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Health activism and the logic of connective action. A case study of rare disease patient organisations

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ABSTRACT

This exploratory work investigates the role of digital media in expanding health discourse practices in a way to transform traditional structures of agency in public health. By focusing on a sample of rare disease patient organisations as representative of contemporary health activism, this study investigates the role of digital communication in the development of (1) bottom-up sharing and co-production of health knowledge, (2) health public engagement dynamics and (3) health information pathways. Findings show that digital media affordances for patient organisations go beyond the provision of social support for patient communities; they ease one-way, two-way and crowdsourced processes of health knowledge sharing, exchange and co-production, provide personalised routes to health public engagement and bolster the emergence of varied pathways to health information where experiential knowledge and medical authority are equally valued. These forms of organisationally enabled connective action can help the surfacing of personal narratives that strengthen patient communities, the bottom-up production of health knowledge relevant to a wider public and the development of an informational and eventually cultural context that eases patients' political action.

Introduction

The role of digital communication in contemporary mobilisation has become a topical subject across social movement and media and communication studies. The question often centres on the level of influence digital media have on emergence, development and sustainability of collective action, given different political opportunity structures. However, the relationship between digital media and health activism, despite the importance of the impact of health activism on public health services and scientific research, has so far remained unexplored.

By drawing upon the 'logic of connective action' (Bennett & Segerberg, 2012, 2013), this study specifically investigates the affordances of digital communication for patient organisations and it does so by focusing on rare diseases patient organisations.

The article will review research on health activism with a specific focus on the role of patient organisations, and work interested in the relationship between health and digital media. Then, case study, data and methods will be introduced. The remainder of the paper will discuss the role of digital media in bottom-up health information sharing, production and engagement and in the construction of alternative health information pathways.

Health activism

In the late 1960s, the women's health movement began challenging patriarchal norms embedded in medical stereotypes, framing those norms as detrimental for women's health. Twenty years later, AIDS patients advocated for clinical research that could lead to the discovery of a treatment for their disease and mental health activists marched for the rights of mentally disabled patients (Brown, Adams, Morello-Frosch, Senier, & Simpson, 2010, p. 380; Cordner, Brown, & Morello-Frosch, 2014; Epstein, 1995, 1996; Zoller, 2005, p. 342). In the 1990s, for the first time, breast cancer activists drew public attention to the environmental causes of breast cancer (Brown et al., 2004; McCormick, Brown, & Zavestoski, 2003; Pezzullo, 2003). These and many other Health Social Movements (HSMs) share a common element: in one way or another, they challenge traditional conceptions of medical authority.

HSMs advocate for the inclusion of non-scientific and non-governmental views in the management of public health, as the 'scientization of decision-making […] can exclude the public from important policy debates and diminish public capacity to participate in the production of scientific knowledge itself' (Brown & Zavestoski, 2004, p. 681). Brown and Zavestoski (2004, p. 681) advance that contemporary 'societal rationalisation' – or the assumption according to which policy-making has to be primarily informed by scientific evidence – foregrounds the role of scientific expertise by simultaneously downplaying that of public knowledge. The target of HSMs' critiques is then often the absent-to-limited power of patients in the management of public health that is common in traditional forms of patients' exclusion from health consultations and in paternalist approaches to patient involvement (Thompson, 2007). Hence, HSMs hold a twofold relationship with medicine, on one hand they do depend on medical expertise in the development of scientific research with diagnostic and prognostic objectives but on the other hand they challenge social, cultural, economic and often politicised dominance of medical authority in health decision-making.

Drawing upon the American tradition of social movement theory, Brown and colleagues provide a typology of HSMs that describes three ideal types: health access movements – that 'seek equitable access to healthcare and improved provision of healthcare services' –, constituency-based health movements – that 'address health inequality and health inequity' across social groups –, and embodied health movements – that 'address disease, disability or illness experience by challenging science on aetiology, diagnosis, treatment and prevention' (2004, p. 52). Now, while other HSMs categorisations have perhaps provided more comprehensive explanations of HSMs' mobilising potentials (Scambler & Kelleher, 2006) and political orientation (Zoller, 2005), Brown and colleagues' issue-based taxonomy directly focuses both on specific areas of action and on the institutional outcomes HSMs try to achieve. In particular, embodied health

movements (EHMs) are characterised by three elements that make them the most contemporary instances of health activism: they introduce the embodied experience of a disease in activist performances, they directly challenge medical science's success in solving health problems that are often 'socially and economically mediated' (Brown et al., 2004, p. 2), and they ease collaborations between patients, patients' families, health professionals and lay people via what we may call instances of fluid interaction.

Given that EHMs move the boundaries 'between what are considered to be patient skills and initiatives and what remains the responsibility of the doctor' (Barbot, 2006, pp. 538–539), they have also been given the attribute of 'boundary movements' (Brown et al., 2004; McCormick et al., 2003). EHMs, as boundary movements, blur traditional distinctions between lay people and professionals and 'A central vehicle for blurring these boundaries is the use of what we term the "citizen/science alliance," a lay-professional collaboration in which citizens and scientists work together on issues identified by laypeople' (McCormick et al., 2003, p. 547). In the emergence of these alliances between patients and health professionals, patient organisations obviously play a pivotal role.

