

EDITOR'S PICK

For my first Editor's Pick I have highlighted the paper 'The Role of eHealth technologies in driving patient participation'. As technology-assisted healthcare expands, we must ensure that those often left behind and disadvantaged are included and prioritised. To echo the views of Robert Wachter, as mentioned in my foreword, technology provides us with the tools for human endeavour, but does not yet replace it!

Dr Mike Bewick

DEMOCRATISING HEALTHCARE: THE ROLE OF eHEALTH TECHNOLOGIES IN DRIVING PATIENT PARTICIPATION

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ABSTRACT

Digital technologies are changing how we practice and experience healthcare. This review focusses on the role of eHealth technologies in facilitating patient participation within the healthcare process. The central claim of this paper is that interactive, web-based technologies allow individuals to become more active participants in the healthcare process, thereby opening up new perspectives and opportunities for improving healthcare.

By drawing on findings from recent research, the review seeks to highlight how the increasing availability of health information and individuals' ability to easily connect to others around the globe can facilitate knowledge exchange and collaboration between the general public, patients, healthcare professionals, and researchers. Acknowledging some of the potential challenges and pitfalls further shows how these new technologies, if used appropriately, can promote a new form of patient participation that goes beyond the individual level and as such, constitutes an invaluable resource for healthcare research and practice.

Keywords: Digital healthcare, eHealth, collaboration, innovation, patient participation, participatory research.

INTRODUCTION

Digital technologies such as artificial intelligence, nanotechnology, three-dimensional (3D) printing, augmented reality, social media, and wireless sensors are evolving at an ever increasing pace and are penetrating all areas of society

including healthcare.¹ According to Goodall et al.,² the application of digital technologies in healthcare can be classified as measures targeting three broad areas: i) the improvement of healthcare practice by enabling better management of clinical records and patient information, and provider-to-provider communication; ii) the facilitation

of patient involvement in the care process; and iii) the increased availability of health information for patients and their families. As such, digital healthcare technologies are not only revolutionising the ways in which we collect, access, and share health data but also how we transform them into meaningful information and actionable knowledge.¹ This in turn leads to changes in traditional relationships, roles, and practices in healthcare.³ It has been suggested that digital technologies have particularly contributed to strengthening the role of the patient by reducing the knowledge and power asymmetry prevalent in the healthcare setting.^{4,5}

By reviewing the pertinent literature in the field, this paper aims to demonstrate how digital technologies are enabling individuals to become more active participants in the healthcare process thereby laying the foundations for the democratisation of healthcare. Moreover, it seeks to discuss some of the potential challenges and pitfalls these developments entail. In order to provide a concise and informative overview of relevant research in the field, a narrative review was conducted. PubMed was searched in August 2016 using search terms that were identified through key publications within the field.^{4,6-10} To complement this search strategy, a hand-search was performed on Google Scholar and a reference list of the identified studies included.

PATIENT PARTICIPATION AND eHEALTH TECHNOLOGIES

As a part of the shift away from a top-down approach to care toward a more patient-centred perspective, the concept of patient participation has come into focus.¹¹ Traditionally, patient participation refers to the patient's active role in his or her own care process including aspects such as shared decision-making and self-management of chronic health conditions.¹² It emphasises the patient's right to choice and control over medical decisions concerning his or her own health¹¹ and has widely been recognised as a promising strategy to improving healthcare.¹²

An extensive body of literature covers topics related to patient participation in the context of web-based technologies that enable individuals to access health information and services online via their computer, smartphone, tablet, or smartwatch, including electronic health records,¹³ health information websites,¹⁴ interactive virtual patient networks,¹⁵ smartphone applications,¹⁶

and web-based decision support systems.¹⁷ These technologies are commonly referred to as eHealth technologies⁶ and are considered valuable tools for patient participation that can be utilised not only to promote the adoption of healthy behaviours and disease prevention but also to facilitate the early detection of emerging health issues.⁷ Increasingly, they are also used to support patients in managing chronic health conditions.^{18,19} In this context, wireless sensors and devices have gained increasing attention as a convenient way for individuals to track body functions, activities, and geolocation.²⁰ With their increasing accuracy and reliability, the data from these monitoring devices offers more transparency to patients and can facilitate the early detection of medical emergencies and diseases.²¹ However, evidence on the impact and additional long-term benefits of eHealth technologies is not conclusive.^{7,10,22,23}

eHEALTH TECHNOLOGIES: FOSTERING A NEW FORM OF PATIENT PARTICIPATION

Besides the debatable impact of digital technologies on long-term outcomes such as quality of care, health outcomes, or healthcare costs, it is evident that digital technologies have changed how health information and services are accessed and used by both patients and the general public. Findings indicate that web-based technologies can improve access to health information and services²⁴ which can in turn, foster a new form of patient participation that goes beyond the traditional understanding of patient participation, extending beyond the individual patient's health.

