PRODUCING COMMUNAL HEALTH THROUGH SELF CARE: THE EMERGENCE OF DIGITAL PATIENT ACTIVISM

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PRODUCING COMMUNAL HEALTH THROUGH SELF CARE: THE EMERGENCE OF DIGITAL PATIENT ACTIVISM

Research paper

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Abstract

This study shows how patients co-produce health knowledge when they use digital technology (such as health apps and online platforms) to manage their health and the implications technological self-care has for communal health. It presents results from a qualitative study that took place in the English healthcare context and involved a range of stakeholders such as policy makers, patient organisations and patient experts, and health IT developers (e.g. health apps). The paper moves away from how patients use digital interfaces to ‘consume’ information towards how they are ‘activated’ on the basis of the information they have consumed or created and the implications of their activation for others. We argue that a care for the other emerges when patients self-manage their health through technological interfaces. We name this phenomenon digital patient activism and show that this is an effect of self-care (albeit a conditional one), which although associated with a neo-liberal discourse that assumes self-responsibility merits attention and recognition given the value it creates for the community.

Keywords: activism, patienthood, digital technology, UK

1 Introduction

Since 1990s patients in England have been at the heart of various health policy initiatives with digital technology playing a pivotal role in materializing such patient centricity. The rhetoric of patient-centricity has been intertwined with that of digitalisation of health and constituted the basis upon which health IT initiatives have been legitimized (Klecun, 2015; Mort & Smith, 2009). The rationale behind this co-constitutive relationship is that technology provides back to patients timely and up-to-date information that helps patients make choices and decisions about their condition, empowering them (but also rendering them responsible) to manage their health and care in ways that were not possible before (Henwood et al., 2011; Lupton, 2016; Mort et al., 2009; Schüll, 2016; Vezys, Timmons, 2015). Self-management is typically associated with the management of chronic diseases (Moore et al., 2015). Its use however has expanded to incorporate uses of technology patients make in order to take care of themselves more broadly. Digital technology gives patients the opportunity to produce health information by ranking healthcare providers, sharing their health experience in online communities or using health apps to track their health (Adams, 2011; Barrett et al., 2016; Lupton & Jutel, 2015; Lupton, 2016). We gradually see patients taking on the role of the ‘prosumer’ producing and consuming health information simultaneously (Adams, 2011; Ritzer et al., 2012).

Our study is situated in the literature that examines the ways in which patients (co-)produce knowledge as they engage with digital technology. In the light of this literature some studies have looked into how the information patients produce, like for example their experiences of healthcare delivery, is used to improve products and policies (Adams, 2011); to provide care (Radin, 2006) and to monitor and gain a better understanding of one’s health (Lupton, 2016). Other studies have emphasized on how value is created and leveraged in online health communities (Barrett et al., 2016; Osei-Frimpong et al., 2016) – including commercial and business value (Lupton, 2014) – how patient-
reported health data transform medical research and expertise (Kallinikos & Tempini, 2014) and how they could lead to forms of activism (Radin, 2006). This study aims to show how patients produce health knowledge when they use digital technology (such as health apps and online platforms) to manage their health and more importantly what the implications of technological self-care are for communal health. We move away from how patients use digital interfaces to ‘consume’ information towards how they are ‘activated’ on the basis of the information they have consumed or created and the implications of their activation for others. We argue that a care of the other emerges when patients self-manage their health through technological interfaces. We name this phenomenon digital patient activism and show that it is an effect of self-care (albeit a conditional one), which although associated with a neo-liberal discourse that assumes self-responsibility merits attention and recognition due to its positive ramifications for the community.

The remainder of the paper is organized in the following way. Next section describes the shifting nature of patienthood and how different conceptualizations of patient identity condition health activism. The subsequent section outlines our methodology, which is followed by a presentation of our findings. The penultimate section discusses our research vis-à-vis relevant literature and some final conclusions are presented.

2 The Shifting Nature of Patienthood & the Emergence of Health Activism

The identity of the patient has undergone substantial changes over time given changes in the health policy rhetoric and also in technological advancements. Armstrong (1984) compares the patient of 1930s to a subjected body, a locus of medical signs, whose main involvement in the medical encounter was through the articulation of the disease. The doctor-patient relation was a relation of unequal power, and the patient was reduced, at best, to a historian or a fact-teller. Over time more emphasis was placed on disease as being not only of medical nature but also as having social facets as well as ramifications and emphasis was placed on how patients experience health and illness. This phenomenological shift towards the patient as a meaning-giving subject signalled a transformation of the patient from an ‘object to be known’ towards a ‘knowing subject’ (Pols, 2005).

