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(submitted version)

The making of digital health citizenship

Health access and care are among the most regulated, policed and often politicised, hence contested, issues in contemporary societies. And yet, little do we know about how mundane digital practices shape these dynamics, with research just starting to explore how extremely heterogeneous forms of participation are developing through the digital. This note, drawing on digital media research, the sociology of health and illness and science and technologies studies, reflects on the notion of «digital health citizenship», an umbrella term used to label contemporary instances of digital citizenship emerging in relation to health and illness. It specifically draws on work interested in the values emerging in so-called contemporary «biosocieties», critical studies exploring the political economy of digital health and research investigating digital platforms as technological agents of citizenship.

Keywords: Digital health citizenship; digital health; digital citizenship; social media, *biosociety*

Cittadinanza digitale e salute

L'accesso alla salute è tra le questioni più regolate, politicizzate e, di conseguenza, contestate nelle società contemporanee. Mentre le pratiche digitali quotidiane hanno un impatto sempre più rilevante su queste dinamiche, la ricerca sociale ha solo recentemente iniziato ad esplorare come forme di partecipazione estremamente eterogenee stiano emergendo attraverso il digitale. Questa nota, attingendo alla ricerca sui media digitali, alla sociologia della salute e agli studi di scienza e tecnologia, riflette sulla nozione di «digital health citizenship», un termine ombrello usato per indicare esempi di cittadinanza digitale focalizzati su temi legati alla salute. La nota si concentra in maniera specifica su lavori interessati ai valori emergenti nelle cosiddette «biosocieties» contemporanee, su approcci critici all'economia politica della salute digitale e su lavori di ricerca che studiano le piattaforme digitali come agenti tecnologici della cittadinanza.

Keywords: Cittadinanza digitale; salute digitale; social media; *biosociety*

There is a sort of mundanity in the way we relate to our digital media. A mundanity that is double-edged: we keep these media in the fixed background of our everyday, but we also increasingly *need* them — essential *infrastructures* to connect and function. As physical objects (i.e., smartphones) and intangible spaces (i.e., social media), they are increasingly ubiquitous and part of the norm. Against these dynamics, evolving forms of participation are emerging and thriving, with research increasingly exploring the way «participatory cultures» have grown to intertwine with digital practices (Jenkins *et al.* 2016). That is, exploring old and new opportunities for citizens to craft and voice their opinions, experiences, interactions and forms of resistance to promote cultural or social change. But how does this resonate to the domain of health and illness? And does it matter?

Despite health being personal and «embodied» (Brown *et al.* 2004), its access and care are among the most regulated, policed and often politicised, hence contested, issues in contemporary societies. 1990s and early 2000s research (e.g., Brown and Zavestoski 2004; Epstein 1995) has clearly pointed to the emergence of different and more or less institutionalised forms of resistance to accepted ways of understanding and regulating health access, care and research. This body of work has approached meaning making through the lens of power, namely exploring how lay (e.g., patients and carers') takes on health and illness have challenged pre-existing structures in health policy or decision-making, knowledge production, expertise and self-care. In most cases, these takes have been shown to advocate for widened participation, carving space for lay voices to shape scientific development, health care policing and drug approval systems[1]. And yet, little do we know about how contemporary digital practices shape these dynamics (Lupton 2017), with research just starting to explore how extremely heterogeneous forms of participation are developing through the digital. In this note, cutting across digital media research, the sociology of health and illness and science and technologies studies, I am going to reflect on the notion of «digital health citizenship» as an umbrella term to indicate contemporary instances of digital citizenship emerging in relation to health and illness. In the next sections, I will specifically draw on work interested in the values emerging from contemporary biosocieties (Petersen *et al.* 2019), critical studies exploring the political economy of digital health (Van Dijck and Poell 2016) and research investigating platforms as technological agents of citizenship (Petrakaki *et al.* 2021).

From biosociality to biological citizenship. Do digital media matter?

