The Commodification of Patient Opinion: the Digital Patient Experience Economy in the Age of Big Data

Sydney Health & Society Group Working Paper No. 3

Deborah Lupton

Department of Sociology and Social Policy,

University of Sydney

The Commodification of Patient Opinion: the Digital Patient Experience Economy in the Age of Big Data

Sydney Health & Society Group Working Paper No. 3

Deborah Lupton

Published by the Sydney Health & Society Group, Sydney, Australia, 2013

Abstract

As part of the digital health phenomenon, a plethora of interactive digital platforms have been established in recent years to elicit lay people's experiences of illness and healthcare. The function of these platforms, as expressed on the main pages of their websites, is to provide the tools and forums whereby patients and caregivers, and in cases medical practitioners, can share their experiences with others, benefit from the support and knowledge of other contributors and contribute to large aggregated data archives as part of developing better medical treatments and services and conducting medical research. However what may not always be readily apparent to the users of these platforms are the growing commercial uses by many of the platforms' owners of the archives of the data they contribute. This article examines this phenomenon of what I term 'the digital patient experience economy'. In so doing I discuss such aspects as prosumption, the phenomena of big data and metric assemblages, the discourse and ethic of sharing and the commercialisation of affective labour via such platforms. I argue that via these online platforms patients' opinions and experiences may be expressed in more diverse and accessible forums than ever before, but simultaneously they have become exploited in novel ways.

Introduction

In recent years there has been a turn within some parts of medicine and healthcare towards the use of digital media technologies as a means of measuring and monitoring patients' health states and their healthcare experiences and encouraging self-care. Medicine has been moving inexorably towards a focus on the value of data as an apparently 'objective' source of medical knowledge about the human body for some decades now (Waldby, 2000; Nettleton, 2004; Blaxter, 2009; Mort and Smith, 2009). This emphasis has progressed towards the embracing of the new digital media technologies that have been enabled by Web 2.0 as a means of producing and sharing such data, both by healthcare providers and patients in what has been variously described as 'e-health', 'Health 2.0', 'Medicine 2.0' or 'digital health' initiatives.

I have elsewhere (Lupton, 2013a) employed the term 'the digitally engaged patient' to describe the phenomenon by which lay people have been encouraged to take an active role in producing and consuming information about health and medicine by using digital technologies. In the discourse of the digitally engaged patient two ideals meet. One is the notion of 'patient engagement' or 'patient empowerment' (often termed 'patient activation' in the USA) that has recently emerged in healthcare policy in many developed societies (Andreassen and Trondsen, 2010; Veitch, 2010; Barello *et al.*, 2012; Morden *et al.*, 2012). In this discourse, ideal patient/citizens are positioned as taking active steps in the interests of preserving and promoting their own good health, including accessing relevant information, self-monitoring their health and taking

responsibility for managing their medical conditions. These actions are promoted as having the potential to relieve the financial burden on the healthcare system in the current era of austerity (Veitch, 2010; De Vogli, 2011).

The other ideal contributing to the concept of the digitally engaged patient is that of patients employing appropriate digital media technologies to become more knowledgeable about their health and illness states and medical treatments and to provide information to other patients and healthcare providers. Digital media technologies are now promoted for use in patient self-care and self-monitoring, conducting medical encounters remotely and collecting data about healthcare use (Adams, 2011; Swan, 2012a, 2012b; Lupton, 2013a). In some forums lay people are encouraged to 'digitise' themselves: that is, render their bodies into digital form using the new wearable monitoring technologies to produce data that may be quantified and transmitted to others for their perusal (Topol, 2010; Lupton, 2012, 2013b; Swan, 2012b, 2012c). In others, they are encouraged to use social media to engage with other patients by sharing experiences of their conditions and treatments and relating accounts of healthcare encounters (Orizio *et al.*, 2010; Adams, 2011, 2012; Griffiths *et al.*, 2012; Mazanderani *et al.*, 2012).

Online patient support networks have existed for some time as a means of patient support and information sharing. Several sociological research studies in the late 1990s and into the first decade of the 2000s were devoted to exploring how lay people used these internet technologies for seeking information and engaging in online patient support communities (for a recent overview of this research, see Kivits, 2013). The term 'e-scaped medicine' (Nettleton and Burrows, 2003; Nettleton, 2004) was employed in relation to Web 1.0 technologies to describe the ways in which medical information and knowledge had apparently moved beyond the boundaries of the clinic and the medical journal to online sites that were easily accessible to lay people as well as providing them with the opportunity to contribute to knowledge about medical and health issues.

In the Web 2.0 era, further technological developments have brought with them even greater opportunities for lay people to not only seek information across an ever-growing array of websites and blogs directed at health and medical issues but also to engage in patient support and activism communities, the evaluation of medical care and contribute to the aggregation of data about medical procedures and drug therapies for specific illnesses and diseases. Through social media platforms dedicated to specific illnesses or conditions such as Facebook pages, Twitter hashtags and YouTube videos of patient experiences and medical techniques and therapies, as well as the more traditional format of online discussion sites, information can be exchanged, discussion facilitated and activism mobilised across the globe in real-time. Not only can people now blog about their illness and medical experiences, they can make and upload their own YouTube videos and Instagram images, and update their social media profiles constantly with comments and data about their health state and treatments. There is now much talk of patient 'participation' , 'collective knowledge of the masses' (or in more recent web-parlance, 'crowdsourcing') and 'collaborative' relationships between

patients or lay people and healthcare professionals and providers in terms of producing and sharing data on medical and health topics.

