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EDITORIAL

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HEALTH, MEDIA AND PARTICIPATION

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ABSTRACT

THIS SPECIAL ISSUE, ENTITLED "HEALTH, MEDIA AND PARTICIPATION", CONSISTS OF SEVEN ARTICLES THAT EXPLORE SOME OF THE DIFFERENT WAYS THAT MEDIA PARTICIPATION AND HEALTH PARTICIPATION INTERTWINE IN CONTEMPORARY MEDIA CULTURE. IN THESE SEVEN ARTICLES, PARTICIPATION IN HEALTH AND MEDIA IS ADDRESSED IN THE ANALYSIS OF A VARIETY OF PRACTICES: PATIENTS THAT USE MEDIA TO BECOME PARTICIPANTS IN CO-DECISION AND SELF-CARE PROCESSES, PATIENTS AND CITIZENS BEING MORE OR LESS ABLE TO USE MEDIA TO ENGAGE IN (PATIENT) COMMUNITIES, PATIENTS COMMUNICATING WITH (AND AFFECTING) INSTITUTIONS AND AUTHORITIES IN NEW MEDIATED WAYS, HEALTH PROFESSIONALS USING SOCIAL MEDIA TO CREATE PUBLIC AWARENESS ABOUT POLITICALLY URGENT ISSUES AND HEALTH PROFESSIONALS CO-DESIGNING DIGITAL LEARNING TECHNOLOGIES. ALL THE CONTRIBUTIONS ARE IN THIS WAY UNITED BY TAKING AN INTEREST IN THE DEMOCRATIC POTENTIALS AND DILEMMAS OF *PARTICIPATING IN HEALTH THROUGH MEDIA PARTICIPATION*. THE ISSUE ALSO INCLUDES ONE OPEN SECTION ARTICLE. THE SPECIAL ISSUE IS EDITED BY MAJA KLAUSEN, ANETTE GRØNNING AND CARSTEN STAGE.

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Conceptualising health, media and participation

This special issue, entitled "Health, media and participation", consists of seven articles that explore some of the different ways that media participation and health participation intersect in contemporary media culture. This is done through different disciplinary lenses and understandings of both media participation and health participation as concepts.

The concept of 'participation' has been key to understanding current developments and transformations in media and cultural studies and research on health. In media studies, the participatory potentials of the internet and social media have been highly debated – and increasingly problematized – over the last decade (Carpentier, 2011; Dijck, Poell, & Waal, 2018; Jenkins, 2006). If we adopt a media and cultural studies approach, health-related 'media participation' could thus refer to processes as different as (see Stage, 2019): 1) users' *interaction with* or *production of media content* (e.g. telling illness narratives) (Bruns, 2008; Jenkins, 2006); 2) users engaging in forms of *mobilization, connective action and soft structures of political engagement* (e.g. health hashtags (#fuckcancer)) (Bennett & Segerberg, 2012; Papacharissi, 2015); 3) users participating in *mediated processes of decision-making* about issues that they are not normally able to affect (e.g. regarding treatment, medicine or research projects) (Arnstein, 1969; Carpentier, 2011; Pateman, 1970); 4) users using media to *adapt to biopolitical expectations* of being a vital, happy and participatory citizen engaged in health issues (Mol, 2008; Stacey, 1997); 5) users contributing *free, participatory and affective labour* on platforms that promote their own ability to foster democracy and participation (Fuchs, 2014; McCosker, 2013; Terranova, 2000); 6) platforms' transformation of 'media usage' into 'valuable participation' through complex technological infrastructures that are themselves participative by enacting affective relations and extracting sellable knowledge through particular, and often hazy, procedures (Gerlitz, 2016; Gerlitz & Helmond, 2013; Gerlitz & Lury, 2014).

What is implicitly at stake in these different definitions and discussions are often various understandings of whether 'media participation' can occur through mere (platformed) communication and datafication or whether it needs some element of substantial user creativity, whether participation can be used to describe all sorts of social processes of collaboration or whether it should be reserved for activities with a political purpose or even reallocations of power, and finally whether participation should be understood as positive or as a problem in itself (Stage, 2019).