It was the revolutionary work carried out by French anthropologist Paul Rabinow in the early 1990s that advanced the idea of an emergent «biosociality». Drawing on his ethnographic exploration of the Human Genome Project[2], Rabinow (1992) first reflected on the way new classifications of disease based on the genetic information acquired through genome sequencing would influence our societal understanding and management of disease. In Rabinow's (1992) argument, society would gradually move away from monitoring exclusively «the dangerous» and the «the sick» to now focus more and more on «the at risk», with risk being calculated based on genetic make-ups. According to this, older forms of racial and social classification — often resulting in stigmatisation — would intersect with new *genetic* classifications (e.g., sickle cell disease).

It is probably fair to say that Rabinow's view has only partially materialised — and primarily through the integration of preventive gene testing and genomic sequencing in contemporary health systems. But one of the threads of the anthropologist's work that has become most influential, especially starting from 1990s research on new or renewed forms of health citizenship, focuses on how with biosociality came the redefinition of subjects and collectives. Work by Rose and Novas (2005) explored how biology has gradually become central to new ideas of citizenship that draw less on traditional forms of participation in political affairs and access to public services and

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[1] More recent scholarship has pushed this work further in the direction of understanding how these forms of resistance have been embodied by racial minorities and marginalised communities (e.g., Dutta 2007)

[2] The Human Genome Project (1990 to 2003) was the first international initiative aimed at discovering the complete set of human genes and determining the sequence of DNA bases in the human genome (National Human Genome Research Institute, 2022)

more on identifications defined by biology. «Biological citizenship», introduced by Petryna (2002) and elaborated upon by Rose and Novas (2005), came to indicate forms of citizenship growing within patient communities and advocacy groups in which members increasingly connect with and distinguish themselves from others based on biological characteristics. Biological citizenship thrives in a political economy of hope, one where patient advocacy engages in fundraising work, increasingly seeking to influence science. Biological citizens are likely to seek and learn technical information for understanding and managing their condition, combining expert knowledge with knowledge derived from their everyday experience of illness.

Following the trajectory traced so far in this section — and building on it — Petersen and colleagues (2019) have recently drawn attention to a set of dynamics that have somehow remained understudied in debates exploring the making of health citizenship in twenty first century societies. Namely, they have pointed to the role of growing digital infrastructures and everyday social media practices, advancing the idea of an emergent «bio-digital citizenship». In this view, the intersection of identities based on biological characteristics with everyday social media leads to a citizenship that expresses itself primarily in digital (advocacy) practices focused on consuming and producing information, often to collate knowledge. The political economy of hope described in the context of biological citizenship turns here into one where lay people actively advocate to fund research, influence science and lobby for access to drugs, trials and services exploiting digital media structures, affordances and politics. Individuals or groups may sponsor their own research (e.g., on change.org), share information or experience with others (e.g., on a Facebook group or page) and/or contribute to collaborative projects that involve other health stakeholders, like pharmaceutical companies and scientists (e.g., on PatientsLikeMe).

What is perhaps the key point brought forward by Petersen and colleagues is that the forms of advocacy and activism emerging from bio-digital citizenship are now similar to «professional and business-like undertaking [...] where citizens' agency and hopes for treatment are crucial to the creation of economic value» (2019: 490). The economic value Petersen and colleagues pin down here centres on data and A.I. — as in data extraction, mining, collation and modelling. A value that takes on different forms for patients and their communities, for scientists, for private companies and for governments, with digital media becoming the means through which these values are speedily and often opaquely generated.