Patient organisations: from auxiliaries to scientific partners

In EHMs, the traditional division of skills between health professionals and patients – with the former holding power over medical knowledge and policy access and the latter dealing with the psychosocial aspects of illness – was overturned when patient organisations 'joined established actors in the production of medical and scientific knowledge' (Barbot, 2006, p. 539). According to this new model, not only did 'active patients' (Barbot, 2006) share relevant information on their illness and generated resources for self-support, they also engaged in the production of scientific knowledge. In fact, Landzelius introduces yet another label for HSMs that directly challenges traditional boundaries between health professionals and patients, that of '"patient organisation movements": a label that clearly calls attention to the figure of the patient, the phenomenon of organisation, and the dynamics of movements' (2006, p. 530). Landzelius' work – together with that of several scholars primarily from the field of medical sociology (see, among the others, Abma, 2006; Barbot, 2006; Caron-Flinterman, Broerse, & Bunders, 2005, 2007; Epstein, 1995, 1996; Rabeharisoa, 2003, 2006; Thompson, 2007) – focuses on the role of patient organisations in bridging the gap between patients, health professionals and health policy-makers and in providing the grounds for successful interactions.

While different patient organisations may hold alternative views on patients' role in the production of scientific knowledge (Barbot, 2006, p. 548), instances of patient organisations' engagement in biomedical research may be categorised under three models: auxiliary, emancipatory and partnership (Rabeharisoa, 2003, p. 2128). The auxiliary model covers a wide range of organisations that, to different degrees, delegate research decisions to scientific councils, and limit their ability to decide which research to finance. In the most advanced instances of patient organisations' engagement within this model, patient organisations work to acquire scientific knowledge and be able to confront scientific experts (Epstein, 1995). Traditional patient self-help groups belong here. The emancipatory model emerged as a consequence of the health movements in the 1960s–1970s. Then, advocacy groups mobilised to engage more directly in decision-making processes, prioritising their 'experiential knowledge' (Borkman, 1976) over traditional forms of

professional knowledge. The partnership model is particularly relevant to those patient organisations that advocate for new and/or rare pathologies, where scientific knowledge is still scattered, hence those organisations mobilising within EHMs. The role of patient organisations here is of central importance as '(1) the patient organisation is master of its research policy; and (2) patients are specialists' partners in their own right' (Rabeharisoa, 2003, p. 2131).

In sum, at the very least, EHM patient organisations work towards the expansion of discursive space around specific illnesses and ease interactions among different actors involved in biomedical research and policy-making relevant to those illnesses. It should, however, be noted that these communication processes do not happen in a media vacuum; media ecologies certainly shape discourse dynamics and influence interaction processes among different institutional and non-institutional actors.

The digital in health: from eHealth to patients' digital engagement

The term 'eHealth' probably represents the first attempt to combine health and Information and Communication Technologies (ICTs). In 2001, Eysenbach advanced what was to become one of the most popular definitions of eHealth: 'an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies' (Eysenbach, 2001, online). In fact, starting from the 1990s, eHealth has received a plethora of definitions where technology has been primarily described as a means to expand and enhance health-related human activities. There, 'Most commonly, the word *health* was used in relation to health services delivery' (Hans, Carlos, Murray, & Alejandro, 2005, online). The feeling is that in the 51 different definitions of eHealth reviewed by Hans and colleagues (2005), the described technology-enhanced health process is still a top-down one, where ICTs simply ease the delivery of services from health providers to health users. Even when exchange processes are described, those processes are usually not regulated or coordinated by patients or traditional health end users.[1] The now emerging literature on mHealth – defined as 'medical and public health practice supported by mobile devices' (World Health Organisation, 2011; quoted in Whittaker, Merry, Dorey, & Maddison, 2012, p. 12) – applies an approach similar to that of the relationship between health and (mobile) digital communication, by primarily focusing on the way via mobile devices 'information and services can be *delivered* at appropriate times' and '*penetrate into* underserved or disadvantaged populations' (Whittaker et al., 2012, p. 12, emphasis added).

Traditionally, bottom-up ICTs use for health has been described in research investigating online health information seeking and studies interested in online self-support groups. The former research strand primarily highlights that users seek health information online to make health-related decisions, to know about their future and to seek social support (Balka, Krueger, Holmes, & Stephen, 2010). This work also draws attention to health digital divide issues (Wyatt, Henwood, & Hart, 2005), especially social inequalities in technology access (Gustafson et al., 2005; Hsu et al., 2005), literacy skills (Mackert, Champlin, Holton, Muñoz, & Damásio, 2014; Zarcadoolas, Blanco, Boyer, & Pleasant, 2002) and information-filtering skills (Eysenbach & Kohler, 2002).

Studies interested in online self-support groups investigate the impact of such groups on patients and patients' relatives, particularly on the emotional aspects of living with a

disease. Research in this camp has measured the relationship between type of illness and the likelihood for a patient to use online groups of support (Owen et al., 2010) or investigated the importance of online tie support (Cohen & Raymond, 2011; Wright, Rains, & Banas, 2010). Health information seeking and online social support research strands are now merging in studies interested in patients' use of undifferentiated social media (e.g., Facebook) (Greene, Choudhry, Kilabuk, & Shrank, 2011) and specialised social media (e.g., PatientsLikeMe) (Kallinikos & Tempini, 2014; Tempini, 2015) to seek, produce and share personal health data.

An element that is still highly overlooked in research concerned with the bottom-up use of digital media in relation to health is how patients organisations exploit digital affordances in their advocacy and activist action, namely, in expanding health discourse practices and mobilising and connecting different publics.

The logic of connective action

In her work on collective mobilisation on muscular dystrophy, Rabeharisoa (2006) shows how not only do patient organisations act as patients' representatives; in their mobilising for 'the cure' and for patients' recognition, they often work as mediators among different social actors and across different social spaces. But how do contemporary digital media contribute to such processes of mediation and mobilisation?

