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The shifting politics of patient activism: from bio-sociality to bio-digital citizenship

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Abstract

Digital media provide novel tools for patient activists from disease- and condition-specific communities. While those with debilitating conditions or disabilities have long recognised the value of collective action for advancing their interests, digital media offers activists unparalleled opportunities to fulfil their goals. This article explores the shifting politics of ‘activism’ in the increasingly digitally mediated, commercialised context of healthcare, asking: what role have digital media played in the repertoire of activists’ strategies? And, to what extent and how has the use of such media impacted the very concept of activism? Building on sociological ideas on emergent forms of ‘biological citizenship’ and drawing on findings from an analysis of available media, including television and print news reportage, online communications, published histories, and campaign material and other information produced by activists in HIV/AIDS and breast cancer communities, we argue that digital media have profoundly shaped how ‘activism’ is enacted, both the goals pursued, and the strategies adopted, which serve to broadly align contemporary patient communities’ interests with those of science and business. This alignment, which we characterise as ‘bio-digital citizenship’, has involved a fundamental reorientation of ‘activism’ from less of a struggle for rights to more of a striving to achieve a public profile and attract funding. We conclude by calling for a reconceptualisation of ‘activism’ to more adequately reflect the workings of power in the digital age, whereby the agency and hopes of citizens are central to the workings of political rule.

Key words

Digital media, patient activism, biological citizenship, pharmaceutical industry, HIV/AIDS, breast cancer

Introduction

Digital media provide novel opportunities for citizens to manage their health. Recent national surveys reveal that a significant proportion of the population turn to the internet to search for health information (e.g. Fox, 2014; Wong *et al.*, 2014; Jacobs *et al.*, 2017). However, the impact of digital media on personal healthcare goes far beyond information seeking. The user-generated content of social media, characterised as Web 2.0, allows citizens to *produce* knowledge, including about their own experiences, and to advocate for changes in health-related policies and practices, in particular those affecting treatment (Lupton, 2013; 2014; Mazanderani *et al.*, 2013). The Web 2.0 technologies have meant that the way information available online is disseminated has been shifting to a more interactive, ‘dynamic’ knowledge flow comprising credentialed expert information and ‘lay’ experience (Hardey, 2002; Appleby, 2012). Citizens may use digital media to raise funds for research and to gain access to treatments that would otherwise be inaccessible to them because they are clinically unproven or have been approved only for certain applications (Authors). In doing so, citizens are developing distinctive strategies to help achieve their ends, both working with *and* challenging experts and expertise (Labonté, 2013).

This article examines how digital media are shaping the character of patient activism, alternatively known as patient advocacy, which refers to the endeavours of patients as individuals or in groups to express and achieve particular goals related to their disease or condition, such as a cure, access to treatments or improved standards of care. This activism may be through informal grassroots activities, such as raising funds and community events to draw attention to their goals, or more formally, as ascribed policy actors in the political process (Tomes and Hoffman, 2011). We ask, what role have digital media played in activists’ strategies? And, to what extent and how has the use of such media impacted the very concept of activism? Building on sociological ideas on emergent forms of ‘biological citizenship’ and referring to the historical examples of patient mobilisation within HIV/AIDS and breast cancer communities drawn from our analysis, we argue

that ‘activism’ has undergone significant change since the 1990s, in both the ascribed goals and adopted strategies, which is bound up with patient communities’ growing reliance on digital media and related scientific and commercial influence. During this period digital media have become integral to a new analytics of power that has served to align the interests of disease- and condition-specific groups with those of science and business, and thereby shift the focus of ‘activism’ from a struggle for rights to the striving to build a profile and attract funding. We characterise this alignment as ‘bio-digital citizenship’. We conclude by calling for a reconceptualisation of ‘activism’ to more adequately reflect the workings of politics and power in the digital age, where citizens’ agency and hopes for treatment are central to the creation of economic value. To begin, we elaborate on our guiding concepts and the context of our study, before introducing the details of our examples of HIV/AIDS activism and breast cancer activism.

