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# The Cultivation of Digital Health Citizenship

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ABSTRACT

Contemporary health policy discourse renders individuals responsible for managing their health by means of digital technology. Seeing the digital as productive of citizenship, rather than facilitative of it, this paper unpacks the contested role of technology in acts of digital health citizenship. Drawing on longitudinal data collected in the English healthcare context, this article shows that digital health citizenship is produced through patients' involvement in the generation of health knowledge, including 'big' health data, digital artefacts, experiential knowledge and service feedback. The paper adds to existing literature by disaggregating the contested role of technology in displays of digital health citizenship, showing that digital health technology can give rise to expressions of altruism, belonging, and demands for recognition and change in healthcare, whilst responsibilising citizens for the care of themselves and others. The discussion shows how, rather than merely facilitating the actions of a free and autonomous subject, this citizenship often becomes algorithmically produced (e.g. through nudges) and remains isolated to separate instances of engagement without a long-term orientation. Our study enriches the growing sociological literature on health citizenship by exploring how digital technology produces health citizenship at the intersection of biosociality and technosociality.

## Credit author statement

Dimitra Petrakaki: Conceptualization, Methodology, Software, Validation, Investigation, Formal analysis, Resources, Data curation, Writing – original draft, Writing – review & editing, Supervision, Project administration, Funding acquisition, Eva Hilberg: Conceptualization, Methodology, Software, Investigation. Formal analysis, Resources, Writing – original draft, Writing – review & editing, Visualization, Justin Waring: Conceptualization, Validation, Writing – original draft, Writing – review & editing, Visualization, Supervision

## 1. Introduction

Patients are increasingly self-identifying as biological citizens, assuming rights and responsibilities on the basis of their physical constitution and projected health risks (Heath et al., 2008; Novas and Rose, 2000; Petersen et al., 2018; Rose and Novas, 2004). While these forms of engagement have been studied closely, the transformative effects of digital technology on health citizenship remain -with a few exceptions such as Petersen et al. (2018) - underexplored. Thus far, technology has primarily been approached as a facilitator of bio-citizenship, for instance as a means for advertising health 'products' (treatments and tests) and targeting biomedical citizens in a more intrusive way that intensifies individuals' identification with their symptoms or mobilises their pre-symptomatic bodies (Petersen et al., 2018). This approach ignores the foundational role digital technology plays in generating new ways of interacting in an emerging technosociality, defined here as the new social sphere formed by all individual, peer and communal interactions occurring by means of digital technology. In this sphere, health citizenship is one aspect of subjectivity amongst many. Instead of conceiving of digital strategies as separate to the identity and aims of (bio-)citizens, our study foregrounds the foundational role of the digital in producing distinct but, as we show, ultimately unsettled conceptions of health citizenship. Central to this study is an analysis of the role of technology in the production of digital health citizens and its algorithmically conditioned implications and limitations as an ongoing form of health citizenship. Our study contributes to the literature by connecting theorisations of bio-citizenship with analyses of technosociality, pointing to a complex interplay of the social and the technological at this intersection.

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The question of digital technology's influence on health citizenship is prominent for healthcare services in many industrialised countries. In the English health service the rhetoric of 'patient activation' has become increasingly intertwined with strategies for health digitalization and, more recently, invocations of health citizenship. Policy discourse (National Information Board, 2014) redefines the role of the patient as simultaneously 'health service consumer', 'health technology user' and 'health citizen'. The notion of the citizen is different both from the notion of the health consumer, which assumes a relatively non-expert rational and economically oriented recipient of health services, and from the notion of the user, which presupposes a technologically savvy but generally unreflective recipient of a technology. In these different registers, the notion of health citizenship oscillates between normative and ideological agendas that attribute conflicting meanings to what a health citizen is and does. We argue that technology further transforms the meaning and instances of health citizenship, as it activates patients to take responsibility for their selves, others and the community (Lupton, 2013).

In order to capture the content of this particular subjectivity, this paper introduces the notion of 'digital health citizenship', which it defines as a set of rights and responsibilities that emerge through the use of digital technology (health apps and platforms) to meet health-related purposes such as to log the side effects of a treatment; to seek consolation in an online patient community and to provide feedback to a healthcare provider. Our findings disaggregate a performative reading of citizenship (Isin, 2019), made up of acts of altruism, practices of belonging, demands for recognition, and the concomitant instantiation of new rights and responsibilities. Our research shows digital health citizenship to be an unsettled concept that contributes to individuals' biopolitical responsibilisation whilst also being algorithmically produced. It emerges at the intersection of biosociality and technosociality in an environment where social relations and interactions around health are shaped fundamentally by digital technology in a variety of ways, including biosocial and algorithmic nudges.

