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Give Me Your Data, and I will Diagnose You

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The literature on medical and health informatics is full of studies that attempt to contribute to, suggest, or even make a medical diagnosis based on continuous data streams that individuals generate through their interaction with technology, such as smartphones, wearable devices, or social media. The conditions that are being diagnosed are often highly stigmatised (e.g., depression) or incurable (e.g., dementia). The discourse that justifies these studies posits early diagnosis as desirable, since early intervention is thought to reduce health care costs and increase the chances of a cure (for curable conditions). It is also often assumed that rational people will submit to ongoing monitoring merely because they are at risk of developing a condition. I will critically interrogate this discourse through the lens of three concepts: biographical illness work; evidence-based medicine; and neurodiversity. Evidence-based medicine emphasises the uncertain nature of much diagnostic work, and critically questions the basis on which diagnoses are made. Biographical illness work covers how people interpret the diagnoses they receive, how diagnosis affects their identity, and how they cope with preconceptions and stigma associated with a diagnosis. Finally, neurodiversity questions what should be regarded as normal, instead focusing on the experience of people who live with a particular condition. I will conclude by showing how this critical interrogation can stimulate the design of new processes, contexts, and technologies that give people greater control over who infers what about their health from their data.

Presented at Data Power 2017, Ottawa

Slides: https://www.slideshare.net/mariawolters/give-me-your-data-and-i-will-diagnose-you