The commodification of patient opinion: the digital patient experience economy in the age of big data
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Abstract   As part of the digital health phenomenon, a plethora of interactive digital media platforms have been established in recent years to elicit lay people's experiences of illness and health care. The overt function of these platforms is to provide forums where patients and caregivers can share their experiences with others, benefit from the support and knowledge of other users 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 data they contribute. This article examines this phenomenon of what I term 'the digital patient experience economy'. Such aspects of this economy as prosumption (the combination of content consumption and production that is characteristic of the use of Web 2.0 technologies), the valorising of big data, the discourse and ethic of sharing and the commercialisation of affective labour are discussed. It is argued 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.

Keywords: patient-support websites, digital media, big data, prosumption, sociology

Introduction

In recent years there has been a turn in some parts of medicine and health care towards the use of digital media technologies as devices for measuring and monitoring patients' health and healthcare experiences and encouraging medical 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 (Blaxter 2009, Mort and Smith 2009, Nettleton 2004). This emphasis has progressed towards embracing the new digital media technologies that are now often referred to as Web 2.0. Web 2.0 includes interactive websites, social media platforms and mobile devices that can connect to the Internet in virtually any location. Where the online technologies of the Web 1.0 era largely provided information from experts and there were only limited opportunities for users to contribute their own insights and experiences, Web 2.0 technologies encourage the active creation and sharing of content by users themselves. These technologies therefore provide a means of producing and sharing data on health-related and medical-related topics and experiences in what have been variously described as e-health, Health 2.0, Medicine 2.0 or digital health initiatives.

I have elsewhere (Lupton 2013a) used the term 'the digitally engaged patient' to describe the phenomenon in 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, Morden *et al.* 2012, Veitch 2010). In this concept, ideal patient-citizens are positioned as taking steps in the interests of preserving and promoting their own good health, including accessing relevant information, monitoring their own 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 (De Vogli 2011, Veitch 2010).

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 illnesses 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. In some forums people are encouraged to digitise themselves: that is, render their bodies into digital form using the monitoring technologies to produce data that may be quantified and transmitted to others for their perusal (Lupton 2012, 2013a, 2013b). In others, people are encouraged to use websites to access information about medical and health topics and to employ social media to engage with others by sharing experiences of their conditions and treatments and relating accounts of healthcare encounters (Adams 2011, 2012, Griffiths *et al.* 2012, Mazanderani *et al.* 2012, Wyatt *et al.* 2013).

Online patient-support networks have existed for some time as a means of supporting patients and sharing information. Several sociological research studies in the late 1990s and into the first decade of the 2000s were devoted to exploring how 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). In the Web 2.0 era, further technological developments have brought with them even greater opportunities for 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 and the evaluation of medical care and to 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 patients' 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 and treatments. As part of the discourse of the digitally engaged patient 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 (Lupton 2013a).

Healthcare providers and organisations are also increasingly subjected to digitised 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 – and indeed encourage – 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 patients' accounts of illness and therapies (Greaves *et al.* 2013, Griffiths *et al.* 2012, Thielst 2011, Wyatt *et al.* 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 the increasing commercial or research value they have for others. These data have become treated as another form of digital intellectual property, owned not by the patients themselves but by the developers of the platforms who encourage patients to upload their experiences. The data archives thus produced are owned by the developers and they are therefore able to profit from the harvesting of these data, including by on-selling the data to their clients.

Research into the health platforms discussed in this article was conducted in March and April 2013. The platforms included in the study included the following: CarePages, Patients-LikeMe, Health Unlocked, CureTogether, Smart Patients, HealthTap, Treato, Patient Opinion (UK), Ginger.io and three of the various condition-specific platforms managed by Alliance Health Networks. Each one was examined for how it outlined its purpose, its terms and conditions, privacy and membership policies and rules and the types of comments or other data that were uploaded by members.

In the ensuing discussion I draw in particular on writings in sociology, communication and media studies and cultural studies on the phenomena of prosumption (the combination of content consumption and production that is characteristic of the use of Web 2.0 technologies) and big data, and its collection, manipulation and commercialisation in the context of an increasing metricised everyday life as it's enacted in digital transactions. The overarching theoretical perspective structuring the present discussion is the material-semiotic perspective developed in science and technology studies (Latour 2005, Law and Hassard 1999). This approach views material objects such as digital media technologies as active participants that shape human bodies and selves as part of heterogeneous networks, creating new practices and knowledge (Ruppert *et al.* 2013). 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. The concept of the assemblage, derived from science and technology studies as well as the writings of Deleuze and Guattari (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 (Ruppert *et al.* 2013).

