People-centred healthcare systems: opportunities and challenges

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People-centred healthcare systems aim to empower people with their healthcare decisions, make information more accessible and enable more autonomy. 1-12 The goal is to promote well being as much as to treat disease, and to create more collaboration among providers, patients and their families, thus reducing costs and improving health outcomes. Throughout the world growing populations and rising costs are challenging healthcare systems. In numerous countries, healthcare providers cannot meet the needs of many individuals and groups owing to limited budgets, time and staff. An ageing population and rapidly increasing rates of chronic diseases could overwhelm most healthcare systems. 13-19

Although information and communication technologies can connect healthcare providers with each other and the consumers they serve, no group, organisation or government has overcome the roadblocks to implementing a wide people-centred health system. Ideally, such a system would put the needs of the public first, enable individuals to take greater responsibility for managing their own health and health services and promote optimal levels of health and resource utilisation. In this paper, we explore a vision for future people-centred healthcare systems that could provide better access to information and decision-making tools for patients, healthcare providers and

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the general public. We also examine key challenges to creating such systems.

The people-centred healthcare vision

Healthcare organisations often talk about patient-based or patient-focused care. The vision for a people-centred healthcare system goes beyond being patient-based or patient-focused. A people-centred health system enables people to take control of their own health and wellness and strives to support them in that endeavour through multiple means.⁸⁻¹² One major 'means' is information. Within a people-centred healthcare organisation, information is provided to patients and also to the families who care for and support them, as well as to other people who support wellness. In addition to patients and families, healthcare professionals themselves are key stakeholders in a health system. They provide care and also make health information available and understandable. Other groups within the vast healthcare system, such as government healthcare agencies, regional and local public healthcare units and non-profit groups and non-governmental agencies, are also integral parts.

Various definitions of people-centred healthcare systems have appeared from the 1940s through 2010.1-12 One early vision³ noted, "people need care when sick; they need preventive services; they need workable information. The needs do not change: perception of need changes. Expectations of how and to what extent needs can be met also changes." Another view defines e-patients as individuals "who are equipped, enabled, empowered and engaged in their health and health care decisions ... where there is an equal partnership between e-patients and health professionals and the systems that support them."8

The Canadian Association for People-Centred Health⁹ bases its concept on four key principles: (1) responsibility—people are responsible for their health and wellness; (2) autonomy people make their own decisions affecting their health and wellness; (3) informed health management—people have the information needed to manage and make informed decisions about their health and wellness; (4) partnership—people partner with healthcare providers to ensure the best possible outcomes. The Society for Participatory Medicine describes participatory

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medicine as "a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners."10 The Markle Foundation defines a person-centred health system as one "that will make available the most effective professional and institutional resources to assist people when they can no longer manage their own health without that help."11

In 2001, the US Institute of Medicine¹² wrote: "The current health care delivery system is not robust enough to apply medical knowledge and technology consistently in ways that are safe, effective, patient-centred, timely, efficient, and equitable. As we strive to close this gap, we must seek health care solutions that are patient-centred, that is, humane and respectful of the needs and preferences of individuals." This report noted the importance of integrative medicine as a means of addressing the mental, emotional and physical needs of patients during the healing process and the need for greater patient involvement in healthcare.

Why create people-centred healthcare now?

Incidence of chronic disease in populations around the world continues to accelerate rapidly, 13-19 and some healthcare providers

emphasise the need for prevention and education before an individual becomes a patient. Most healthcare systems do not embrace these health-related activities as part of care because they are not billable or reimbursable. Global surveys of the public show that people are frustrated and unhappy with their health services.^{20–23} Most are not participating in healthy living programmes. Nor is technology playing a major role in promoting healthy living and self-care programmes. Consumers are expressing interest in more electronic access to their healthcare providers.

There is an opportunity to bring more healthcare services and prevention information to the public. Information and the timely delivery of educational and decision-making materials are essential to effective prevention and public health strategies. Before prevention and public health education can be used as part of a true people-centred health system, information flow among key stakeholders must be improved.

The complexity of health knowledge exchange

Information flow among healthcare consumers, professional healthcare providers, government agencies and private corporations involved in healthcare is often fragmented or non-

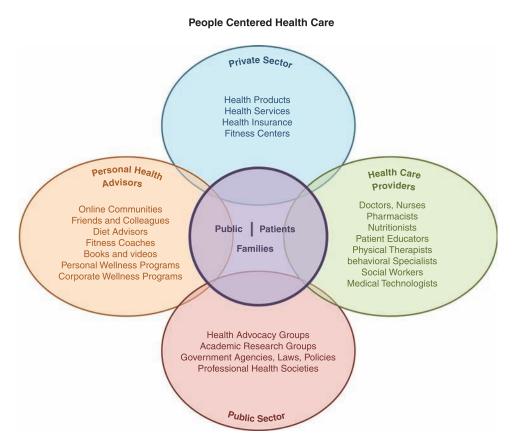
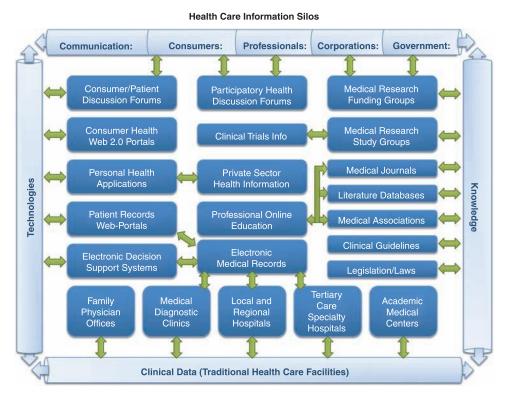


