

Patients Like Me

PatientsLikeMe; HealthTalkOnline (websites)

Introduction

While conventional healthcare models certainly dispense treatment for conditions, they often do not provide an outlet for patients' actual experiences of diseases – both emotional and physical. They rarely put patients in charge of their own healthcare, emboldening them through real-world statistics and data.

The openness and accessibility of the internet could play a pivotal role in not only democratising patient data, but also improving effective and successful research into conditions based on that data. How can web platforms place patients at the heart of healthcare? What role could technology play in improving health?

PatientsLikeMe

PatientsLikeMe is a website that allows people to share stories of their medical conditions, while aiming to aid healthcare industry partners to understand patients' real world-experiences of disease and its progression. Co-founded in the US in 2004 by brothers James and Benjamin Heywood, and Jeff Cole, the site was prompted by Stephen Heywood's diagnosis of ALS. They built a health-data sharing platform to transform the way patients manage their own conditions, and change how the industry conducts research.

The core values of the website, which in 2014 had over 250,000 members, includes putting patients first, promoting transparency and fostering openness. As a for-profit research company, the website is free from adverts and instead sells aggregated anonymised data to its partners which include pharmaceutical companies and medical device manufacturers.

Anyone can join the website and enter real data on their conditions, treatment history, symptoms and quality of life on an ongoing basis. PatientsLikeMe then produces a detailed longitudinal record allowing patients to gain insight and identify patterns.

Heywood says PatientsLikeMe users had fewer A&E visits and felt their health was under better control than non-users.

HealthTalkOnline

Also prompted by a personal diagnosis, HealthTalkOnline is a website run by UK charity DIPEX that allows patients to share their health stories. The charity describes itself as conducting: "Research into patients' experiences of ill-health and health related issues and creation of a database of such experiences. Dissemination of these experiences principally via websites for the benefit of the general public, patients, teachers and health professionals to enable them to make better informed decisions about healthcare. Creation of educational materials, based on personal experiences."

HealthTalkOnline has a well-defined business model to ensure its sustainability and support its team of 20 researchers at the University of Oxford. It is an active fundraiser with a wide network of funders, founders, sister organisations and links to policy makers. Funding has

ranged from £260,000 to £462,000 between 2009 and 2014, and stems from organisations which have an interest in one of the conditions.

HealthTalkOnline covers 80 conditions including cancer, autism, depression and motor-neuron disease. Advice is provided on topics such as making decisions about health and treatment, talking to friends and family, and dealing with financial practicalities.

While the PatientsLikeMe data is provided by individuals themselves, HealthTalkOnline material is garnered by the Health Experience Research Group (HERG) based at Nuffield College, Oxford. It collates information through up to 50 video interviews per condition and uses 'rigorous qualitative research methods' to present information on the website. The HERG archive now contains over 3,000 interviews with patients, carers and other family members. The website is a unique resource with enormous potential in academic and policy areas.

Conclusion

Both platforms provide free, reliable information about health issues by sharing people's real-life experiences. However while patients are at the centre of both websites, the approaches taken are fundamentally different.

The founders of PatientsLikeMe assume a wider interest in the data beyond academics and other patients. They believe health data belongs to the patient, who can share this with anyone, from caregivers and researchers, to companies and physicians. PatientsLikeMe connects patients, acting as a crowd-sourced information bank with real examples of self-care. It's a community-driven programme, led by patients themselves.

By contrast HealthTalkOnline is an academic venture with a top-down perspective. Patient-to-patient contact doesn't exist; while this may maximise academic benefit, it limits information to pre-determined parameters chosen from a clinical outlook.

HealthTalkOnline is a functional offering of data through a disciplined academic lens, while PatientsLikeMe is personal, connected and empathetic. The latter offers a glimpse into a possible future of the NHS as a social movement.

Researcher: Julia Manning