Queries

No.	Query
	Please confirm that all author information, including names, affiliations, sequence, and contact details, is correct.
	Please review the entire document for typographical errors, mathematical errors, and any other necessary corrections; check headings, tables, and figures.
	Please confirm that the Funding and Conflict of Interest statements are accurate.
	Please ensure that you have obtained and enclosed all necessary permissions for the reproduction of artistic works, (e.g. illustrations, photographs, charts, maps, other visual material, etc.) not owned by yourself. Please refer to your publishing agreement for further information.
	Please note that this proof represents your final opportunity to review your article prior to publication, so please do send all of your changes now.
AQ: 1	

Digital health and citizen engagement: Changing the face of health service delivery

E Oborn and SK Barrett

Warwick University Scarman Road Coventry, CV4 7AL Cambridge

Corresponding author: Eivor Oborn, Warwick University Scarman Road Coventry, CV4 7AL Cambridge, Email: Eivor.Oborn@wbs.ac.uk

Abstract

We highlight two contemporary trends that would benefit from more focused research as they have the capacity to significantly reshape health system delivery in the coming decade. The first is digital health and big data science. The second potential landslide is the growing phenomenon of patient and citizen engagement. This paper outlines the key features and rationale for how digital health and increased engagement can reshape health services, pointing to key areas that warrant careful research by healthcare management scholars. We further point to the relationship and overlap of these two areas and suggest that examining the synergy between these two related trends is a third area of priority in health research.

Keywords

Participation, Information technology, Health service reform, Change, Patient satisfaction, Patient empowerment

Health services have been known as bastions of tradition, where real change has often been to be partial, contested and resisted (Degeling Kennedy Hill 2001, Ferlie et al 2005; Oborn & Dawson 2010; Denis et al 2010). Nonetheless numerous governments have invested significantly for change in health systems with the aim of tackling rising costs, building efficient infrastructure and ensuring adequate professional training. Amongst others, there has been a focus on initiatives to increase the uptake of research and effective best practice across health systems (Swan et al 2007; Exworthy, Bindman, Davies Washington 2006; Oborn et al 2013; Lomas 2003; Ferlie et al 2005), strengthen international collaboration in policy formulation (e.g. European Commission), research (e.g. genome) and disease outbreak (e.g. SARS, Ebola) as well as greater focus on tackling public health disparities and inefficiency (Exworthy & Washington 2006).

Despite these important developments, we wish to highlight two contemporary trends that would benefit from more focused attention as they have the capacity to significantly reshape health system delivery in the coming decade. The first potential landslide to change health services is digital health and the concomitant big data science with which it is associated (Swan 2013). The second potential landslide is the growing phenomenon of patient and citizen engagement (Burelli et al 2012), particularly in the move from passive consumers to more active forms of accountability and contribution (IOM 2001; Lupton 2013). This paper outlines the key features and rationale for how digital health and increased engagement can reshape health services, and thereby pointing to key areas that warrant careful research by healthcare management scholars. We further point to the relationship and overlap of these two areas which has been recently termed, 'the perfect storm' (Rozenblum and Bates 2013). We suggest that examining the synergy between these two related and important trends as a third area of priority in health research.

Digital Health.

In what has been variously described as 'e-health', 'Health 2.0', 'Medicine 2.0' or 'digital health', new digital technologies have become an important means for producing and sharing data related to health (Lupton 2013). Mobile technologies, sensors, genome sequencing, and advances in analytic software now make it possible to capture vast amounts of information about our individual makeup bodily function, lifestyle characteristics and the environment around us (McQuade 2014; Nosta 2013).

By definition, big data in healthcare refers to electronic health data sets so large and complex that they are difficult (or impossible) to manage with traditional software and/ or hardware; nor can they be easily managed with traditional data management methods (Raghupathi & Raghupathi 2014; Minelli et al 2013). Yet, these large data sets which integrate multiple types of different (structured and unstructured) data can be analysed computationally to reveal patterns, trends, and associations, and so inform action (e.g. Kallinikos and Tempini 2014; Swan 2012). The metrics derived from digital sources make visible aspects of individuals and groups that are not otherwise perceptible, because they are able to 'join-up' a vast range of details from multiple sources. Individuals, social groups or populations can be moulded into multiple aggregations that can be manipulated and changed in various ways depending on what aspects are focused on or searched for (Lupton 2013).