The political economy of digital health

Digital media, including digital health apps, capitalise on the participatory drive that has been associated with the Internet since its early adoption in the 1990s. In fact, one of the most common rhetoric used to promote digital health apps thrives on the promise to offer personalised answers to health questions while simultaneously helping the public good via «participatory practices», «patient engagement» and «data openness» (Van Dijck and Poell 2016). Platforms are often promoted as means to build new ways to connect with others and develop relations, primarily via information (i.e., data) sharing practices. When it comes to health, these practices are themselves often framed as altruistic, oriented to the public good, and part of a new «moral economy» (Fotopoulou 2018). Elsewhere, I have discussed a range of dynamics associated with the political economy of digital health, among which the dataist turn of self-tracking and monitoring practices, the often-ephemeral openness of «open data» in proprietary systems, and the infrastructural turn of giant tech companies (Vicari 2021, pp. 133-152). Here, I will focus on work by Van Dijck and colleagues to discuss contemporary platform-based economics as a framework embedded in contemporary societies (Van Dijck *et al.* 2018) and reflect on how this aligns or clashes with the idea of «digital health citizenship».

As mentioned earlier, while becoming central to our daily life, digital media have undergone a process of infrastructuralisation, with major corporate entities (e.g., Apple, Google) becoming hubs of the overall digital ecosystem and dominating services of public value through profit-driven corporate models. Platform companies' handling of the personal data collected, stored and/or shared on digital platforms often turns lay people into data donors, with the alleged goal to «advance research». When it comes to data donated in the context of patient groups, the process often turns patients into auxiliary to research, annihilating most of the participatory agency achieved by patient advocacy groups in the 1990s and early 2000s. In other words, this turns «active patients» back into «data donors». Meanwhile, the transactions characterising these data handlings open up new space for commercial entities to shape health and care decision-making. In fact, digital health platforms often work as «dataveillance systems» (Lupton 2016)—grounded in rational and objective understandings of health and illness dictated by market-driven norms. In these systems, data are commodified entities and hardly «open»: their access is restricted to platforms' «partners» or «clients». Even data originally shared in a non-profit context are often channelled into proprietary data flows controlled by one corporation. This scenario may allow soft forms of resistance (Nafus and Sherman 2014) but excludes more radical, alternative, or bottom-up participatory initiatives from the mainstream.

To picture some of the dynamics described so far, we can draw on Van Dijck and Poell's (2016) discussion of 23andme, arguably the largest commercial direct-to-consumer DNA testing service available on the market. At the time of writing, 23andme's website welcomes you with «Know your genes. Own your health». Scrolling down the page, you are then prompted to «Know you're making a difference. When you opt in to participate in our research, you join forces with millions of other people contributing to science. Your participation could help lead to discoveries that may one day make an impact on your own health, the health of your family and ultimately, people around the world. (Look at you go)». (23andme 2021, emphasis added). 23andme's model of company-consumer relationship is based on a «gift exchange» that blurs commercial transactions and financial beneficiaries by exploiting participatory narratives and digital playfulness (Harris *et al.* 2013). 23andme consumers, when sending their saliva sample to the company, pay for the sample to be analysed and for a report to be sent back to them. With the purchase of this service, they are however also invited to sign a consent form that allows the company to store the sample's genomic data and exercise proprietary claims on them, ultimately transferring the rights to any financial gain from future research to the company (Van Dijck and Poell 2016). In the process, consumers are then given the chance to «participate» in research and benefit the wider community. «Participation», however, here primarily means waiving personal data ownership. Not only do consumers "gift" their genomic information; they are also nudged to share additional personal information via fun surveys and interactive features (Van Dijck and Poell 2016, p. 3). Saukko describes this as «a flow-inducing experience of wandering along and getting lost in exploring different paths, companionship and conversations» (Saukko 2018, p.

1318). In sum, this experience is designed in a way to engage and connect consumers in a prolonged and enjoyable immersion.