Changes of this nature go hand in hand with policy frameworks. NHS reforms over the course of the eighties and nineties introduced the notion of the patient as a consumer and the healthcare sector as a quasi-market. This was ostensibly in order to enhance patient choice for instance the choice of location for specialist treatment or in fact the choice of treatment from a range of alternatives or of a digital health technology (Fotaki, 2011; Schüll, 2016). The agenda of patient choice is also accompanied by an assumed patient rationality (McDonald et al., 2007) whereby patients are presented as being capable to make decisions for themselves on the basis of well-defined needs. Closely associated with the idea of patient choice is the portrayal of the patient since 1990s as an ‘informed consumer’ (Henwood et al., 2003; Henwood et al., 2011). The logic behind this is that the greater the availability of information (for example about the quality of healthcare providers), the more informed patients become and thus also more empowered to make decisions and choices about treatments for themselves (Barrett et al., 2016; Osei-Frimpong et al., 2016; Vezyridis & Timmons, 2015). Studies have shown the importance of social networks and the Internet more broadly in allowing patients to seek health information, and to monitor and assess their health-related choices (Gray et al., 2005; Griffiths et al., 2012; Oudshoorn & Somers, 2006). The notion of the patient as an informed consumer is compared to the patient as becoming quasi medically expert (Griffiths et al., 2012; McDonald et al., 2007).

A number of studies have taken a critical perspective towards the above conceptualization of patients showing patients’ reluctance to challenge medical expertise from fear of damaging their relationship to their doctor (Henwood et al., 2003; Osei-Frimpong et al., 2016) and how choice is undermined given that patients often just need to oblige with a treatment rather than choose between alternatives (Blaxter, 2009; Devisch & Vanheule, 2015; McDonald et al., 2007, p.435; Nyberg, 2012; Petersson,
Several scholarly work has also suggested that the assumption that patients are able to make choices suppresses variations between patients and sidelines communal values (Vezyridis & Timmons, 2015).

With the additional possibilities the Web 2.0 offers to citizens the above portrayal of patients has given way to the ‘reflexive patient’ (Adams & de Bont, 2007; Adams, 2011) and to the ‘digitally engaged’ (Lupton, 2013; Lupton, 2014) patient. Reflexivity and engagement suggests that patients are actively participating in their healthcare conduct by not merely consuming information given to them but also actively seeking for meaningful information and publicizing information that matters to them and perhaps to others (Adams, 2011). Studies have shown the significant role health apps play in allowing patients to collect information about their health and care providing back to individuals detailed reports of their self-care activities (Schüll, 2016). Barrett et al (2016) has shown how patients in online communities create epistemic value by producing health-related knowledge such as online ratings of specific healthcare providers, information about medical conditions through the sharing of experiences and knowledge about disease profiles. Patients’ engagement also gradually blurs the boundaries between the medical expert and the lay patient (Adams & de Bont, 2007; Barrett et al., 2016; Kallinikos & Tempini, 2014) and has the potential to transform the doctor-patient relationship irrevocably (Griffiths et al., 2012).

Although one would welcome the above initiatives seeing them as a token of patients’ autonomy, studies have reported concerns about the implications of these new patient roles and of the conditions under which they can be enacted. Adams (2011) suggests that the reflexive patient is not an identity we choose to perform but is an expectation of what we need to be doing as good citizens-patients. Patients’ autonomy is restricted further by the design of the technology and the way it structures how and what type of data patients can input and share online. Some form of moderation and editing is expected to ensure good quality of information (Adams, 2011; Tempini, 2015). Medical research networks, such as PatientsLikeMe, that rely on patients’ self-reported outcomes (Kallinikos & Tempini, 2014) require that these are first approved by medical experts before being posted online. Thus, although patients are encouraged to be involved in the production of health knowledge, this process remains bound to medical expertise.