Indeed, more and more healthcare organisations have started to increase their online presence to provide their patients and the general public with high-quality medical information.²⁵ Some also use social media channels to promote behaviour change (e.g. smoking cessation)²⁶ or to communicate public health risks to the public (e.g. Ebola outbreak).⁹ Moreover, as a result of the open access movement, patients have gained access to additional information resources, like medical journals and scientific publications, that were formerly only available to a selected audience of medical professionals and researchers.²⁷

In contrast to traditional online health information resources, where the information flow is usually unidirectional in the form of patient education, the

emergence of peer-to-peer support networks allows for multidirectional information exchange among individuals.²⁸ This means that individuals can not only access health information and services online, but they themselves can become active information providers, health advocates, and collaborators.^{8,29,30} As such, patients can assume new roles, tasks, and responsibilities that go far beyond the traditional concept of patient participation.⁸

NEW ROLES AND OPPORTUNITIES

Peer-to-Peer Support and Collaboration

More and more individuals are becoming active online to share health information and their personal experiences. Some of these efforts are directed at the general public, for example to promote a certain lifestyle (e.g. physical activity), while others are targeted at specific patient audiences with the purpose of sharing and discussing health condition specific topics, like diagnosis, treatments, or side effects.^{31,32} Qualified by their lived experience, individuals can assume the role of health coaches that guide and motivate others to adopt certain behaviours or to engage in effective self-management practices for chronic health conditions.³³ The interactivity of social media channels enables individuals to use different types of media formats to provide clear and easy-to-follow instructions or recommendations. It also allows visual demonstration of the effects of different treatments or procedures for example, in the form of videos or before and after pictures. This sharing process helps to transform individuals' personal experiences into experiential evidence that can show the effectiveness or ineffectiveness of certain measures or treatments.³⁴ With an increasing number of individuals sharing their experiences, the value of this database of experiential evidence increases substantially. It can not only be an important resource for patients and their families but also for healthcare professionals and researchers.^{31,34-36}

The increasing popularity of crowdsourcing platforms has further contributed to the distribution of power and information in healthcare. Broadly speaking, crowdsourcing, as the name suggests, refers to the outsourcing of a task. This assigns tasks usually left to specific individuals to a large, anonymous group of individuals, i.e. the crowd.³⁷ Crowdsourcing platforms allow individuals to engage in collaborative tasks, such as 'Question & Answer' sites or physician rating websites

that are driven by the 'wisdom of the crowd'.³⁸ Crowdsourcing platforms can help individuals gather large amounts of information and may thereby support them in making informed decisions. Furthermore, web-based collaborative mapping has gained increasing importance in healthcare.³⁷ A prominent example of such a collaborative mapping project is Wheelmap, a service focussed on crowdsourced mapping of wheelchair accessible places to help individuals identify whether a certain location is accessible or not.³⁹

More recently, in addition to sharing health-related information, individuals have also started to engage in innovation and co-creation activities by sharing their ideas on how to improve existing or develop entirely new technologies, tools, and devices to improve their health and/or quality of life.^{30,40-42} This process of what is commonly referred to as patient-driven or patient-led innovation.^{43,44} It is not merely a phenomenon of the online world however, digital technologies have certainly facilitated the exchange and dissemination of innovative ideas and practices among individuals. It has been suggested that the adoption of open source approaches that give all users the unrestricted right to study, modify, and distribute information, can indeed help to reduce costs and contribute to increasing the pace of innovation in healthcare, underlining also the role that patients can play in this process.⁴⁵

