Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

Can Digital Health Save Democracy? Meeting the Cosmopolitical Challenge of Digital Worlds

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Abstract

This article explores the challenges and opportunities of social media health activisms to shape public participation in the digital future of healthcare. As health becomes ever more entangled with digital technologies, a growing ecology of digital health services promise greater individual autonomy to learn about and managing medical conditions, as well as accessing health services and engaging in forms of self-care. Cautioning against optimist visions of digital health and their promise of empowerment and autonomy, the article explores how health activisms on social media are reclaiming visions of healthcare that move beyond individual and depoliticised models of health technologies. The notion of cosmopolitics is employed to conceptualise relations between technology and health that implicate human and non-human interests in entanglements between health, morality and technology.

Keywords: health, digital health, surveillance, politics, social media, healthcare futures

The potential of social media platforms and digital health technologies to improve healthcare has been widely discussed in medical literature, public health and popular media in recent years. The rapid adoption of digital health technologies and artificial intelligence in medical research and clinical practice is making possible new organisational approaches to healthcare provision (Martínez-Pérez et al., 2013), where the aggregation of large databases yields new forms of value (Parry & Greenhough, 2018). These technologies have come hand in hand with new capacities for observation, tracking and prediction, underwritten by promises of greater autonomy and better health for users, and of growth for service providers and new enterprises linked to the endless analytic possibilities of health-related data (Milne, 2018)[i]. These technologies enact socio-technical interactions where patient identities, clinical roles and illness worlds are transformed by technological mediation. In making new kinds of communication possible within and across groups, digital technologies enable access to health services, and

become drivers of systemic transformations of the kinds and quality of healthcare services, while the also pose new challenges of access and integration for health services.

Data-centrism in general medical practice and public health is generally understood as inevitable. However, despite a promise of endless progress derived from the analysis of information aggregates, research shows that the reality of data driven healthcare is also riddled with risk and frictions. As Prainsack (2017) has noted, data driven processes pose new challenges to clinicians, patients, health authorities and enterprises, who struggle to turn unprecedented amounts of data into meaningful and actionable analyses. As health becomes ever more entangled with digital technologies, the growth of medical services increasingly also necessitates a new model of healthcare delivery where active patients are willing to be involved as participants in producing and interpreting data, as well as using digital technologies to learn about and manage their conditions (Lupton, 2013). In this context, data that was previously understood not to be relevant to healthcare, such as user produced lifestyle data stored in apps and social media, is now understood as a resource to complete medical histories and power personalised treatments. The increasing complexity of digital health ecosystems poses new interoperability challenges to work across multiple infrastructures and data sets, and users have less control of how their data travels in 'seamless' models of data driven healthcare (Wadmann & Hoeyer, 2018). Although research points to ways in which medical technologies are routinely appropriated by users and clinical professionals to creatively pursue their own ends, for example in terms of reproduction, education and health optimisation, data driven processes pose new risks for individuals and populations as automated decision-making and decisions by data can harbour old and new forms of social violence and inequality (Eubanks, 2017; Noble, 2018; O'Neil, 2016).

As data worlds demand governmentality challenges of renewal to respond to the challenges of information societies (Floridi, 2014), digital politics are increasingly understood as a response to calls for accountability, transparency and access that are now central to defining how collaborations between public and private sector organisations need to be regulated (see, for instance, Sorell, 2017; Draper & Sorell, 2013). However, it is still far from clear how a public interest in embedding ethical practice in data driven healthcare can shape the commercial interests of health corporations and venture platforms. Questions about how ethics should underpin data-centric healthcare have taken central stage as new actors and processes threaten to erode public models of healthcare in favour of integrating an array of diverse actors and third party services, which pose new difficulties to health authorities in terms of quality standards and regulation. Powell et al. (2016) have argued that public rights in relation to digital health empower users through a new model of digital citizenship – one that could come with new rights and obligations over data, as well as yet to be established responsibilities for organisations. These new forms of digital citizenship situate data as a key currency of epistemic value that comes with new and changing sets of rights and responsibilities attached[ii]. As networks-in-formation, data worlds assemble users and organisations through information pathways and solidarity networks, social media is becoming ever more central to finding information and articulating patient concerns than any other source (Vicari & Cappai, 2016, p. 1665). In this context, the effective use of social media can become key to shaping the role of patient voices in the future transformation of healthcare. For example, in the United Kingdom, the Patient Voices network[iii] situates digital storytelling at the core of attempts to involve patient voices in the transformation of healthcare (Hardy & Sumner, 2018). Weighting the 'evidence of experience' against mainstream evidence-based healthcare agendas, this network uses digital stories as devices to improve healthcare delivery by effectively engaging patient concerns, generating dialogue, with the aim to transform organisations and healthcare delivery.