Our study is situated at the intersection between digital health technology and patient activism, looking more specifically into how the technologies patients choose to use for their self-care end up producing healthcare knowledge that has beneficial implications for communal health too. We call this phenomenon digital patient activism. The study assumes that health activism cannot be dissociated from the meaning patienthood gets over time; it is actually constitutive of it (Landzelius, 2006). This means that health activism could take different forms over time depending on the assumptions and the roles attributed to patients.

Health activism has typically been associated with groups (such as patients’ organisations) that construct an identity around a specific disease (or healthcare more broadly) and take action on the basis of this identity (Epstein, 1995; Landzelius, 2006). An institutional, formal and top-down character is thus attributed to them. Actions are directed towards intervention in clinical trials and methodologies and towards the production of clinical/medical knowledge (Rabeharisoa et al., 2014). Epstein (1995) for example has shown the tactics health activists follow to improve their credibility and promote their requests and interests in relation to knowledge construction about AIDS. Radin’s study (2006) has shown that forms of activism may also emerge from online patients’ communities. It has presented how activities such as peer support, sharing of information and participation in projects constitute forms of activism that ‘plan the seeds of revolution’ despite the fact that they are not inherently political. Our study intends to contribute to the above studies by showing how activism emerges in the digital world as a consequence of patients’ self-management of their care. We study forms of activism conditioned upon digital health interfaces such as online health platforms and health apps patients use to manage their health and care. We take a non-institutionalized approach to
activism. Activism is not seen here as an intended process of forming a group around a specific disease and neither is it a type of a social movement. Rather, it refers to the productive power that digital technology has to facilitate self-care leading to the production of communal health. Our study shows that activism emerges from patients’ co-creation of epistemic value. This in many cases extends the use of information for personal purposes such as involvement in clinical decision making (Osei-Frimpong et al., 2016) and refers to the production of knowledge that can be of use to other stakeholders such as patients (Barrett et al., 2016), healthcare professionals and IT designers.

3 Research Methodology

The paper draws upon a qualitative interpretive study (Crotty, 1998) that aimed to investigate the role digital technology plays in enabling patients’ self-management of their health. Given the broad and complex landscape of health technology, we restricted our focus to digital health interfaces such as patient online platforms and health apps and excluded other medical devices that are used for the management of chronic diseases such as insulin pumps. We also looked primarily into digital technologies that are intended for patient use, excluding technologies that are designed exclusively for clinical purposes. Having said this we need however to acknowledge that as technology becomes more advanced processes of convergence seem to take place between what used to be well-defined boundaries. For instance as we will also be discussing later on technological developments and advancements blur the boundaries between a health app and a medical device as well as the boundaries between patient and clinicians.

The study aimed to respond to the following questions:

1. How do patients use digital technology to manage their health?
2. What are the consequences of technological self-care for others?

The study took place between August 2014 and May 2016 and focused on the English healthcare context within and outside the boundaries of the National Health Service (NHS). This was unavoidable given the fact that policy makers have been in the process of setting up standards for endorsing health apps and incorporating them in the NHS whilst simultaneously there has been an abundance of digital health interfaces that have been having impact on how patients manage their health and mobilise themselves to improve their and others’ care. To capture these practices and processes we had to work both within and outside the NHS boundaries. We gathered information through the collection and analysis of documents and through semi-structured interviews.

Specifically, we conducted 31 interviews in total with three main stakeholders: health policy makers (n=8) (e.g. NHS England; Health and Social Care Information Centre (HSCIC); National Institute of Clinical Excellence (NICE); Digital Health and Care Alliance (DHACA); National Data Guardian); individual (expert) patients (n=4), patient organisations (Parkinson’s UK) n=1 and organisations working for patients’ interests (n=5) (10 interviews in total)(e.g. HealthWatch, Patient Opinion; Patient Information Forum) and digital health technology experts (n=13) working in the area of the development of apps and patient platforms such as PxHealthcare; Patient Journey; Umotif, Painsense etc. Interviewees were selected purposively according to their role in the organizations we initially identified. A snowball approach was also used following recommendations of previous interviewees. The patients who participated in our study were selected on the basis of their use of technology to manage their health condition, with some patients being considered expert patients and others simply being keen on learning how to use technology to self-care and also based on recommendations offered by participants. We acknowledge that our sample is not representative of the ‘average’ patient as it did not really engage, despite our attempts, with patients who have been reluctant to use digital health technology for health purposes. Under patients’ views we also collected the views expressed by representatives of patient organisations and organisations working for patients’ interests, most of
which were social enterprises and had a non-profit character. We believe that these organisations are strongly positioned to represent patients’ views given their continuous involvement with patients and their social purposes; most of them also dealt with patients concerning their use and non-use of technology to get health information and to manage their condition. In terms of the digital health technology group some experts were funded by the NHS to deliver their technology; some were social enterprises that mediated the process of technology development and some were patients or carers who led the design of these technologies.