An example of such a collaborative effort is the Nightscout initiative, a do-it-yourself mobile technology system for individuals with Type 1 diabetes mellitus that was created by patients, for patients, using open source software code. The Nightscout community continuously generates new personalised digital solutions that allow patients, their caregivers, and health professionals to better monitor, predict, and manage diabetes.⁴⁰ Being publicly available through open source, anyone can access, use, modify, and share the code to further improve or personalise existing solutions to better meet their needs. Another frequently mentioned example of collaborative co-creation is the Enabling the Future project, which has dedicated its efforts to providing disabled children with low-cost, personalised upper limb prosthesis. The e-NABLE community involves over 1,500 engineers, students, parents, healthcare professionals, and designers that interact via social media websites to exchange ideas for new designs or improvements of existing prosthesis, request help, or donate.⁴¹ The availability of the required resources online

and the support from the community make the production of 3D-printable prosthetics affordable and simple. Some of the designs are in fact so simple to assemble that it can easily be done by children themselves.⁴¹

In this context, the concept of open source and crowdsourced health research will become increasingly important, as outlined by Swan. The author points to the emergence of self-run clinical trials and structured self-experimentation of patients, highlighting the potential of this new form of patient-led research to contribute to our understanding of rare health conditions that may not be prioritised by pharmaceutical companies and other funding bodies.⁴⁶

Patient-Provider and Research Collaboration

Over the past decades, the understanding of the patient's role has changed dramatically.⁴⁶ Formerly perceived as a passive consumer of care, patients have evolved to become active decision makers and participants in relation to their own health, for example, by engaging in self-management activities. More recently, their role has extended beyond the individual level. Increasingly, patients are recognised as knowledgeable collaborators and partners both in healthcare research and practice.

As patient-helpers, patients are recognised as an important resource for other patients and as allies for healthcare professionals. They are not in competition with physicians, but rather complement existing healthcare services.⁸ Indeed, the value of peer-led self-management support and its potential to improve health literacy and foster patient empowerment have been demonstrated repeatedly within the offline setting.⁴⁷ A prominent example is the Stanford Chronic Disease Self-Management Program which includes small, patient-led group interventions. Patients leading these self-management workshops assume a role model function and are trained in a structured way on how to lead the workshops.⁴⁸

Similarly, patients are also becoming more and more involved in research activities.⁴⁹ While traditionally patients were subjects of research (e.g. randomised controlled trials), participatory research approaches, where patients join research projects as equal partners, have gained increasing attention.⁵⁰⁻⁵² In this context, patients have been described as essential components of healthcare research, including medical conferences⁵³ and

publishing.⁵⁴ It has been suggested that patient participation in these traditionally closed communities can indeed provide researchers and healthcare professionals with a better understanding of the actual needs and problems of patients, fostering collaboration between the different stakeholders.^{53,55}

eHealth technologies can help to facilitate this collaboration process.^{49,56-58} The digital aggregation of experiential evidence by patients can not only help to track and predict disease trends but can also provide new insights into comorbidities and treatments.^{36,59,60} In this context, Riley and Gagnier⁶¹ underlined the potential of combining case reports produced by practitioners with patient reports, referring to organisations such as Cancer Commons, Patients Like Me who are promoting a more active form of patient participation within healthcare research. Other examples of web-based collaborative efforts include the CureTogether, MedHelp, and Inspire platforms (for more examples see Swan⁴⁶). Moreover, it has been shown that patient online communities can provide healthcare professionals with valuable insights into patients' needs and perceptions which can in turn be used to anticipate patients' questions or fears, to identify and address topics of public concern, to advocate for the introduction or change of policies, or to prioritise certain areas of research and funding.^{34,35}

One of the key benefits of this novel form of online collaboration between patients, healthcare professionals, and researchers is that findings are disseminated more efficiently, offering immediate clinical utility for patients.^{49,62} Indeed, it has been highlighted how the use of personally controlled health records can foster patient participation as a driving force in the healthcare process. Contrary to electronic health records that grant patients better access and control over their health information, these are entirely controlled by the patient, who decides who can read, write, or modify their personal records.⁵⁷

CHALLENGES

As outlined above, eHealth technologies provide individuals with the possibility to assume a more active role in the healthcare process that is, by no means limited to, taking charge of their own health. However, these developments do not come without risks and potential pitfalls, most of which are related to the lack of control over the quality

of online health information, poor health and/or digital literacy skills, privacy and data protection, and the impact of the use of these new technologies on the doctor-patient relationship.⁶³