Drawing upon Schüll (2016) and Yeung (2017) we define digital nudges as a wide range of algorithmic interventions that aim to shape individuals' choices and practices through specific prompts and the pre-selection of digital context. Nudges can take two forms. Micro-nudges are mechanisms that operate in a visible but silent mode. They do not prompt users to take a specific action but convey information that could encourage specific behaviours (for instance healthy eating). Examples of digital micro-nudges, as we show, are indicators for the readership of a post, endorsements, likes etc. Nudges can also operate in a more visible and explicit manner taking the form of prompts. These are, for instance, notifications and messages that pop up on the screen and encourage you to take a specific action. Our study contributes to the literature by showing that the role of the digital in the generation of health citizenship remains contested for two reasons. First, although the digital creates opportunities for new forms of responsibilities and new forms of agency to emerge, these forms of agency are often algorithmically produced-through nudges- and do not emerge from an autonomous health-subject as is typically assumed. Second, the paper shows that enactments of this form of citizenship often remain isolated instances of engagement, which are not attached to mechanisms of accountability that would render this form of citizenship sustainable in the future.

### 1.1. From biological to digital health citizenship

Contemporary healthcare discourses are inculcated with neo-liberal ideas around individual responsibility, 'activation' and consensual subjection to governmental programmes (Lupton, 1999; Rose, 1999; Tutton and Prainsack, 2011). Theorizations about active citizenship and patienthood illuminate rights and responsibilities for personal health but also for the health of others (social responsibilities around Covid-19 are an illuminating example of this). Concepts of patient participation share common ground; they seek to empower individuals and democratise health-related decision-making (Petersen et al., 2010). Here, citizenship can be interpreted as a marker of a new 'biosociality' (Rabinow, 2008), in which social relations are fundamentally remade through practices that coalesce around pathologies. Biological citizens (Rose and Novas, 2004) for example voice collective demands for equal inclusion and recognition in the remit of health services (Cataldo, 2008; Heath et al., 2008; Klawiter, 2008; Rhodes et al., 2013). This form of identification invokes rights and responsibilities, as it recasts morality in terms of health (Rose, 2008). In the end, citizens' participation relies on exercising self-control in a 'highly reflexive' form of selfhood (Petersen and Lupton, 1996).

While much work on bio-citizenship focuses on genetic conceptions of health, recent studies begin to engage with the role of the Internet and social media in bringing together patients in online communities. Instances of 'bio-digital citizenship' show how digital media help patient activist groups to raise their profile, attract funding and negotiate access to treatment (Petersen et al., 2018). Here, the digital is conceptualised as a means of expressing bio-citizenship by 'build [ing] communities, curat [ing] and shar [ing] narratives of illness, treatment and recovery and rais [ing] […] profile in order to attract funds and lobby for research' (Petersen et al., 2018, p.481).

Over the last decade the English NHS has put technology at the centre of the activation agenda and elevated information to a '*health service in its own right*' (Department of Health, 2012, p.50). Citizens' engagement is enabled through '*online and mobile access to records, electronic communication with professional teams, health and care transactions online, and the ability to rate services and provide feedback*' (Department of Health, 2012, p.14). The National Information Board's Personal Health and Care 2020 framework seeks to create '*a technology and data enabled care system that has the citizen at its centre*' (2014, p.16). The language of '*patients, services users, citizens and professionals*' (National Information Board, 2014, p.7) highlights the interchangeable way in which policies construct patients and citizens.

Drawing on the above, we take 'digital health citizenship' to be an assemblage of discourses, technologies and practices at the intersection of biosociality and 'technosociality'. This citizenship inscribes ways of being an 'active' and 'responsible' individual with regards to individual health choices, to the health of others, the community, and the health service (Novas and Rose, 2000). In contrast to Petersen's (2018) notion of 'bio-digital citizenship', our concept places analytical emphasis on the ways in which technologies shape (not only facilitate) displays of citizenship, especially where it comes to rights and responsibilities emerging from the use of digital technologies (such as adding patient-reported data or sharing patient experiential data– often after being prompted to do so by digital nudges). This paper does not examine specific biological/corporeal factors in the shaping of citizenship (although the body is a fundamental part of identity) and neither does it focus on specific patient groups/organisations, whose condition might require the use of specific technologies, such as for example diabetic patient groups. Instead, it looks at patients' interactions with and through digital technology and the ways in which these interactions enact health citizenship.