Prosumption, big data and metric assemblages

The new digital health technologies participate in the growing accumulation of what has been termed big 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 (Beer and Burrows 2013, Boyd and Crawford 2012, Ruppert *et al.* 2013). These digital traces include the data that are gathered on users' activities when they visit websites,

including the searches they conduct, the products they buy, the telephone numbers they call and the government agencies and commercial entities with which they interact. Big data 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 *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: 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: 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 groups' behaviour (Adkins and Lury 2011, Beer 2009, Beer and Burrows 2013, boyd and Crawford 2012).

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 (Adkins and Lury 2011, Burrows 2012, Ruppert 2011, Savage and Burrows 2007). They argue that numerical data collected on groups, in particular, are a specific means of constructing certain metric assemblages of individuals or groups 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 diverse 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. Behaviour 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 fine detail to be produced on individuals and groups (Adkins and Lury 2011, Burrows 2012, Cheney-Lippold 2011, Ruppert 2011, 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, Ruppert *et al.* 2013).

Digital data are both drawn from the actions and interactions of individuals and shape them, either by external agencies using the numbers to influence or act upon individuals or by individuals themselves who use the data to change their behaviour in response. A continual interactive loop is therefore established between data and behaviour (Ruppert 2011, 2012). Concepts of citizenship and consumers are now frequently phrased via the discourses of metricisation and big data, as governments and private enterprises laud the apparent benefits they offer. 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 knowledge about citizens and consumers (boyd and Crawford 2012, Ruppert 2012). Underpinning these assumptions are the beliefs that digital data are neutral, unmediated and clean forms of knowledge because they are produced by computerised systems, and that the more data, the better.

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 volumes 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 and discussion on the power of the vast data archives gathered by digital technologies both to inform patients about their own bodies and health states and to provide information to healthcare providers about the health of groups and the use of health care (Adams 2011, Greaves *et al.* 2013, Harris *et al.* 2012, Harris 2012, Swan 2012b, Wyatt *et al.* 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 well as in the popular media, largely uncritically as providing an unprecedented opportunity to improve medical care (Harris *et al.* 2012, Swan 2012a, 2012b, Topol 2012). The data utopian viewpoint is aptly suggested in the headline of one online 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 (Lupton 2013a), 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 other means of collecting information about people's behaviour, experiences and opinions.

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 (2013), PatientsLikeMe (2013), Health Unlocked (2013), CureTogether (2013), Smart Patients (2013), Treato (2013) and 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, 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, triggers of symptoms, 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' (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 (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 (2013) has been developed as one such tool. Healthcare providers are encouraged to suggest to patients with diabetes, adult attention-deficit hyperactivity disorder, 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 website calls this information passive data). Other health-related information is collected when the patient enters it regularly into the app after receiving a prompt (referred to as active data). These data are then processed, using algorithms provided, to healthcare providers and researchers to predict individual behaviour and identify trends in the aggregate data. Healthcare providers can use the data and the warnings produced by the algorithmic calculations of the app to be informed if patients are not adhering to their treatment protocols or if their behaviour patterns differ from their usual routines. Patients are told that these data will both help themselves and also contribute 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. It is claimed that participation will 'build your support circle' 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:

> [W]e 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'.

Part of the ethic of sharing expressed on many of the websites is users' agreement to making these data increasingly available (in aggregated or anonymised form) to medical researchers, pharmaceutical companies, medical device makers, healthcare policymakers and healthcare providers. As shown in 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 individuals 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, Harris *et al.* 2012, Wyatt *et al.* 2013). 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 health care 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 process of dying, 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 themselves frequently drawn upon narratives of illness and healthcare experiences to conduct research on these topics (Mazanderani *et al.* 2013, Wyatt *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 (Adams 2011, McCosker and Darcy 2013, Mazanderani *et al.* 2012, 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 and is actively promoted by such platforms (Harris *et al.* 2012). 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 many of the new patient-support websites that have emerged in the Web 2.0 era and earlier patient-support and information sites is that they have not been established 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 new 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 a 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 (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, attention deficit disorder 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, however, is found on a page directed at potential commercial clients rather than at the patients who use the site. On patient community sites, for example in 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 made clear only 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 on '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.