Interviews were conducted between September 2014 and May 2016; lasted about an hour, were recorded and transcribed verbatim. All interviews were done physically with the exception of one that was conducted over the phone. We used interview guides for each stakeholder group in order to have some structure to the interviews we held but these were flexible enough to leave a lot of room for additional themes to emerge and be discussed adequately. The interviews with policy makers aimed to explore existing strategies and technologies for technological self-care and to unpack how the patient is portrayed in policy discourse; the interviews with developers focused on the assumptions they make about patients when they design their technologies and the interview guide with patients focused on how and why they use technology to self-care. In our interview guides we did not aim to explore specific activistic behaviours as this concept emerged from our interviews. We designed and conducted our research according to the research governance frameworks set by our institution and our funder, the Wellcome Trust, and received approval by our institution’s Research Ethics Committee. All research participants received an information sheet that explained the aims, procedure, and use of the data they would provide prior to their involvement in the project. We received informed consent in writing from all participants (oral consent was provided in the case of the phone interview). We also collected relevant health policy reports published by the Department of Health, NHS England, HSCIC and other documents such as newspaper articles, documents provided by participants, reviews of relevant websites etc. We treated the documents we collected in a similar manner as we did with interview transcripts.

We analysed all our findings following a thematic process and used NVivo as a tool to help us organize the information we collected and visualize our themes so that analysis is done more systematically. Our initial themes and sub-themes (n=81) were informed primarily by our findings but also from the review of the literature. As research progressed themes were refined, some themes were merged and new relations between themes emerged. Next section presents some indicative and relevant findings.

4 Findings

4.1 Technological self-care

Following the dismantling of the National Programme for Information Technology (NPfIT) in 2011 the Department of Health (DH) reoriented its digital strategy towards decentralisation of health technology looking into the creation of standards and benchmarks that would facilitate local choice and flexibility (Department of Health, 2012). The Health and Social Care Information Centre (HSCIC) is currently working on the development of standards that would allow DH to accredit health applications so that doctors can recommend them for patient use.

A focus on patients and on the importance of information to manage health conditions by means of technology – what we name here as technological self-care - is at the heart of this digital strategy. Policy makers argue that patients need to be ‘enabled to make the right health and care choices’ by having access to health information and by using ‘NHS-accredited health and care apps and digital information services’ (Department of Health & National Information Board, 2014, p.6). Greater and easier access to health-related information is supposed to be sufficient to ‘empower’ patients giving them the opportunity to make decisions for their health and care, to benchmark services, to evaluate
and feedback on healthcare providers improving patients’ experience and the quality of healthcare services. Information plays a central role in meeting those purposes so much so as to be reduced to ‘a health service in its own right’ (Department of Health, 2012, p.50) sufficient for enabling patient choice and empowerment. In another report it is argued that patients, especially those with chronic conditions, will eventually become ‘experts by experience’ (NHS England, 2014, p.12) and will draw on the data they generate digitally to make informed decisions. The political rhetoric of patients’ responsibility to manage their health and care was epitomized in a speech the current Secretary of Health, Mr Jeremy Hunt, gave in July 2015 arguing that individuals are in charge of managing their health: ‘the best person to manage a long-term condition is the person who has that long term condition. The best person to prevent a long term condition developing is not the doctor - it’s you’ (Hunt, 2015).

The DH and other agencies involved in the materialization of its strategy focused on encouraging and supporting patients to use digital health interfaces such as health apps and patient online platforms, in order to manage their health conditions. Policy makers re-cast health not as an issue that should be of concern to us occasionally and during periods of ill-health only but rather as an issue we should take care of constantly. Health therefore is not confined into a health institution, such as a hospital, neither is it reduced to its delivery but it becomes a matter that should be of constant concern to us. Closely associated with the above view is the idea that digital health interfaces and the possibilities they provide for managing health are also perceived as re-presenting an absent doctor. The rationale for this is that clinical encounters are typically scarce in any given period of time and even for patients with long-term conditions whereas the responsibility for one’s health is constant and unending. Health apps thus is a solution that fills in those gaps between constant health needs and periodic medical encounters.