From ‘bio-sociality’ to ‘bio-digital citizenship’

Writing at the beginnings of both the internet and a context of rising interest in the biosciences, especially genetics, Paul Rabinow (1992) pondered the implications of what he then saw as an emergent ‘bio-sociality’, involving new individual and group identities and practices linked to new genetic disease classifications. Rabinow wondered whether the technoscience developments that they reflected, such as genetics and the infiltrations into ‘nature’, would lead to the ‘death of the clinic’ and the demise of older forms of domination based on medicalisation and normalisation, such as those linked to race and sexuality, and their replacement by newer forms, such as networking, communication design, and stress management (1992: 245). In these latter references, Rabinow’s observations seem prescient in foreshadowing the now-significant role of information and communication technologies in structuring interactions and providing the foundation for new digitally-based means for the self-management of health conditions that have come to typify the contemporary era of ‘bio-digital citizenship’. Rabinow concluded that older forms of cultural classification of bio-identity had not disappeared but that the meanings and practices that constitute

them were changing. Thus, new genetic classifications, such as sickle-cell disease, reinforced pre-existing racial and social categories, even where the distribution is wider than particular communities, for example, the African-American community. He predicted that, in fact, older classifications would likely be joined by ‘a vast array of new ones, which will cross-cut, partially supersede and even redefine the older categories in ways that are well worth monitoring’ (1992: 245).

Writing a decade or more later, other scholars documented the ways in which the biology of citizens was becoming central to the workings of politics and power (e.g. Petryna, 2002; Rose and Novas, 2005). They saw this as manifesting in governmental programs focused on the health of populations and with risk management and the surveillance of diverse aspects of life from birth to death. It was also evident in new conceptions of citizenship that were based less on entitlements—for example to participate in political affairs or to enjoy health and welfare access—than on identifications and affiliations defined by biology and biological difference. The term ‘biological citizenship’, coined by Petryna in her study of post-Chernobyl Ukraine (2002) and subsequently elaborated by Rose and Novas (2005) in their analysis of genetic support groups, captured the sense in which individuals may link with and distinguish themselves from others in biological terms. These scholars were writing in the wake of gene-mapping projects, such as the Human Genome Project, optimism regarding the potential to apply the insights of research in biomedicine and the growing significance of genetic classifications as the basis for citizen activism (Rose, 2009). In Rose and Novas’ view, the politics of biological citizens is enacted within a political economy of hope that, in their view, both captures the kinds of fundraising and political activism undertaken by citizens themselves and patient groups that represent them as they seek to influence science, and ‘the ways in which life itself is increasingly locked into an economy for the generation of wealth, the production of health and vitality, and the creation of social norms and values’ (2005: 452). As Rose argues elsewhere, ‘contemporary biological citizenship operates within the field of hope’ in that it plays a fundamental role in structuring the actions of those in situations where illness or fear

of illness can lead to despair in the face of the future (2007: 135-136). This active quality of ‘hope’ draws attention to the horizon and to things that can be imagined and imbued with desire or ‘desire with expectation’ (Rose 2007, citing Brown, 1998). Other scholars writing in the early 2000s (including one of the authors) similarly documented the then emergent ‘genetic citizenship’ that involved an active orientation to one’s future health, through linking discussions of rights, recognitions and claims with concerns about inheritable identities and biophysical differences (Authors; Heath, *et al.*, 2004).

Over the quarter of a century since Rabinow’s reflections on ‘bio-sociality’, the internet and social media have profoundly transformed virtually all spheres of life—at least in those parts of the world with high internet penetration—and laid the foundation for a new form of citizenship that may be called ‘bio-digital citizenship’ (Author). This form of citizenship is characterised by the entwining of biologically based identities and digital based practices accompanying and facilitated by citizens’ growing use of the internet and social media to *both* consume and produce knowledge founded on biological categories, typically genetics. Social media enables a level of interactivity that was unimaginable until relatively recently with the advent of Facebook and other online platforms (Lupkin, 2014). Social media changed not just individuals’ access to information about health but also their ability to create, adapt and use information; for example, they may use sites such as Change.org to lobby for access to drugs and medical treatments (Mackey and Schoenfeld, 2016). Using digital media, those who self-identify on the basis of genetic or other biologically defined conditions were henceforth able to build communities, curate and share narratives of illness, treatment and recovery, and raise their profile in order to attract funds and lobby for research. This form of citizenship is also enacted within a political economy of hope, encompassing both individual patients’ and patient communities’ efforts to influence science agendas and authorities’ endeavours to generate wealth through the ‘bio-economy’ (Authors). In some cases, citizens may sponsor their own research, share experiences and knowledge with others (e.g. the Smart Patients website), or contribute to collaborative biomedical research ventures (e.g. PatientsLikeMe and

CureTogether). Furthermore, these ‘prosumers’ may work collectively with other communities of interest, including pharmaceutical companies and clinicians, to gain access to treatments, such as stem cell treatments and cancer treatments, that have yet to be approved or have been approved for only certain applications (Authors).