### 1.2. Digital production of knowledge and health citizenship

Central to the production of digital health citizenship is patients' involvement in the generation of health data. Since 1930s patients' subjective experience has become recognised as a valuable source of health knowledge in the diagnostic encounter (Pols, 2005). Today, patients are expected to use the Internet and social media to share experiences of health with peers and to access information sources in order to manage their health, and develop some form of expertise in their condition (Griffiths et al., 2012; McDonald et al., 2007). Advanced technology collects patient-reported data either automatically through daily use (e.g. health-tracking apps, wearables) or through patients' input (e.

g. online ratings of healthcare providers, blood pressure readings) (Petersen, 2019; Schüll, 2016). These technologies open up different types of agency, ranging from community-building forms such as digital health citizenship to the 'quantified self', an iconic example of a reflexive self-tracking and self-governed subject (Lupton, 2016a, 2016b). While these subjectivities are not mutually exclusive, they need to be appraised separately in order to evaluate their inherent emancipatory claims, such as for example regarding the community-building effects of technology.

The health data that patients produce and share online may generate value for the wider community (Petersen, 2019). For example, aggregated patient experiential knowledge can help identify gaps in clinical practice that could not otherwise be identified. In this way lay experiential knowledge can contribute to disease research (Tutton and Prainsack, 2011). Vicari and Cappai (2016) show how social media allow patient organisations to 'crowdsource' experiential knowledge and to challenge existing medical authority whilst blurring the boundaries between the medical expert and the lay patient (Adams and de Bont, 2007; Barrett et al., 2016; Griffiths et al., 2012).

Despite these merits, patient activation often does not primarily seem to be a matter of choice but a policy expectation. Several studies have pointed to patients' responsibilization for collecting and producing health data and the risks of prioritizing data over care (Henwood et al., 2011; Lupton, 2013; McDonald et al., 2007; Petersson, 2016; Tutton and Prainsack, 2011). Furthermore, patients' autonomy is restricted by the design of technology and the way it structures how and what type of data patients can produce and share with others (Kallinikos and Tempini, 2014; Tempini, 2015). This indicates the tentative nature of patient-produced knowledge, which remains continuously ambiguous and amenable to interpretation and change (Saukko 2018). Our paper adds to these studies by illustrating how algorithms shape citizenship through nudges embedded in the design of the technology. The algorithmic shaping of citizenship is important in as far as it affects not only the type of data individuals can add to their device but also the types of relationships they enable with other peers in the community.

Taking the production of health knowledge as a foundational element for an emergent digital health citizenship, our paper shows that digital technology generates a field of rights and responsibilities - including altruism, a sense of belonging to a community, recognition and demands for change. The paper then argues that the resultant form of citizenship is unsettled as it becomes limited to isolated and often narrowly prescribed instances of engagement, questioning its potential to become a sustainable form of activation and participation for the future.

## 2. Research methodology

### 2.1. Study design

The study brings together the views of key groups in the English healthcare context namely policy makers, digital health experts, patient organisations and (digitally activated) patients. Given the broad and complex landscape of digital health, we restrict our focus to an online platform and health apps that received funding from the NHS for their further development and were endorsed to be used more widely. We also look primarily into digital technologies that are intended for patient use, excluding technologies designed for clinical purposes. The study took place in two phases. In the first phase (2014–2016) we collected data about the digital health policy in England and explored the range of digital health technologies developed to realise policy. In the second phase (2017–2018) we looked more closely into one of them, an online health platform for patient feedback, Care Opinion (CO), and collected data about patients' motivations and expectations for using it.

CO is a non-profit organisation that aims to give patients the chance to offer feedback to health providers (NHS Trusts, hospitals, GPs) leading to improvements in healthcare. It is designed in line with commercial ranking platforms such as TripAdvisor. The platform mediates between patients and healthcare providers as a site where feedback can be addressed by providers through specific changes in how they organise and deliver health. We selected CO because it is politically independent of the NHS (unlike NHS Choices) and second because of its non-profit character (unlike PatientsLikeMe). As such, the platform has no conflict of interest regarding the content of the posts they publish. Nevertheless it functions in line with NHS policy specifically around patient choice, feedback, patient empowerment and activation (Department of Health, 2012). Patients and healthcare providers use the platform voluntarily.

### 2.2. Data collection

We gathered information through the collection and analysis of 55 documents and 52 semi-structured interviews. The interviews included eight health policy makers (NHS England; Health and Social Care Information Centre (HSCIC); National Institute of Clinical Excellence (NICE); Digital Health and Care Alliance; National Data Guardian); 13 technology providers; 10 representatives of patient organisations (such as Parkinson's UK; HealthWatch; Patient Information Forum etc.) and 21 patients who used the feedback platform. Interviews with health policy makers focused on the rationale, promises, expectations and delivery of digital health, whereas interviews with technology providers looked into the assumptions embedded in the design of those technologies. Interviews with representatives of patient organisations explored their views of the potential and current use of technology to manage health and produce knowledge. Some of these representatives also identified themselves as digitally activated patients. Finally, interviews with patients examined their motivations and expectations for using CO. We also collected relevant health policy reports published by DH, NHS England, HSCIC etc. newspaper articles, health blogs and websites related to digital health and documents that were recommended to us by our research participants (app assessment, user survey etc.).