When compared with other industries such as banking and travel, healthcare has long been in the backwater of the data revolution. However, this is changing with the rise and pervasiveness of digital technologies (Minelli et al 2013; Lupton 2013). Thus forecasters suggest that the amount and variety of data that can now be captured about our health has the potential to dramatically change how medicine and healthcare more generally is provided (Nosta 2013; Freudenheim 2013; Fox 2012; Byrnes 2014). Yet, the key to digital health is making the vast volumes of data integrated and accessible so that they can be acted on, analysed and used to inform and impact care. Though most health systems are capturing more health

data digitally, for a wide range of reasons most health systems struggle with meaningfully integrating data across relevant systems and making the (integrated) data accessible to those who can act upon the information and knowledge being generated. Research on this challenging area needs to go beyond the technical aspects of systems integration, to consider wider social issues such as power, inequality, ownership and accountability.

One example where digital health *is* making changes in healthcare services is genetics. Traditionally, genetics care processes involved several experts expending considerable time locating applicable research papers to assess a patient's tumour and then identify which mutations have impacted on which cells. IBM and collaborators are trialling new software, called 'Watson' that can be loaded with the patient's genomic data so that a schematic can signal to doctors which cells have altered and been mutated into cancer (Simonite 2014). Whilst previously getting from a genome sequence to a treatment decision could take several months, using Watson, it takes minutes (Simonite 2014). This is a huge leap forward especially in a situation where time, and starting early treatment is crucial, in order to stop the cancer spreading to other areas.

In addition to various professionally orientated technologies that collect and store health data, there are numerous apps for mobile devices that are being used by patients to monitor health conditions or vital functions, a process some have termed enacting the 'quantified self' (Swan 2013; Augemberg 2012). For example diabetics can get devices that constantly monitor blood sugar levels. Data can help inform patients on how to regulate their insulin and food intake; however the data is also being used to generate new research findings by compiling data from the massive stores generated by users (Rojahn 2014). Fitness enthusiasts can use monitors attached to their watches to record calorie consumption and daily exercise levels. In addition to the potential of integrating this data with individual medical records, aggregate and population level profiles can be developed to gain a range of new insight into disease trajectories as well as feasible prevention programs. Using Twitter data, researchers have been able to detect an array of activity, most notably disease outbreaks such as cholera and influenza (Chunara et al 2012; Signorini et al 2011) or data about symptoms like headaches (Linnman 2012). These new forms of data collected through social media are particularly valued for research because they are collected as a by-product of behaviour rather than directly via purposive surveys or interviews, and also because they can be collected in real time.

Healthcare providers are also increasingly subjected to digitalised representations of their services and treatment processes, for example through performance indicators or online rating devices. Service users access social media sites, online forums and their own blogs and websites to provide information about the various services that they have experienced. Diverse interactive digital platforms have been established specifically to elicit lay people's accounts of illness and therapies (Thielst, 2011; Griffiths *et al.*, 2012; Greaves *et al.*, 2013). These multiple forms of data sources are now available as another form of digital intellectual property, owned not by the patients themselves but by the companies that seek to accumulate the

data in archives for repurposing to support digital health initiatives (e.g. Kallinikos and Tempini 2014) and develop new business models with various health service providers (Barrett et al 2015).

However, as with many relatively new technologies there are challenges integrating and making accessible digital data in healthcare. One of the biggest and most important challenges is privacy and security. This is particularly important because companies and organisations must keep the trust of patients in order to keep gathering information. If the patient finds their data being misused they may stop giving permission for the use of their data. Furthermore, technology has advanced so much that it is becoming increasingly difficult to remain anonymous even if individuals do no identify themselves directly in the data; the technology is able to triangulate data and can correlate certain attributes to specific individuals. We suggest the best way forward for companies in healthcare collecting big data is to be as transparent with their statistics and use of statistics as possible (as well as keeping patient data strictly confidential), so as to keep the trust of the patients and not to cross the ' creepy line'. Further health organisations and professionals need to find new ways to partner with technology specialists, build trust and become integrated into the wider digital health ecosystem (Oborn et al 2016).

Patient and citizen engagement.