Ultimately, for the consumer, the gift exchange enhanced in their starting a relationship with 23andme translates into «intangible benefits such as enhanced selfworth, enhanced reputation, a sense of public good, personal satisfaction and the prospect of reward or reciprocity» (Harris *et al.* 2013, p. 245, emphasis added). For the company, it results in the financial benefits deriving from the commodification of consumers' data, in what Lupton (2014) defines as the «digital patient experience economy». In this economy, individuals' experiences of health and illness acquire a commercial value that directly benefits those hosting and aggregating data sharing practices. This means that any forms of participation or potential citizenship developing through a single platform are highly shaped —and/or constrained —by the corporate entities controlling key hubs of the overall digital ecosystem.

Digital platforms as technological agents

While work by Van Dijck and colleagues is central to reflect on issues that have to do with governance, regulations and economies of digital (health) platforms, scholarship focused on information systems and infrastructures helps us see the technological shaping of citizenship developing on or through digital media. In their (2021)'s study of the English healthcare context, Petrakaki and colleagues provide a key discussion of these issues. In this section, I will specifically focus on their analysis of Care Opinion, a non-profit organisation offering a feedback website that uses a similar design to that of commercial ranking platforms (Petrakaki *et al.* 2021, p. 3).

Originally based in the UK (Sheffield and Stirling), Care Opinion now has branches in Ireland and Australia. On careopinion.org, anybody can share feedback about specific health and care service providers (e.g., hospitals). This feedback is moderated by a team from within the organisation and redirected through the platform to referents from the said service providers. These referents are then invited to respond. The platform is designed in a way that «Everyone can see how and where services are listening and changing in response» (Care Opinion 2022). In June 2022, the platform had collected 505,852 feedback stories, had 12,337 health and care staff subscribed to «listen» to these stories and had received a response for 79% of the stories received in the previous month (Care Opinion 2022).

Care Opinion is the rare example of a digital health platform holding the status of non-profit organisation, being primarily funded through subscriptions from health and care service organisations. In other words, neither do data collected through the platform become an element of financial transactions (e.g., 23andme), nor do they enter the data flows of the wider digital ecosystem. In fact, when social science research started discussing the commodification of patient data through digital health platforms, Care Opinion would be used as a yardstick for comparison. For instance, Lupton (2014, p. 866) would write: «What is the nature of the digital assemblages [...] configured via interaction with a platform such as PatientsLikeMe compared with those produced by interacting with Patient Opinion[3], for example? What kinds of value, commercial or affective, do these assemblages produce and attract? What are their politics?».

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[3] Care Opinion was formerly called «Patient Opinion».

Since Lupton's remarks, research on Care Opinion has drawn attention to the «digital assemblages» forming on its platform, that is, it has shed light on the way users engage and interact with technologies embedded in it, resulting in new forms of knowledge practices, sociality and, potentially, participatory dynamics. In particular, Petrakaki and colleagues (2021, p. 2) have analysed Care Opinion to explore how digital health platforms may enact forms of digital health citizenship as «an assemblage of discourses, technologies and practices at the intersection of biosociality and technosociality». Drawing from Novas and Rose (2000)'s conceptualisation of «biological citizenship», Petrakaki and colleagues picture digital health citizenship as happening through the use of digital health platforms and as forming through individual and collective health choices that can have an impact on the community. Their focus is very much on the way technological «nudges», in the form of, for instance, prompts, metrics, or recommendation systems, while motivating patients to engage with the platform, produce «communities» that are algorithmically defined and, as such, not necessarily long-term expressions of citizenship.

Care Opinion also clearly exemplifies how engagement with digital health platforms does not necessarily translate into agency concretising beyond the platform themselves: «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» (Petrakaki *et al.* 2021, p. 7). Responses may also vary in the extent to which they are specific to the patient's story, transparent and informing action planned to improve future care delivery. What is certain is that, whether or not response is enacted, platforms like Care Opinion provide an opportunity to engage with actions of care — care for a public service to be improved and care for others (an imagined community?) to receive a better service (Mazanderani *et al.* 2021).