In seeking to fulfil their hopes, citizens may work with a diverse range of experts and expertise. For example, in lobbying for ‘compassionate use’—otherwise known as ‘pre-approval access’ or ‘expanded access’—of treatments that have yet to be approved for clinical application, patients often work in collaboration with pharmaceutical companies (e.g. Janssen), clinicians, bioethicists and other experts (e.g. NYU Langone Health, 2018). Using digital media, patient activists and their partners, such as the ‘Friends of the NYU Langone Health Working Group on Compassionate Use and Pre-Approval Access’ (CUPA), are increasingly working in collaboration with pharmaceutical companies such as Johnson & Johnson to organise events (NYU Langone Health, 2018). Groups of this kind may combine knowledge produced by credentialed experts and members’ own ‘experiential’ knowledge to affect change. The notion of ‘evidence-based activism’, developed by Rabeharisoa and colleagues (2013), captures the intertwining of ‘experiential knowledge’ and credentialed expertise that characterises individuals’ and groups’ efforts to tackle issues that they deem important to them. At the same time, the internet and new digital platforms such as Facebook, allow patients and their families to establish links with others similarly placed, to share experiences, to gain a profile for their conditions in order to raise funds to support their operations and research and to forge links with various experts and companies who offer support. This growing convergence of perspectives and interests between patient communities and scientific and commercial communities that has been facilitated by digital media, we suggest, profoundly alters the character and goals of ‘activism’ in ways that we elaborate below.

Method

The paper is based on an analysis of media produced by patient activists and reportage on activism in the HIV/AIDS and breast cancer communities, as it related to digital media. The study was undertaken between February and October 2017. Using combinations of the search terms HIV, AIDS, breast cancer, activism, digital or social media, internet, online and support group, we reviewed campaign material, websites, online forums, video documentaries and other materials produced by activists, reports on activist issues, activities and events in news media (print, television and online) and published histories on activism (books) from the 1980s until the present day. This date range was chosen to capture commentary on early AIDS activism where relevant and to reflect the time period when the internet began to emerge.

The online databases Scopus, Medline, Google and university library collections were used to search for material to review. This method meant that we did not consciously limit our analysis to any single geographical area. However, the search engines used ensured that all content uncovered was in English and reported on events in the English-speaking world. This represents one of the key limitations of using online platforms in research where, for example, some websites may be more prominent in search hierarchies, others could be inaccessible for technical reasons (such as updating) and yet others may be privileged due to language or cultural preferencing. In addition, we found that information about patient activism in the United States (US) was by far the most abundant in the narratives about the history of activism in the HIV/AIDS and breast cancer communities. Therefore, these texts have dominated the historical picture we were able to build on the trajectories of activism in the communities we focused on. There is clearly a need for empirical work on patient activism in areas outside of the US, which the authors' current work aims to address.

News media reporting on HIV/AIDS and breast cancer activism were also searched through Newsbank and further internet sources were accessed via Trove (a source of archived material held by the National Library of Australia). Television content was identified via Informit TV news, which includes a comprehensive repository of television programs of potential interest. Trove holds

a web archive for both health communities including government policies and campaign material developed by patient groups. The Australian Government Archive, also available through Trove, holds a repository of websites with links to Australian government policies pertaining to both health communities. The international web archive, Internet Archive, which also holds a repository of webpages, news and public affairs, was also searched using the terms above. News coverage of activist issues, activities and events for both conditions was collated by the same method. Reference lists of materials once found were also searched.

In total, the search identified 76 items; 32 for HIV/AIDS and 44 for breast cancer. These texts were thematically analysed for each health community and a map of themes for each condition created. The manual analysis was guided by questions such as: Who are the activists and what are their stated objectives? Is there any evidence that the strategies and the outcomes of activism have been enabled or facilitated by digital media use (e.g. social media-based campaigns)? Do activists use particular strategies to advance their aims and, if so, what form do these take? In employing these strategies, do they use scientific information and/or offer medical advice and, if so, is this accompanied by disclaimers? To what extent and how has activism impacted on news media coverage of treatment-related issues? According to this coverage, what are the main events, activities or issues and who are the influential actors? Is there evidence of interaction between activists' digital media use (e.g. online materials) and news coverage of issues, for example, do media link to or reference other media; e.g. by use of hyperlinks? The article draws on the most prominent themes that emerged from the analysis and those that emerged as relevant to both HIV/AIDS and breast cancer.