‘…what drove a lot of the apps ... was also to fill the gaps of what they were not getting from their healthcare systems. Being able to you know peer to peer support, community, information. All the treatment options. When you get ten minutes talking to a GP or a consultant once a year maybe, what do you do with the rest of the time? You need to monitor and be responsible for your health 365 days a year.’ (PatientView).

An overarching theme of our findings has been the appreciation of the value that information has in the way in which patients are informed and make decisions about their health. The DH actually presents information as ‘an essential service in its own right’ (Department of Health, 2012, p.11). Despite the significant ramifications such statement has a representative of Patient Information Forum seemed to be supportive of it arguing that seeking for health information is a prerequisite for any patient who is interested in her health and a patient said that ‘…information is by far a more powerful therapy in some cases than drugs’.

Further, an emerging theme from our findings is a gradual appreciation and acceptance of a shift in patienthood that sees patients neither solely as passive recipients nor only as consumers of healthcare but as individuals that develop expertise in their health condition over time. One of our interviewees went further to distinguish clinical expertise from the expertise a patient has of his/her condition in relation to her life and along similar lines another interviewee suggested that all patients have expertise in their health because health is what everyone owns.

‘Health is the only thing we have ...We all have it. We all know what we are talking about. We are all experts’. (patient)

Our study shows that patients’ expertise emerges from a deep understanding of their condition as this evolves and fits in (or not) with their lifestyle. In this sense, health (good health and ill health) is seen
as an inextricable part of who a person is and not as an entity that is outside of us. This is in congruence with the idea that health is a matter of choice and of a constant concern to us as responsible individuals-citizens. Next section discusses the implications of technological self-care for the community.

4.2 Emergent forms of digital patient activism

Health policy makers promote patients’ responsibility for the management of their health because they see it as a way of increasing adherence to treatment, reducing healthcare costs by reducing patients’ visits to their GPs and improving patient experience as a result of having more understanding of their condition and more involvement in its handling. Our study also suggests that apart from the individual benefits that emerge when patients’ get involved in self-care significant unexpected consequences emerge when patients use technology as a part of the everyday management of their health. This section explores in particular how patients promote communal health when they use digital technology for self-care.

Findings from our research suggest that patients become contributors to the production of large amounts of patient-reported health data that are used for clinical research purposes in order to improve existing clinical knowledge on certain treatments or conditions. Clinical data are collected as patients add information to digital health interfaces about their diagnosis, condition, treatment, side effects and lifestyle choices on top of other demographic type of information they add when they sign up to use a health app or to participate in an online platform (age, smoking status etc.). According to a representative of a health app the collection of longitudinal patient-reported outcomes are vital for medical research to understand how patients respond to treatment. The amount of information patients feed in the technology is dependent on the frequency and level of usage they do as well as the stage they are in their health journey. Often however it is also dependent on the perceived purposes data collection serves. Our study suggests that patients find meaningful the collection of personal health-related data such as data related to treatment, medications and diagnoses that could contribute to clinical research purposes and support it by making eager use of it.

‘…We wanted to boost our recordings so we sent a note out to our users saying, did you know that by using this device daily you help us learn about heart health. We saw a tremendous boost in our recordings. People felt they were contributing. It wasn’t just a meaningless trace’ (AliveCor).

Our findings also indicate an emerging form of patient not only as a mere user of a health app but also as an active participant in its development and as a designer herself – the ‘patient entrepreneur’. This is the case of patients, or sometimes carers and patient organisations, who motivated by their health condition and by the expertise they have developed over time managing it, make a decision to proceed to the development of an app that meets their specific needs and the needs of other patients who have the same disease. This transcends the cases whereby patients are consulted to provide their input to the design of a technology, what is commonly known as participatory design. Said for example one of our interviewees, a patient himself, about an app intended for use by diabetic patients:

‘People are building apps from any age, young people. They are doing it for different reasons. Some are doing it for loved ones. Some they are doing it for themselves. So with the example of My Sugar, it’s developed by a guy called, … and he doesn’t really have too much software expertise. But he has Type 1 Diabetes and he built it with a load of friends and then other people that have Type 1 Diabetes. I think the reason why they are getting it right is because they need to use it every day’ (patient).