The most contemporary literature interested in the relationship between media and mobilisation focuses exactly on the extent to which digital media can change traditional dynamics of social contention, especially in conditions of poor or limited resources. The point at stake here is that for the formation of collective actors and the diffusion of collective action frames, a certain amount of resources is needed, in terms of organisational support, communication strategy and formal membership dynamics. The most popular explanation of the role of digital media in contemporary protest is that they may become resources themselves and cover for most of the mobilisation processes that traditionally had high costs (Bennett, 2003). This explanation implies that digital media do not change the dynamics of collective action; they simply ease its emergence where resources are limited.

However, recent instances of mobilisation have shown what have been defined as 'fluid' forms of mobilisation (Gerbaudo, 2012), where traditional dynamics of collective action – like the emergence of a collective actor with defined leaders and claims and clearly supported by institutional organisations – seem to be less evident than in the past. In these instances of mobilisation, individuals – free from organisational ties and detached from strongly defined ideological claims – connect and disconnect more fluidly. Social networking has been described as at the centre of these dynamics of engagement: 'when people who seek more personalised paths to concerted action are familiar with practices of social networking in everyday life […], they are already familiar with a different logic of organisation: the logic of connective action' (Bennett & Segerberg, 2013, p. 29). The idea is that digital media can replace traditional organisations, allowing the emergence of activism based on personal – rather than collective – frames of action shared on technological platforms. In the realm of 'connective action', traditional organisations are either absent or only responsible for a loose coordination of action. Bennett and Segerberg (2013) distinguish between the forms of mobilisation derived from these two different

organisational settings, calling them 'crowd-enabled' and 'organisationally enabled' connective action, respectively. According to Bennett and Segerberg, 'digitally networking mechanisms' – from web links to website organisational devices like calendars and information sharing tools – 'help calibrate relationships by establishing levels of transparency, privacy, security, and interpersonal trust' (2012, p. 753). As such, digitally networking mechanisms may offer different routes to engagement where Dahlgren's parameters of public engagement – intensity, depth, disposition, mode, field, socio-cultural origins and maintenance (2015) – can vary considerably.

By drawing upon the logic of connective action, the study tackles the question of how digital communication contributes to – and possibly shapes –EHM activism.

Case study: rare disease patient organisations

A disease is defined rare when it affects 1 in 2000 people in the European Community and 1 in 1250 people in the USA. Most of the over 6000 rare diseases so far identified are chronic and life-threatening (Eurordis, 2015; Nord, 2015). Rare disease patients face extremely adverse conditions primarily because of the lack of information and knowledge on their disease in both the medical community and the general public. As Brown and Zavestosky suggest:

> When a condition has no name, or a name that does not receive medical legitimacy, the formation of illness identities, and thus a politicised identity, is constrained. Also, even if people with such a condition succeed in developing a politicised collective illness identity, they have a much more difficult time generating scientific knowledge. (2004, p. 74)

As a matter of fact, until the 1980s the pharmaceutical industry neglected rare disease research because it considered it not profitable. The situation changed, thanks to lobbying by the rare disease community that advocated for the implementation of specific policy to ease the development of treatments for rare diseases (Aymé, Kole, & Graft, 2008).

Given that the first obstacle to public and private intervention in the case of rare diseases is the limited number of patients affected by each individual disease, patient organisations have started networking across patient communities, drawing attention to the overall impact of rare diseases. In fact, on the websites of the major umbrella organisations for rare diseases in the EU and the USA, one reads: 'An individual rare disease may affect only one person in a million, but all together, rare disease patients comprise 6% to 8% of the EU population' (Eurordis, 2015). 'While each [rare] disease is rare, when considered together they affect nearly 30 million Americans or almost 1 in 10 people' (NORD, 2015). Therefore, rare disease patient communities are working towards building a rare disease 'solidarity network' (Rogers, 2004), to both generate support for rare disease patients and raise awareness in the general public.

Rare disease patient organisations are representative of EHMs because they often focus on the embodied experience of a disease, challenge existing – or non-existing – medical knowledge, and pursue partnerships between patients, patients' families, health professionals, health policy-makers and lay people. Also, given the lack of knowledge and expertise in rare disease diagnosis and treatment, patient organisations usually follow a partnership model of engagement in biomedical research (Aymé et al., 2008; Barbot, 2006; Rabeharisoa, 2003). Finally, rare disease patients and patients' families have been

defined as extremely active in searching and exchanging online health information (Fox, 2011).

Taking rare disease patient organisations as a case study, this research aims to investigate how digital mechanisms shape EHM activism. This goal is driven by three specific questions:

RQ1: How do EHM patient organisations exploit digital mechanisms for bottom-up sharing and co-production of health knowledge on specific issues (e.g., a rare disease)?

RQ2: How do EHM patient organisations exploit digital mechanisms to generate public engagement?

RQ3: To what extent do EHM patient organisations exploit online linking to endorse varied health information pathways?

Data, sample and methods

This study is exploratory in nature. It specifically focuses on the websites of rare disease patient organisations as websites are usually the 'most public of faces' for activist organisations (Bennett & Segerberg, 2013, p. 60). The analytical procedure applied here is similar to Mager's (2009) sociotechnical approach to provision and use of online health information. In particular, we investigate websites' digital mechanisms (i.e., various more or less interactive website elements) as what Bennett and Segerberg define 'potential network agents alongside human actors (i.e. individuals and organisations)' (2012, p. 753). In fact, the study's goals required an analytical design where online content and content connectors could be identified, categorised and mapped.