Healthcare providers and organisations are also increasingly subjected to digitalised representations of their services and assessments in this new age of digital health. They have begun to use social media sites, online forums and their own blogs and websites to provide information about their services and about preventive health and medical treatments in general. These sites also often allow people to make comments about their experiences with healthcare providers and even to formally evaluate and rank them online. Furthermore, numerous 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; Rozenblum and Bates, 2013).

It is upon these latter-mentioned social media platforms that I focus in this article. I discuss what I term 'the digital patient experience economy', in which patients' online accounts and details of their medical conditions and their ratings and opinions of healthcare providers and institutions have become valued not only for the support and information they offer to other patients but also for their increasing commercial value they have for other actors. These data have become treated as another form of digital intellectual property, owned not by the patients themselves but by the companies that encourage patients to upload their experiences that accumulate in the data archives they own and over which they have control or which profit from the harvesting of these data and on-selling them to their clients. In the ensuing discussion I draw in particular on writings within sociology, communication and media studies and cultural studies on the phenomena of prosumption and big data, and its collection, manipulation and commercialisation in the context of an increasing metricised everyday life as it enacted in digital transactions.

The overarching theoretical perspective structuring the present discussion is that derived from science and technology studies, sometimes referred to as the material semiotic or the socio-technical approach. This perspective views material objects such as digital media technologies as active participants that shape human bodies and selves as part of heterogeneous networks. Human actors (the users of these technologies) participate in configuring the meaning and uses of the technologies, just as technologies themselves enact human action, embodiment and meaning (see, for example, Timmermans and Berg, 2003; Mol and Law, 2004; Nicolini, 2007; Oudshoorn, 2011). The concept of the 'assemblage', also derived from science and technology studies as well as Deleuze and Guattari's writings (Marcus, 2006), is employed as a way of acknowledging both the material and non-material, the human and the non-human, the fleshly and the ideational in ever-changing configurations. It therefore recognises the dynamic nature of people's interactions with technologies in a world in which the digital is increasingly part of everyday lives, social relationships and concepts of subjectivity and embodiment.

Prosumption, big data and metric assemblages

The new digital health technologies participate in the growing accumulation of what has been termed 'big data' or 'transactional data': that is, the vast quantities of data, both quantitative and qualitative, that are the digital traces or by-products of users' interactions and transactions with digital media technologies. These digital traces include the data that are gathered on users' activities when they visit websites, including the products they buy, the telephone numbers they call and the government agencies and commercial entities with which they interact. It also includes 'user-generated content', or data that have been intentionally uploaded to social media platforms by users as part of their participation in these sites. This phenomenon has been entitled 'prosumption' by some writers; a term used to convey the simultaneous production and consumption of content (Beer, 2009; Beer and Burrows, 2010; Ritzer and Jurgenson, 2010; Ritzer *et al.*, 2012).

While prosumption has been a feature of capitalist economies for some time, the new digital media technologies have provided the conditions for an expansion of these activities and new ways of commoditising the data that are generated from them (Ritzer *et al.*, 2012). The data generated both by digital prosumption and by routine transactions have become important sources of commercial information for the 'new media capitalists' (Gehl, 2011, p. 1230). These data are particularly valued 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. Users of these new digital media platforms have subsequently become 'a valuable source of digital artifact processing' for the platforms' owners (Gehl, 2011, p. 1229). The data they prosume are used to construct profiles of consumer habits and to market to consumers in ever more detailed and personalised ways as well as by government agencies to track populations' behaviours (Beer, 2009; Adkins and Lury, 2011; boyd and Crawford, 2012; Beer and Burrows, 2013).

Sociologists have begun to direct attention at the ways in which questions of measure and value have begun to permeate many aspects of social life (Savage and Burrows, 2007; Adkins and Lury, 2011; Ruppert, 2011; Burrows, 2012). They argue that population metrics, in particular, are a specific means of constructing certain metric assemblages of individuals or populations using digital data gathered from a variety of sources. The metrics derived from digital databases make visible aspects of individuals and groups that are not otherwise perceptible, because they are able to 'join-up' a vast range of details derived from various sources. Individuals and social groups or populations are thereby rendered into multiple aggregations that can be manipulated and changed in various ways depending on what aspects are focused on or searched for. Behaviours and dispositions are interpreted and evaluated with the use of the measuring devices, complex algorithms and opportunities for display afforded by these technologies, allowing for finer detail to be produced on individuals and populations (Adkins and Lury, 2011; Cheney-Lippold, 2011; Ruppert, 2011, 2012; Burrows, 2012). These metrics may be used to make assessments about the performance of people,

groups and things (for example, government agencies or schools, and in the case of medicine, healthcare services or therapies) (Ruppert, 2012).