Results

HIV/AIDS and breast cancer activism

One can best grasp the changing character of ‘activism’ by tracing the origins and development of what many consider to be the vanguard activist groups, namely the HIV/AIDS and breast cancer communities. These communities forged their identities through struggles to redress what members saw as injustices and stake claims to social and civil rights and non-discriminatory policies, employing a distinct language and forms of collective struggle, especially political campaigning, street marches and other forms of public action. In this respect, these communities took their cue from the earlier civil rights movements of the 1950s and especially 1960s; namely, feminism, anti-racism movements and gay rights.

Inspired by the civil rights movement, feminism, gay rights and women’s health movement of the 1960s and 1970s (*United in Anger*, 2012; Diedrich, 2016), HIV/AIDS activism followed a tradition of challenging ‘experts’, such as doctors and scientists, and promoting the legitimacy of expertise held within a patient community, such as amongst people living with HIV and AIDS (PLWAs) (Gillett, 2003a). Biomedical dominance, where homosexuality was denoted as a medical condition which could be ‘cured’ was beginning to be challenged, in the same way that feminists had earlier challenged physicians’ control over women’s bodies; for example, the Boston Women’s Collective. The arrival of a new disease that came to be known as HIV provided a call to arms to many people involved in both the gay rights and feminist struggles. Subsequently, HIV/AIDS activist organisations were formed, using much of the experience acquired in these parent movements.

HIV activists, many of whom were PLWAs, were themselves becoming experts in their condition and lobbying for new drugs and treatments. HIV/AIDS activism, therefore, provides a defining example of activists influencing political, health and public policy agendas, in relation to research and access to treatments (Wachter, 1992; *United in Anger*, 2012; Diedrich, 2016).

HIV/AIDS activism was galvanised partly because of failure on the part of government, public institutions and the mass media to give voice to all relevant groups (especially women, people of colour and the LGBT community) in the early AIDS crisis of the 1980s. HIV/AIDS activists were

thus compelled to become knowledgeable about the condition. One of the major stakeholders, the US government of the time, for example, was not keen to fund research into a new disease that, initially, appeared to affect certain oppressed groups disproportionately. The US government was also believed to be discriminating against and marginalising groups based on their HIV status or lifestyle factors on the one hand and, on the other, not allowing some groups (especially women) to access official HIV status which meant they were then not entitled to vital social benefits (*United in Anger*, 2012). This was significant because, although there was no proven treatment for HIV/AIDS in the early days of the epidemic in the 1980s and early 1990s, adequate social service provision was at that time a key indicator of outcomes for HIV positive individuals and PLWAs (Borneman, 1988; *United in Anger*, 2012). The inadequacy of public health systems to deal with the early AIDS epidemic was believed to be illustrative of government priorities and policies at that time, particularly in the US context (Altman, 1994; Stockdill, 2003; Gould, 2009). These factors together provided the impetus for AIDS activist movements such as ACT UP (AIDS Coalition to Unleash Power) to emerge.

Like AIDS activism, breast cancer activism originated as a ‘bottom-up’ movement, with members—many of whom were also breast cancer sufferers—becoming experts in their own condition and advocates for policy change. They used public forums to develop a profile for a disease—arguably now ‘the biggest disease on the cultural map’ (Ehrenreich, 2001)—that previously was not spoken about in public (Lerner, 2002; Sulik, 2014). Feminism and the women’s health movement were instrumental in changing the way breast cancer was portrayed by creating a social environment in which the disease could be discussed freely as well as challenging the male, medical dominated paradigms by which this disease was originally treated and, thus, often hidden (Ehrenreich, 2001; Lerner, 2002; King, 2004; McHenry, 2015). Breast cancer activism also took its cue from the 1980s and early 1990s HIV/AIDS activist movements that were seen to have been successful in pressing their claims (Potts, 2001).