Concluding remarks: Health, participation and citizenship in the contemporary digital

In conversation with Mizuko Ito and danah boyd, Henry Jenkins reminds us that «Many of the debates of our time center around the terms of our participation: whether meaningful participation can occur under corporately controlled circumstances, when our ability to create and share content is divorced from our capacity to participate in the governance of the platforms through which that content circulates» (2016, p. 12). Our everyday engagement with digital platforms turns into traces that live at the intersection of the private and the public, get translated into data easily transferable across platforms' gateways (i.e., Application Programming Interfaces) and acquire economic value that primarily benefits platform corporations (Van Dijck *et al*., 2018). Is this then the right context for the emergence of a digital health citizenship? Or, what is the making of this citizenship in the context of the current push towards digital health initiatives responding to the Covid-19 crisis (e.g., Wamsley and Chin-Yee 2021)?

On the one hand, since the 1990s onwards, experience has growingly proven key to understanding a dimension of disease that was previously overlooked: its lived aspect. On the other, a tension to familiarise oneself with professional knowledge has turned evident across patient groups, especially in relation to conditions about which information is limited and/or hardly accessible, giving way to forms of citizenship that have been defined as «biological» (Rose and Novas 2005). In sum, the 1990s progressive shift in the understanding of patienthood as an active form of engagement with health conditions, and the increasing relevance of lay expertise to citizenship practices, have provided a fertile background for the proliferation of personalised forms of engagement and knowledge co-production that came into being with the turning mundane of social media practices. Digital socio-technical infrastructures have probably accelerated and enhanced the public or semi-public manifestation of these pre-existing or emerging participatory dynamics in what have become «bio-digital» forms of citizenship (Petersen *et al.* 2019). It is then probably due to this combination of non-platform bound sociocultural dynamics and platform-specific socio-technical infrastructures that the public voice of collective advocacy actors and individual patient advocates has progressively grown in prominence.

In one way or another, all points above take us back to the political economic forces that drive contemporary societies. Whether we look for agency carved within market, biopolitical or technicist systems or investigate the evolution of lay expertise as a digital participatory practice, we end up having to account for the «(overwhelmingly corporate) global online platform ecosystem that is driven by algorithms and fueled by data» (Van Dijck *et al.* 2018, p. 4). In fact, when it comes to data donated in the context of patient groups, the process seems to downsize the participatory agency achieved by patient advocacy actors in the 1990s and early 2000s. Meanwhile, the transactions characterising these data handlings open up new space for commercial entities to shape health and care decision-making. In the resulting «dataveillance systems». (Lupton 2016), data are then often commodified entities and hardly «open»: their access is restricted to platforms' «partners» or «clients». Even data originally shared in a non-profit context are often channelled into proprietary data flows controlled by corporate entities.

Together, the points above suggest that digital health citizenship can be seen as «platformed», in both its agentic constraints and potential. Constraints to agency cannot but emerge in an ecosystem whose very essence is defined by contemporary platform politics: these politics are shaped by capitalist values driven by the giant corporations that act as infrastructural hubs; they function through algorithmic norms that define what (e.g., content, users) should or should not be visible; they shape social interactions via affective vernaculars voiced through platform markers (e.g., emojis). Digital health citizenship, as platformed, is however also allowing and enhancing connective, personalised and crowdsourced forms of agency that are inclusive of fluid and loose instances of participation, and that were rarely possible in the pre-digital age. These dynamics translate in a context hardly conducive to quick systemic changes or radical projects. A context that, however, offers new opportunities for illness subcultures to grow, especially around minorities (e.g., rare disease or non-communicable disease communities) whose members have little opportunities to find each other «offline» (e.g., Vicari and Cappai 2016). It also translates in forms of «togetherness» that can take a myriad of shapes, as digital connective structures also offer means of engagement for individuals unwilling or unable to strongly commit to traditional advocacy or activist action. Finally, it manifests itself in the heightened visibility of lay forms of expertise that previously only primarily grew within contained or dedicated—thus often «invisible»—social spaces.

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