Metrics are both drawn from the actions and interactions of individuals and also shape them, either by external agencies using the metrics to influence or act upon individuals or by individuals themselves using the metrics gathered about them to change their behaviour in response, so that a continual loop is established between data and behaviour (Ruppert, 2011, 2012). Concepts of citizenship and consumers are now frequently phrased via the discourses of metricisation, as governments and private enterprises laud the apparent benefits offered by the accumulation of big data via digital transactions. It is assumed that as long as efficient systems are put into place that are able to gather, share and interpret these data, this will lead to greater governmental efficiency and the flourishing of business enterprises as a result of the production of better knowledges about citizens/consumers (boyd and Crawford, 2012; Ruppert, 2012).

These discourses are clearly evident in the digital health literature, in which the digitally engaged patient is configured as ideally developing both self-knowledge and knowledge of healthcare providers and the healthcare system is represented as benefiting from accumulating large masses of data about patients, treatment outcomes and healthcare providers. The digital health phenomenon as it configures the ideal of the digitally engaged patient seeks to privilege the body that is measured, monitored, quantified and visualised in ever greater detail through the efforts of the patient as well as healthcare professionals (Lupton, 2012, 2013b). The lure and potential of big data have had a major impact upon healthcare policy. There is now much focus on and discussion concerning the power of large masses of data gathered by digital technologies both to inform patients about their own bodies and health states and also to provide information to healthcare providers about the health states of populations and the use of healthcare (Adams, 2011; Harris, 2012; Swan, 2012b; Ayers *et al.*, 2013; Greaves *et al.*, 2013; Rozenblum and Bates, 2013). These data include blogs posts and comments on health-related websites and social media platforms, online medical records, digital records of healthcare use, patients' ratings of healthcare workers and institutions and the data collected by self-tracking mobile or wearable devices or websites. These data are commonly represented in the medical and healthcare literature as providing an unprecedented opportunity to improve medical care (Swan, 2012a, 2012b; Topol, 2012), as well as in media reports, suggested in the headline of one news item: 'Better medicine, brought to you by big data' (Harris, 2012).

Here again, prosumption is an integral concept in understanding the ways in which digital technology users interact with their technologies, particularly in a context in which they are invited (or mandated) to produce their own personalised data, as in the project of 'digitising the self', or to rate others such as healthcare providers. Representations of the value of 'digitising' oneself and 'measurement-based medicine' suggest that data in themselves (whether they are the personalised data individuals collect by using self-tracking or self-care technologies or the big data accumulated on the internet from the activities of a mass of individuals) are more powerful and accurate

sources of knowledge than are other means of collecting information about people's behaviour.

The new patient support online platforms

As part of the digital health phenomenon, a number of online platforms have been developed that have been designed explicitly to encourage patients and their caregivers to share their experiences with each other and contribute to a massive database of information. These platforms include CarePages (*CarePages*, 2013), PatientsLikeMe (*PatientsLikeMe*, 2013), Health Unlocked (*Health Unlocked*, 2013), CureTogether (*CureTogether*, 2013), Smart Patients (*Smart Patients*, 2013), Treato (*Treato*, 2013) and Patient Opinion (*Patient Opinion*, 2013). Many of these websites have attracted large numbers of regular users. The developers of Health Unlocked, for example, claim that it is the most well-used patient support site in the UK, receiving over 700,000 visits a month, while it is asserted on the CarePages site that it receives over a million visits a month.

   Digital health platforms often emphasise the opportunities they provide for users not only to self-track details of their disease or condition but also to contribute to a large mass of aggregated data. Thus, for example, on the PatientsLikeMe website, lay people are invited to register as members to gain access to others' uploaded data on their disease or health condition and to upload their own data by creating their personal health profile. This then allows users to compare their own experiences with others. Such physiological markers as severity of symptoms, quality of life, mood, symptom triggers, responses to new drugs or therapies and side-effects may be tracked on the website and shared with other users. The website aggregates the data from all users with the same condition as well as providing personalised graphs and charts that allows users to identify patterns in their experiences. The focus is on quantifying these markers as much as possible, in what the website's co-founder, Jamie Heywood, describes as 'measurement-based medicine' (quoted in Marketwire, 2013).

   Recent innovations in online technologies directed at eliciting data voluntarily from patients have explored ways to connect diverse sources of data for the use of both patients and healthcare providers. The HealthTap (*HealthTap*, 2013) website and related app is explicitly directed at both patients and doctors. It provides information to patients and connects them with healthcare providers, allowing them to ask questions about health and medical issues that are answered by doctors, and to search for doctors in their area and make appointments online. The doctors who participate answer questions and at the same time are able to build a professional profile and online reputation and advertise their services. Medical practices, clinics and hospitals and digital technology developers are also encouraged to participate, providing information on their services and reaping the benefits of the data that are produced by the contributions of patients and doctors. Doctors' answers to patients' questions are aggregated so that the patients can see the level of agreement and seek second opinions, while doctors are ranked according to the quality of their responses. Such platforms,

therefore, represent both patients and doctors as the generators and beneficiaries of the data collected. In this digital data economy there is a mutual exchange of data, each reliant on the other party to participate in the exchange to produce the value of the data.

Other platforms have been designed specifically to encourage patients to share data they have collected on their bodies with healthcare providers and researchers. The Ginger.io platform (*Ginger.io*, 2013) has been developed as one such tool. Healthcare providers are encouraged to suggest to patients with diabetes, adult ADHD, heart disease and inflammatory bowel disease that they install the Ginger.io app on their digital device (such as a smartphone). The app then automatically collects information on the patients' bodily movements and call and texting habits (the websites calls this information 'passive data'). Other health-related information is collected when the patient regularly enters it into the app after receiving a prompt (referred to as 'active data'). These data are then provided to healthcare providers and researchers to predict individual behaviours and identify trends in the aggregate data. Patients are told that these data will both help themselves and also to medical research that will eventually result in better care for themselves and others with their condition. The platform's motto is 'Big Data, Better Health'.