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However, despite the promise of digital storytelling in clinical contexts, the capacity of patient organisations to effect change, as Rabeharisoa (2006) notes, grows around biosocial entanglements that can mobilize patient identities, knowledge and political action. Beyond weak individual interactions, traditional patient organisations facilitate effective forms of participation, visibility and direct action. As collective actors, patient organisations are shaped by public and scientific knowledge as they link knowledge, citizenship and action spaces. Rabeharisoa et al. (2013) suggest that the expertise and effectiveness of patient organisations 'lies in their capacity to articulate various knowledges, so much so that what constitutes evidence for patients may also count as such for scientific and health professionals' (p. 11). Their role is to translate medical knowledge and help concerned parties develop background knowledge to back statements and claims that can support them pursuing a diagnosis and care. Digital worlds, by contrast, don't simply mirror or coexist with healthcare frameworks, but, rather, become as an affordance of information infrastructures, testament of their world-making capacities. Media platforms generate new imaginaries of citizenship no longer tied to emplaced identities but assembled in the coming together of people, issues, and infrastructures demanding rights through data (Isin & Ruppert, 2015; Marres, 2006). Social media platforms make possible forms of cooperation and collective thinking that shape how issues matter, contributing to 'counter-emplot' (see Dumit, 2006) illness narratives and health experiences in continuities between life, media and technologies (Kember & Zylinska, 2012). While multiple interests shape how digital platforms collect and use data, people often use social media platforms to make public the experience of living with illness, and to create public spaces that reframe what should count as expert health knowledge (Page, 2012). Digital environments make visible ways of knowing, and living, otherwise, link health practices to everyday social worlds, and provide a background for experimental definitions of both health and politics (Ginsburg & Rapp, 2013; Goggin & Newell, 2003).

Yet the contrast between organised patient associations and digital activisms is not merely between reformist and confrontational approaches to advancing healthcare users' agendas. While ethical questions regarding the integration of digital technologies in healthcare often presume the inevitability of their adoption, highlighting the need for public voice in overarching themes of consent, fairness and rights, Lupton (2017) has shown that users' own maps of the promises and potential of digital health highlight the need to think more critically about ethical and social issues, and pay particular attention to the distinctions that emerge in contextual technological adoption. In Lupton's study, participants felt that overarching discussions of ethics did not adequately capture the multi-sided effects of self-management for patient identities, or the forms of exclusion generated due insufficient infrastructures, socioeconomic disadvantage, health status, or because of inadequate framing of the health needs of particular populations.

The following sections explore some ways in which digital health practices in social media environments can challenge universal logics of progress associated with discourses about the central role of technology in healthcare futures. By pointing to subversive or excessive uses of technology as central to definitions of health, digital activisms make a significant contribution toward reshaping the core issues emerging from living in a digital age, changing conversations about what should matter in health debates. Problematising distinctions between 'life-nurturing and life-negating habitation', these activisms challenge premises and promises of data centric healthcare by becoming a public domain where claims about health can be made without necessarily seeking health reform. In this sense, these activisms allow us to frame the politics of technology beyond formal distinctions between personal and algorithmic agency, and crucially without recourse to distinctions that pit data ethics against politics. Rather, I propose to propend the prefix cosmo- to digital health politics to recuperate technological politics as multiple, situated, processual and unfinished, politics implicated in multiple processes, and which not concern only a priori ethical