We initially followed a purposive sampling strategy and then a snowball approach using recommendations from our interviewees. Health policy makers were selected according to their role in delivering the NHS digital strategy or working on the establishment of standards for health apps. We sampled technology providers who were funded or collaborated with the NHS to produce digital health technology. Interviews lasted about an hour, were conducted in person (except one telephone interview) and they were recorded and transcribed verbatim. We used thematic guides for each stakeholder group in order to have some structure to the interviews we held but guides were flexible enough to enable additional themes to emerge. We accessed patients through CO. A senior administrator of the platform contacted a random set of 100 patients who used the system in a randomly selected month, December 2017, and informed them about the study's aims and prospective use of its results. The users who expressed an interest to participate in the study were then invited to take part in a telephone interview, given patients' geographical dispersion. Interviews with patients lasted between 15 and 60 min, were audio-recorded with consent and transcribed verbatim.

We designed and conducted our research according to the research governance framework set by the lead institution and our funder, and received ethical approval by our institution's Research Ethics Committee. All research participants provided informed consent prior to their involvement.

### 2.3. Data analysis

We used NVivo to organise and systematically code all collected data (interviews and documents). We followed an iterative thematic content analysis process (Green and Thorogood, 2018). Themes were both empirically and theoretically created with findings and the literature shaping each other. Our analysis followed six stages: i) familiarization

with data, ii) code generation, iii) grouping of codes (e.g. levels of interaction), iv) theme creation, v) refinement of themes, and vi) writing-up (Braun and Clarke, 2006).

Following close reading of both interview and documentary data sources to familiarise ourselves with their content, we commenced open coding of data to identify and categorise data that related to our research aims and the wider literature. For example, informed by literature we created the code 'patient entrepreneurs' to refer to patients who were actively involved in the development of health apps intended to manage long-term conditions such as diabetes.

Next, we grouped our codes further by looking into their boundaries and relationships. We came up with three levels of online interaction: a) patient-digital technology b) patient-patient c) patient-community. Although potentially all digital health technologies could mediate these three types of interaction, in our study we found that health apps were primarily designed for individual use whilst the platform reflected community-building aspirations. Apps were often directed towards the management and monitoring of a condition (for instance breast cancer) and the promotion of good self-care practices (such as teeth brushing), while the platform was designed for feedback purposes.

Codes and groups of codes were subsequently refined (merged, synthesised and reviewed) as we looked for novel meanings and interpretations that converge or diverge with the literature. Following numerous meetings as a research team, we conducted more granular analysis leading to the creation of higher level themes. Table 1 in the Appendix illustrates examples from our data, from codes, and from emerging themes and their interpretation.

The next sections set out the data collected on the digital health platform and the health apps, relating them to theorisations of the rights and responsibilities of citizenship (Petersen et al., 2010; Rabinow, 2008; Rose and Novas, 2004). They are organized around the three main themes namely: patients' production of big health data; expressions of belonging in a community; and demands for recognition and change. We show on each level the potential and limitations of digital technology in enabling the emergence of citizenship through knowledge production (big health data; patient-led apps; experiential health knowledge; feedback data).

### 2.4. Patients' production of big health data

This section identifies different ways in which digital devices produce data while allowing patients to manage their condition. We show how policy portrays health citizens as in charge of their own health and the health of others, and how altruism thus becomes an expected responsibility for digital health citizens. While altruism is a multifaceted concept, for the purposes of this paper we draw on Tutton and Prainsack (2011) and Petersen and Lupton (1996) who conceptualise altruism as participation in medical research (e.g. through a systematic recording of symptoms and reporting of experiences), for the public good. Our data show that displays of digital altruism often emerge as a result of nudging rather than philanthropy.

Policy reports in England present digital health technologies such as '*NHS-accredited health and care apps and digital information services*' (DH & National Information Board, 2014, p.6) as vital for patients to manage long-term conditions and to self-care. Technologies generate data through their tracking functionality or patient input. For example, data about side effects or health indicators, such as blood pressure, can be used for monitoring and decision making. Going beyond individual needs, a policy maker confirmed that the notion of health citizenship is inscribed with patients' responsibilisation not only for their own health but for the health of others.

> 'This is about active citizenship and active participation … we have as much responsibility for our own health and to contribute to our communities and that whole notion of co-production' (policy maker).

Health technology experts have long emphasised the potential of patients to routinely contribute large amounts of health data as they use digital health interfaces. These big health data could then be used for a number of purposes, including clinical research (Kallinikos and Tempini, 2014; Saukko, 2018; Tempini, 2015). 'Big data' can refer to large amounts of data about health conditions, treatments, side effects and lifestyle choices, in addition to general demographic information (age, smoking status etc.).

