

Design and impacts of integrating digital advocacy into online chronic health communities

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- Thousands of people living with an invisible chronic health condition who connect online in solidarity.
 - Inflammatory Bowel Disease forums have been used since 1995
- Social Media Networking Platforms have **amplified and redistributed conversations** into spaces not fundamentally designed for such information sharing.
- Mass data collection, processing and selling by online companies such as Facebook and Google
- “Predictive privacy harms” (Crawford & Schultz, 2014) that could have adverse real-world effects
 - Creation of PII through algorithms e.g. Target data-mining (2012)
 - Nathalie Blanchard lost disability insurance benefits from snooping health insurer (2012)

“Any time someone puts a lock on something that belongs to you and wont give you the key, that lock isn’t there for your benefit”

Cory Docotorow, 2014

The Right to Explanation does not oblige companies to inform users of the process in which an algorithm determines a predictive ‘conclusion’. (Wachter et al. 2016)

- Support groups are generally underpinned by a duty of care
- General lack of awareness and understanding of what [explicit and implicit] data sharing might come to mean
- Many resources and tools already available to the public to help obscure their data trails; **are these resources and tools deployed effectively? Are they framed appropriately to support users to make informed choices about their privacy? Do they resonate with people?**

- Develop digital learning intervention(s) **through participatory action research** co-developed with the Inflammatory Bowel Disease community.
 - Requirements > design > deploy > feedback > redevelop
- To do this I will need to:
 - Understand users social media selection process, **through critical design making theory: understanding goals, information available, expectations and motivations.** Thus, establishing whether there is a correlation between types of motivations/values and social networking sites/features.
 - Find the knowledge gaps and user 'requirements' to help frame the design of the interventions
- Then understand whether there is a change in attitudes; a desire to change behaviours; and a desire **to advocate for different practices** within their communities.