Understanding privacy for patients with a chronic illness using social media platforms for support

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Abstract

For patients living with acute and chronic illnesses, social support serves as an important part of their lives and can improve quality of life. Web-based technologies have provided individuals with the tools to connect with other patients on the internet for the past 25 years, to share experiences and seek support. With the proliferation of smart devices and with half the world connected to the internet, social media platforms have become a home to these health communities. Support is never far away as patients can conveniently seek information, guidance and encouragement from others through a device in their pocket. Digital technologies play an increasingly significant role in primary healthcare and personal health management through data driven innovation. However, as technologies are embedded into care and daily life, their wider implications on society require careful consideration to ensure that personal values are respected. The research focuses within the context of privacy on social media. Using patients with Inflammatory Bowel Disease as an exemplary group, their privacy perceptions, concerns and behaviours were explored. Her qualitative work offers detailed insights into how social media platforms are used, what privacy looks like to patients using social media, and the benefits and disadvantages therein. It surfaces challenges of personal agency and regulation to ensure that individuals can continue to benefit from technology, without unexpected outcomes.

Biography

Kate O'Leary is an interdisciplinary doctoral researcher based at the University of Nottingham, UK. Her work in online privacy has been recognized by the British Council and the Internet Society, who awarded her as one of the 25 under 25 leaders in making positive change to the internet in 2017. She has been a Fellow at the Royal Society of the Arts (RSA) since 2016. Her focus has turned towards the health sector, where technology plays an increasingly more important role in diagnostics, preventative medicine and illness management.

Publications

1. Kate O'Leary, Neil Coulson, Elvira Perez-Vallejos, Derek McAuley. Towards understanding how individuals with inflammatory bowel disease use contemporary social media platforms for health-related discourse. 2020. Computers in Human Behavior.
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