principles or universal notions of progress. For Isabelle Stengers (2011), the question about cosmopolitics demands taking seriously the limitations of universal logics to accommodate resolution to political relations. Stengers' demonstration of cosmopolitics in the context of physics illustrates how, against a priori teleologies of scientific practice based on a universal rationality, the space of science demands that the conditions of politics be invented (Stengers, 2011, pp. 354-355). For Stengers, 'the prefix [cosmo] makes present, helps resonate, the unknown affecting our questions that our political tradition is at significant risk of disqualifying' (2011, p. 355). Cosmopolitics is a speculative concept that relies on alterity and context to avoid identifying with a progress story to define politics beyond slogans and disparities between absolute concepts, not least, as Stengers notes, disparities between 'ourselves' and 'others' (2011, p. 356). The anthropologist Marisol de la Cadena, for example, conceptualises cosmopolitics in relation to indigenous political worlds that emerge from the need to reconceptualise politics beyond colonial narratives of progress. De La Cadena's (2010) engagement with cosmopolitics renders politics newly relevant to postcolonial and neoliberal crises. Importantly, cosmopolitics encompass arrangements of human and non-human beings, representing a need to 'slow down reason' to locate more than human practices that may allow new interpretations and responses (p. 337). Indeed, for Latour, cosmopolitics can prevent both the premature closure of politics by resisting meanings of cosmos that mean a final list of entities to be included in politics, while it also sets politics against a premature closure of the notion of cosmos, for example, around idioms that link politics to human sets of human relations (see Latour, 2004, pp. 454-455).

While the application of a cosmopolitical framework may not necessarily be new in the context of scientific practice, I argue that it is particularly relevant to sedimented media histories. As neoliberal policies exacerbate the fragility and uncertainty of care, cosmopolitics open up the temporalities of the political to new objects, agencies and processes, and can lead to recognising value in a slow, 'idiotic' approach to politics. While the debate about digital health development has often focused on the agenda of large service providers and corporations, bringing to the foreground localised digital activisms around health extend definitions of the political to critical and utopian thinking through media practices. Cosmopolitics, in this sense, can be described as an experimental concept of political relations concerned both with the affirmation of life at the margins and, as Farias suggests, 'an opening toward the unknown, toward alternative definitions of the common world' (Farías, 2017, p. 36). Digital worlds afford new contexts in which new kinds of health politics come to matter, demanding recognition of forms of living which do not neatly fit neatly mainstream biomedical models. Rather, these uses of technology evince how technological mediations re-situate health experience in pre-digital inequalities, as well as new data centric logics, to pursue health agendas that are not pre-given, but emerge as a result of sociotechnical interactions, making possible to demand health rights through data, and participation in changing conversations about healthcare futures.

Technical Objects, Interfaces and Disaggregation

Let me briefly conceptualise the ways in which digital data adds value to health systems. As digital data have become ever more ingrained in everyday life, their purchase in redefining health comes hand in hand with the reliance of venture services on user data in order to improve clinical outcomes within and across user groups (Lupton, 2014). Clinical professionals and patient groups use social media to share medical knowledge with wider communities, to gain new knowledge about health, and to provide information, patient education, and advertising goods and services. Digital data makes possible modes of extra-clinical observation which allows clinicians to form more complete medical histories, bringing life activities and behaviours which may not have been considered

relevant to healthcare provision to bear on diagnostic and treatment outcomes (Sosnowy, 2014). Multiple devices, platforms and fora offer interfaces to control users' health practices through a range of affective, haptic, and functional atmospheres (Ash et al 2018; Tucker & Goodings, 2017). Through design and usability aspects, they become 'sites of desire and recipients of affect' (Shah, 2015, p. 2) shaping everyday health practices, and revealing, through design and usability features, semiotic patterns at play in how institutions work and think.