There is a range of ways in which patient-support websites position themselves as for profit, not for profit and somewhere in between. Patient Opinion, for example, is a solely not-for-profit platform and makes this clear on its site. Some platforms represent themselves as a free service for researchers or companies who want to make use of these data (for example, Health Tap). The PatientsLikeMe About Us pages describe 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 they provide for their own financial gain as part of a business enterprise.

In a further development, some platforms have been developed specifically to scrape the web for patients' accounts of their experiences in blogs and forums. Web scraping (also referred to as data harvesting or data mining) involves sourcing and gathering data from online archives for specific purposes. The Treato platform (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 the intellectual property of the website owners. As part of protecting this property, no users are able to data-mine or scrape the site systematically and they must agree to these terms before signing up as members.

Discussion and concluding comments

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 digitised patient experience) are configured via the most recent digital media technologies. These assemblages work together to enact an emergent digital patient experience economy, in which patients' experiences of illness and medical treatments and their opinions on health care as they are uploaded to online platforms have become valorised, and in some contexts, monetised. 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 health care, 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 other interested parties who may or may not pay for these data. These parties then use the data to evaluate their goods or services or market them 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 patients of their medical conditions, their treatments and their interactions with healthcare providers. 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. People are not offered and nor do they receive financial compensation for providing their experiences. The value prosumers derive is non-commercial, while the exchange value of the data they create is accumulated by the for-profit 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 people who engage in 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. It is important to note that patients do potentially benefit in other ways 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 (Isupova 2011, McCosker and Darcy 2013, Mazanderani *et al.* 2013, Wicks *et al.* 2012, 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 a better understanding of their condition or the provision of facilities that may benefit themselves or others with their condition (Adams 2011, Harris *et al.* 2012, 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).

However, despite the claims of big data utopianism, data – digital or otherwise, big or small – are not neutral fonts of information. Like any other forms of knowledge they are social constructions: political, messy and not only reflective but also constitutive of subjects, identities and communities (Beer 2009, Boyd and Crawford 2012, Cheney-Lippold 2011, Ruppert 2011, Ruppert and Savage 2011). So too, the other actors that work together to produce digital data – the web hyperlinks, algorithms, search engines and engineering of the infrastructure of the Internet itself – 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 (Ruppert and Savage 2011). 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 (Adams 2011, Halford *et al.* 2013, Mager 2009, Seale 2005).

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 (Mager 2009, Oudshoorn and Somers 2006, Seale 2005). Patients themselves are rarely encouraged to participate in the design of websites (Oudshoorn and Somers 2006) or in the design, analysis and writing phases of research studies using their data (Harris *et al.* 2012). 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 providing data 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 affective and altruistic labour that they invest in sharing their experiences on online sites. The use value of the information commodities that users 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 or enter as part of their electronic medical records or that are generated as part of their participation in clinical trials. 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 (2013) which has been designed to assist them to gain access to their data (Heussner 2013).

As this suggests, even in this age of Web 2.0, big data and dominant rhetoric of citizen participation in knowledge generation via their prosumption activities on the Internet, there remain limits to the contribution that patients and lay people in general are able to make to medical knowledge, the authority they are able to develop and the benefits they are able to accrue. While the rhetoric suggests that platforms for prosumption serve to create 'new informational gatekeepers and data interpreters' (Ruppert and Savage 2011: 87) (that is, members of the digitally empowered public), 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 people are putting the new 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.

On a wider level, we do not yet have much understanding of how concepts of health, medical self-care, the patient, lay knowledge, expert knowledge and the doctor–patient relationship are shaped via these kinds of digital technologies. Adopting a material-semiotic theoretical perspective allows consideration of the ways in which such features as digital hardware and software such as algorithms, coding and computer platform design are social actors that work with those who interact with them to enact and produce specific types of assemblages, forms of sociality and knowledge practices. What is the nature of the digital assemblages and 'algorithmic identities' (Cheney-Lippold 2011) configured via interaction with a platform such as PatientsLikeMe compared with those produced by interacting with Patient Opinion, for example? What kinds of value, commercial or affective, do these assemblages produce and attract? What are their politics? What are the implications for healthcare professionals and their relationships with patients? Given the vast and ever-growing array of digital technologies designed to configure the digitally engaged patient, a critical sociological approach that is able to challenge the dominant techno-utopian approach evident in digital health discourse is important in future research.

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