

Examining the role of patients' experiences as a resource for choice and decision-making in health care: a creative, interdisciplinary mixed-method study in digital health

Sue Ziebland,^{1*} John Powell,¹ Pamela Briggs,² Crispin Jenkinson,³ Sally Wyke,⁴ Elizabeth Sillence,² Peter Harris,⁵ Rafael Perera,¹ Fadhila Mazanderani,⁶ Angela Martin,¹ Louise Locock,¹ Laura Kelly,³ Margaret Booth,⁷ Bob Gann,⁸ Nicola Newhouse¹ and Andrew Farmer¹

¹Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK

²Department of Psychology, Northumbria University, Newcastle upon Tyne, UK

³Nuffield Department of Population Health, University of Oxford, Oxford, UK

⁴Institute of Health and Wellbeing, University of Glasgow, Glasgow, UK

⁵School of Psychology, University of Sussex, Brighton, UK

⁶School of Social and Political Science, University of Edinburgh, Edinburgh, UK

⁷Lay Representative, Oxford, UK

⁸Widening Digital Participation, NHS England, London, UK

*Corresponding author

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Plain English summary

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Plain English summary

The internet has seen an explosion of websites featuring people's accounts of their experiences of health and illness, through, for example, blogs, patients forums, online ratings sites and voluntary organisation websites. These are popular, but are of uncertain benefit. We explored how we might best understand how online patient experience influences health.

A series of studies included a review of the published literature and a new questionnaire. We observed and talked to people about how they looked for online information about giving up smoking, having asthma or caring for someone with multiple sclerosis. We used these studies to help us understand how best to include video, audio and written clips about people's experiences of these conditions on a website.

We developed three experience-based websites and three comparator websites and invited people to participate in a randomised exploratory trial to compare their use. We recruited 148 people with asthma, 87 people who wanted to give up smoking and 42 carers of people with multiple sclerosis. The participants had 2 weeks' access to a website. The participants, who ranged in age from their twenties to their late seventies, found it easy to take part, and over three-quarters completed questionnaires after 2 weeks. We interviewed 30 trial participants, who highlighted the value of facts, figures and experience. We conclude that it is feasible and acceptable, but probably not useful nor a good use of public money, to run a larger trial comparing such websites. In real life, individuals seek and combine individual information sources to suit preferences that shift over time.

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Editorial contact: nihredit@southampton.ac.uk

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