Digital models of patient participation encourage patient activation by engaging users with their personal data – encouraging active responses to accessing records, information and advice online. In this context, new questions emerge around the transformation of personal data as a driver of healthcare. First, as Aicardi et al. show, the personal and the individual are no longer synonymous in the digital age. As technological objects reshape patient identities implicating technicity in the process of managing illness (Mackenzie, 2002, pp. 16-19), digital health raises new fundamental questions about the interdependency of digital and political worlds. The materiality of information now 'operate(s) as a site of analysis which is simultaneously technical and cultural' (Aicardi et al., 2016, p. 58). Technical objects expose cultural fictions that bound together people and technologies and evince how technical and cultural realms are bound together (Schwennesen, 2017; Seaver 2017) producing continuities and spatial proximities between people, devices and infrastructures. But while digital interfaces shed light on how institutions produce health as a capacity newly reimagined though informational materialities[iv], healthcare is no longer about whole human persons, but rather, the digitised fragments, samples and data that interfaces can work with. Data processing, particularly machine learning, poses new ethical challenges as algorithms 'hover high above the flow of data, attempting to force fit the snippets of information in to patterns that represent its target' (McQuillan 2018a, p. 5).

In this sense, human-technology interactions are no longer located at the centre of technological politics as non-human agencies gain centrality as recipients of information flows (reference?). The new imaginary that derives from these data worlds, as Shah suggests, reverts the social to an ontology of interactions: data circulation does not primarily derive its value from being interpretable by human readers, but is aimed at mechanic processors which can make sense of information flows. Third parties providing digital healthcare services rely on software and agile working to undertake digital transformations in health services. These technological 'solutions' are developed by external supply-side vendors who effectively develop and market technology (Lidell et al., 2008). This operating model is underpinned by economic interests realised through commercial partnerships, where health data becomes part of large scale aggregates analysed and re-analysed through speculative processes of algorithmic learning, leading to health data not simply being collected but emerging over time as datasets are cleaned, re-analysed and linked to other data sets.

In this context, ethical issues surround the production, collection and use of health related data, and yet the assessment of the social implications of technology have only partially included public voices[v]. The becoming of digital worlds brings together multiple agendas, involving people, organisations and infrastructures in defining and pursuing healthcare futures. However, these futures may not be easily accommodated under single definitions of the public good. Promises of venture platforms such as PatientsLikeMe's much debated campaign 'Data for Good', which aimed to encourage data sharing to help data make medical science 'advance faster' while promising 'a better future to someone like you', are now shown not to have delivered on their promise of democratisation[vi]. Tempini and Del Savio's (2018) empirical research paints a bleaker picture of the platform as a business model for medical research: while driven by the exceptional medical knowledge accrued by patients with chronic conditions, the platform has done little to advance their medical agenda, often voiding the promise of return to patients who

drive the platform by donating their data (Prainsack, 2017). While the platform seeks to involve patients in their own self-management, and improving their autonomy from biomedical knowledge and services, in practice the model entails that the labour and investment of patients goes unrecognized. Indeed, in this model, people are not passive objects who receive the expert knowledges at the end of a data cycle, but become the primary human resource to shape not only biomedical research, but unknown technological futures predicated on future values of their data.

For Aicardi et al, an important consequence of the data shift in biomedicine is that it raises new questions about the possibility of replicating benchmarks of privacy and confidentiality that subjected the collection and use of personal data in ethical research. These (what?) have become impracticable at a time when multiple platforms (something missing here). Aicardi et al. note the difficulties in providing informed consent, a mainstay of ethical research, as data operations are (something missing here). Furthermore, they note that in an age of aggregation and data science,

> The challenge ahead is not so much that of extending existing ethical principles and reflecting on how they play out in a changing landscape of data collection and use. Instead, along with methodological changes, the management of health databases and biobanks is accompanied by changes in the social, economic, and moral order, which require a new language in which we frame and address the ethical challenges arising (Aicardi et al., 2016, p. 211).