One perhaps of the most interesting ways in which patients become activated in online platforms is by sharing their experiences of healthcare delivery and clinical encounters in order to provide feedback to
healthcare providers. Online patient stories can be shared and accessed by a number of other interested users, be that patients, carers, doctors or nurses. By being made online they become public, sharable and social having broader effects on other people. A representative of Patient Opinion, an online platform intended for enabling patients to share online feedback on the basis of their experience, described the sharing of patients’ stories as a way of healing the self. Healing emerges here from patients’ awareness that their story matters to other people too, often because they can sympathise with them, rather than solely herself. In this way a community is created around a patient’s story.

‘…a health service user who posted her story on the site about a crisis service and what she found was that hundreds of people were reading her story. She could see that from the statistics we provide. And that made her feel that her story was important that it mattered to other people and that made her feel better about herself and she tells us that that stopped her from self harming, because she felt that other people were interested in the difficulties she was having with her crisis service.’

(Patient Opinion)

Further, because in many cases patients’ stories have some form of intentionality in the sense that they are directed towards a specific service, healthcare organisation, clinic or doctor they are likely to trigger a response that addresses a problem that is reported or implied in the patient story. In this way, patients’ stories may activate a response from healthcare providers leading to change and thus to communal benefits. Patients’ stories may also play a pedagogic role in healthcare as they constitute a knowledge base out of which doctors learn about patients’ experiences, about areas that are considered as problematic and the reasons they may be considered as such and think about potential actions or best practices.

‘Staff use the stories that people put there in all kinds of ways. And now we are seeing them used in teaching as well, so they have about 3000 students who are using the site to look at patient experiences. Now all those things are possible simply because it’s a public and shared resource.’

(Patient Opinion)

Apart from sharing stories patients also share solutions, provide advice and exploit the wisdom of the crowd to share their views and opinions on specific health-related questions. Health Unlocked, a social network for health, for instance provides space for patients with heart conditions to ask questions, usually of troubleshooting type, about their apps and devices and perhaps more importantly to post their heart rhythm readings getting in return a form of ‘crowd-diagnosis’. This then attributes a collective character to healthcare.

‘People trust peer recommendations a lot more than they trust those from healthcare professionals and even pharmaceutical companies people trust even less. But when you get patients saying, this is what I’ve done and this is how I am managing my diabetes, you say, okay, if they are doing it maybe I can do it. Maybe it is trusted or is it suitable and all that kind of thing’.

(Patient).

This section presented our findings on how patients make use of digital technology in order to manage their health and how in doing so they end up co-producing health knowledge that matters not only to them but also to the community (other patients; healthcare providers, and IT designers. The final section discusses the relationship between technological self-care and communal health in more detail and in relation to the literature.
5 Discussion and concluding remarks

Our findings indicate that developments in digital health technology, such as health apps and online patient platforms, intended for patients’ management of their health give rise to a phenomenon of digital patient activism. The study suggests that there are at least four modes in which patient activism becomes manifest. The first is through the production of data for clinical purposes. This refers to patients that provide health data as they use digital technology - e.g. health apps – to manage their condition or to patients who have been cured and wish to reciprocate by providing information about their diagnosis and/or treatment to other patients who may be going through the same experience. The second is through patients’ involvement in the design of health apps. This refers to patients who decide to become entrepreneurial by designing health technologies that will be of use either to them as patients or to family members and/or friends who have been diagnosed with a condition, usually chronic. The third is through the use of health IT channels (e.g. patient platforms) where patients share stories and narratives of their experience of health. Sharing stories with peers has a therapeutical effect both for the author of the narrative as well as the reader of it. The fourth is in online patient platforms where patients provide feedback to healthcare organisations and professionals (nurses, doctors etc.) about their experience of healthcare delivery. In doing so, they create a knowledge base that is being used for educating healthcare professionals in the future. We argue that communal health is improved as a result of the production of health knowledge (apps; crowd-diagnosis, clinical expertise etc.) and show that this is a result of patients’ technological self-care that is when they perform the role policy makers have ascribed to them (i.e. when they provide online feedback to healthcare providers; when they become enterprising subjects responsible for their health; when they generate self-reported health data to improve clinical data etc.). Our study thus indicates how patients’ production of health knowledge (Adams, 2011; Barrett et al., 2016; Kallinikos & Tempinin, 2016; Lupton & Jutel, 2015; Lupton, 2016) results from an imperative to self-care and how it generates value to the community (Osei-Frimpong et al., 2016).