The investigation focuses on a purposive sample of 31 rare disease patient organisations designed in August 2013. A list of rare diseases was initially generated on the basis of the most recent approvals for rare disease treatments by the EU and US regulatory authorities (i.e., European Medicine Agency (EMA) and Food and Drug Administration (FDA), respectively). This was meant to provide relevant information on active rare disease patient communities advocating for treatment research. Then, the name of each retrieved disease was searched on google.com to identify the online top-ranked organisations advocating for that disease, so to isolate the relevant patient organisations that were strategically exploiting online information politics (Mager, 2009, pp. 1127–1129). When the websites of patient organisations from different countries appeared in the list of the first 10 retrieved webpages, all organisations were included in the sample. Table 1 provides details of the study's sample.

The first analytical step was functional to address RQ1 and RQ2 and as such comprised the investigation of the websites' digital mechanisms specifically meant to disseminate patients' health knowledge (RQ1) and provide elements for public engagement (RQ2).[2] In this phase, the authors conducted a preliminary sample screening to familiarise with the data and operationalise a codebook for data collection. Then, a first coder conducted data collection and a second coder carried out data cleaning and input versus output verification, namely, she tested consistency between gathered information and codes' definitions (Freeman, 2004, p. 78).[3]

Table 1. Sample: rare diseases and patient organisations.

Rare disease	Patient organisation	Location	Website address
Addison's disease	Addison's Disease Self Help Group	UK	www.addisons.org.uk
Amyloidosis	Amyloidosis Foundation	USA	www.amyloidosis.org
Ataxia	Ataxia UK	UK	www.ataxia.org.uk
Blood cancer	Leukaemia &Lymphoma research	UK	leukaemialymphomaresearch. org.uk
Childhood auto Inflammatory disease	Stop CAID Now	USA	www.stopcaidnow.org
Childhood cancer	Children with Cancer UK	UK	www.childrenwithcancer.org.uk
Chronic lymphocytic leukaemia (CLL)	CLL Support Association	UK	www.cllsupport.org.uk
Chronic Myelogenous Leukaemia (CML)	The National CML Society	UK	www.nationalcmlsociety.org
Cryopyrin-associated periodic syndromes (CAPS)	Nomid Alliance	USA	www.nomidalliance.org
Cystic fibrosis	Cystic Fibrosis Trust	UK	www.cysticfibrosis.org.uk
Cystic fibrosis	Cystic Fibrosis Canada	Canada	www.cysticfibrosis.ca
Cystic fibrosis	Cystic Fibrosis Foundation	USA	www.cff.org
Friedreich's ataxia	FARA	USA	www.curefa.org
Gaucher disease	Gaucher Association	UK	www.gaucher.org.uk
Gaucher disease	National Gaucher Foundation, Inc.	USA	www.gaucherdisease.org
Hereditary angioedema	US Hereditary Angioedema Association (HAEA)	USA	www.haea.org
Hereditary angioedema	HAEUK	UK	www.haeuk.org
Idiopathic pulmonary fibrosis	Pulmonary Fibrosis Foundation	USA	www.pulmonaryfibrosis.org
Leukaemia	Leukaemia Foundation	Australia	www.leukaemia.org.au
Lymphoma	Lymphoma Research Foundation	USA	www.lymphoma.org
Lynch syndrome	Lynch Syndrome International	USA	www.lynchcancers.com/
Multiple myeloma	Multiple Myeloma Research Foundation	USA	www.themmrf.org
Myeloma	International Myeloma Foundation	USA	myeloma.org
Myeloma	Myeloma UK	UK	www.myeloma.org.uk
Myeloproliferative neoplasms	MPN Research Foundation	USA	www.mpnresearchfoundation. org
Pituitary disease	The Pituitary Society	USA	www.pituitarysociety.org
Pulmonary fibrosis	Coalition for Pulmonary Fibrosis	USA	www.coalitionforpf.org
Short bowel syndrome	Short Bowel Support (SBS)	USA	www.shortbowelsupport.com
ShortbBowel syndrome	Short Bowel Syndrome Foundation	USA	www.shortbowelfoundation.org
Tuberous sclerosis	Tuberous Sclerosis Alliance	USA	http://www.tsalliance.org
Tuberous sclerosis	Tuberous Sclerosis Association	UK	http://www.tuberous-sclerosis. org

The second analytical phase comprised the investigation of the organisations' online links to other entities. In fact, Rogers' (2013) approach to online linking strategies was applied to interpret how and to what extent patient organisations exploit online networking structures to provide alternative informational pathways around health issues (RQ3).

Analysis

Patient-generated health knowledge and routes to health public engagement

The coding process provided evidence that patient organisations use a wide range of online elements to inform and engage different publics. Ready-made informative elements are the most traditional items, turning websites into repositories of information. Diagnostic information may range from descriptions of symptoms to information on inheritance patterns, on to information on disease causes, details on patients' life expectancy, patients'

testimonies on symptoms, list of relevant scientific publications, information on diagnostic centres, expert answers and FAQ sections. Treatment is usually covered by providing information on existing cures, general data on clinical trials, patients' testimonies on treatments and clinical trials, lists of scientific publications, expert answers and information on support centres. Overall, these elements provide contextual information that could be of use and support for patients, patients' relatives, lay people and GPs willing to know more on a specific disease. Details on the presence of a patients' registry are also often a key piece of information, especially to know whether a patients' database is available for future clinical trials.

