



Chronic disease in a digital health environment

Christopher Pearce¹⁻⁵

Abstract

Although we know that there are benefits to individual patients from electronic data, the next potential, and potentially the biggest, benefit will come from the technologies known as *big data*, *machine learning*, and *artificial intelligence*. Harnessing the potential of computers to sift through large amounts of data will result in the possibility of generating insights into individual patients, and into whole populations, predicting the risk of hospital admission for an individual, or tracking influenza epidemics to prepare adequate responses. Once the data are reliable, recorded in a computer-interpretable way, new horizons will open.

Keywords: Ehealth; digital health; chronic disease; patient centred medicine; health systems

Significance statement: The health care of individual patients and communities is being affected by two distinct changes: the increase in chronic disease (with emphasis on continuing management and preventive care) and the development of digital health using electronic tools to manage and improve care. Caring for patients with chronic disease requires regular monitoring of progress, the involvement of multiple health professionals who are often not in the same institution, and the involvement of the patient and the patient's family. Thus care becomes as much about managing information. Digital health is crucial to this process, with the ability to share information across institutions and with the patient. But to do so the information must be structured in such a way as to be machine interpretable, as well and human interpretable.

1. Australasian College of Health Informatics
2. Outcome Health
3. Department of Health Informatics, University of Melbourne
4. Department of General Practice, Monash University
5. Digital Health Committee of the Australian College of Rural and Remote Medicine

CORRESPONDING AUTHOR:
Christopher Pearce, PhD,
MFM, MBBS, FRACGP,
FACRRM, FACHI, FAICD
250 Mont Albert Road, Surrey
Hills, VIC 3127, Australia
E-mail: drchrispearce@mac.com

Received 3 September 2017;
Accepted 1 November 2017

Take-Home Messages:

- Chronic disease management is all about information management and sharing.
- Chronic disease is also information-intensive disease.
- Record all data in an electronic system in a structured, machine-readable way.
- Never forget the narrative.
- The patient is an equal partner in managing care.

Introduction

One of the major challenges facing modern primary care is the change from sequential acute care episodes to managing increasingly complex and chronic diseases. Whereas once people lived short lives and died of a single disease, modern medicine has become very successful at managing many diseases (such as heart disease and diabetes) to increase both the quantity and the quality of life [1]. China



is no exception to this [2, 3], with diseases such as diabetes and heart disease on the rise [4, 5].

But this comes at a cost, and the cost is the increase in the number of people who now:

- Survive longer than in the past
- Have more than one disease
- Require constant care and monitoring (both by health professionals and by themselves) to maintain their health
- Require medications and other interventions on a regular basis, increasing costs and other impositions on the health care system

These costs apply in any nation and its health system. In publicly funded, universal health care systems (think of the United Kingdom, Australia, and Cuba) these costs accrue to the state. In private systems (e.g., in the United States) they apply to individuals, with increasing inequality of access to care. China, with its large population and variety of funding mechanisms across urban and rural settings and across social classes, faces particular challenges in this regard [6].

The important outcome is that these patients, and their disease, require not a single drug or intervention but a systematic and holistic approach to management, over a long period, and often involving multiple health care practitioners [7]. The patients themselves are crucial to the process of care, and a shared decision making (SDM) model (where patients are an active participant in choosing care options) is the desired model for chronic disease care [8]. SDM makes the patient's views, desires, and objectives for care of equal weight to those of the health professionals. SDM is the extension of patient-centered care [9]. Patient-centered care encourages the health care system to consider the patient's views; SDM requires the health care system to consider the patient as part of the team.

SDM requires that the patient's views, concerns, cultural background, and indeed wishes be considered in the delivery of care. Patients are to be given the information they need to make a decision, including the possible consequences, and then supported in their decision. There is no "one size fits all" approach. SDM is often a challenge to institutions, where protocol-driven approaches are easier to implement.

Alongside the change to a chronic disease model are the changes to society in general (and health care specifically) caused by the digitization of society. No part of health care is untouched, whether it be e-mail communication, electronic health records [10], smartphone and app adoption [11], or "big data" all leaving their mark [12]. Although the adoption of these technologies is variable, their use is only going to increase over time. Computers are entering all aspects of health care, in differing ways. A fully electronic health record is the ideal, but computers can run recall systems, manage communication and referrals, and simplify prescribing [13]. It all depends on local need and availability.

