

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

iPEX Briefing Paper 3

Work package 1b – Secondary analysis of narrative interviews

Background

This programme had access to a unique archive of over 2,000 narrative interviews which at the time of the study covered more than 60 health conditions collected by the Health Experiences Research Group in the Nuffield Department of Primary Care Health Sciences at the University of Oxford. Through analyses of these existing narratives, we have identified aspects of health that may be affected by exposure to online patient experiences (PEX). These can be grouped into the broad domains of support, knowledge, decision-making, self-management, health behaviour, and health status.

Objectives and approach

We analysed 10% of the HERG interview archive with the following aims:

- To gather evidence about how and why online information based on other patients' experience is sought and used.
- To select quotes from interview transcripts for an 'item pool' to illustrate participants' views on their use of the internet for health information, for a questionnaire (the e-health impact questionnaire).
- The qualitative secondary analysis using a modified grounded theory approach.



Fadhila Mazanderani and Laura Kelly

Health conditions

Interview transcripts on the following health conditions were analysed:

- Neurodegenerative conditions (patients and their family carers): motor neurone disease (MND), Parkinson's disease, dementia, multiple sclerosis;
- Young people's experiences of chronic conditions: epilepsy, diabetes (type 1), depression, asthma, eczema, chronic pain, congenital heart problems, cystic fibrosis, epilepsy, kidney disease, chronic fatigue syndrome, muscular dystrophy, morphea, sickle cell disease and scoliosis;
- Cancers: leukaemia, pancreatic cancer, testicular cancer, cervical intraepithelial neoplasia 3 (CIN3);
- Mental health: ethnic minority experiences, psychosis;
- Learning disability: autism;
- Conditions of the skeletal system: rheumatoid arthritis and osteoporosis.

Key dimensions of internet PEx from the secondary analysis

- Major charity groups, the NHS and pharmaceutical companies remain key players in the provision of online information, including internet PEx.
- How people use the internet and the information sharing activities they engage in are highly specific.
- When dealing with experiential information it is extremely difficult to separate 'practical' from 'emotional' information.
- The same information may be interpreted differently at different times and by different people.
- Questions of identity formation play a key role: the tension between developing a sense of solidarity and community versus illness becoming an all-consuming identity.
- Sharing experiences of illness has a strong ethical dimension as people try to reach out and help others.

Themes for further analysis

Potential themes or areas of interest were identified for further analysis. These themes included: tensions and ambiguities generated through accessing other people's experiences, questioning the role that the medium used for articulating experience plays in negotiating these tensions (for example, written stories, photographs, film and face to face meetings) and issues relating to identification and normalisation – the sharing of PEx to make one either feel 'similar to' or 'different from' someone else.

Publications

Mazanderani, F., Locock, L. & Powell, J., (2012). Being differently the same: The mediation of identity tensions in the sharing of illness experiences. *Social Science and Medicine*, 74 (4): 546-553.

Locock, L., Mazanderani, F. & Powell, J., (2012). Metaphoric language and the articulation of emotions by people affected by motor neurone disease. *Chronic Illness*, 8 (3): 201-213.

Mazanderani, F., Locock, L. & Powell, J., (2013). Biographical Value: Towards the conceptualisation of the 'commodification' of illness narratives in contemporary health care. *Sociology of Health and Illness*, 35 (6): 891-905.

Contact

Health Experiences Research Group,
Nuffield Department of Primary Care Health Sciences,
University of Oxford.
Tel: 01865 289373
email: angela.martin@phc.ox.ac.uk
www.ipexonline.org

The iPEX programme presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0608-10147). The views expressed in this briefing sheet are those of the authors, representing iPEX, and not necessarily those of the NHS, the NIHR or the Department of Health.