> 'the aim of collecting the data is to understand how patients respond to treatment … there are very few parties who really collect the patient reported outcome data well … that is needed to understand who and what type of patient's respond and in what way to different treatments and to help the development of better treatments. (technology provider).

A medical specialist who designed a health app for breast cancer patients observed that often patients add data over time related to their diagnoses, treatment, medications and mood in order to help other patients who are, or will go through a similar condition. The quote that follows demonstrates how technology providers see the sharing of personal health data for the 'public' good as embedded in the use of this technology.

> ' … in the first couple of years when they're ill, they don't have a lot of altruistic feeling … [Once] They have been treated and they don't have too many symptoms any more or results from the treatment they start thinking yeah, I would like to do something back' (technology provider).

Another technology provider explained how patients started adding more data about their heart condition (e.g. height, weight, smoking status, heart rate) onto a health app when they were informed that it would be used to further clinical knowledge. The example below indicates how requests to share personal data gets entangled with expectations that you are helping others.

> ' … 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' (technology provider).

The example above suggests that the amount of information patients feed into the technology is dependent on the frequency and level of usage. Our data shows that usage can be influenced by inscribed reminders or nudges that patients get on their digital devices e.g. their phones. Nudges are built into digital technologies and operate in a wider personalised informational environment (Schüll, 2016; Yeung, 2017). Their role is to activate patients and encourage the use of technology, to structure interactions, and even to interpret behavioural data such as to remind patients to contact their doctor if they feel unwell. Patients' activation thus does not always or necessarily emanate from an autonomous reflective self (Rose and Novas, 2004) but can be governed and produced technologically (Schüll, 2016). Nudges work through 'a reconfiguration of the choice landscape'; effectively outsourcing the 'anxiety-provoking work of lifestyle management' (Schüll, 2016, p.13) instead of engaging an autonomous subject presupposed by care of the self and biopolitics (Foucault, 1997, 2010).

> 'We have some automated ways of telling patients whether or not they should have to call a doctor or actually feel okay about their wellbeing … A list of questions comes with it [health app]. Treatment, plan, diary, trends. There's questions for you to ask your doctor.' (technology provider).

> 'You can also do the other things like set reminders to remind people to brush twice a day and you can make notifications to spit and not

rinse, because that's very important and reduces the risk' (technology provider)

' … apps prompt you. They beep at you.' (technology provider).

Over time, patients develop expertise of their condition that, in combination with altruistic motivations, can activate them to get engaged in technology design. This activation is deeply imbued with neoliberal incentives, with one participant describing these people as 'patient-entrepreneurs'. This is the case of patients who use their acquired expertise to develop a bespoke platform or app for the wider community of patients – blurring the boundary between designer and user. Such involvement transcends the notion of participatory design, in which patients are merely consulted to provide input about the design of digital technology. It also exceeds the needs of an individual as it has broader effects for other patients diagnosed with the same disease who wish to use the new technology. This also suggests that (some) patients can use the digital health marketplace to regain some sense of control over the technologies that are being designed and produced for self-care. Such expert patients thus contribute to the production of an entrepreneurial health citizenship, expressing regard to fellow patients while also shouldering the responsibility of finding a solution to their health issues.

'When we started, so six years ago, we started because no-one was producing what we actually wanted. So we decided we could produce it ourselves … There are individuals out there who are actually producing things for themselves..' (patient organisation rep).

'People are building apps … for different reasons. Some are doing it for loved ones. Some are doing it for themselves. My Sugar, is developed by a guy … 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 organisation rep).

Digital health knowledge production thus can promote expressions of altruism – authentic but also triggered by digital nudges – and acts as a source of new responsibilities for individual and collective health. Performances of this altruism range from individual instances of sharing personal health data to being actively involved in the production of digital technologies. As the next section sets out, over time these individual encounters with digital technology generate feelings of belonging to a community of peers.

### 2.5. Expressions of belonging in a community

This section illustrates three ways in which digital health technology brings health citizens together in a community in order to share (experiential) knowledge. Online peer interactions are social acts that create feelings of belonging, but our data also point to how feelings of belonging can be algorithmically produced, and the limits of equating sociality with publicity. In addition to the ability to share experiental knowledge online, the publicity of social media combined with algorithmically produced metrics of 'likes' or views constitute micro nudges for further online peer interactions.

First, patients value online peer support because they see it as a way to share and receive experiential knowledge that may not always be provided by clinicians. This, as the quote below illustrates, could be knowledge about possible side effects after a particular treatment. In this case, online peer interaction generates cognitive value that extends the knowledge patients get out of a medical encounter.