Participation as a concept has, as mentioned, also affected health research as such through an increasing interest in patient involvement, patient perspectives, patient communities and patient choice. Media play a crucial role in this re-envisioning of the role of the patient in the health sector as a 'digitally engaged patient' (Lupton, 2013). Through the affordances of digital technologies and social media, patients are becoming involved in their health, illness and treatments – an involvement which can be framed as primarily empowering (Morden, Jinks, & Ong, 2012; Swan, 2012) or through a critical lens as reinforcing patient consumerism (Lupton, 2013). One outcome of enhanced opportunities for patient involvement is a change of the traditional doctor-patient roles and the power balance ascribed hereto (Eeckman, 2015; Hardey, 2001). Online communities and fora have the potential to function as networks of support through the sharing of illness stories (Kingod, Cleal, Wahlberg, & Husted, 2017; Lagerkvist, 2017; Stage, Hvidtfeldt, & Klastrup, 2020). Moreover, the stories being shared present insights into patient perspectives and the embodied experiences of patienthood to healthcare professionals.

Following Annemarie Mol, we are in the midst of a grand transformation, where patients are increasingly framed as citizens who should take care of themselves, be involved in treatment and less as people in crisis that need care. Patients are envisioned to contribute to the achievement of value-based, efficient healthcare and patient self-care to grow, e.g. when patients track and share additional contextual information that may be relevant for evaluating their health and recovery status. This approach to patienthood is underpinned by what Nettleton has described as a shift from 'mechanical' medicine to 'informational medicine' (Nettleton, 2004). The envisioning of the patient as citizen can be a problem, Mol argues, as the citizen-body is most often expected to be in control, to tame his or her emotions and to act in enlightened ways, while the patient-body is allowed to be unruly and unable to control emotions or to act rationally. According to Mol, the logic of citizenship is sneaking into healthcare through the idea of the participatory patient, while the logic of care which accepts and cares for the patient-body is threatened (Mol, 2008).

The concept of 'the participatory patient' was coined and defined by Jackie Stacey in her influential book *Teratologies* (1997), in which she suggested that a new generation of cancer patients is under development:

> The desire for information, and the confidence to access it, is often the privilege of those with certain educational histories, and race and class backgrounds, but also belongs to a new generation of what I call "participatory patients". On the whole, my parent's generation, for example, have far less inclination to be put in the picture. They are happier to leave it to the medical experts and to avoid the burdens and responsibilities such knowledge might demand. But those of us who have been influenced by the information cultures of the last twenty years are more susceptible to the desire to know and to the fantasies of knowledge as power (Stacey, 1997, pp. 3-4).

Following this line of thinking, the participatory patient is a certain type of patient characterized by an increased desire for visibility, by a non-compliant attitude towards being treated purely as a medical object, and by having a fantasy of 'knowledge as power' – the idea that knowing and continuously researching your body will also guarantee subjective agency and your ability to act on illness in constructive ways. Media are crucial for understanding both the rise and practices of these participatory patients. To 'act on' your own health requires information and knowledge of the body and illness that can be accessed and shared outside the medical system. The participatory patient of today is thus also often a patient able and willing to engage with his or her own biology through mediated health resources on the internet and social media; e.g. patient forums, homepages of medical organisations, medical apps, patient blogs and profiles and citizen-led crowdfunding for treatment or research (Høybye et al., 2010; Lupton, 2016; Orgad, 2005; Stage, 2017).

The era of 'participatory patienthood' is, according to Nikolas Rose, shaped by the ideal of a new form of active 'biological citizenship' with a focus on the individual's responsibility towards their own biology. Biological citizenship is, however, also expressed through more activist forms of activity or collectives around biological problems; i.e. new forms of 'biosociality' (e.g. patient communities or patient voices on the web). Biological citizenship thus can unfold through new forms of 'biological activism' (e.g. the AIDS activism of ACT UP) in which the subject actively deals with health and treatment in new politicised ways (Rose, 2006). These activisms help "pluralize biological and biomedical truth, introduce doubt and controversy" (Rose, 2006, p. 142) and create "novel forums for political debate, new questions for democracy, and new styles of activism" (Rose, 2006, pp. 136-137). These can be *informational* (focused on creating specialized knowledge about specific conditions), *rights-orientated* (focused on fighting against stigma and securing proper treatment) or *digital* (based on online communities and interaction) (Rose, 2006, p. 135).