This brings us to the intersection of these two concepts: chronic disease management and digital health. The two areas where digital health enables chronic disease management are the communication and management of information. The aim is to bring together the members of the team in an integrated, digital environment (see Fig. 1) [14]. Of note, in Fig. 1, the care team are surrounding the patient (embodied) and the patient's health data (the patient inscribed). One is no longer complete without the other.



Fig. 1. The health care team.

PCEHR, personally controlled electronic health record.



Digital health

No longer can the patient, or the primary care practitioner, be the repository of all the information regarding the patient's care. The amount of information about a patient is increasing exponentially, with serial blood tests and radiology, all of which must be reviewed on a regular basis. Managing that information is increasingly the prime activity of health care workers. Information management is not just about accessing information, it is about collating it, reconciling results in time and from different sources, and understanding the various uses of data. And data are not just points of measurement. For each patient, data have many forms:

- The story that the patient tells – both the history of the disease and also the story of the patient's life, perceived need, and preferences for care [15].
- The physiological measurements – the things about the patient that can be measured, such as blood pressure and pulse rate.
- The investigations – which can be hard measures such as a hemoglobin level, but also interpretive, such as a chest X-ray and echocardiography.
- The knowledge- and experience-based interpretive elements – usually applied by the physicians. An elevated hemoglobin A_{1c} level suggests diabetes, for example. Or a history of central chest pain suggests ischemic heart disease [16].

All of these are acted on by time, as time series changes the data and their interpretation. All data must be interpreted, and this interpretation is the heart of information management.

Information communication is the next element, for in a connected health care system information not shared is information lost. Too often information is locked up within the silo of a specific institution. Information can be shared in a number of ways. Often the patients themselves are the best way to ensure communication, but increasingly information is too complex for patients to hold it themselves. A digital magnetic resonance imaging scan needs to be shared by digital means – a CD or cloud repository. Thoughts and interpretations of health care workers also need to be shared, which may mean e-mail communication or a centralized repository. All these issues must be dealt with. Also, the nature of these patients means

that sometimes they have issues that make them unable to help their health professionals. Strokes and dementia may create problems through cognitive impairment or low health literacy.

Also soon to impact on care delivery will be the fields of patient-generated data and advanced computing techniques. In the former, the advent of wearable technologies and self-monitoring smartphones will provide ever more sources of data for clinicians [17], as well as assisting patients in their own care [18]. These large sets of data are increasingly going to be used by techniques such as machine learning and artificial intelligence to develop insights and guidance for clinicians and patients alike [12, 19].

Information management

In a digital environment good information management requires systems that can manipulate data, and the requirements of electronic systems are different from those of human systems, which is the crux of the problem. A computer requires data. Any piece of health data needs four attributes, which we will call *structure*, *identity*, *metadata*, and *form*. The following example is intended to demonstrate why clinicians must spend time ensuring the data they enter are interpretable by the computer.

Let us take blood pressure – a simple measurement (120/80 mm Hg). To communicate this across platforms (semantic interoperability) we need a top number and a bottom number, with some rules such as that they are numbers of either two or three figures, and the bottom number can never be larger than the top number (quality check – physiologically impossible).

That is the structure, or the “information model.” Next comes the identity, which is the terminology used and the code therefore attached. Here we will use SNOMED CT (an international standard), and therefore the code is 75367002. Metadata are the simple information that says this blood pressure reading is from Dr. X, and on this date.

The form is the “wrapper” in the transmitting of the data – the thing that says “ok strange computer system, this is a bodily observation of this patient and it has a code and I think you should put it here.” This is the purpose of Health Level 7 (HL7), and in the current world we would use the Fast Health care Interoperability Resources (FHIR) kit – Resource



Observation – Content. So that is it. What to humans is a simple statement (120/80 mm Hg) becomes: <FHIR –resource observation – content [systolic 120 mm Hg diastolic 80 mm Hg. STC-75367002. IHI 8111 6011 2892 8012 Date 12/01/2016 UTC 13.01] > – a semantically interoperable complete description of blood pressure. With this structure, computer systems can manipulate the data.

On top of that, you need to add usefulness and usability, because the description above relates to computer communication, not human communication. So, for example, physicians are used to writing “120/80 mm Hg,” not putting figures in specific boxes, and also reading it in that form in documents and therefore looking for it in electronic records. Similarly, the information needs (usefulness) have so many determinants that context must always be emphasized. A normal blood pressure is different in a young health person from that in someone undergoing dialysis for kidney failure. A good information system is a user-friendly one – one that considers workflow as well as data needs. Such a system can be created if users (chronic disease patients and health professionals) are engaged in the early stage of information system development [20].

