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Selected Papers of #AoIR2022:  
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## **"YOU CAN'T SEE IT BUT IT'S A MATTER OF LIFE AND DEATH". OF PLATFORMS, POWER AND THE INVISIBLE**

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### **Platform hegemony or user power?**

Empirical work interested in the impact of social media use on discursive practices in general – and participatory dynamics in particular – tends to split into two main camps.

On the one hand, research investigates the consequences of the infrastructural turn of contemporary digital structures: social media are increasingly becoming ubiquitous and in so doing, they are turning into essential and mundane infrastructures of our everyday life (Plantin et al., 2018). As most mainstream social media are commercially owned and regulated, this also means that structures, interfaces and norms designed by profit-driven companies – namely, platforms' "techno-commercial" mechanisms (Van Dijck et al., 2018) - are increasingly influential to people's lives. These mechanisms generate platform bias: they shape how we present and represent ourselves and the issues we care for but also the information that we learn, see, and share.

On the other hand, research has drawn attention to the way platforms' socio-technical infrastructures can actually destabilize traditional (commercial and state-centered) power roles in the construction of meaning and practices around issues of public interest. Not only has the very structure of contemporary social media platforms been shown to open new routes for minority voices to make a point, be heard and be seen, for example through "networked counterpublics" (Jackson et al., 2020). There is also clear evidence that social media cultures can develop practices of resistance able to circumvent commercial governance, for instance, in platforms' moderation systems (Gerrard, 2018).

### **Social media, the embodied and the invisible**

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While debates feeding into one or both of the two camps discussed so far are now well established and growing, still little do we know about how these dynamics work in relation to power and meaning making centered on health and illness (Lupton, 2017). Even in research based on the analysis of health-based interactions on online platforms (e.g., webforums, chats, microblogging sites), little attention has been drawn to how platform mechanisms and user practices meet. In fact, existing research mostly approaches “online media” as “a conduit for information and a traversable space” (Koteyko et al., 2015), rather than as influential to the very health practices being studied. The scarcity of empirical work in this domain becomes ever more evident when attention is drawn to rare, uncommunicable, or generally least known – and least studied - health conditions and diseases (Vicari and Cappai, 2016).

To address this gap, we draw on initial findings from an ongoing Leverhulme Trust-funded project focused on social media uses relevant to hereditary cancer syndromes. These syndromes mark health conditions linked to known genetic mutations, also called “cancer genes”, that heighten the risk of having cancer from an early age. These conditions are *invisible* in at least three ways. Cancer genetic risk is evidence-based and embodied, but not bodily visible. General health practitioners rarely know about hereditary cancer syndromes. Overall, hereditary cancer syndromes have not yet entered the wider collective imagination.

Existing research provides clear evidence that individuals with these conditions turn to social media to seek, learn, produce and share information about their condition (Allen et al., 2020). It is also evident that this information often derives from a complex combination of lay and expert sources, like personal storytelling and scientific publications (Vicari, 2021). However, little do we know about how these practices form at the intersection of “embodied experiences” of health and illness (Brown et al., 2004), everyday social media uses, and platform mechanisms. In this paper we explore these dynamics drawing on a social media analysis that incorporates data from Twitter, Facebook, TikTok, and Instagram.

### **Data and Methods: Combining the computational and the netnographic**

The article draws on the collection and analysis of social media content relevant to two hereditary cancer syndromes: the Hereditary Breast and Ovarian Cancer Syndrome (also known as BRCA 1/2) and Lynch Syndrome. Drawing on existing conceptualizations of digital methods for cultural research (Vicari and Kirby, 2022), we developed a research design that followed a quanti-quali trajectory. We used a combination of computational techniques and tools to access, collect and handle posts (i.e., data and metadata) about these conditions published by Twitter (public accounts), TikTok (public accounts), Instagram (public accounts) and on Facebook (public pages) over the course of six months. Then, we used netnographic techniques (Kozinets, 2019) to *disassemble* these data on the basis of emerging themes and interpret these themes by *recombining* data within and across their platforms of origin. Ultimately, this allowed us to both learn about lived experiences of hereditary cancer *and* identify the bias deriving from platform mechanisms.

### **When the invisible becomes visible: (Un-)Ordinary leaders and local worlds**

Our preliminary findings show that when it comes to *invisible health conditions*, the voice of ordinary social media users easily overcomes that of traditional elite entities (e.g., health professionals). *Local* platform mechanisms differently shape how information is shared and *who* (e.g., breast cancer advocate, health data expert) and *what* (e.g., conference poster, photo of mastectomy procedure) become more visible and credentialed in these sharing practices. They also influence how and which *personal* experiences are curated and shared. These initial findings suggest that social media platforms are essential in making the invisible visible but raise questions on how participating in one or more platforms' "local worlds" might affect the lived experience of those who embody this invisible.

## References

- Allen, C. G., Roberts, M., Andersen, B., & Khoury, M. J. (2020). Communication about hereditary cancers on social media: a content analysis of tweets about hereditary breast and ovarian cancer and lynch syndrome. *Journal of Cancer Education*, 35(1), 131-137.
- Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Gasior Altman, R. (2004). Embodied health movements: new approaches to social movements in health. *Sociology of health & illness*, 26(1), 50-80.
- Gerrard, Y. (2018). Beyond the hashtag: Circumventing content moderation on social media. *New Media & Society*, 20(12), 4492-4511.
- Jackson, S. J., Bailey, M., & Welles, B. F. (2020). *#HashtagActivism: Networks of race and gender justice*. Mit Press.
- Koteyko, N., Hunt, D., & Gunter, B. (2015). Expectations in the field of the Internet and health: An analysis of claims about social networking sites in clinical literature. *Sociology of health & illness*, 37(3), 468-484.
- Kozinets, R. V. (2019). *Netnography: The essential guide to qualitative social media research*. Sage.
- Lupton, D. (2017). Introduction. In Lupton, D. (Ed.) *Digitised health, medicine and risk* (pp. 1–3). Routledge.
- Plantin, J. C., Lagoze, C., Edwards, P. N., & Sandvig, C. (2018). Infrastructure studies meet platform studies in the age of Google and Facebook. *New Media & Society*, 20(1), 293–310. <https://doi.org/10.1177/1461444816661553>
- Van Dijck, J., Poell, T. and De Waal, M., (2018). *The platform society: Public values in a connective world*. Oxford University Press.
- Vicari, S. (2021). Is it all about storytelling? Living and learning hereditary cancer on Twitter. *New Media & Society*, 23(8), 2385-2408.

Vicari, S., & Cappai, F. (2016). Health activism and the logic of connective action. A case study of rare disease patient organisations. *Information, Communication & Society*, 19(11), 1653-1671.

Vicari, S., & Kirby, D. (2022). Digital platforms as socio-cultural artifacts: developing digital methods for cultural research. *Information, Communication & Society*, 1-23.