' … before I had my operation they didn't go through the possible repercussions afterwards. Nobody told me I would have emotional issues afterwards … I think it's nice to tell other people that yes after this major operation you do get psychological side effects' (patient 2)

Second, online peer support affords patients a position of health expertise, giving rise to claims of what one health technology developer rather enthusiastically called 'crowd diagnosis'. This extends the idea of 'crowd sourced communication' (Vicari and Cappai, 2016) and 'collective intelligence' (Radin, 2006) that rely largely on the exchange of information between patients as it has more direct impact on patients' decisions and actions about their health.

'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 it is suitable and all that kind of thing' (patient organisation rep.)

Peer support also contributes to the growing responsibilisation of patients to share their health experiences when there is limited opportunity for clinical encounters or when the demand for clinical support outweighs the supply. Medical conditions can present with ongoing symptoms that patients cannot discuss with their medical practitioner in the frequency they would like. In those cases, digital health interfaces offer a medical substitution, even if this means reassurance about the normality of a condition's effects.

'Sometimes you start experiencing things and you think, is it normal? Is this just me? But it's not until you read those stories that you think, oh no, actually, this is quite common and happens to more people and it is like a normal thing. Or it isn't and you think 'well I could get this sort of checked out'. It's nice to know that other people are experiencing the same sort of thing as you. It's a bit comforting' (Patient 18).

Third, digital technology opens up spaces for consolation, and emotional support. A patient's experience can have almost therapeutic effects for readers who have gone through a similar health experience and who due to fear, embarrassment or reluctance have never expressed it.

'Reading other people's experiences and seeing service providers respond … inspired me to speak out. Care Opinion has had a tremendous impact on me. Sometimes it has stopped me from harming myself. Instead of internalising my anger when treated badly by a professional, I have been able to voice the shame and grief I have felt'.(Patient as cited in Care Opinion, 2015 p.26)

For managers and designers a technology's capacity to enable peer-to-peer interactions suggests its potential to widen the user-base. The underpinning assumption is that by rendering the information patients produce (such as a health experience of a particular treatment or of a specific healthcare provider) publicly available, a wider community gets created around it. This establishes a public community-building element of technosociality.

' … that can be empowering and sometimes healing for people themselves to be able to share that story with others in a very public way and we sometimes hear from authors who say, you know, it's taken me ten years to be able to write this, but now I can and actually the act of sharing that story online can be very powerful for people. So, one of the interesting things that happens online is because so many things become public and shared they become social. They can have impacts that are more broad than the impacts they can have when they're private' (technology provider).

Often however the publicity of a patient's experience is not primarily intended to create a community but serves individualistic purposes, such as the need to be heard or read. Online publicity thus makes patients feel they are not silenced but they are listened to and considered by healthcare providers, by other peers and by the public at large. The public nature of comments posted on social media add further weight to

each comment.

> 'sometimes it's 'I want this to be public'. I want people to see .. Sometimes people feel like they are kind of trying to be silenced. They want to feel listened to' (technology provider).

These community-building effects are however also algorithmically produced and nudged into being. Digital health technology provides metrics about the impact a patients' post has on other participants in an online community. This usually comes in the form of information related to the number of people who have read a story or endorsements, and whether their story has received responses or led to an improvement in health delivery; it does not however go further than this to create a dialogue. Algorithms thus offer a quantified approach to the notion of community, reducing it to a number of readers; followers; endorsements and to one-off engagements. This engagement consists of micro-nudges whose presence may encourage some people to check the readership of their story or to write in a way that could attract public attention.

> ' I did go back [to my story] a couple of times to see whether it had any other comments. … I did notice on there the number of readers. I thought, at least, people have looked at it. I thought, it's obviously reaching somebody. So that was quite nice' (patient 18).

> ' You can see how many people have read it on the public site and you can also see how many people have responded to it' (technology provider).

The community-building capacity of digital health citizenship thus allows (and expects) the sharing of experiential knowledge with peers; offers emotional or cognitive assistance when this is needed or substitutes for scarce clinical encounters. At the same time, however our findings point to an algorithmically produced 'community' or technosociality, based on relatively isolated interactions (defined by number of likes and endorsements) that may serve individualistic purposes rather than communal needs.

### 2.6. Demands for recognition and change

Offering feedback to healthcare providers has been an expectation deeply inscribed into policy accounts of health citizenship (Department of Health, 2012; NHS England, 2014). A range of tools have been utilised to implement this purpose including surveys, questionnaires and, more recently, dedicated platforms such as NHS Choices and Care Opinion. According to the NHS, the collected data constitute a knowledge repository that helps healthcare providers better meet patients' needs whilst also rendering them more accountable to patients. This section draws on interview data from patients who used Care Opinion in order to illustrate how these platforms give rise to a responsibility to praise or criticise the NHS but also create the right to expect a change in response to the feedback provided. We show below what form these rights and responsibilities take and the limits of this form of activation when understood as a long-term citizenship.