As we will explain, on the basis of evidence drawn from diverse media, including online communications, published histories, campaign material and other information produced by activists themselves, the public discourse surrounding both HIV/AIDS and breast cancer has changed significantly over the last three decades, along with the goals and strategies adopted by the respective communities. During this period, ‘activism’ in both communities moved from the margins of society to become a mainstream political presence and commercial undertaking; that is, the communities’ aspirations have become less oppositional in terms of their challenging cultural norms and credentialed experts and expertise, and more oriented towards building their public profiles through the use of digital and other media and working with science and business to achieve their goals. The struggle for rights and non-discrimination has been gradually eclipsed if not replaced by the striving to create a public profile for particular conditions, through the use of branding and related marketing techniques, in order to attract funding for research into new treatments and cures. A new, bio-digital citizenship, involving claims based on biological identities and advanced via the use of digital media, was beginning to emerge.

The shifting media landscape

As in other patient communities, activists in HIV/AIDS and breast cancer communities have made extensive use of media to disseminate information, to share stories of hope, to organise campaigns and other community events and to publicise their issues. Traditional media were a key component of the earliest HIV/AIDS activism (Altman, 1994, Gillett, 2003a; Gillett, 2003b; Diedrich, 2016) with different manifestations, including video, artworks (e.g. the Gran Fury collective), ‘zines (Long, 2000) and the AIDS memorial quilt (Gambardella, 2011). More traditional (i.e. non-digital) forms of media have in the past been significant vehicles for activist communities to disseminate health messages, provide advice, or challenge dominant portrayals (or the lack) of heterogeneous disease communities—and they continue to be so (Fuhrmans, 2002; Abbott, 2013; Smith, 2015; Mackey and Schoenfeld, 2016). Nonetheless, since the 1990s digital media have played a

progressively central role in the media landscape and in activist practice and are increasingly seen as the optimal way to reach target audiences. Digital media platforms were viewed as ‘empowering’ at the start because they were largely free and open to everyone who had access to a computer (Appleby, 2012). However, it remains the case that digitally mediated activist campaigns gain much wider attention if traditional media forms, such as newspapers, also pick up on stories that are trending on digital media (Smith, 2015). For example, in the case of stem cell treatments, mainstream media coverage of patients’ day-to-day struggles with conditions such as multiple sclerosis and spinal cord injury have served to provide a public profile for issues and thereby provide leverage for activists’ social media campaigns to gain access to treatments or to support particular clinics or providers (Authors).

While digital media have enabled citizens to gain access to a wider array of information than previously available and to build their communities’ profile and lobby for change, they have also served to confine debates and actions to those established by or closely aligned with scientific and commercial interests that have sought to extract economic value from patient data. In the case of HIV/AIDS activism, priorities were beginning to shift during a period corresponding with growing digital media penetration, but before the advent of social media. Writing in the mid-1990s, Epstein suggested that the emerging nature of HIV/AIDS activism was less a form of resistance and more a forum for information exchange and encouraging behaviour change (Epstein, 1996). Various observers noted that, from this period, HIV/AIDS activism was becoming less political (Altman, 1994; Gillett, 2003a). In the latter days of ACT UP in the 1990s, HIV/AIDS activists were accused of ‘consorting with the enemy’ because they had started working *with* pharmaceutical companies instead of engaging in more oppositional activism (Independent Lens, 2012). Members of ACT UP who formed the Treatment and Data Committee worked closely with pharmaceutical companies to develop and test AIDS drugs. At the time, their actions were criticised for being complicit with the interests of pharma (Altman, 1994; Independent Lens, 2012; Diedrich, 2016).

The shift in the priorities and strategies of HIV/AIDS activism from a rights-based approach to a more funding oriented one cannot be attributed solely to increasing internet penetration in general, or to social media specifically. Various issues such as the increasing biomedicalisation of HIV/AIDS through the 1990s, associated in particular with the introduction of antiretroviral therapy (1996/7)—which impacted significantly on rates of mortality and morbidity and paved the way for other therapeutic developments that can potentially keep infected individuals well for decades (Bailey and Fisher, 2008)—re-focused the priorities of AIDS activists. In part, AIDS activism morphed into a more institutionalised form in conjunction with the growing professional network of organisations providing AIDS information and services (Gould, 2009). The reasons for the decline of AIDS activist organisations such as ACT UP are contested even now amongst those who were involved on the ground (Gould, 2009). However, the rise of digital media undoubtedly greatly facilitated the forging of networks between HIV/AIDS communities, business interests, and medical researchers and served to install a more centralised, bureaucratised control of information and coordination of activist campaigns. Digitalisation has meant that the bottom-up, grassroots activism of early AIDS activism has been replaced in many cases with a more top-down version with activists taking less of a role than in the past in constructing meaning (Gillett, 2003b). In addition, a key role for current HIV activist websites is to filter the massive abundance of information online and assist users to navigate it (Gillett, 2003b). In Australia, the Australian Federation of AIDS Organisations (AFAO) website exemplifies this transformation.