Figure 1 People-centred healthcare stakeholders.

Table 1 Challenges to effective sharing of health information	
Challenge 1	Defining the key stakeholders and goals of a people-centred healthcare system
Challenge 2	Motivating stakeholder groups to communicate efficiently across healthcare systems
Challenge 3	Developing common understanding and shared expectations of desired services and outcomes among stakeholders
Challenge 4	Improving the technologies for public access to personal healthcare data and information
Challenge 5	Developing successful models for prevention and public health education that are effective and sustainable
Challenge 6	Developing strategies to involve and engage patients, their friends and families in this new system
Challenge 7	Narrowing the bench-to-bedside gap. The interval between research studies and the clinical use of information at the point-of-care can be as long as 24 years



Health information sources and information flows.

existent owing to a lack of technology adoption and incentives to communicate.24-27 Figure 1 illustrates a comprehensive model of a people-centred healthcare system that includes prevention and public health as key components. In many lowincome countries, people lack access to high-quality healthcare services and seek help from various individual services, such as small pharmacies or healers, unconnected with other health systems. Even in more industrially developed societies, many healthcare providers are unable to collect and share information efficiently among themselves or with patients and their families, either because of incompatible technologies or lack of financial incentives. Figure 2 shows some of the sources of healthcare information and how this information could flow between stakeholders.

Existing workflow models frequently introduce errors, hamper productivity and make data sharing difficult among distributed healthcare systems.^{28–31} Technology could provide new ways for stakeholders to communicate with each other and advance more desirable healthcare outcomes. Innovations in digital technologies, when properly used, could overcome the logistical barriers to information sharing by introducing more efficient methods for collecting, sharing and storing data, and providing better tools to support data analysis and improve clinical decision-making and health outcomes.32-35

Challenges

In order to ensure effective communication of information within a people-centred healthcare system, several challenges will need to be overcome, as summarised in table 1.

One of the first challenges in creating a people-centred health system is identifying the system's key stakeholders, beginning with patients or consumers. 36-39 In many healthcare systems, a person is considered to be a patient only after he or she exhibits observable symptoms or after he or she is given a clinical referral or diagnosis. However, many people who have not been identified as patients have existing medical conditions that put them at substantial health risk, including those who are obese, mentally or chronically ill or who are ill but do not have symptoms or a diagnosis. Defined as patients or not, all consumers are stakeholders in the system. Another challenge is determining the role of a patient's family in the system. Often, healthcare systems do not view family members as key stakeholders, and services focus exclusively on the patient.

Defining the key stakeholders and goals of people-centred healthcare systems (challenge 1) depends on each country's funding models for healthcare and the cultural values its citizens place on healthcare services. 40-44 The USA is currently restructuring its healthcare system. In many countries private and public healthcare systems overlap. Groups such as the Society for Participatory Medicine (http://www.participatorymedicine.org) are bringing together stakeholders from various disciplines to discuss future health systems. Leaders from all sectors will need to act jointly to help develop visions of people-centred healthcare systems.

Challenge 2 is to motivate stakeholder groups to communicate efficiently across healthcare systems. 45-55 Lack of communication reflects the absence of both an effective system for sharing information and perceived benefits for participants. It perpetuates missed opportunities to improve point-of-care clinical practice and prevention activities. In some instances, improved health outcomes and reduced costs might encourage data sharing as, for example, in the implementation of common treatment protocols for collaborative research.⁴⁵ One way to communicate health information is through online social networks. There are social networks^{46–54} for patients (http://www.PatientsLikeMe. com), physicians (http://www.sermo.com), academic researchers (http://network.nature.com), biomedical scientists (http:/// www.scilinks.org), professional medical personnel (https:// www.Cure4Kids.org) and laboratory scientists (http://www. labspaces.net). To maximise the benefit of these networks, we will need to find ways to bridge communications among these groups, possibly through semantic indexing technologies.⁵⁵

Challenge 3 is related to developing common understanding and shared expectations among providers and consumers.^{20–23} Healthcare providers and consumers sometimes do not understand each other's expectations. Bridging these gaps in expectation and understanding will be important. Surveys show that consumers have difficulty understanding the healthcare system.²⁰ Increasingly people want to access some of their services via the internet, and doing so could reduce some frustrations and wasted time.21-23 To overcome this challenge, we need continued discussion among stakeholders to define the desired services and health outcomes, and improve the ease of use of online tools for consumers^{56–58} and professionals.^{59 60}