These central informative elements, primarily used to ground the most relevant data available on a disease, are often coupled with more dynamic elements like organisational devices as calendars and news sections where the organisation presents future activities, video material on YouTube and/or Vimeo and social media feeds (e.g., RSS, Facebook, Twitter). Overall, this first set of digital mechanisms does not constitute more than a list of one-way information channels, where end users are given the opportunity to browse more or less basic information on the disease at stake and, as such, given the chance to engage in knowledge acquisition rather than in any real form of action. These elements belong to the pool of digital mechanisms where 'information can be observed moving in largely *one-way* flows from an organisation to its publics (e.g. via newsletters, closed calendars)' (Bennett & Segerberg, 2013, p. 137).

A second set of digital mechanisms is of those where end users are given the option to access further one-way information channels. The analysis showed two similar mechanisms of this type used in different websites: newsletter registration and email update registration. These items add an action element to the first list of digital mechanisms as they require the end user to take minimal action to access further information. These elements build a loose tie between the organisation and the end user as the latter, upon registration, will start receiving messages from the former.

When engaging with the third set of digital mechanisms, the end user is given the option to contact the organisation and start a real information exchange. These items add a collaborative element between the end user and the organisation as they enhance communication processes that 'can emerge through *interactive* information sharing' (Bennett & Segerberg, 2013, p. 137). This may happen via Contact us or Registration/log in forms or via a more or less direct involvement with the organisation's activity as the end user may directly donate money or purchase merchandise to indirectly participate in the organisation's fundraising. In these cases the end user, if taking the action, shares more of her personal sphere with the organisation and engages in a more or less developed exchange of information with it.

While the first three sets of digital mechanisms enhance one-way or two-way communication processes, the very last group of digital mechanisms is that of digitally networking mechanisms. Here the end user is given the possibility to engage in crowdsourced communication processes. This could happen in different ways: on the one hand, the end user can engage in websites' internal forums, chats or blogs or share material like videos or photos. On the other hand, website links can lead to external social media platforms: there, the end user can follow the organisation's Facebook page or join its Facebook group, join the organisation's circle on Google+, follow the organisation on Flickr or Twitter, link to the organisation's LinkedIn page, join mailing lists, share

or bookmark the organisation's website address or access forums, chats or blogs. These action opportunities are highly unstructured, that is, the organisation may gradually move to the background of the communication process, with different publics connecting and engaging in health personal knowledge sharing and co-production.

Now, a way to interpret these four different models of health knowledge transition (i.e., one-way communication processes) or exchange (two-way or crowdsourced communication processes) is by looking at the form of engagement they require. To measure the deriving engagement models, we can draw upon two of Dahlgren's (2015) parameters of engagement: 'intensity' and 'depth'. The first parameter translates as the degree of agency exerted by the end user in engaging in the issue at stake. Looked at through this prism, public engagement eased by digital mechanisms varies from one where individuals exert very limited agency and only engage in increasing their personal health knowledge to one where different publics potentially get involved in active discussions on health, exchanging their experiential knowledge. Evaluating the depth of engagement means measuring 'how much of the self is involved' (Dahlgren, 2015). As shown in Figure 1, starting from the second set of the digital mechanisms described above, end users are required to partially *become public* and share some of their personal information, with the organisation in the second and third sets of digital mechanisms, and with different publics in digitally networking mechanisms.
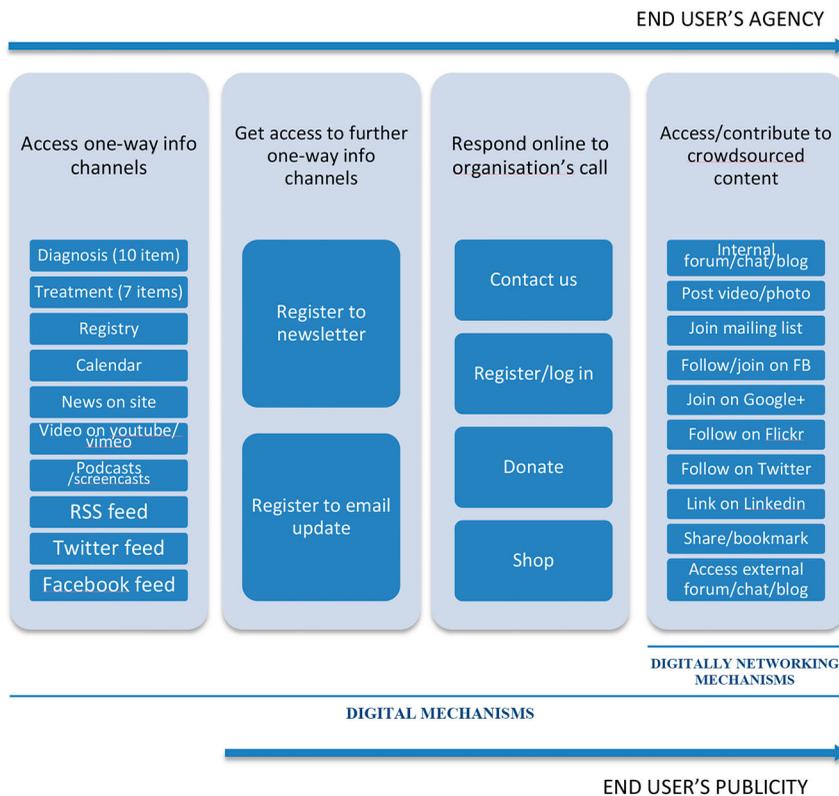

Figure 1. Digital mechanisms on the websites of rare disease patient organisations.

In sum, digital mechanisms on rare disease patient organisation websites provide at least four different types of communication processes where bottom-up selected and/or generated health knowledge is delivered to the end user, exchanged between the patient organisation and end user or crowdsourced by different end users and possibly – but not necessarily – by the patient organisation. These different channels for health knowledge transition and exchange generate different dimensions of public engagement where intensity and depth – or agency and publicity – can vary considerably.