In our study of Care Opinion, patients indicated how they expect their online posts to improve the quality of health service for future patients by identifying problems or shortcomings. The quote below of a carer clearly indicates her motivation to contribute to health improvement for future adolescents with mental health conditions.

> 'The main motivation is to try and improve the situation for people such as my daughter who arrived in a very distressed state at A&E to help and to try and do something about other people that might arrive like that … ' (Patient 6)

The patients we interviewed expected to get a response to the feedback they provided, if not an immediate change in ineffective processes. The platform collates feedback and responses to feedback and displays them publicly. A response to patients' feedback was interpreted by many as an indication of accountability.

> 'I hoped that I would get a response and because I got a response it gave me a feeling that they are responsible people in the department, who are properly trained to deal with it' (patient 3)

In many cases patient stories and posts would trigger a response that addresses the identified problem. For instance, a hospital changed its referral criteria in response to a story posted by a carer about her daughter's depression.

> 'We have changed our referral criteria … This will mean that anyone under 18 referred to our Trust will instead be redirected to the more specialist and age-appropriate service. I appreciate that this does not re-write your daughter's story, but I hope it is an important step towards ensuring that people at this often difficult and vulnerable stage in their lives receive age-appropriate mental health services' (Hospital Provider – as cited in Platform's name, 2011, p.13).

According to some patients, the public visibility of comments makes social media more effective in terms of rendering healthcare providers accountable to patients compared to the paper-based process of making a complaint to a hospital. The platform even works as a mechanism to exercise pressure over a healthcare provider to respond and make changes as it makes patients' feedback publicly available. Publicity thus works as a digital nudge that motivates patients to identify and report weaknesses.

> 'If it's coming in writing well, it's not public and so nobody is sort of going to challenge them to respond to it and if they wanted to, they could just sort of hide it or ignore it. [the platform] does help to provide health organisations and the Trusts with a responsibility to respond and identify anything that anybody has commented on and address' (patient 11).

> 'a part of me thinks if I put it on Care Opinion ..the fact that it's public might poke them into doing something about it' (patient 10).

Other patients, however, were sceptical not only about the extent to and the conditions under which patients' stories could effect changes in healthcare delivery but also about the mechanisms of auditing those changes. For more critical patients, a response to a post is not equivalent to change, highlighting therefore the need for better long-term auditing mechanisms to ensure healthcare improvement.

> ' … people put something on Care Opinion and then there is a response, but then you don't know what happens after that. Were the issues dealt with to the patient's satisfaction?.. for a lot of the stuff either didn't get a response or the response is so general that it doesn't mean anything. The devil is always in the detail. They don't get the detail' (patient 16).

The platform also allows patients to express their gratitude to NHS providers and clinicians, often to balance out the negative critique the NHS has received in the media in recent years concerning low quality of care. What is particularly interesting in this case is how technology enables patients to assume responsibility for the NHS as a public good, and defend it against criticism they perceive as unfair.

> ' … too often the tone of the stories that is covered in the press is negative and discouraging and I think it doesn't match up with the vast majority of people's experience of contact with the health service. … I felt strongly that if I had a positive experience, I feel duty bound to put it up there in some way to counteract the many negative experiences that I hear about' (Patient 19).

Indeed, many patients expressed their feelings of duty and justice behind the use of the platform and a willingness to compensate for the negative criticism the NHS receives by sharing their experience publicly. Taken together, these different motivations for providing feedback

contain a more active role with rights and responsibilities for patients as citizens contributing to the production of healthcare as a public good.

> ' … everybody is really quick to be negative about waiting times and about how long they have taken to be seen. I wanted to give some sort of feedback to show staff that not everybody just has something bad to say. … people who have a good experience probably don't tell anybody. People that have a bad experience tell everybody. It must be very demoralising for nurses and medical staff and all the staff involved really to get negative all the time.' (Patient 11)

These expressions of citizenship are however conducted within the parameters of the platform in terms of the types of exchanges it allows and envisages. Individuals are aware of the publicity that online media gives to demands for recognition and change, and use this publicity in a reflexive way. But this publicity also invokes health as a public good, and can be interpreted as a performance of digital health citizenship – which however remains limited by its digital context and by the often individualised and unaudited nature of engagements.