The discourses of these sites focus on patient support and the democratic sharing of information, allowing contributors to benefit from others' knowledge and experience of their medical conditions. 'Build your support circle' it is claimed on the CarePages website. The CureTogether website asserts that users 'will love CureTogether' because: 'You'll learn from people going through the same thing.' Patient support websites often include statements about the importance of sharing as the integral part of what they are trying to achieve. The developers of PatientsLikeMe, for example, claim on a page entitled 'Openness Policy', that: 'we believe sharing your healthcare experiences and outcomes is good. Why? Because when patients share real-world data, collaboration on a global scale becomes possible. New treatments become possible. Most importantly, change becomes possible.' Some sites, such as Patient Opinion, focus more narrowly on eliciting patients' experiences of health services (in this case, UK's National Health Service) with the aim of directly informing service providers of the positive and negative experiences that patients have so that services may be improved: 'We pass your stories to the right people to make a difference.'

Incorporated into this ethic of sharing and democratisation, and the focus on the needs and welfare of the patients who contribute their experiences that dominate in such statements on many patient support websites, is the act of making these data increasingly available (in aggregated or anonymised form) to medical researchers, pharmaceutical companies, medical device makers, healthcare policy makers and healthcare providers. As evidenced by the words quoted above from PatientsLikeMe, it is argued that such 'sharing' is part of the project of 'making patients' lives better'. As part of a general 'rhetoric of democratisation' and 'participatory cultures' (Beer, 2009; Beer and Burrows, 2010), it is suggested that lay people become 'good citizens' by participating in these technologies and contributing their experiences so that they may be aggregated for the greater good (Adams, 2011, 2012). Being a digitally engaged

patient, therefore, involves considering the benefits offered by one's participation to others as well as to oneself.

The digital patient experience economy

There are various ways in which patients' experiences of illness and healthcare have been commodified in recent decades. These include the publication of books or magazine articles relating a particular individual's experiences of disease or even the dying process, interview material from patients to contribute to news media reports or documentaries and the use of illness narratives for the purposes of eliciting donations for charities devoted to patient support or medical research. Sociologists and other researchers have frequently drawn upon narratives of illness and healthcare experiences to conduct research on these topics (Mazanderani *et al.*, 2013). Patients' prosumption activities on social and other digital media platforms represent another, rapidly expanding way in which their illness narratives may be commodified.

It has been contended that the labour of producing blog posts or other media communicative texts about one's illness or medical treatments is outside the field of commercial value and that instead it has personal value as communicative, ethical and affective labour (Radin, 2006; Adams, 2011; Mazanderani *et al.*, 2012, 2013; McCosker and Darcy, 2013). As noted above, the ethic of sharing in social media – conveying one's thoughts and feelings to others as a means of connection and support, as a type of gift -- is a major dimension of such platforms. This concept of sharing excludes the use of these data for commercial purposes (John, 2013). However, while in some cases these data are offered to any user free of charge, increasingly they are provided for a fee, incorporating a financial as well as a philanthropic motive into the data sharing project that these sites seek to establish.

Indeed a major difference between the newer patient support websites that have emerged in the Web 2.0 era and earlier patient support and information sites is that they have been established not by patient communities themselves or by charities or other non-profit organisations addressed at supporting specific medical conditions, but by web entrepreneurs or pharmaceutical companies specifically seeking to use the data collected for commercial reasons. In the past, pharmaceutical companies have established or financially supported some patient support websites. This support is not always readily apparent to visitors to these sites (Ball *et al.*, 2006; Read, 2008). The newer patient support websites are building on this commercial involvement in other ways: particularly in the use of the data uploaded by the sites' users. While the initial impetus for developing the website may have come from personal experiences of illness or those of a family member (as is the case of PatientsLikeMe, for example, one of the largest and best established sites), many of the more recent sites have been established with a predominantly commercial motive. These motives include selling advertising, goods and services to users and on-selling data from their archives to third parties.

The arena of clinical trials for new drugs is one form of medical knowledge generation where crowdsourcing via patient-focused social media platforms has been

employed for some years as an alternative to the expensive traditional format of the standard clinical trial. This approach has drawn on the self-interest and voluntary labour of patients and their willingness to self-experiment rather than to be co-opted into the traditional randomised controlled trial to contribute to the innovation process (Cooper, 2012). The recruitment of patients for clinical trials via patient support sites has now become more formalised. PatientsLikeMe, for example, has developed tools for matching registered users with global clinical trials of new therapies and drugs, while Smart Patients provides direct information and information feeds about clinical trials to users.