Though healthcare has been traditionally managed mainly via interpersonal communication between the caregiver and the patient, today social media offers multiple new modes of interaction. Technology also enables patients to inform themselves of their condition and possible treatment options, helping to reduce the historic imbalance in information and knowledge and promoting 'patient choice'. The multiple possible forms of interaction (e.g. with caregivers, other patients, or knowledge repositories) help to shift healthcare away from a primarily professionally led process of disease management to a social phenomenon involving experiential knowledge and ongoing support. This shifts healthcare further away from a solely professional practice to one where patients assume more ownership of their health needs and care practices, for example increasing the profile of self-management.

The role of a passive patient who simply 'receives' services and care has been challenged on many fronts; patients are becoming more engaged in their care and patient perceptions of care has emerged as a major domain of quality (IOM 2001; Jha et al 2008; Grando et al 2015; Darzi 2008; Greaves et al 2013). Thus an important research and management focus in health services has been on how to involve patients and public in healthcare decision making, and thereby incorporate their values and perspectives, with a view to improving care as well as reduce costs and waste (De Vogli 2011). For example, patients are now encouraged to become more active partners, engaged in self-management and giving advice to other patients (Veitch 2010; Gillard et al 2014; Honka et al 2011). Further, patients and public members are increasingly involved in setting research agendas and priorities into areas that interest them, taking some control from the traditional decision makers.

The ongoing change in patient and consumer engagement with health and its management connects along many dimensions with the digital transformation. Patient and service users can share their experiences online, blog about their medications and treatments, and carefully track their symptoms over time. In doing so, they are also expressing and quantifying their medical conditions and their disease histories in new ways, making these both more visible and more knowable to a wider array of stakeholders. Importantly these collaborations and information are not only useful to patients, but also inform health professionals, research based organisations such as pharmaceutical companies or health providers in new ways.

Nonetheless, patients and public are being engaged more as consumers, than citizens with oversight over health as a public good. As consumers, the system is viewed from an individual user perspective and with needs being assessed from the vantage point of self-interest. Yet, a healthy nation and a nation-wide healthcare system could also be considered a resource for the common good. Given the increasing cost burden of healthcare, governments and international health organisations have cautioned that unlimited consumption is not sustainable. As with other scarce resources, sustained consumerist focus by patients and users may lead to a 'tragedy of the commons' (Ostrom 1990). A commons is a large-scale environmental or social system consisting of natural or cultural resources and ideas, the benefits of which are readily accessible to all (Olson 1965). A commons, being accessible to all, yet limited in its supply, is thus prone to misuse, over use and free riding. More research and more services will not sustain a collapse of such commonly held resources; rather new forms of accountability and responsibility may also be required. Although the study of social dilemmas such as the commons has fascinated economists, it has received little attention from health management researchers; yet there is evidence that policy makers are seeking to engage the public in these wider debates (e.g. Wanless 2004).

Thus while there is scope for examining how, and to what effect, patients and service users are increasingly being engaged as consumers and fulfilling an important role in holding governments and providers accountable for health service provision, there is also scope for examining and conceptualising the more political aspects of health services, such as rationing choices, funding allocation as well as how lifestyle choices might influence health service entitlements.

In conclusion, health information technology has traditionally supported patients by enabling better access to records, integrated diagnostics and information searches as supported by Web 1.0 capability. However with Web 2.0 social media and the new generation of Web 3.0 patients can engage with their health and services in new ways. In so doing, patients and service users are also creating new forms of data, evidence, knowledge and support that can offer value to different stakeholders including the public, healthcare providers and possibly regulatory bodies and governments. For example, new care models that put greater emphasis on the role of the patient (Ham C, Dixon A, Brooke B. 2012) are moving toward activities carried out by the patient on a self-management basis by using new mobile technologies. Creating, sustaining, and maximising this synergy between health information technology and patient engagement

thus forms another important area for future health services research. Research might examine how digital technologies that enable patients to interact with other patients, communication with their wider health team or coordination of care across multiple providers might influence health outcomes, care ownership, service efficiencies or access to care remain important yet unanswered questions (Grando et al 2015).

Declaration of conflicting interests

Funding

References

Augemberg K. 2012. Building that Perfect Quantified Self App: Notes to Developers, Part 1. Available online at www.measuredme.com/2012/10/building-that-perfectquantified-self-ap

Barello S., Graffigna G., and Vegni E. 2012. Patient engagement as an emerging challenge for healthcare services: mapping the literature. *Nursing Research & Practice* Available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3504449

Barrett M., Oborn E., Orlikowski W. 2015. Performing business models in on-line health communities, Paper presented at EGOS July Athens.