## 3. Discussion

This article contributes to health citizenship literature (Rose and Novas, 2004) by exploring the role of the digital (Petersen et al., 2018; Schermuly et al., 2020) in the production of health citizens. It contributes to this literature in two ways. First, the paper positions the digital at the intersection of biosociality (social relations defined by pathological factors) and technosociality (termed here as social relations defined by technology). In doing so, it argues that the digital does not merely facilitate the biological citizen (Petersen et al., 2018) by for instance offering the means to target citizens more effectively or to organise them collectively around common pathological characteristics or needs. Our study shows that digital technology actively generates distinct ways of being a digital health citizen. It disaggregates this form of agency into altruistic behaviours entangled in practices of big health data production; practices of belonging in a peer community and demands for recognition and change in the healthcare service.

Our findings point to the ways digital technologies reshape social relations and interactions around health as patients interact with it and, through it, with others (technosociality). Technology does not merely enable individuals to identify on the basis of their biological/pathological characteristics (Petersen et al., 2018) but through the use of technology a new set or rights and responsibilities opens up for health citizens (Barrett et al., 2016; Radin, 2006; Vicari and Cappai, 2016). These include responsibilities to input data for medical research; to inform and educate on matters that are unknown unless experienced (such as side-effects of breast cancer treatment); to seek and offer re-assurance in the absence of easily accessible medical advice; and to feedback in order to correct problems in healthcare organisation and delivery. Patients' responsibilisation however simultaneously generates the right to publicly criticise healthcare providers and the duty to provide feedback data. Digital health citizenship thus entangles patients' expressions of altruism with enterprising characteristics as defined by healthcare policy (Rose and Novas, 2004; Tutton and Prainsack, 2011). Further, this new set of rights and responsibilities moves away from the self and the practice of self-care that the quantified subject enacts (Lupton, 2016b) towards practices that are orientated towards the care for others.

The second argument our paper makes is that while technology reproduces the normative expectations of digital citizenship (expressed in terms of rights and responsibilities), this form of agency remains unsettled. The analysis of our data points to two reasons why this is the case and to their implications.

First, our study suggests that digital health citizenship is partly algorithmically produced. Our findings illustrate how micro-nudges (Schüll, 2016; Yeung, 2017) and prompts embedded in health apps and platforms encourage patients' practices towards desirable behaviours. Altruistic behaviour thus might partly be a result of technological nudging, with prompts reminding individuals to add data. Patient-reported data could then be used to enhance medical knowledge of certain diseases. Further, micro-nudges (e.g. readership of a post) operate in a more discreet yet visible mode motivating patients to engage with digital health technologies. These interactions however produce a quantified version of community based on 'endorsements', number of 'followers', responses to posts, in which micro-level encouragements are backed up by the systemic nudge of online visibility, motivating both patients and institutions to take part in a dialogue. This then indicates that digital health citizenship does not only emanate from an autonomous health-subject but is, in part, generated algorithmically, questioning its longevity as a form of citizenship.

Second, this form of digital health citizenship is not accompanied by systematic forms of accountability that could potentially institutionalise it as a form of agency within a healthcare service. Despite the best of intentions, demands for change raised in feedback platforms remain structured by their digital environment and are not embedded in the wider healthcare environment. As a result, patients' feedback might not necessarily be properly addressed. This then renders digital health citizenship a transient and limited form of agency that is set apart from more long term forms of engagement with healthcare based on biological citizenship.

The algorithmic conditionality of digital health citizenship points to inherent limitations of this subjectivity. On top of this, performances of this agency rely on an assumed availability and accessibility of technology; on patients' literacy and technical skills to use technology and on their willingness to partake in these initiatives. Policy recommendations for an increasing digital engagement of patients often do not acknowledge these limitations and conditionalities while promoting an increasing confluence between the ethics of biocitizenship (Rose and Novas, 2004) and an equally normative digital activation agenda. Our study shows that promoting wider participation in the use of certain health apps or platforms algorithmically has the general potential to activate patients and enable the co-production of health research as a public good – it however also questions the possibility of this form of agency to become sustainable and long-term.

Our findings derive from examples of technologies that have been funded in part or endorsed by NHS authorities. They reflect the nature of the participating organisations to some degree and thus constitute best case examples. Our findings and conclusions about the different roles of technology in the promotion of digital health citizenship will nevertheless be of value to studies of for-profit technologies. We found, confirming existing literature, that patients do not necessarily know the secondary purposes (other than clinical, medical, health-related) of apps or platforms they use (for instance if they are profit oriented etc.) Indeed, studies have reported how profit oriented platforms, such as Patients Like Me, generate feelings of belonging despite the platform's profit orientation (Kallinikos and Tempini, 2014; Tempini, 2015). In many ways the question of the contested role of digital health technology comes secondary to the effects it can generate, ie. an orientation towards altruism, community spirit and the public good. A more systematic tracking and auditing of the social value that is generated online could enable a long-term orientation of this new form of civil engagement. Further studies could formulate concrete new criteria for evaluation of digital health platforms that purport to have the best interest of patients and the health service at heart.

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## Appendix A. Supplementary data

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