Other websites promoting patient engagement and support using social networking are funded by companies that then use the websites to sell advertising and the data collected to interested parties, such as health product marketers. This is the strategy developed by Alliance Health Networks (*Alliance Health Networks*, 2013), for example. They have established more than 50 condition-specific social networks on websites with related apps (including such condition as diabetes, obesity, Alzheimer's disease, arthritis, ADD and epilepsy) that allow patients to share their experiences with others, ask questions of experts, access news articles on their condition, post product reviews and so on. The owners are quite open in their website about their use of these social networks to provide information to health marketers, noting that: 'Each platform includes myriad ways for marketers to engage with consumers – from banner ads and offer programs to microsites, targeted email campaigns and sponsored educational newsletters.' This information is, however, found on a page directed at potential commercial clients rather than at the patients who use the site. On the patient community sites, for example Diabetic Connect (*Diabetic Connect*, 2013), it is noted on the 'About' page that the site 'is owned and operated by Alliance Health. Our mission is to create social health networks that connect people to support communities for a growing number of health conditions.' No mention is made here about the commercial mission of Alliance Health: this is only made clear if the user takes the trouble to click through to the Alliance Health website itself or to read through the Privacy Policy page.

As this example suggests, it often not until people access the fine print in sections of the sites such as their terms and conditions of use and their privacy policy that the ways in which the sites' owners employ users' data in various ways for commercial purposes is made apparent. While some sites include a direct statement concerning 'how we make money', this is not always made entirely clear. For example, it is noted on some websites that the data aggregated on the site by users' contributions are used 'to conduct scientific studies' or 'research', with no direct mention made of the fees that the developers may receive for providing these data to their clients. On some sites it is not until an individual begins the 'sign up' process to become a contributing 'member' that the terms and conditions and privacy policies are revealed. Some platforms represent themselves as a 'free service' for those who contribute data that also offers 'paid services' for those who use it (for example, Health Tap). The PatientsLikeMe 'About Us' page describes their model as 'for-profit' but 'not one with a "just for profit" mission',

suggesting their dual purpose: to seek both to help patients and also to use the data members provide for the developers' own financial gain as part of a business enterprise.

In a further development, some platforms have been developed specifically to harvest or 'scrape' the web for patients' accounts of their experiences in blogs and forums. Treato (*Treato*, 2013) is one such example. It focuses on harvesting patients' accounts of drug therapies across the spectrum of social media and other digital platforms, including seeking out accounts of how well drugs work, their side-effects and why patients may switch one brand for another. It uses a form of semantic analysis called 'Natural Language Processing' to convert the written accounts of patients into quantified data. Treato provides free access to the general data that are collected but also offers a more targeted service to pharmaceutical companies that incurs fees. This company is merely one of many engaged in data brokering and web scraping for commercial reasons in what is a rapidly expanding industry (Gehl, 2011).

Given the increasing commercial value of the data uploaded to patient opinion platforms, it is not surprising that the representation of patient experience as intellectual property is rendered explicit in the terms and conditions of some of the newest websites. For example, the developers of the recently-established Smart Patients website note in the site's Frequently Asked Questions page under the question 'How do you make money?' that: 'We compile anonymous data from the website and conduct voluntary surveys and projects among our members to answer questions of biopharma companies, scientists, researchers, and educators.' In this platform's Terms of Agreement section it is made clear that what the developers term 'user content' is their intellectual property. As part of protecting this property, users are informed that they are not permitted to data-mine or scrape the site systematically, and they must agree to these terms before signing up as members.

Discussion and conclusion

I have argued in this article that a new form of patient assemblage, the digitally engaged patient, and a new form of data assemblage, the patient experience as it is rendered into digital data formats, are configured via the most recent digital media technologies as they have been employed in relation to health and healthcare. In the context of the currently dominant ideal of the digitally engaged patient in healthcare policy, the role of gathering data on oneself and employing these data both for self-interested purposes and for the benefit of others is privileged. The accumulation of big data that is afforded by the new digital media technologies is positioned as an innovative way forward for healthcare, supposedly providing better, more informed and more economically efficient medical treatment.

Prosumption as it takes place on such websites involves a flow of data between the prosumers themselves (patients, caregivers and sometimes medical practitioners) and also to other interested parties who may or may not pay for these data and who then use the data to market or evaluate their goods or services to the patient, caregiver or medical practitioner. Just as other forms of digital prosumption have been

expropriated by capitalist enterprises in the interests of profit (Gehl, 2011; Rey, 2012), so too patient experience prosumption has generated new avenues for commercial endeavours by enterprises that have seen the opportunity for expropriating its value. In the new data economies of digital data production and harvesting, the digital patient experience economy hinges on the commercialisation of written accounts or rankings by lay people of their medical conditions, their treatments and their interactions with healthcare providers. Lay people's experiences and opinions as they are expressed in digital media forums, with all the suffering, hope, despair, frustration, anger and joy that are often integral aspects of coping or living with a medical condition or surgical procedures, have become commercial properties for market exchange. They are not offered and nor do they receive financial compensation for providing their experiences. The value they derive is non-commercial, while the exchange value of the data they prosume is accumulated by the companies that provide the platforms for patients to share their experiences or trawl the web to harvest the data and render it into a form that is valuable for commercial entities.