Chunara R., Andrews JR., Brownstein JS. 2012. Social and news media enable estimation of epidemiological patterns early in the 2010 Haitian cholera outbreak. *Am J Trop Med Hyg*; 86:39–45.

Degeling P., Kennedy J., Hill M. 2001. Mediating the cultural boundaries between medicine, nursing and management— the central challenge in hospital reform. *Health Services Management Research* 14, 36-48.

Darzi A. 2008. *High quality care for all: NHS next stage review final report*. No. 7432. The Stationery Office, UK.

De Vogli R. 2011. Neoliberal globalisation and health in a time of economic crisis. *Social Theory & Health* 9(4): 311-325.

Exworthy M., Bindman A., Davies H., Washington A. 2006. Evidence into Policy and Practice? Measuring the Progress of U.S. and U.K. Policies to Tackle Disparities and Inequalities in U.S. and U.K. Health and Health Care *The Milbank Quarterly*, 84(1) 75–109.

Exworthy M., Washington A. 2006. Organizational strategies to tackle health-care disparities in the USA *Health Service Management Research* 19(1) 44-51.

Fox S. 2012. Pew Research Center's Internet and American Life Project 2012. *Mobile Health* Available online at www.pewinternet.org/*/media//Files/Reports/2012/PIP_MobileHealth2012.pdf

Freudenheim M. 2013. More Using Electronics to Track Their Health. *New York Times* Available online at www.nytimes.com/2013/01/28/health/electronic-health-trackingincreasingly- common-researchers-say.html?_r = 1&

Grando M., Rozenblum R., Bates D. 2015. Information Technology for Patient Empowerment in Healthcare. Berlin, De Gruyter.

Ham C., Dixon A., Brooke B. 2012. Transforming the Delivery of Health and Social Care: The case for fundamental change. Kings Fund Report, London UK.

Honka A·, Kaipainen K., Hietala H., Saranummi N. 2011. Rethinking health: ICT-enabled services to empower people to manage their health. *IEEE Rev Biomed Eng*. 4:119-39.

IOM. 2001. Institute of Medicine Report. Crossing the Quality Chasm: A new health system for the 21 century. Washington DC, National Academy Press.

Jha AK., Orav EJ., Zheng J., et al. 2008. Patients' perceptions of hospital care in the United States. *N Eng J Med*;359:1921–31.

Linnman C., Maleki N., Becerra L., et al. 2012. Migraine tweets—what can online behavior tell us about disease? *Cephalalgia* Published Online First 7 November doi:10.1136/ 0333102412465207.

Nosta J. 2013: The Year of Digital Health. *Forbes* Available online at www.forbes.com/sites/johnnosta/2013/01/02/2013-the-year-of-digital-health/

Oborn E Prince K, Barrett M (2016) '*Knowledge mobilization across inter-organisational health care innovation partnerships: A network ambidexterity perspective*' In Swan, J.A., Newell, S. and Nicolini, D. Mobilizing Knowledge in Healthcare: Challenges for Management and Organization. Oxford: Oxford University Press.

Ostrom E. 1990. Governing the Commons: The Evolution of Institutions for Collective Action Cambridge University Press, Cambridge, UK.

Susan Young Rojahn 2014. June 21, http://www.technologyreview.com/news/529026/blood-sugar-crash/

Rozenblum, R., and Bates D.W. 2013. Patient-centred healthcare, social media and the internet: the perfect storm? *BMJ Quality & Safety* 22(3): 183-186.

Signorini A., Segre AM., Polgreen PM. 2011. The use of twitter to track levels of disease activity and public concern in the U.S. during the Influenza A H1N1 pandemic. *PLoS One* 6: e19467.

Swan M. 2012. Scaling crowdsourced health studies: the emergence of a new form of contract research organization. *Personal Medicine* 9:223–234.

Veitch, K. 2010. The government of health care and the politics of patient empowerment: New Labour and the NHS reform agenda in England. *Law & Policy* 32(3): 313-331.

Wanless D. 2004. *Securing Good Health for the Whole Population* HM Treasury London UK.