The character of activism in breast cancer communities was also changing during this period, to become less focused on the struggle for rights than on profile building and fund raising, again, with growing reliance on pharmaceutical and corporate sources. Breast cancer activism was originally inspired by feminism and employed the strategic tools of the women's movement. This was both due to the age of the commonly affected population (many of whom were involved directly in Second Wave Feminism) as well as feminist and women's health movement principles being involved in challenging the male, medical hegemony which breast cancer activism often

entailed. However, from the outset, breast cancer activism has been characterised by conflicting goals and strategies. No single narrative encapsulates the breadth and diversity of breast cancer activism (McHenry, 2015). However, the most well-known and ‘mainstream’ form of breast cancer activism is epitomised by pink ribbon culture, which focuses on building the community’s profile, early detection especially through screening and fundraising for biomedical research with the hope of finding a cure. King (2004) has documented a shift in the public discourse of breast cancer from the 1970s, from a disease that is best dealt with in private and in isolation, to a neglected epidemic worthy of political action and debate, to an affirmative experience for women ‘survivors’. It is in this context, King (2004) suggests, that pink ribbons became a ‘symbol of hope’, used to attract philanthropic support, the supply of which ensures that the ‘fight’ against the disease remains an unqualified success. ‘Green’ or environmental breast cancer activism, on the other hand, provides a challenge to the dominance of pink ribbon culture and the way it operates, focusing less on individual experiences of survivorship and ‘cures’ and more on prevention and the possible environmental causes of the disease (McHenry, 2015).

Contemporary feminists within and outside breast cancer activist communities have tried to encourage a shift in priorities from the key focus being screening, treatment and a cure to focusing on prevention (Ehrenreich, 2001; Potts, 2001). Critics of mainstream breast cancer activism argue that there is not enough focus on the prevention of the disease and on social and environmental causes such as pesticides and other pollutants (Ehrenreich, 2001; Lerner, 2002; King, 2004; Pitts, 2004; Radin, 2006; McHenry, 2015). It is also argued that pink ribbon culture conflicts with many of the principles of feminism in its connotations. The focus on pink, the colour itself and the use of teddy bears and other childish symbols in marketing, has been a major point of contention, in that it infantilises women. Furthermore, to date there has been little interest in prevention from the powerful groups that support breast cancer activism; indeed, it has been suggested that some companies are even complicit in preventing close examination of environmental carcinogens they may themselves have a hand in producing (Landman, 2008). As both Landman (2008) and

Ehrenreich (2001) argue, the pharmaceutical and medical device companies that heavily fund breast cancer activism are more interested in screening and treatments than prevention. Finding a cure for the disease would not serve their or their shareholder's financial interests (Ehrenreich, 2001).

In this context, our analysis indicates that internet forums have served to discursively frame debates in terms of the experiential aspects of the disease and the treatment process, and to provide a location where those diagnosed with breast cancer and their carers can get support and information. Online platforms have been used less to advance struggles for rights than to facilitate grassroots responses to the condition in the form of online support groups (Pitts, 2004). Online breast cancer support groups enable a patient or their carer to access information and find treatment should it exist (Pitts, 2004; Radin, 2006). This model of activism utilises internet forums, information accessed online and personal narratives, often showcased via blogs (Lerner, 2002; Pitts, 2004; Radin, 2006). However, there remains a lack of clarity about whether apparent 'personal empowerment' for breast cancer patients online actually translates into significant improvements in the everyday lives of women with breast cancer (Pitts, 2004). Digital media did not initiate a dismantling of the borders between types of knowledge; this process was already underway with the women's health movement of the 1960s and 1970s being a prime instigator of this trend—at least in the rich Western or northern metropolitan parts of the world. Yet, digital media technologies, especially social networking sites (SNSs) did provide capabilities that greatly accelerated the proliferation of different kinds of knowledge. SNSs also enabled, indeed encouraged, lay people to share their personal, experiential knowledge, which complemented and sometimes challenged credentialed expert knowledge (Epstein, 1996; Hardey, 2002; Koay and Sharp, 2013; Labonté, 2013) enabling the aforementioned 'evidence-based activism'. At the same time, new media opened new possibilities for marketers to garner information on consumers' desires, online behaviours and purchasing habits and to use this information as the basis for algorithm-driven, 'personalised' advertising.