Given that the information about the commercial uses to which data archives are put is often buried on these platforms and must be actively searched for, or else is couched in ambiguous terms, it is likely that many of the patients who engage in social media networks and patient experience and opinion platforms for personal or altruistic reasons are not fully aware of the extent to which their accounts have become valuable commodities. Patients do potentially benefit from their prosumption activities on patient support or opinion websites and other digital platforms in which they can recount their experiences, such as blogs and social media sites such as Facebook and Twitter. They may derive use value, if not exchange value (Rey, 2012), from the immaterial products (data) they produce and consume. Research suggests that many patients appreciate the greater access to information about their conditions and the emotional support, opportunity to express themselves, feeling part of a community and greater sense of control over their illness that they may gain from their participation in such forums (Lamberg, 2003; Radin, 2006; Im *et al.*, 2007; Bender *et al.*, 2011; Isupova, 2011; Wicks *et al.*, 2012; Mazanderani *et al.*, 2013; McCosker and Darcy, 2013; Yli-Uotila *et al.*, 2013).

Lay people may also engage in resistance to dominant medical forms of knowledge and power via websites such as pro-anorexia community sites (Fox *et al.*, 2005) or fat activism online communities (Saguy and Riley, 2005). They may further gain satisfaction from contributing to scientific research, the production of better understanding of their condition or the provision of facilities that may benefit themselves or others with their condition (Radin, 2006; Adams, 2011; Mazanderani *et al.*, 2013). Data from the PatientsLikeMe website, in particular, have been used for several academic research studies that have provided insights into the efficacy or side-effects of medical treatments for chronic diseases such as multiple sclerosis and Parkinson's disease (Swan, 2012a).

What is lost in the utopian claims of the big data enterprise is the awareness that data -- digital or otherwise, big or small -- are not neutral fonts of information. They are

political, messy, incomplete, and are not only reflective but also constitutive of subjects, identities and communities (Beer, 2009; Cheney-Lippold, 2011; Ruppert, 2011; boyd and Crawford, 2012). As Ruppert (2011, p. 225) puts it; 'Data are not simply "collected", but are the result of multiple sociotechnical arrangements of technological and human actors that configure agency and action.' It should also be acknowledged that not only are digital data themselves social products, but so too are the web hyperlinks, search engines and engineering of the infrastructure of the internet itself that structure and delimit the ways in which people are able to search for and find relevant information or indeed upload and manipulate their own data (Seale, 2005; Mager, 2009; Adams, 2011; Halford *et al.*, 2013). Those groups and organisations that have access to greater resources are able to pay for technical expertise and for their websites to achieve greater visibility. As a consequence, in relation to health or medical-related information, dominant medical views tend to receive prominence over alternative perspectives offered from outside medicine, including those of patient activists and support groups (Seale, 2005; Oudshoorn and Somers, 2006; Mager, 2009). Patients themselves are rarely encouraged to participate in the design of websites (Oudshoorn and Somers, 2006). When lay people are uploading their experiences to patient support or healthcare rating and evaluation websites, they must conform to the organisational demands of these platforms, which typically do not offer full scope for criticism of healthcare providers. Therefore the sites themselves monitor and discipline patients who are giving their opinion as part of official forms of monitoring healthcare quality and patient satisfaction (Adams, 2011, 2012).

Nor do users have control over the products of the emotional and altruistic labour that they invest in sharing their experiences on online sites. The use value of the information commodities lay people prosume is restricted by the limits imposed by the platform they are using. Indeed it can be extremely difficult for people to retrieve for their own purposes the data they upload to patient experience platforms, enter as part of their electronic medical records or that are generated as part of their participation in clinical trials. Lay people's efforts to collate their own small data aggregates may be frustrated in the face of the interests of commercialised big data: hence the recent development of the Small Data website (*Small Data*, 2013), designed to assist them to gain access to their data (Heussner, 2013).

As this suggests, while medical knowledge and authority may have 'e-scaped' to some extent from the clinic, even in this age of Web 2.0, big data and dominant rhetorics of citizen participation in knowledge generation via their prosumption activities on the internet, there remain limits to the contribution that lay people are able to make to medical knowledge, the authority they are able to develop and the benefits they are able to accrue. The digitally engaged patient as an ideal-type is configured through dominant and often continuing hierarchies of power and knowledge operating as part of the new digital media economies. Patients' opinions and illness narratives may be expressed in more diverse and accessible forums than ever before, but simultaneously they have become exploited in novel ways in the era of digital health.

Little sociological research (or indeed any other type of research) has been conducted on the uses to which lay people are putting the newer forms of patient support and opinion websites discussed in this article. We know little about to what extent the people who contribute to these sites are aware of how their data are used by third parties, commercially or otherwise; how they feel about this use if they are aware of it; how they experience the sites as users; and to what extent they may wish to gain access to their own data for their own purposes. This is a clear and important avenue for future research.

References

Adams, S. (2011) Sourcing the crowd for health services improvement: The reflexive patient and 'share-your-experience' websites. *Social Science & Medicine* 72(7): 1069-1076.

Adams, S. (2012) Post-panoptic surveillance through healthcare rating sites. *Information, Communication & Society* 16(2): 215-235.

Adkins, L., and Lury C. (2011) Introduction: special measures. *The Sociological Review* 59(s2): 5-23.

Alliance Health Networks (2013) http://www.alliancehealthnetworks.com

Andreassen, H., and Trondsen M. (2010) The empowered patient and the sociologist. *Social Theory & Health* 8(3): 280-287.

Ayers, J., Althouse B., Allem J.-P., Rosenquist J.N., and Ford D. (2013) Seasonality in seeking mental health information on Google. *American Journal of Preventive Medicine* earlyview online.

