

Examining the role of patients' experiences as a resource for choice and decision-making in health care.

iPEX Briefing Paper 2 Work package 1a - Conceptual work

How might exposure to online patients' experiences influence health?

The Department of Health is committed to giving reliable and timely health information to the public and patients. Traditional health information has been based on facts and figures, not the experiences of patients. Many different types of patient experience (PEX) are available on-line in health information sites, social networking sites and on-line support groups. PEX may support and inform people but there are also concerns, for example people may make poor decisions if they identify with powerful stories that are not relevant to their circumstances.

Objective and approach

Our objective was to review the literature in order to identify theories, mechanisms of action and the potential impact of PEX and to establish the conceptual and theoretical framework for the broader study.

The PI and another senior member of the team reviewed the literature and tabulated the findings.

The output of the review was discussed with experts in the field and at a user panel meeting attended by 30 interested users (mostly recruited via the Oxfordshire PCT) who were selected to be representative of the community as a whole. Input from the user panel enabled further modification of the table.



Sue Ziebland and Sally Wyke

The literature studied included disciplines such as sociology, social and cognitive psychology, information sciences, e-health, and health services research.

The review:

- underpinned all later stages of the programme;
- clarified which aspects of health are likely to be affected by exposure to online PEx;
- identified different types of PEx and theories relevant to the underlying mechanisms of action through which PEx might operate;
- identified the different types of outcomes that might be relevant to online PEx;
- contributed to the development of the e-Health Impact Questionnaire assessment tool to be used later in the programme.

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Key Messages

The review identified seven domains through which online patients' experiences could affect health. Each has the potential for positive and negative impacts.

- Finding information
- Feeling supported
- Maintaining relationships with others
- Affecting behaviour
- Experiencing health services
- Learning to tell the story
- Visualising disease

Ziebland S, & Wyke S. (2012). Health and Illness in a Connected World: How Might Sharing Experiences on the Internet Affect People's Health? *Milbank Quarterly*, 2012 Jun; 90(2): 219–249.

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