More importantly, digital interfaces provide a new scale to think through the coming into existence, the erasure and transformation of health as an experience. As global health databases expand to include and aggregate multiple types of health data, users are also turning to social media in order to claim new rights around data, including rights to access services and to shape discussions about the future of healthcare. Isin and Ruppert (2015) note that the process of becoming citizens in digital worlds not only comprises processes of shaping internet regulation, but how technologies are embedded in socio-technical arrangements that create new ways of subjectivity and citizenship -as users and producers of digital technologies- (2015, p. 6). Citizenship, in digital societies, is a changing notion shaped by internet participation, which, among other processes, may lead to imaginative ways of engaging with government practices. In this context, digital infrastructures become a condition of citizenship. Yet, rather than adopting the existing figure of the citizen gaining rights through internet participation, Isin and Ruppert (2015) think of the digital citizen as 'an embodied subject of experience who acts through the Internet for making rights claims' (p. 11) What is important regarding the act of defining digital citizens, they argue, is to account for a transversing political subject who becomes global by engaging multiple struggles, a cosmopolitical citizen defined through digital practices. The political subjectivity that digital technologies afford, in their view, requires theorising digital life and political life in non-deterministic ways, as subjects are enacted through struggles across multiple domains. Indeed, for Isin and Ruppert there is a critical dimension of digital citizenship that emerges clearly though how people use internet practices to disrupt politics as usual.

Health, Experience and Mediation

Digital citizenship can enliven debates around digital health by providing new relevance of the distinction posed by Foucault and Deleuze between politics and the political (see Foucault & Deleuze, 1977). For Foucault and Deleuze, politics may refer to the continuity of institutions and the management of populations (potestas), while

the political emerges as a capacity for subversion linked to the disruptive capacities of critical events (potentia). Although these two dimensions have separately been deployed to analyse how commercial technological applications make bodies and persons more amenable to surveillance, it also applies to how social media's affective atmospheres shape the experience of politics (Papacharissi, 2014). Digital health activisms, particularly on social media, appropriate technology to experiment with alternative definitions of health, and explore the potential of these interventions to address health inequalities experiments in thinking critically, while at the same time leading to ruptures in both. Ethnographic studies of social media use among healthcare users point out the capacities of social networks to generate communities of trust, highlighting the everyday significance of media worlds to make or break sociality. For example, Miller's (2017) study of social media use among terminal patients explores how social media 'solved' communication problems for many cancer patients, who used digital technologies to communicate about their illness, were empowered by choices regarding when and how they could communicate about their illness, sometimes posting information preceeding offline encounters, or choosing the amount of information given to acquaintances. Miller understands social media as an extension of local cultural scripts that dictate how people socialise and communicate in the public domain. However, while social media may afford intimacy despite geographical distance, their potential to make or break relations was not equally evident to all participants in Miller's ethnography. Rather, Miller contends that platforms are part of ecologies or polymedia that allow users control over social situations, making some social relations possible or inviable, promoting participation or forcing distance, and providing a background for social lives to cohere. Not only do they provide proximities between people living with illness and health professionals, but, more importantly, they call into being social ways of feeling by making public issues that may otherwise be obscured by forms of structural prejudice at the level of public discourse.