Special issue articles

In these seven articles, participation in health and media is addressed in the analysis of a variety of different practices: Patients that use media to become participants in co-decision and self-care (Lomborg, Moring & Kensing), citizens or patients being more or less able to use media to engage in communities (De Souza, Butt, Jethani & Marmo; Nikolova & Stelzmann), patients communicating with (and affecting) institutions and authorities in new mediated ways (Klausen & Grønning; Møller, Fage-Butler & Brøgger), health professionals using social media to create public awareness about politically urgent issues (Brøgger, Nielbo & Fage-Butler) and health professionals co-designing digital learning technologies (Marchetti & Petersen). In other words, participation as a concept is used to highlight aspects of co-decision, inclusion/exclusion, new communicative relationships, activism and co-design across the seven articles. All the contributions are in this way united by taking an interest in the democratic potentials and dilemmas of participating in health through media participation. In the article "Communication as ongoing care: Patients as active partners in care work with MyChart", Stine Lomborg, Camilla Moring and Finn Kensing present their fieldwork among patients and clinicians at two Danish hospital units around the implementation and use of a new patient portal named MyChart. Through the conceptual lens of self-care and self-tracking, they develop an understanding of the experiences, opportunities and challenges MyChart presents to patients. Their focus is here on how the platform provides information and facilitates communication that enable patients to engage as active partners in their own treatment. One of the key questions is: To what extent does the communication facilitate patient participation in terms of self-care and collaborative decision-making with clinicians through MyChart? The analytical findings lead to a discussion of the possible renegotiation of medical authority and responsibility in care and point to the potentials and drawbacks of patient participation in digital care infrastructures. They conclude that the usefulness of MyChart is contingent on the communicating parties' active participation in ongoing communication and their translation of information into meaningful points of action.

In the article "Participatory Research Methods for Investigating Digital Health Literacy in Culturally and Linguistically Diverse Communities", Ruth De Souza, Danny Butt, Suneel Jethani and Chris Marmo present findings from a pilot study amongst Australian women from culturally and linguistically diverse (CALD) backgrounds. The authors explore health participation by examining the value of 'design probes' (playful, physical and tangible objects) in engaging CALD women in discussions about health in the context of pregnancy, parenting and self-tracking through pre/peri-natal apps. De Souza, Butt, Jethani and Marmo question the participatory potentials of these digital technologies for marginalized groups, as the apps appropriate the cultural interface that has otherwise been managed by clinicians. Focusing on participation as both a research method (the use of design probes) and as an intended outcome for the women using the technologies, the authors point to the use of design probes as enabling modes of participation that stimulate dialogue on health literacy and health participation for marginalized groups.

Karina Nikolova and Daniela Stelzmann explore how young Germans with mild intellectual disabilities (yPmIDs) participate in and through social media. The article "More inclusion through participation? About the Access, Interaction and Participation on Social Network Sites of Young People with Mild Intellectual Disabilities" draws on findings from a qualitative study of eight interviews with young Germans (and their caregivers) on their uses of and experiences with social media. The authors trace connections between inclusion and participation and depart from Carpentier's (2015) concepts of access, interaction and participation to address how the youngsters to varying degrees interact with, participate and feel included in the online public sphere (Carpentier, 2015). The findings are further discussed in relation to barriers (e.g. hate speech and the caregiver's inability to assist the client in navigating the internet) and potentials (e.g. making new friends and structuring the everyday life) for online participation for this specific group of people.

Maja Klausen and Anette Grønning's article, "My throat "tickles": Bodies in affective discourse in patient–doctor email consultations", focuses on a different mediated aspect of patient participation by exploring the interaction between health professionals and citizens aged 65+. More specifically the article investigates the multiple ways in which bodies present themselves in email consultations (econs) between patients and general practitioners (GPs) and it stresses that econs create both new challenges and new opportunities for participation in and the exchange of communication within this relationship. Klausen and Grønning argue that the patient's body is affectively present in six different ways in the econs being explored: Through sensations, emotions, countings, medication, visuals and movements. Theoretically the article adds to the understanding of mediated patient participation by opening up the concept of participation to include not only moments of direct citizen influence and power redistribution, but also the participatory intensities that can be found in more mundane practices as well as in feelings of empowerment. The analysis thereby stresses econs' participatory potential for patient self-reflection and patient agenda-setting in the clinical encounter.

