical implications. It is challenging for users to evaluate the calibre of health information accessible on websites due to the low cost and low technical requirements for website development. Additionally, it is easy to make the website look very expert and equal to those of well-known companies. It is ethically required of health website designers to present accurate and current information.

Consumer health informatics is a progressively significant facet of the computerization of health practice and communication. Similar to other areas, it necessitates thorough ethical analysis and scrutiny.

VI. CONCLUSION

Patients have become active consumers of health-related information. In addition, they are encouraged to take a more active role in obtaining medical information, managing their health requirements and medical care, and participate in medical care decision-making. The application of consumer health informatics (CHI) can provide patients/consumers with information, promote self-care, cultivate healthy behaviours, facilitate informed decisionmaking, and promote peer information exchange and social support. The use of CHI tools such as electronic health records (EHRs), personal health records (PHRs), home monitoring, patient portals, telemedicine, and smartphone applications, facilitates the delivery of highquality healthcare to patients. Numerous health-related websites are accessible to consumers, but their content is not always reliable. Ethical issues may arise from the perspectives of patients, healthcare providers, Web site developers, programmers, and information and communication technology (ICT) personnel. The dynamic character of Web site developers and ICT development presents ethicists and stakeholders in this field with ongoing new challenges. Developers of ICT and Health websites bear an ethical obligation to effectively communicate precise and up-to-date information to patients and the general public. Additionally, they must rigorously uphold the principles of confidentiality and patient privacy.

REFERENCES

- [1] Demiris G. Consumer Health Informatics: Past, Present, and Future of a Rapidly Evolving Domain. Yearb Med Inform 2016;Suppl 1:S42-7
- [2] Eysenbach G. Consumer health informatics. BMJ. 2000 Jun 24;320(7251):1713-6. doi: 10.1136/bmj.320.7251.1713.
- [3] Abaidoo B, Larweh B T. Consumer Health Informatics: The Application of ICT in Improving Patient-Provider Partnership for a Better Health Care. Online Journal of Public Health Informatics. 2014; 6(2): e188
- [4] Wickramasinghe N, Goldberg S. How M = EC2 in Healthcare. *International Journal of Mobile Communications*. 2004;2(02):140–56.
- [5] Wickramasinghe N, Troshani I, Tan J. Contemporary Consumer Health Informatics. New York: Springer; 2017. ISBN-13: 978-3319259710
- [6] Geisler E, Wickramasinghe N. The Role and Use of Wireless Technology in the Management and Monitoring of Chronic Diseases. Washington D.C.; 2005
- [7] Wickramasinghe N, Goldberg S, Bali R. Enabling Superior M-health Project Success: A tri-Country Validation. *International Journal of Services and Standards*. 2008;4(01):97–117.
- [8] Eysenbach Design and evaluation of consumer health information web sites. Lewis, et al., editors. Consumer Health Informatics. 2005: 34-60.
- [9] Linda A. W-M, Pat S. B, Joseph M H, Goldstein M, Hill T, Nisbet R, Walton N, Miner G D. Practical Predictive Analytics and Decisioning Systems for Medicine. Book 2015. Elsevier