Pharmaceutical funding of patient groups

Recent evidence from the US reveals the consolidation of close ties between many patient activist groups and the pharmaceutical industry (McCoy *et al.*, 2017; Rose *et al.*, 2017). Research undertaken by McCoy *et al.* (2017) found that among 104 of the largest patient activist organisations based in the US, over 83% received financial support from drug, device and biotechnology companies, and at least 39% had a current or previous industry executive on the governing board. Based on publicly disclosed information, these figures are likely to be an underestimation. The generalisability of these findings to other countries is not known. However, in Australia, pharmaceutical companies have been known to sponsor events for online patient activist organisations, such as the HealtheVoices™ conference, hosted by Janssen Pharmaceuticals Inc., a Johnson & Johnson company (HealtheVoices™, 2018). Events such as these allow companies to better understand their consumer base and engender support for technologies, new treatments and devices, including health apps and wearables. In recent years, pharmaceutical companies, along with health insurance companies, internet companies such as Apple and Google and technology companies such as HealthWizz have made considerable efforts to forge links with patient communities and portray themselves as defenders of patients' rights and allies in campaigns to gain 'pre-approval access' to treatments and more effective and affordable care.

Digital media both facilitate the involvement of pharmaceutical companies in online patient activist organisations and enable internet companies such as Facebook, Google and Twitter to monetise patients' health information; that is, use it for the development of new treatments or other technologies (e.g. wearable devices, cloud computing) that generate profits (Aubusson, 2017; McCoy *et al.*, 2017; Rose *et al.*, 2017). In the wake of the March 2018 Cambridge Analytica scandal it emerged that Facebook planned to match patient data from US hospitals with Facebook profiles to assist medical agencies in finding patients that could need additional treatment (Ramsay, 2018). This deepening entanglement of corporate interests with patient community interests, especially in regard to co-hosting events to attract funding and the sharing of marketing strategies,

is not without its critics. Some within the breast cancer community, for example, have labelled the model of activism that draws support from the business sector as ‘pink washing’—a term modelled on ‘whitewashing’, to indicate how attention is diverted from the insidious aspects of an industry—which leads the public to assume that the company in question is donating a significant amount of their profits towards breast cancer activism (Landman, 2008; Selleck, 2010; Sulik, 2014; McHenry, 2015). This pinkwashing, it is argued, may lead the public to believe that by supporting a pink branded product they are doing something significant to combat breast cancer whereas in fact they are mainly boosting the profits of the company, given the small proportion of proceeds that are customarily donated per pink branded item. Brands accused of pinkwashing are numerous and include BMW, Revlon and Estée Lauder (Landman, 2008). This commercial model of patient activism, it has been argued, is leading to the commodification of breast cancer (Sulik, 2014). The corporatisation of breast cancer activism has also resulted in a narrow focus on the biomedical aspects of the disease (Ehrenreich, 2001; Sulik, 2014; McHenry, 2015) which aligns with corporate and big pharma objectives, serving to mute efforts to consider prevention as a priority of breast cancer activism. Pharmaceutical responses are similarly highly prevalent in the discourse around HIV/AIDS. While there is no equivalent of the pink branding that dominates the marketing of breast cancer activism, antiretroviral therapy (ART)—and more recently PrEP (Pre-Exposure Prophylaxis), which involves taking medication as prevention against HIV—have effectively made AIDS a chronic condition for individuals (or those with health care systems) that can afford it. This overwhelming focus on drug treatments, however, diverts attention from targeting the social determinants of HIV risk, an approach that could potentially benefit more people overall.