Jane Ege Møller, Antoinette Fage-Butler and Matilde Nisbeth Brøgger also explore the doctor-patient participation in email consultations (econs) in their article "Complexity and simplicity in doctor-patient email consultations". Theoretically, they draw on media richness theory (Ishii, Lyons, & Carr, 2019) and Carpentier's (2015) concepts of access, interaction and participation. Based on inductive readings of email correspondences from 40 patients in four different clinics, they show how both quantitative and qualitative complexity are evident in this kind of digital health communication. Their findings challenge existing understandings of econs as best suited for simple communication and highlight the need for theoretical development as well as the value of re-examining existing policies and guidelines regarding expectations for econs use. Likewise, Møller, Fage-Butler and Brøgger underline the need for studies of authentic email content as most of the research on doctor-patient email includes perceptions of use rather than analyses of content.

Focusing on participation as activism, Matilde Nisbeth Brøgger, Kristoffer Nielbo and Antoinette Fage-Butler explore the use of the hashtag #detkuhaværetmig (#itcouldhavebeenme) in creating public awareness and enabling solidarity amongst healthcare professionals on Twitter in their article "#detkuhaværetmig: How Twitter enabled the expression and propagation of solidarity among healthcare professionals". The hashtag was created to express solidarity with a junior doctor who was initially declared negligent after oral instructions were not written down and followed up on. Using a mixed methods approach and computational analysis gauging negative and positive emotions associated with solidarity, the article combines an analysis of a range of chosen functionalities of Twitter with a discussion of how solidarity with fellow medical professionals is expressed and propagated. Methodologically, the article presents a novel combination of mixed methods for exploring participation and sentiments on Twitter. Theoretically, the authors point to participation as closely linked to solidarity while at the same time underscoring that the hashtag activism of #detkuhaværetmig also had effects beyond Twitter (e.g. media awareness) and the mere enabling of expressions of solidarity.

The article by Emanuela Marchetti and Camilla Kølsen Petersen, "Digitalization of healthcare practice. Changing media, evolving language games", presents and discusses the results of a participatory design inquiry aimed at developing a simulation for Occupational Therapy (OT) education. In the article, 'media participation' is defined as a question of letting users (cf. OT graduates) take part in the design of a digital learning technology. The study presents an analysis of the design process that revealed that OT professionals and teachers articulate a new awaiting reality for OT graduates where not all of them will be able to get a traditional clinical position. The article uses Wittgenstein's notion of 'language game' to tease out the different articulated professional trajectories for OT graduates in the material: A traditional language game focusing on OT work as a healer in the clinic, a language game describing the OT graduate as a freelancer selling services, a language game where OT graduates help develop new technological products, and a language game where OT graduates work in municipalities as an intermediary between different actors. According to the article's interviewees, most OT students see themselves as future clinical healers of their patients. However, recent changes are compromising this traditional core professional identity of occupational therapists, and Marchetti and Petersen therefore suggest that the OT education should strengthen its focus on the OT students' ability to successfully engage in a variety of professional ecologies. The article subsequently proposes an interactive learning environment, *ErgoWorld*, which trains the OT students' capacity to consider different professional possibilities, identities and career paths.

With this introduction and special issue, we seek to illustrate the manifold ways that participation in health has become interwoven with contemporary media culture. We wish you an inspiring read and hope that this issue will provide a deeper understanding of the implications, barriers and potentials of health participation with and through media.

Besides the seven articles dealing with media, health and participation the issue also includes an open section article by Vaia Doudaki and Nico Carpentier. It explores how to engage societal partners in the start-up phases of projects that aim for participatory knowledge production. More specifically the article reports the outcomes from a project on environmental communication and provides guiding principles and a toolkit aiming to foster and enable increased participation in the production of academic knowledge.

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