Health information pathways

Not only do digital mechanisms ease sharing and co-production of health knowledge via offering different routes to engagement. By exploiting hyperlinking structures, they also ease online bridging among different social actors and bolster the development of health information pathways.

By using Issuecrawler software for online crawling, we tracked the outlinks of our sample organisations. The crawler was set to use a snowball crawling method, namely to crawl seeds [i.e., sample websites] and retain URLs with at least one link from those seeds. The crawling was set at depth 2, which means that the results reported the webpages linked to in the sample's homepages and in the homepages' internally linked webpages.
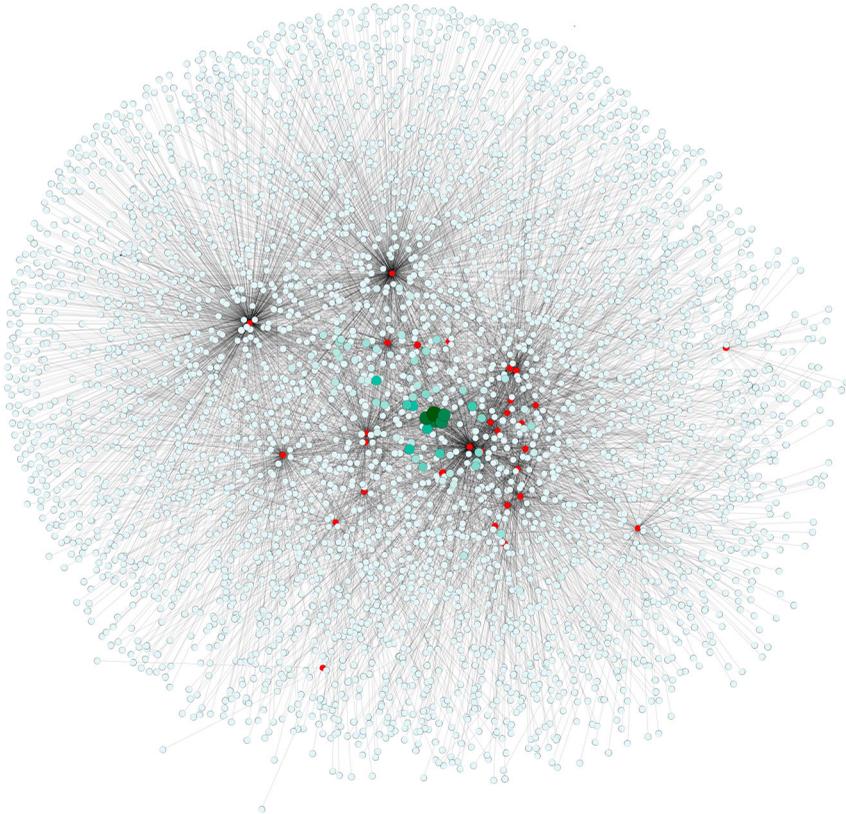

Figure 2. Sample snowball 1st degree network (network crawl by issuecrawler.net, courtesy of the Govcom Foundation).

Figure 2 shows the derived network, where red nodes represent the sample organisation websites and all the other nodes stand for websites they link to. Green shading and node size measure in-degree Freeman centrality, or the number of links received by a website: bigger and darker the colour, higher the in-degree value.[4] Now, this network is populated by 3971, with 410 websites being linked to by more than one sample website. In fact, Figure 2 shows that in the derived network 30 of our 31 sample websites link to other entities, some of which, namely those 410 websites, are in more (in-degree) central positions than others.

Nodes range from other patient organisations, umbrella networks of patient organisations, websites of national health services, public and private research centres, private companies offering patients' assistance, biomedical sources of information, news outlets and social media platforms of different types. This indicates that patient organisations do not so much use online linking affordances to create coalitions of patient organisations, or solidarity networks (Rogers, 2004), around patient communities but rather to redirect end users to a wide range of social actors and information sources more or less directly involved in the health issue they mobilise for.

Now, taking Freeman centrality as a network measure of node power, those websites receiving links from more than one of the sample websites can be considered as influential in the derived network. In order to focus more specifically on these central nodes, we ran a co-link crawling, one where the 'crawl seeds and retain URLs with at least two links from seeds' (Issuecrawler.net, 2015). With the crawler being set again at depth 2, the derived network (Figure 3) is only populated by 30 sample websites and the 410 websites whose
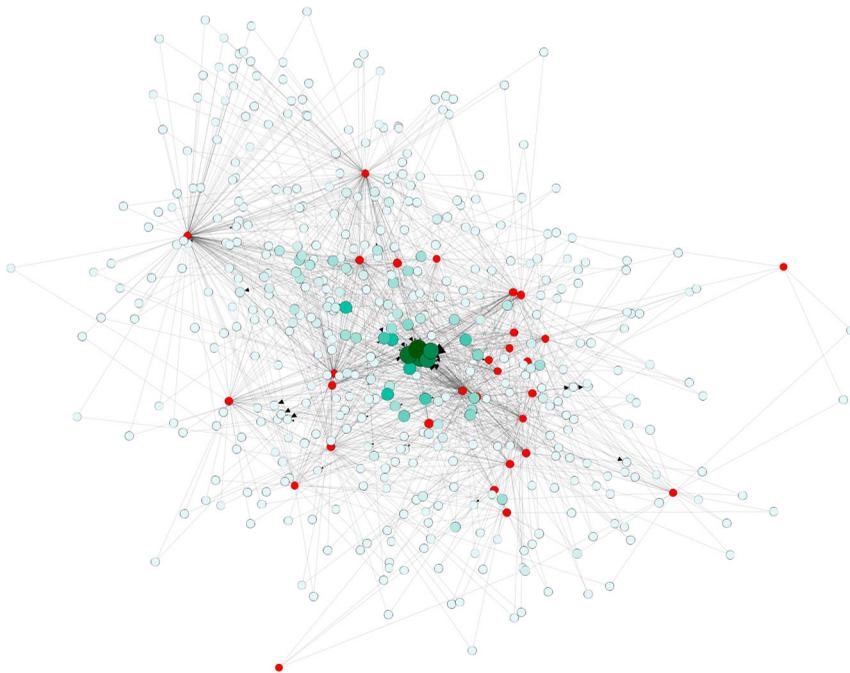