As highlighted by Wald et al.,⁶³ the lack of control over the quality, quantity, and access to online health information constitutes a major public health concern. Inadequate utilisation of eHealth technologies may for example, result in patients' inappropriate use of health services, unnecessary anxiety, or adverse events.⁶³⁻⁶⁶ This in turn may have a significant impact on healthcare systems. Research further suggests that patients' use of online resources to gather information may be perceived as a threat to medical authority, thereby putting a strain not only on the doctor-patient relationship but on the healthcare system.^{67,68} Some authors have even attributed the lack of proven success of eHealth initiatives to resistance in adoption. It has been suggested that current adoption and acceptance rates are not yet high enough for eHealth technologies to reach their full potential and that there is a need for healthcare professionals to adapt their practice to the changing healthcare environment.^{46,69} However, findings indicate that healthcare professionals in particular, who are the driving force in promoting eHealth initiatives and patient participation, are concerned with issues related to the performance of eHealth technologies as well as the effort needed to implement and sustain them.^{12,69} Strict policies and regulations present in the healthcare sector may further decelerate progress with respect to eHealth initiatives.⁷⁰

Moreover, despite increasing coverage, there are still parts of the population lacking adequate access to, or knowledge of, modern eHealth technologies. Authors have noted that these technologies may in fact contribute to reinforcing existing health inequalities within the population and that more research is needed to better understand the use of eHealth technologies by medically underserved and disadvantaged social groups.⁷¹⁻⁷³ Findings indicate that particularly people belonging to disadvantaged social groups may lack access, knowledge, and confidence in using eHealth technologies.^{71,73,74} This can in turn intensify existing social inequities and disparities, leading to poor health outcomes in disadvantaged populations, like ethnic minorities, the elderly population, or individuals with low socio-economic status.⁷¹ In this context, some authors have also pointed to the risks of victim-blaming that may result from

the adoption of eHealth technologies that 'nudge' individuals to engage in self-management in their own interests.⁷⁵ By implementing interventions focussed on changing individual behaviours and beliefs rather than addressing overarching social factors responsible for particular health conditions, the responsibility is shifted from the state to the individual.⁷⁶

Another imminent issue related to the adoption of eHealth technologies arises from ethical concerns regarding the privacy and protection of individuals' personal health information.^{77,78} In some instances, this information is willingly generated by individuals themselves, while in others it is the result of imposed data surveillance.⁷¹ The latter in particular raises important questions related to individuals' rights to their own health information: Who has the rights to access, manipulate, or analyse individuals' publicly shared information? Who has the right to draw conclusions from individuals' search queries or information shared on a message board? And can these rights be revoked? These questions become even more critical with the entry of more and more commercial entities, like pharmaceutical or insurance companies, into digital healthcare, as they may have conflicts of interest.⁷⁹ By limiting access to records through patient consent, some of these ethical-legal concerns over data protection and privacy may be attenuated.⁵⁷

CONCLUSION

Digital technologies are breaking down traditional hierarchies, barriers, and power dynamics in healthcare contributing to a democratisation of healthcare. Once dependent on healthcare professionals as the sole source of information, digital technologies in general and the internet in particular, have opened up new opportunities for patient participation that extend beyond the individual level. As patient-helpers and research collaborators, patients can actively contribute to shaping and improving healthcare research and practice by sharing not only their health information but also their insights and experiences.

However, it needs to be kept in mind that all of these technological developments entail certain risks and ethical concerns related to the dissemination and adoption of potentially harmful information that may not only put a strain on healthcare systems and professionals but may indeed jeopardise individuals' health. In this

context, special attention should also be paid to disadvantaged social groups who may lack access, knowledge, or confidence in using the available technologies. This is why the active involvement of healthcare professionals, researchers, and policy makers is essential to the success of patient participation.

The adoption of a more inclusive and collaborative approach to care, that combines medical and

experiential knowledge, has the potential to improve healthcare by ensuring that efforts are aligned and tailored to the actual needs of those affected by a particular health condition. Recognising the challenges this entails requires healthcare institutions and policy makers to develop adequate strategies and incentives to foster this new form of patient participation in healthcare.

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