Information communication

Communication is the next battleground, and here we have two main models: peer to peer and one to many. Peer to peer is what we best know now as e-mail, but increasingly other modes of one-on-one communication are being used [21]. Electronic communications are faster and often simpler than post and even fax, and can be sent directly from the electronic health record. General e-mail is deemed insecure for a variety of reasons [22], so either the e-mail system must be encrypted or specific apps that encrypt information should be used. Within a closed system such as a hospital, virtual private networks can be used, but we know that good chronic disease management requires information communication across such systems. Therefore the growth is in the area of “one to many” or shared information platforms. These platforms allow information from various providers to be pooled and made available to others, including, crucially, the patient. They can involve large, state-sponsored information gathering [14] or can be smaller, disease-specific models [23]. Diseases

such as diabetes are particularly well suited to a platform where providers and patients can lodge information such as blood glucose levels and other measurements in a form that all can see. The challenges for these more open systems relate to information standards, security, and access [24].

Information standards were dealt with earlier – for a computer to integrate blood pressures from different sources, it must understand them to be the same thing. Security is the next element. Security is different from privacy. Security relates to the safe transfer and holding of information, so when information is being sent to the central repository, it must be kept safe from prying electronic eyes. Similarly, the repository must be secured from hackers. The medical information itself is of little value, but the repository will usually contain sufficient information such that this will encourage identity theft and targeted phishing.

Privacy is the next complex area. Privacy in this context is not about keeping information secret, but is about controlling who has access [25]. In keeping with the SDM model, patients should have the right to control who has access and who does not. However, this should be considered in the context that where such controls are implemented they are rarely used. Patients generally wish to share their information when they understand it will give them better care.

An example of care

Mrs. W is a 68-year-old woman who lives with her husband and has two children, both married, and two grandchildren. For the past 10 years she has had hypertension, managed with medication. She gave up smoking 5 years ago, although her husband still smokes. Four years ago she had a small myocardial infarction, and received a diagnosis of diabetes at the time. She has since developed heart failure related to an enlarged heart. She had a transient ischemic attack 2 years ago, and has just had a foot ulcer that took 6 months to heal. She has been in hospital four times in the past 2 years, twice for heart failure and twice to manage the foot ulcer. She takes six medications – two for her heart and blood pressure, two for her diabetes, one for her transient ischemic attack, and one for her foot ulcer. She has a primary care physician, who she sees on a regular basis, but she also sees a hospital physician and three other health care practitioners to manage various aspects of her care. She is assisted in her care by her daughter, who lives in the next building.



Using the example of Mrs. W, we will see how her health care can be helped by the digital environment. She has at least five health professionals looking after her, as well as being helped by her daughter. There are several parameters that require constant measurement and monitoring over time: blood pressure and hemoglobin A_{1c} and cholesterol levels, for a start. These need to be communicated between the primary care physician and the hospital physician. A new problem such as a chest infection may affect many aspects of her care. But a shared platform will allow the podiatrist to also know what is going on. If the primary care physician gives Mrs. W antibiotics for a foot infection, this information will be available to all her carers, including her daughter. Mrs. W can also self-monitor – watching her blood pressure and seeing her progress. It also allows some time savings. Allergies, for instance, can be recorded once and checked only when relevant. Time spent with the patient can be more about asking how the patient is, rather than filling in demographic details.

How this is done is less relevant than ensuring that it occurs at all. Good and timely e-mail communication will suffice, but a central platform makes access and monitoring easier, and crucially makes it easy to involve the patient and her carer.

Conclusion

A final word on the future possibilities of chronic disease care in the digital environment is in order. Although we know that there are benefits to individual patients from electronic data, the next potential, and potentially the biggest, benefit will come from the technologies known as *big data*, *machine learning*, and *artificial intelligence*. Harnessing the potential of computers to sift through large amounts of data will result in the possibility of generating insights into individual patients, and into whole populations, predicting the risk of hospital admission for an individual [19], or tracking influenza epidemics to prepare adequate responses. Once the data are reliable, recorded in a computer-interpretable way, new horizons will open.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