The internet has not increased transparency in this regard, nor is it likely to given the powerful corporate online gatekeepers such as Google, Facebook, Twitter and their revenue driven ideologies which align with a consumer driven model of digital patient activism. Research undertaken by Marcon *et al.* (2017), involving analysis of 224 published articles drawn from a list of websites identified as containing ‘fake’ or ‘junk’ news on stem cell research, identified

‘organized misinformation networks’ that produced distorted, decontextualized information. Market competitors often generate ‘fake’ information about health, medical and other products and services via bots to drive up each other’s costs (Cookson, 2016; Lanchester, 2017).

Discussion and conclusions

This article has explored the shifting dynamics of digital patient activism, with reference to the experiences of the HIV/AIDS and breast cancer communities, respectively. These communities’ experiences are potentially highly instructive since, firstly, they have relatively long histories, representing the ‘first wave’ of patient group mobilisation focusing on rights that developed in the wake of identity-based social movements of the late 1960s and 1970s, particularly gay rights and feminism, and, secondly, they evolved during a period in which digital media were gaining increasing significance in patient communities, as means to build networks, develop sociality, and stake claims. Writing in the early 1990s against the backdrop of heightened optimism regarding the potential of the life sciences to advance understanding of human behaviour and lay the foundation for new life saving and economic value creating ‘breakthroughs’, scholars noted the then emergent forms of bio-based sociality and citizenship that patient activists typified. As Rose and Novas observed (2005), a new biological citizenship was being enacted within a political economy of hope that both reflected the aspirations and activities of citizens in seeking to shape science and the growing tendency to integrate life itself into the economy of wealth creation.

As we suggested, the 1990s represents something of a watershed period in the history of patient activism in that, increasingly, group identities were being forged via the interaction of bio-based identity claims *and* digitally mediated practices. While, as we argued, a number of developments have significantly shaped ‘activism’ from this period, digital media have been crucial to a new analytics of power that has served to closely align the goals of activist groups with those of science and business. Citizens have been encouraged (‘empowered’) to become less reliant on the state and to be more accountable for their own health and to use the internet and a host of new

online resources that were being created by various authorities and patient communities themselves (Author). Moreover, from the early 2000s social media were beginning to be employed by those who were seeking to profit from the development and sale of new treatments and devices using direct-to-consumer marketing, Facebook, and other digital platforms to bypass credentialed experts and established regulatory mechanisms. On the other hand, citizens increasingly were beginning to combine different kinds of knowledge—both scientific and experiential—to create and disseminate their own narratives, including hopeful stories, to raise funds for research, and to gain accelerated access to treatments that would otherwise be destined for the long, costly and uncertain path of clinical translation. This ‘evidence-based activism’, we suggest, is less oriented to challenging cultural norms and credentialed experts and expertise than to building profiles in order to attract funding. In short, ‘activism’ has been transformed over the last two decades from less of a social struggle for rights to more of a professional and business-like undertaking, with activist groups using the insights, expertise and financial support of science and corporations to achieve their goals.

Our analysis underlines the need to reconceptualise ‘activism’ to more adequately reflect the workings of politics and power in the digital age, where citizens’ agency and hopes for treatment are crucial to the creation of economic value. Such a reconceptualisation will necessitate greater recognition in research and in public communications of the crucial and growing significance of personal data, especially health data, in contemporary economies and the implications of this for activist efforts. Personal data, especially health information, has become a highly valuable resource—described as the ‘new oil’—that can be ‘mined’ by big tech companies such as Google, Apple and Amazon, along with smaller enterprises, to create economic value and when combined with other data (e.g. health behaviours, clinical records) to generate further profit or, alternatively, used by governments for purposes of surveillance and control. This data provides the basis for new asymmetric relationships between those who collect, store and mine data and those who are the collection targets; namely ordinary citizens for whom processes of mining and analysis are opaque (Andrejevic, 2014). In this context, bio-digital citizenship is serving a crucial role in aligning

citizens' hopes for improved health and corporate and government interests in the emergent digital healthcare economy. The extent to which the harvesting of citizens' personal data ultimately serves the interests of disease- or condition-specific communities—especially in regard to preventing their diseases or conditions or alleviating their suffering, which call for very different responses—is questionable. Users of digital health platforms may not be aware of the growing commercial uses of such sites, such as selling goods and services to users, generating advertising income and selling on data to third party organisations (Lupton, 2014). While health data about individuals that is posted online can potentially be of value for individual patients themselves (see van Dijk and Poell, 2016), its monetisation should cause activists who work on behalf of patient communities to reflect on their goals and strategies.

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