Challenge 4 is to improve the technologies for public access to personal healthcare data and information. 61-64 People-centred health systems must include access to clinical records and personal health record platforms distributed among various providers. 61 62 Some personal health record systems, such as Microsoft Health Vault (http://www.healthvault.com) and Google Health (https://www.google.com/health), attempt to consolidate information from various providers. However, to be effective, these technologies must operate among the various levels of technology, provide privacy controls and must ensure that only accurate data are transferred. 63 Future systems will need to be designed with interoperability⁶⁴⁻⁶⁸ to access data from multiple providers, and interoperability should be measured and incentivised. To overcome this challenge there will need to be greater adherence to information standards. The problem is not that we do not have standards for data interchange, but that groups cannot agree on which standards to use. Leadership from government and key providers will be needed to accomplish greater standardisation. We will need to evaluate the cost of these systems. 69-71 have effective strategies for introducing new technology⁷² and also quality-of-life indicators from the perspectives of patients and the general public.^{73–77}

Challenge 5 is to develop successful models for public health education and prevention programmes that are cost effective, vield useful and measurable health outcomes and are scalable and sustainable. Many large-scale public health initiatives have been developed to help deal with issues such as nutrition,7879 exercise, 80-82 smoking, 83 yet despite billions of dollars of research and public health expenditure, obesity, heart disease and preventable cancers remain large public problems.84-86 There needs to be greater urgency placed on new models, incentives and rewards for successful prevention programmes. The current approaches are not yielding scalable or sustainable solutions. Since the problem is complex, we will need new approaches that combine multiple disciplines such as medicine, public health, engineering, social sciences and need to create

new innovative solutions to these problems. New training programmes in eHealth and public informatics are examples of this emerging multidisciplinary approach to problem solving. 87-90

Challenge 6 is how we can develop the opportunities and strategies to effectively involve and engage current/future patients and their families in the new system. This challenge revolves around building trust in the patient-centred healthcare model. Connecting patients with information and personal action for change will require a number of strategies and processes that will be dependent on local cultural norms. We will need innovations in health technologies and healthcare delivery that connect patients, families and health providers together. 91-94 Another approach is to design new hospitals with prevention in mind and with education and collaboration areas built into the design of the buildings.95 96

Challenge 7 is related to synthesising information collected from clinical experience and research studies for use in practice. New research discoveries can be integrated into clinical practice guidelines or continuing education materials for healthcare professionals. The time required for research results to be incorporated into practice, or knowledge used at the point-of-care can be as long as 24 years, and translation is sometimes delayed by regulatory oversight. 97 98 Clinical data are often collected by multiple healthcare groups such as hospitals, clinics and diagnostic laboratories. These groups are often independent and distributed making the analysis and synthesis of data difficult, and often impeded by the lack of a framework or system for sharing information. There are some free tools which can be used to find current research information such as PubMed Central for biomedical journal literature, ClinicalTrials (http://www.clinicaltrials.gov) for clinical research studies and the National Guideline Clearinghouse (http://www.guidelines.gov) for clinical practice guidelines. Better public search tools are needed to search, interpret and analyse the data to support decision-making. 56-60 Denmark has made significant progress in electronically connecting its healthcare institutions^{40 40a 41 99} and providing patient rights and information and ranks first in a recent European survey, 100 but more will need to be done locally, regionally and globally.

Conclusions

The need to evolve people-centred systems is increasing owing to rising levels of chronic disease. 13-19 Chronic disease, according to the WHO, comprises the major chronic conditions of heart disease and stroke (cardiovascular disease), cancer, chronic respiratory disease and diabetes. Over half of the deaths in the world are due to just four chronic conditions—diabetes, lung diseases, some cancers and heart disease—caused by three risk factors—smoking, poor diet and lack of physical activity.

A WHO report¹³ notes that "chronic disease epidemics take decades to become fully established; given their long duration, there are many opportunities for prevention that require a longterm and systematic approach to treatment. Health services must integrate the response to these diseases along with the response to acute, infectious diseases."

Given how complicated it is to develop people-centred healthcare systems, why do it? The increasing incidence of chronic diseases and the associated rising healthcare costs have made this a global urgency. 15 The need to find cost savings and improve health outcomes has become critical in many countries. Meeting this need is unlikely in the current fragmented healthcare systems. To provide more effective prevention and proactive consumer healthcare systems, we will need to develop more integrated people-centred healthcare systems. Overcoming challenges 1–3 are essential first steps if we are going to have a consensus roadmap for the future. New solutions are required that are cost effective and scalable. A new multidisciplinary approach is needed. We need to act on the basis of common needs and shared goals. Such a complicated collaboration will require trust, vision, leadership and innovation.

Competing interests None.

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