References

1. Starfield B. Primary care: an increasingly important contributor to effectiveness, equity, and efficiency of health services. SES-PAS report 2012. *Gac Sanit* 2012;26 Suppl 1:20–6.
2. He J, Gu D, Wu X, Reynolds K, Duan X, Yao C, et al. Major causes of death among men and women in China. *N Engl J Med* 2005;353(11):1124–34.
3. Wang R, Yan Z, Liang Y, Tan EC, Cai C, Jiang H, et al. Prevalence and patterns of chronic disease pairs and multimorbidity among older Chinese adults living in a rural area. *PLoS One* 2015;10(9):e0138521.
4. Yang W, Lu J, Weng J, Jia W, Ji L, Xiao J, et al. Prevalence of diabetes among men and women in China. *N Engl J Med* 2010;362(12):1090–101.
5. Yang ZJ, Liu J, Ge JP, Chen L, Zhao ZG, Yang WY, et al. Prevalence of cardiovascular disease risk factor in the Chinese population: the 2007–2008 China National Diabetes and Metabolic Disorders Study. *Eur Heart J* 2012;33(2):213–20.
6. Chen M, Zhao Y, Si L. Who pays for health care in China? The case of Heilongjiang province. *PLoS One* 2014;9(10):e108867.
7. Yabbarpour Y, DeMarchis E, Bazemore A, Grundy P. The impact of primary care transformation on cost, quality and utilization. Washington: The Robert Graham Center; 2016.
8. Charles CA, Whelan T, Gafni A, Willan A, Farrell S. Shared treatment decision making: what does it mean to physicians? *J Clin Oncol* 2003;21(5):932–6.
9. Stewart M, Brown J, Weston W, McWhinney L, McWilliam C, Freeman T. Patient-centred medicine: transforming the clinical method. 2nd ed. Oxford: Radcliffe Medical Press; 2003.
10. Jha AK, Doolan D, Grandt D, Scott T, Bates DW. The use of health information technology in seven nations. *Int J Med Inform* 2008;77(12):848–54.
11. Dicianno BE, Henderson G, Parmanto B. Design of mobile health tools to promote goal achievement in self-management tasks. *JMIR Mhealth Uhealth* 2017;5(7):e103.
12. Goetz T. Sergey Brin's search for a Parkinson's cure. *Wired* 2010 June 22. Available from: https://www.wired.com/2010/06/ff-sergeys_search/.
13. Pearce C, Haikerwal MC. E-health in Australia: time to plunge into the 21st century. *Med J Aust* 2010;193(7):397–8.
14. Pearce C, Bainbridge M. A personally controlled electronic health record for Australia. *J Am Med Inform Assoc* 2014;21(4):707–13.
15. Scott D, Purves I. Triadic relationship between doctor, computer and patient. *Interacting Comput* 1996;8(4):347–63.
16. Mol A. The body multiple: ontology in medical practice. Durham: Duke University Press; 2002.



17. Milani RV, Lavie CJ. Health care 2020: reengineering health care delivery to combat chronic disease. *Am J Med* 2015;128(4):337–43.
18. Al-Marshedi A, Wills G, Ranchhod A. Guidelines for the gamification of self-management of chronic illnesses: multimethod study. *JMIR Serious Games* 2017;5(2):E12.
19. Pearce CM, McLeod A, Patrick J, Boyle D, Shearer M, Eustace P, et al. Using patient flow information to determine risk of hospital presentation: protocol for a proof-of-concept study. *JMIR Res Protoc* 2016;5(4):e241.
20. Pearce C, Macdougall C, Bainbridge M, Davidson J. Ensuring clinical utility and function in a large scale national project in australia by embedding clinical informatics into design. *Stud Health Technol Inform* 2013;192:28–32.
21. Stone JH. Communication between physicians and patients in the era of e-medicine. *N Engl J Med* 2007;356(24):2451–4.
22. De Meyer F, De Moor G, Reed-Fourquet L. Privacy Protection through pseudonymisation in e-health. In: De Clercq E, De Moor G, Bellon J, Foulon M, van der Lei J, editors. Collaborative patient centred eHealth. Proceedings of the HIT@Healthcare 2008 Event. Amsterdam: IOS Press; 2008. pp. 111–7.
23. Fuji KT, Abbott AA, Galt KA. A qualitative study of how patients with type 2 diabetes use an electronic stand-alone personal health record. *Telemed J E Health* 2015;21(4):296–300.
24. Greenhalgh T, Stramer K, Bratan T, Byrne E, Mohammad Y, Russell J. Introduction of shared electronic records: multi-site case study using diffusion of innovation theory. *Br Med J* 2008;337:a1786.
25. Stone MA, Redsell SA, Ling JT, Hay AD. Sharing patient data: competing demands of privacy, trust and research in primary care. *Br J Gen Pract* 2005;55(519):783–9.