Ball, D.E., Tisocki K., and Herxheimer A. (2006) Advertising and disclosure of funding on patient organisation websites: a cross-sectional survey. Available at http://www.biomedcentral.com/1471-2458/6/201

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

Beer, D. (2009) Power through the algorithm? Participatory web cultures and the technological unconscious. *New Media & Society* 11(6): 985-1002.

Beer, D., and Burrows R. (2010) Consumption, prosumption and participatory web cultures: an introduction. *Journal of Consumer Culture* 10(1): 3-12.

Beer, D., and Burrows R. (2013) Popular culture, digital archives and the new social life of data. *Theory, Culture & Society* early view online.

Bender, J.L., Jimenez-Marroquin M.-C., and Jadad A.R. (2011) Seeking support on Facebook: a content analysis of breast cancer groups. Available at http://www.jmir.org/2011/1/e16

Blaxter, M. (2009) The case of the vanishing patient? Image and experience. *Sociology of Health & Illness* 31(5): 762-778.

boyd, d., and Crawford K. (2012) Critical questions for Big Data: provocations for a cultural, technological, and scholarly phenomenon. *Information, Communication & Society* 15(5): 662-679.

Burrows, R. (2012) Living with the h-index? Metric assemblages in the contemporary academy. *The Sociological Review* 60(2): 355-372.

CarePages (2013) https://www.carepages.com

Cheney-Lippold, J. (2011) A new algorithmic identity: soft biopolitics and the modulation of control. *Theory, Culture & Society* 28(6): 164-181.

Cooper, M. (2012) The pharmacology of distributed experiment – user-generated drug innovation. *Body & Society* 18(3-4): 18-43.

CureTogether (2013) http://curetogether.com

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

Diabetic Connect (2013) http://www.diabeticconnect.com/about

Fox, N., Ward K., and O'Rourke A. (2005) Pro-anorexia, weight-loss drugs and the internet: an 'anti-recovery' explanatory model of anorexia. *Sociology of Health & Illness* 27(7): 944-971.

Gehl, R.W. (2011) The archive and the processor: The internal logic of Web 2.0. *New Media & Society* 13(8): 1228-1244.

Ginger.io (2013) http://ginger.io

Greaves, F., Ramirez-Cano D., Millett C., Darzi A., and Donaldson L. (2013) Harnessing the cloud of patient experience: using social media to detect poor quality healthcare. *BMJ Quality & Safety* 22(3): 251-255.

Griffiths, F., Cave J., Boardman F., Ren J., Pawlikowska T., Ball R., Clarke A., and Cohen A. (2012) Social networks – The future for health care delivery. *Social Science & Medicine* 75(12): 2233-2241.

Halford, S., Pope C., and Weal M. (2013) Digital futures? Sociological challenges and opportunities in the emergent Semantic Web. *Sociology* 47(1): 173-189.

Harris, D. (2012) Better medicine, brought to you by big data. Available at http://gigaom.com/2012/07/15/better-medicine-brought-to-you-by-big-data

Health Unlocked (2013) http://www.healthunlocked.com

HealthTap (2013) https://www.healthtap.com

Heussner, K.M. (2013) It's not just about big data: here's why small data matters to your health. Available at http://gigaom.com/2013/04/17/its-not-just-about-big-data-heres-why-small-data-matters-to-your-health

Im, E.-O., Chee W., Lim H.-J., Liu Y., Guevara E., and Kim K.S. (2007) Patients' attitudes toward internet cancer support groups. *Oncology Nursing Forum* 34(3): 705-712.

Isupova, O.G. (2011) Support through patient internet-communities: Lived experience of Russian in vitro fertilization patients. *International Journal of Qualitative Studies on Health and Well-Being* 6(3): 1-13.

John, N.A. (2013) Sharing and Web 2.0: The emergence of a keyword. *New Media & Society* 15(2): 167-182.

Kivits, J. (2013) E-health and renewed sociological approaches to health and illness. In: K. Orton-Johnson and N. Prior (eds.) *Digital Sociology: Critical Perspectives*. Houndmills: Palgrave Macmillan, pp. 213-226.

Lamberg, L. (2003) Online empathy for mood disorders: patients turn to internet support groups. *Journal of the American Medical Association* 289: 3073-3077.

Lupton, D. (2012) M-health and health promotion: the digital cyborg and surveillance society. *Social Theory & Health* 10: 229-244.

Lupton, D. (2013a) The digitally engaged patient: self-monitoring and self-care in the digital health era. Submitted for publication.

Lupton, D. (2013b) Quantifying the body: monitoring, performing and configuring health in the age of mHealth technologies. *Critical Public Health* early view online.

Mager, A. (2009) Mediated health: sociotechnical practices of providing and using online health information. *New Media & Society* 11(7): 1123-1142.

Marcus, G. (2006) Assemblage. *Theory, Culture & Society* 23(2-3): 101-106.

Marketwire (2013) PatientsLikeMe unveils new tool to match patients with clinical trials worldwide. Available at http://www.marketwire.com/press-release/patientslikeme-unveils-new-tool-to-match-patients-with-clinical-trials-worldwide-1767363.htm

Mazanderani, F., Locock L., and Powell J. (2012) Being differently the same: The mediation of identity tensions in the sharing of illness experiences. *Social Science & Medicine* 74(4): 546-553.