Figure 3. Sample co-links network (network crawl by issuecrawler.net, courtesy of the Govcom Foundation).

absolute in-degree centrality was equal to or bigger than 2. Hence, from the perspective of website end users, Figure 3 shows the most likely online informational pathways originated by rare disease patient organisation websites.

Table 2 shows the network nodes that receive links from six or more of the sample organisation websites.

The most evident consideration to be drawn here is that social media are more central to the network than any other online source of information or site for action. More specifically, Facebook is linked by 23 of the sample organisations, directly followed by YouTube with 20 links and Twitter just three positions down in the ranking with 17 links. It is certainly interesting to notice that Facebook and YouTube are sources of information slightly more likely to be linked than institutional entities such as ClinicalTrials.gov (global registry of clinical studies) and ncbi.nlm.nih.gov (repository of biomedical and genomic information) and definitely more popular than international patient organisations like raredisease.org (NORD, US Umbrella network of rare disease patient organisations). In other words, it is more common for rare disease patient organisations to redirect end users to platforms where information is shared and co-produced by different actors in individualised processes of crowdsourced communication rather than to entities representative of scientific knowledge or institutionalised advocacy.

In sum, these results suggest that online digital networking mechanisms ease the development of information pathways that neither develop around clusters of patient organisations nor exclusively centralise on traditional authoritative sources of biomedical

Table 2. Most central (in-degree) nodes.

Label	Site type	Absolute in-degree value
facebook.com	Social medium	23
youtube.com	Social medium	20
clinicaltrials.gov	World registry of clinical studies	19
ncbi.nlm.nih.gov	Repository of biomedical and genomic information	17
twitter.com	Social medium	17
fda.gov	(USA) Regulatory authority for drug administration	11
cancer.gov	(USA) Centre for cancer research	10
nature.com	Scientific publication	10
nih.gov	(USA) Medical research agency	10
linkedin.com	Social medium	9
nlm.nih.gov	(USA) Library of medicine	9
rarediseases.org	(USA) Umbrella network of rare disease patient organisations	9
onlinelibrary.wiley.com	Online library	8
en.wikipedia.org	Collaborative online encyclopaedia	7
geneticalliance.org	World umbrella network of rare disease patient organisations	7
justgiving.com	Social medium for fundraising	7
uk.virginmoneygiving.com	Social medium for fundraising	7
caringbridge.org	(USA) Charity for patients' support	6
cdc.gov	(USA) Centre for disease control and prevention	6
inspire.com	Social medium for patient communities	6
lls.org	World health organisation	6
mayoclinic.com	(USA) Medical care and Research Centre	6
medicare.gov	(USA) National health insurance	6
medscape.com	Scientific publication	6
nejm.org	Scientific publication	6
nhs.uk	(UK) National health service	6
nytimes.com	(USA) News outlet	6
patientadvocate.org	(USA) Charity for patients' support	6
patienttravel.org	(USA) Charity for patients' support	6
rarediseases.info.nih.gov	(USA) Centre for rare disease research	6

information representative of scientific knowledge and medical authority. In fact, EHM patient organisations develop online health information pathways that often privilege crowdsourced processes of knowledge production and exchange (i.e., digitally networking mechanisms in Table 1) over information-seeking processes targeted at traditional scientific sources and advocacy actors.

Discussion and conclusion

In their work on collective action in contemporary media ecologies, Bimber, Flanagin and Stohl write:

> one of the chief obstacles to human interaction is informational: the discovery of shared interests, shared desires, or common experiences and acquaintances. Technologies that help people identify and overcome these information and communication obstacles can readily facilitate the beginnings of social behaviour. (2005, p. 382)

Our study focuses exactly on the ways digital communication helps EHMs – where patient organisations are most likely to seek partnership roles with the medical community and health policy-makers – overcome informational obstacles among patients and between patients and other actors, ease the emergence and dissemination of patient-generated health knowledge and provide the informational and eventually cultural context for bottom-up agency around health issues.

The analysis shows that the digital mechanisms used in EHM patient organisation websites generate different dynamics for health knowledge sharing (one-way communication processes), exchange (two-way communication processes) and co-production (crowdsourced communication processes), where individuals can engage in different forms of health activism. In fact, digital mechanisms blur the traditional boundary between private and public domains and allow the development of forms of engagement that are less personally bonding than in traditional practices of*public* engagement. Even in the most public form of engagement, that eased by digitally networking mechanisms, the website end user is allowed to form loose ties both with the organisation and with other end users. By allowing greater individual control over how to engage with a health issue, digital communication enhanced by these organisations eases the emergence of individualised identifications that can be more inclusive than traditional collective framing of health activism. It also increases the potential for personal networks to play a central role in health activism. We may rename these dynamics as of 'intraconnectivity' as they help bonding dynamics (Putnam, 2000) in easing emergence, development and consolidation of the illness identity (Brown & Zavestoski, 2004) of a patient community.