Our research contributes to the literature that explores forms of health activism (Epstein, 1995; Landzelius, 2006; Rabeharisoa et al., 2014) especially by means of technology (Radin, 2006). For our purposes here digital patient activism does not refer to a particular social movement. Neither is it an institutionalised initiative led by patient organisations (Epstein, 1995; Landzelius, 2006; Rabeharisoa et al., 2014). It refers to the possibilities digital health technology provides for patients to get involved in the co-production of health knowledge, creating in this way benefits not only for other patients (Barrett et al., 2016) but also for healthcare providers, for designers and for medical trainees. Our study thus adds to Radin’s work (2006) that sees health activism as an unanticipated effect that is produced by individual patients and not by a patient organisation or another authority that speaks for patients. We suggest that given changes in how patients are portrayed in policies (as responsible enterprising individuals that care for their health), forms of individualistic activism may become more frequent or more explicitly articulated. We also need to highlight that we take activism to be here an effect rather than an intention; in other words, the co-production of communal health is often unanticipated rather than necessarily being a deliberate effort to improve the health of the community, which constitutes another difference from more conventional conceptualisations of activism.

We refer to patients’ co-production of knowledge because the type of knowledge patients produce cannot happen independently of a sociotechnical context within which they find themselves. This context is both discursive and material, including a political rhetoric that gives meaning to patient activation; digital health technology that constitutes the main facilitator of patients’ activism; other patients and carers that listen to, seek for or provide help, administrators that approve and moderate patients’ content; designers that create the technology and a range of social enterprises and brokers that mediate this production process. Production of health knowledge is thus an outcome of the interplay of a number of players in the field and cannot occur outside and independently of them; this is why we name it co-production.
Findings suggest however that not all patients can become activists; neither are they all necessarily willing to display an activist behavior. Some patients are excluded from this possibility technology provides due to poor literacy skills, low socioeconomic status, demographic reasons (e.g. the elderly) and also due to medical conditions that deprive patients of any capacity to become activated such as patients with dementia. We therefore see here how this new policy rhetoric undermines variations between patients threatening equity (Vezyridis & Timmons, 2015). Digital patient activism is not an inherent ability patients have, as recent health policy suggests, but is conditional and performative. This means that patients become activists when and as they use technology to take care of themselves, ending up caring for the other. They are not activists in and by themselves and neither can all patients perform this role. In addition, we acknowledge that not all technologies ‘afford’ the same opportunities for digital health activism (Hutchby, 2001; Leonardi, 2011) rather the ways in which they are designed may provide more or less opportunities for interaction with peers, for narration, for collection of patient-reported data etc. Our study has not looked into the role of technology design in ‘engineering’ health activism but suggests that this constitutes a significant topic for future research.

We would also like to emphasize that although the consequences of digital patient activism are beneficial in that they generate value from which the whole community can benefit, as a phenomenon it draws on conditions that are problematic and require further enquiry. We refer here mostly to the assumption that underpins recent policy that information is ‘health service in its own right’ (Department of Health, 2012, p.50). Although some of our interviewees recognize significant value in health-related information, its uplifting to health service is dangerous in that it supposes a clear and perhaps exclusive transfer of the responsibility for health from the state and the profession to the individual patients. Chronic diseases may be amenable occasionally to self-management nevertheless diseases take various non-chronic forms and despite the expertise that patients may develop in their health and life, diagnoses and treatment are irreversibly a responsibility of the medical profession and should remain within their remit.

In this paper we presented digital patient activism as an unanticipated consequence of self-care facilitated by technology. Given the epistemic value that activism creates to the community, we have attributed to it a positive meaning. In doing so however we do not forget that patient activism cannot be dissociated from a neo-liberal discourse according to which individuals (in our case patients) are responsible for making choices, previously taken by the state or the professionals, and for governing their healthcare conduct in line with the rhetoric expressed in healthcare policy. To conclude, the ethos of self-care seems to be inextricably linked to the ethos of the new liberal self nevertheless our study highlights the positive ramifications that may emerge from it in the context of healthcare.

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