Mazanderani, F., Locock L., and Powell J. (2013) Biographical value: towards a conceptualisation of the commodification of illness narratives in contemporary healthcare. *Sociology of Health & Illness* early view online.

McCosker, A., and Darcy R. (2013) Living with cancer: affective labour, self-expression and the utility of blogs. *Information, Communication & Society* early view online.

Mol, A., and Law J. (2004) Embodied action, enacted bodies: the example of hypoglycaemia. *Body & Society* 10(2-3): 43-62.

Morden, A., Jinks C., and Ong B.N. (2012) Rethinking 'risk' and self-management for chronic illness. *Social Theory & Health* 10: 78-99.

Mort, M., and Smith A. (2009) Beyond information: intimate relations in sociotechnical practice. *Sociology* 43(2): 215-231.

Nettleton, S. (2004) The emergence of e-scaped medicine? *Sociology* 38(4): 661-679.

Nettleton, S., and Burrows R. (2003) E-scaped medicine? Information, reflexivity and health. *Critical Social Policy* 23(2): 165-185.

Nicolini, D. (2007) Stretching out and expanding work practices in time and space: The case of telemedicine. *Human Relations* 60(6): 889-920.

Orizio, G., Schulz P., Gasparotti C., Caimi L., and Gelatti U. (2010) The world of e-patients: A content analysis of online social networks focusing on diseases. *Telemedicine Journal and e-Health* 16(10): 1060-1066.

Oudshoorn, N. (2011) *Telecare Technologies and the Transformation of Healthcare*. Houndmills: Palgrave Macmillan.

Oudshoorn, N., and Somers A. (2006) Constructing the digital patient: Patient organizations and the development of health websites. *Information, Communication & Society* 9(5): 657-675.

Patient Opinion (2013) https://www.patientopinion.org.uk

PatientsLikeMe (2013) http://www.patientslikeme.com

Radin, P. (2006) 'To me, it's my life': Medical communication, trust, and activism in cyberspace. *Social Science & Medicine* 62(3): 591-601.

Read, J. (2008) Schizophrenia, drug companies and the internet. *Social Science & Medicine* 66(1): 99-109.

Rey, P.J. (2012) Alienation, exploitation, and social media. *American Behavioral Scientist* 56(4): 399-420.

Ritzer, G., Dean P., and Jurgenson N. (2012) The coming of age of the prosumer. *American Behavioral Scientist* 56(4): 379-398.

Ritzer, G., and Jurgenson N. (2010) Production, consumption, prosumption: the nature of capitalism in the age of the digital 'prosumer'. *Journal of Consumer Culture* 10(1): 13-36.

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.

Ruppert, E. (2011) Population objects: interpassive subjects. *Sociology* 45(2): 218-233.

Ruppert, E. (2012) The governmental topologies of database devices. *Theory, Culture & Society* 29(4-5): 116-136.

Saguy, A.C., and Riley K.W. (2005) Weighing both sides: morality, mortality, and framing contests over obesity. *Journal of Health Politics, Policy and Law* 30(5): 869--923.

Savage, M., and Burrows R. (2007) The coming crisis of empirical sociology. *Sociology* 41(5): 885-899.

Seale, C. (2005) New directions for critical internet health studies: representing cancer experience on the web. *Sociology of Health and Illness* 27(4): 515-540.

Small Data (2013) http://smalldata.tech.cornell.edu/register.php

Smart Patients (2013) https://www.smartpatients.com

Swan, M. (2012a) Crowdsourced health research studies: an important emerging complement to clinical trials in the public health research ecosystem. Available at http://www.jmir.org/2012/2/e46

Swan, M. (2012b) Health 2050: the realization of personalized medicine through crowdsourcing, the quantified self, and the participatory biocitizen. *Journal of Personalized Medicine* 2(3): 93-118.

Swan, M. (2012c) Sensor mania! The Internet of Things, wearable computing, objective metrics, and the Quantified Self 2.0. *Journal of Sensor and Actuator Networks* 1(3): 217-253.

Thielst, C.B. (2011) Social media: ubiquitous community and patient engagement. *Frontiers of Health Services Management* 28(2): 3.

Timmermans, S., and Berg M. (2003) The practice of medical technology. *Sociology of Health & Illness* 25: 97-114.

Topol, E. (2010) Transforming medicine via digital innovation. Available at http://stm.sciencemag.org.ezproxy1.library.usyd.edu.au/content/2/16/16cm4.full

Topol, E. (2012) *The Creative Destruction of Medicine: How the Digital Revolution Will Create Better Health Care*. New York: Basic Books.

Treato (2013) http://treato.com

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.

Waldby, C. (2000) Virtual anatomy: from the body in the text to the body on the screen. *Journal of Medical Humanities* 21(2): 85-107.

Wicks, P., Keininger D.L., Massagli M.P., de la Loge C., Brownstein C., Isojärvi J., and Heywood J. (2012) Perceived benefits of sharing health data between people with epilepsy on an online platform. *Epilepsy & Behavior* 23(1): 16-23.

Yli-Uotila, T., Rantanen A., and Suominen T. (2013) Motives of cancer patients for using the Internet to seek social support. *European Journal of Cancer Care* 22(2): 261-271.