Seen from the lenses of health activism, this implies that not only do digital communication in general, and digitally networking mechanisms in particular, ease online health-information-seeking processes (Balka et al., 2010) and the provision and use of health information (Mager, 2009). They also offer the context for patient organisations to form loosely networked publics that produce crowdsourced health knowledge via 'second-order commonality' processes (Bimber, Flanagin, & Stohl, 2005, p. 372). In other words, individuals – by for instance participating in Facebook group discussions or Twitter hashtagged streams – can contribute to health knowledge repositories 'with only partial knowledge of other participants or contributors and without a clear intention

or knowledge of contributing to communal information with public goods properties' (Bimber et al., 2005, p. 372). Hence, personal narratives of illness can connect online and, while certainly providing social support (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004) to the members of a specific patient community, they can also add elements to health knowledge relevant to that community and to a wider public.

Not only does digital networking ease interactions between individuals and patient organisations and among individuals, it also enacts the development of health information pathways specifically endorsed by patient organisations. The website crawling exercise showed that hyperlinking features on EHM patient organisation websites redirect end users towards a heterogeneous range of informational sources, from the websites of other patient organisations, to those of public health institutions, private companies, scientific journals and media outlets. Within this variety, umbrella patient organisations are not extremely popular. This means that hyperlinking strategies do not have 'aspirational' (Rogers, 2013, p. 45) goals, that is, they do not reproduce hierarchical structures and do not represent a desire of affiliation with established, institutionalised actors. Moreover, pages, groups or discussion threads on social media platforms are often more linked than traditional scientific resources. On the one hand, the end user is most likely to be redirected to crowdsourced platforms of communication where the level of moderation by the patient organisation can highly vary. In fact, the organisation's institutional presence may be totally backgrounded to free space for decentralised interactions among end users. This suggests the possibility of a fluid coexistence of 'organisationally enabled' and 'crowd-enabled' (Bennett & Segerberg, 2013) health connective action, with individuals moving from one form of action to the other (and possibly vice versa). This also suggests that a strategic participation of health professionals and health care providers[5] – but also regulators and policy-makers[6] – in digitally networking processes (e.g., on social media platforms) would probably further ease crowdsourced processes of health knowledge construction, especially in the case of controversial or unresolved health issues (e.g., rare diseases).

On the other hand, links to traditional scientific resources allow the emergence of 'boundary' (Brown & Zavestoski, 2004) informational nodes that ease *interconnectivity*, that is, connectivity across patient communities. Most rare disease patient organisations, for instance, advocate for genetic testing and drug development, hence data on genomic information (e.g., ncbi.nlm.nih.gov) and clinical trials (e.g., clinicaltrials.gov) are central across rare disease patient communities. In other words, hyperlinking dynamics ease the emergence of informational nodes that are boundary – 'objects that overlap different social worlds and are malleable enough to be used by different parties' (Brown & Zavestoski, 2004, p. 63), for example, different patient groups, the biomedical community, the pharmaceutical industry and health policy-makers. In this sense, hyperlinking dynamics have bridging potential (Putnam, 2000).

In sum, this study shows that digital media are shaping EHMs – namely the most contemporary examples of health activism – in 'organisationally enabled networks' where 'constituent organisations adopt the signature mode of personalising the engagement of publics. In particular, this means deploying discourses and interactive media that offer greater choice over how people may engage' (Bennett & Segerberg, 2013, p. 48). Digital mechanisms are helping EHM patient organisations expand discursive space, create different dimensions of public engagement and generate informational pathways where

patients' experiential knowledge and scientific information are equally valued. In particular, by favouring processes of crowdsourced knowledge production and exchange, digitally networking mechanisms (e.g., Facebook pages or groups, Google+ circles, Twitter accounts or Twitter hashtagged streams) can ease the emergence of personal narratives of illness that become central to generate and strengthen ties within a patient community, produce, share and disseminate patient-generated health epistemic knowledge and create the context for patients' health political action.

Finally, also given that rare disease patient organisations have been defined as 'among the most empowered groups in the health sector' (Aymé et al., 2008, p. 2050), the 'connective action' uncovered in the present study may prove relevant to other patient communities struggling to mobilise in the public arena.

Notes

1. For an update of the discussion on the definition of eHealth, see Boogerd, Arts, Engelen, and van de Belt (2015).
2. Notice that, differently from Bennett and Segerberg (2012, 2013), we use the term "digital mechanism" to indicate any website element used to share information and the term "digitally networking mechanism" to specifically label digital mechanisms that enable networking dynamics.
3. This study is part of a bigger project that looks at different functionalities of rare disease patient organisation websites. The codebook was used to collect data relevant to the whole project and was designed in the form of a questionnaire with open-ended and close-ended questions. The questionnaire is available at: https://docs.google.com/forms/d/1XSeRxNX pBrIuMqChNA1WtJjjmwRHoydyiwrmP4rDuPQ/viewform. The codebook's part mostly relevant to the present study was informed by both the authors' initial sample screening and Bennett and Segerberg's (2013, p. 136–138) categorisation of "digital networking mechanisms".
4. In asymmetric networks, Freeman centrality measures the number of incoming (indegree) and outgoing (outdegree) ties for each single node (Franzosi, 1979).
5. On the engagement of health professional in social media platforms see, for instance, Vartabedian (2015).
6. EMA and FDA have been enhancing the direct involvement of patients in their activities – for example, inviting patient representatives to participate as panellists in public meetings on drug evaluation – for a few years now (Terry & Patrick-Lake, 2015). The question here is then on how such collaborations could be further eased via digital networking mechanisms.

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