- [10] Keselman A, Logan R, Smith CA, Leroy G, Zeng-Treitler Q. Developing informatics tools and strategies for consumer-centered health communication. J Am Med Inform Assoc. 2008 Jul-Aug;15(4):473-83.
- [11] Wilson L.S., Maeder A.J. Recent directions in telemedicine: review of trends in research and practice. *Healthcare informatics research*. 2015 Oct;21(4):213.
- [12] Gustafson D H, Hawkins R P, Boberg E W, McTavish F, Owens B, Wise Met al. CHESS: 10 years of research and development in consumer health informatics for broad populations, including the underservedIn:Consumer Health Informatics New York, NY: Springer; 2005239–47.
- [13] Ho J. Consumer health informatics. Stud Health Technol Inform. 2010;151:185–94.
- [14] Lewis D, Chang B L, Friedman C P. Consumer health informaticsIn : Consumer Health Informatics New York, NY: Springer; 20051–7.
- [15] Magrabi F, Aarts J, Nohr C, Baker M, Harrison S, Pelayo S et al. A comparative review of patient safety initiatives for national health information technology. *Int J Med Inform.* 2013;82(05):e139–e148.
- [16] Nelson R, Staggers N. Health Informatics-E-Book: An Interprofessional Approach. Elsevier Health Sciences; 2016
- [17] Ricciardi L, Mostashari F, Murphy J, Daniel J G, Siminerio E P. A national action plan to support consumer engagement via e-health. *Health Aff (Millwood)* 2013;32(02):376–84.
- [18] Wetter T. Consumer health informatics. Springer; 2012. Book
- [19] Eysenbach G, Jadad A R. Evidence-based patient choice and consumer health informatics in the Internet age. *J Med Internet Res.* 2001;3(02):E19.
- [20] Sarwal D, Gupta V. Personal Health Record. [Updated 2022 Oct 17]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2023 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK557757/
- [21] Ambinder EP. Electronic health records. J Oncol Pract. 2005 Jul;1(2):57-63. doi: 10.1200/JOP.2005.1.2.57.
- [22] Wade-Vuturo AE, Mayberry LS, Osborn CY. Secure messaging and diabetes management: Experiences and perspectives of patient portal users. *Journal of the American Medical Informatics Association* 2013; 20: 519–525.
- [23] Dennison L, Morrison L, Conway G, Yardley L. Opportunities and Challenges for smartphone Applications in Supporting Health zbehaviour Change: Quantitative Study. J Med Internet Res. 2013; 15(4). E86.
- [24] Tenforde AS, Hefner JE, Kodish-Wachs JE, Iaccarino MA, Paganoni S. Telehealth in Physical Medicine and Rehabilitation: A Narrative Review. PM R. 2017 May;9(5S):S51-S58. doi: 10.1016/j.pmrj.2017.02.013.
- [25] Weinstein R.S., Lopez A.M., Joseph B.A., Erps K.A., Holcomb M., Barker G.P., Krupinski E.A. Telemedicine, telehealth, and mobile health applications that work: opportunities and barriers. Am. J. Med. 2014 Mar 1;127(3):183–187.
- [26] Parimbelli E., Bottalico B., Losiouk E., Tomasi M., Santosuosso A., Lanzola G., Quaglini S., Bellazzi R. Trusting telemedicine: a discussion on risks, safety, legal implications and liability of involved stakeholders. *Int. J. Med. Inf.* 2018 Apr 1;112:90–98.
- [27] Wang X., Zhang Z., Zhao J., Shi Y. Impact of telemedicine on healthcare service system considering patients' choice. *Discrete Dynam Nat. Soc.* 2019 Jan 1 2019.
- [28] Jimison H, Gorman P. woods. Barriers and Drivers of Health Information Technology Use for the Elderly, Chronically III, and Underserved. Evidence Report/Technology Assessment No. 175 (Prepared by the Oregon Evidence-based Practice Center under Contract No. 290-02-0024)
- [29] Tang PC, Lansky D.. The missing link: bridging the patient-provider health information gap. Health Aff (Millwood) 2005 Sept - Oct: 24 (5): 1290-5. Retrieved on 10/5/2013).
- [30] Keselman A, Logan R, Smith CA, Leroy G, Zeng-Treitler Q. Developing informatics tools and strategies for consumer-centered health communication. J Am Med Inform Assoc. 2008 Jul-Aug;15(4):473-83. doi: 10.1197/jamia.M2744. Epub 2008 Apr 24. PMID: 18436895;.
- [31] Beauchamp TL, Childress JF. Principles of biomedical ethics. 6th edition. Oxford University Press; 2009.
- [32] Phillips W. Ethical controversies about proper health informatics practices. Mo Med. 2015 Jan-Feb;112(1):53-7.