In this context, digital citizenship is becoming a fundamental right to enable individuals to participate in the governance of health services, which remains particularly challenging for vulnerable and marginalised groups (Groleau, 2011). Social media generates social worlds that shift the location of health from inside the body to distributed environments, in which technical objects, infrastructures, stories and allegories mark what becomes relevant to health as an experience, contrasting ways of living with the acuteness of diagnostic interventions (Dumit, 2006; Manderson & Smith-Morris, 2010). While the biomedical model of health recognises the importance of translations between physical, psychosocial and social domains, and it has consistently relied on technologies to assess, diagnose and make sense, social media and the internet of things relocate users' experiences of illness in multiple interfaces and algorithmic logics, encouraging users to move between platforms, social media, websites, wearables and apps. As such, these systems are best understood as relational ecologies that organise the present. Indeed, part of the contradiction that social media holds for health activisms is condensed in the politics behind its 'real-timeness'. For Weltevrede, Helmond, and Gerlitz (2014), social media real time is not a flat universal, but rather a distributive fabrication (p. 5) which articulates experience by organising content in relation to multiple temporal frameworks. Not only does this process affect the construction of patient identities (Koteyko & Hunt, 2016), but belonging in multiple and changing units of participation produces experimental forms of thinking and feeling linked to multiple claims to health rights through data. For instance, social movements can make visible conditions and illness experiences while advocating for the right to disengage from media applications for practical, ideological or technical reasons, and demanding public participation in the shaping of healthcare services.

Consider chronic illness activisms. People living with chronic illnesses are widely regarded as the most active patient groups online, bringing together multiple health experiences across platforms, where multiple social media campaigns and re-frame expert health knowledge by demanding inclusive definitions of illness no longer tied to

biomedical diagnostic categories. These activisms use social networks to challenge systemic prejudice against the validity of patient testimonies. These epistemic boundaries have been well documented: Kidd and Carel (2017) report that value distinctions between patient testimonies and those of clinical professionals is the most often reported barrier to inclusion. Epistemic injustice associated with chronic illness not only leads to unequal relations that affect individuals, but can, over time, lead to undermining social confidence and sustaining forms of social injustice. For Kidd and Carel, the routine undermining of existential ways of knowing illness 'others' patients by linking the assumed lack of reliability of patient testimonies with the structural position of an ill person as 'impaired' by their illness. Patient complaints centres denounce the often reported lack of 'testimonial sensibilities' they encounter in clinical relations, the failure of clinicians to connect with patient narratives, and their being perceived by patients as cold, impersonal, and dismissive (p. 7). In contrast, digital health activisms seek to counter epistemic prejudice through solidarity networks that empower people to make associations and enact resistances through criticism and direct action. For instance, London's Chronic Illness inclusion Project, which spreads across a number of platforms and defines the experience of chronic illness as a self-reported condition based on perceived capacities to cope with the weight of everyday activities. Social media users linked to this project advocate for changes to traditional definitions of what counts as chronic illness, and the expansion of diagnostic categories by including forms of self-reporting[vii]. Jennifer Brea's documentary film *Unrest* documents the journey of learning to see differently where biomedical models could not see a complete picture. Social media became a resource in the filmmaker's elusive search for information regarding ME/CFS (Myalgic encephalomyelitis / Chronic Fatigue Syndrome), but the role of social networks in leading to public awareness, organised protest and eventual recognition of the physical symptomatology of the CFS syndrome. Community design projects and Human Computer Interaction practitioners facilitate participation by addressing structural differences and involving communities in defining the impact of issues such as race, income, power and equity that work against populations. As Parker (2013) notes, social involvement in the shaping of technological futures continues to be important in making communities around participation, as well as designing spaces that foster the involvement of public voices in the transformation of health services.

Indeed, these critical stances are all but new. Patient associations have long been involved in in intervening expert definitions of health problematics, and seeking to make medical systems accountable. Although digital health ecologies have been linked to a modernist logic of medicalisation that tends to individualise and depoliticise illness, while maximising the creation of value out of users' data, social media activisms evince how people's use of these technologies transform health experience in public environments where claims about health futures can be made public and negotiated. Social media offers a democratic potential to mobilise dissenting experiences to reframe what is at stake, opening up spaces where knowledge itself is the target of activism, but where, rather than being pre-set at the outset, the goal emerges over time. These processes enable people to invent and contest conventional meanings of health, situating experience across forming and shifting collectives, infrastructures, health and information systems, and mediation. These evidence-based activisms, as Rabeharisoa et al. (2013) have shown, achieve epistemic shifts by foregrounding the experiential knowledge of patient groups and health professionals in healthcare reform. Challenging ableist definitions of health by highlighting the social basis of illness, these activisms contest dominant models of active patienthood predicated on the involvement of individual users in producing and analysing their own health related data. Digital worlds evince the significance of relations, both human and non-human, and change public conversations by making a difference in public debates.

Conclusion: Cosmotechnical Futures

The wide presence of digital technologies in debates about the future of healthcare demands thinking through politics as presupposing multiple logics and rhythms. Rather than uncritically accepting digital technologies as conduits to equity, the essential multiplicity of these technologies demands a critical situated understanding of the relations that produce health. This article has argued that multiple health activisms enabled by digital technologies open up the way in which diverse experiences may inform digital healthcare in the future. Thinking *with* interfaces, digital futures must be open to account for multiple data politics, and for the uncertain. In this sense, their speculative potential must be recognised. As Shotwell has argued, these futures are never pre-given but, rather, 'grounded in the experience of interdependence, politically organized around the idea of identifying into a world that we create starting from the speculation that it could be otherwise than it is' (Shotwell, 2016, p. 193). As speculative health practices become part of this these complex futures necessitates concerted efforts to democratise technology, and to assess their purchase and potential for changing public debates.

Digital worlds afford multiple political agencies as they are constituted differently in particular contexts. Hence, the analysis of their purchase must also take seriously the challenge of their situatedness, as well as grapple with technology as a universalizing force (Dourish & Bell, 2011). Hui has argued that the reconciliation between the general and the particular characterises technologies as a form of cosmotechnics – which reflect the intrinsically multiple status of technologies. Hui (2017) defines cosmotechnics as the 'unification of the cosmos and the moral through technical activities', a definition which needs to attend to historical particularity as much as universal processes of technological acceleration and globalization. Indeed, digital technologies transform not only individual experiences of illness, but social environments, norms and logics of practice. By intervening politics as usual, digital worlds decentre relations and open a space to revalue the politics of experience. Digital health activisms evince the importance of technological mediation to reverse conventional cultural narratives about health experience and social justice activism, as technology provides ways of overcoming barriers of access to knowledge, intervening how and in what contexts issues and publics come to make a difference[viii].

Importantly, social media health activisms health activisms invite us to abandon naïve claims of machinic Neoplatonism, to borrow McQuillan's (2018b) description of the philosophies behind data science. As digital health becomes pervasive, there is an increasingly pressing need to open up democratic participation to address health inequalities through digital technologies, and to diversify the voices and experiences that shape healthcare. Lest health practices be 'fitted' to a digital model where metrics override qualities of health experience, digital health activisms point towards how avoiding a view from nowhere might entail recuperating standpoints from which to refocus healthcare futures. This investigation of data and its real-timeness has the potential to reconfigure what is thinkable by developing sensibilities and new forms of attentiveness to the tensions between surveillance and justice.

Notes

i) See, for example, Scotland's Digital Health Institute's ambitious plan to integrate health and social care at
https://dhi-scotland.com/about-dhi/scotlands-opportunity

ii) A concept that does for data what Heath, Rapp and Taussig (2004) dubbed genetic citizenship for genetics, p. 152.

iii) See http://www.patientvoices.org.uk

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iv) See, as an exception, Wakeford's (2002) model of Citizen's Juries. A number of recent studies have addressed scandals surrounding automated decision-making in welfare. See for example the Robo-Debt debacle in Australia, or the social implications of aggregators determining insurance and welfare claims in O'Neil (2016) and Eubanks (2017).

v) See digital.nhs.uk

vi) See http://news.patientslikeme.com/press-release/patientslikeme-launches-data-good-campaign-encourage-health-data-sharing-advance-medic, accessed January 2018.

vii) See http://inclusionproject.org.uk/about

viii) For instance, see debates around the forum Health Talk Online (http://www.healthtalk.org), which offers a space for people seeking health information and support to share information and participate in research.

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Competing Interests

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