

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

iPEX Briefing Paper 1 Introduction and background to the iPEX project

What is the programme about?

UK health policy values and promotes patient choice, self-care, and patient and public involvement. These aims cannot be achieved unless people can access high quality information. Until now this information has focussed on facts and figures about an illness, the risks of treatment options, and the likely outcomes. But people seek more than scientific facts. They want to know about the experience of illness – the reflections, insights and practical advice from people who have been there – and to be able to share their own experiences with others.

The team has internationally recognised expertise in making patients' 'experiential' information accessible to the public; but the scientific base underpinning this activity needs strengthening. We remain unsure whether, when and how the NHS should provide information based on other patients' experiences. How do people find and interpret online patient experiences and relate it to their own lives? What are the positive and negative consequences?

How might this affect their health and well-being? How do we measure these effects? This research programme was designed to answer these questions.

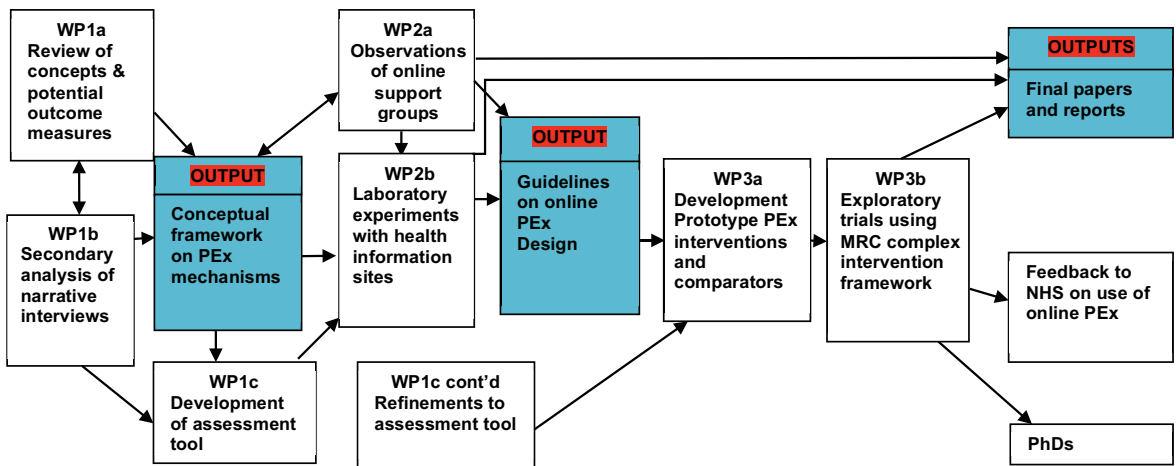
Work packages

Work package 1 developed the concepts and methods to quantify the effects of exposure to on-line patient experiences.

Work package 2 identified how and why people seek, use and interpret patient experiences and establish guidelines for presenting patient experiences on-line.

The outputs of work packages 1 and 2 were integrated to generate a new theoretical framework for the online exchange of patient experiences.

Work package 3 developed on-line patient experience prototype interventions and used exploratory trials to investigate their effects.



The team

Our team comprises researchers and NHS personnel with unrivalled expertise in innovation and research in patients' experiences, internet use, development of health outcome measures, primary care trials of complex interventions, and dissemination of health information.

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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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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.

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iPEX Briefing Paper 4

Work package 1c – Develop and pilot an assessment tool to capture the health effects of exposure to online patient experience

Background

Trials to evaluate the impact of online patient experience need to identify the most appropriate outcomes to be measured. The range of outcomes is potentially large and may be addressed, in part, by some existing measures – e.g. health status and health-related quality of life, emotional adjustment, coping and decisional conflict. However, as research on online patient experiential information is in its infancy, no valid and reliable assessment tool existed that is appropriate to capture the effects of using websites which contain patient experiences as well as 'facts and figures' information.

Objective and approach

To develop a tool to measure the impact of using health-related websites which contain experiential and factual information.

Our approach was:

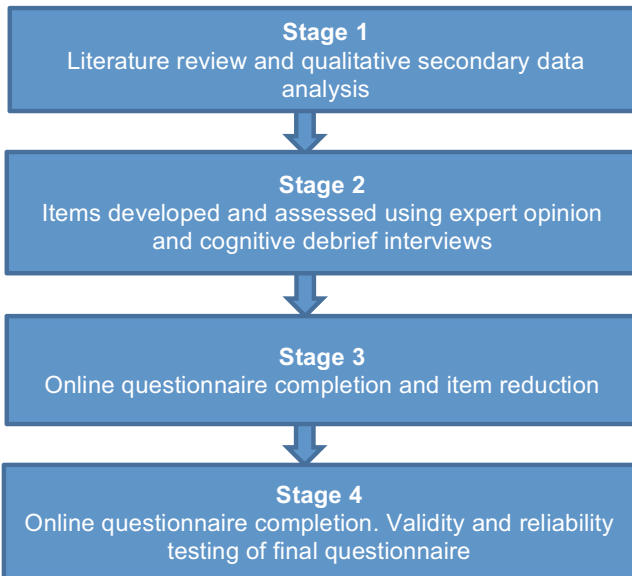
- To inform and construct questionnaire items using a conceptual literature review and secondary qualitative analysis of interviews relating to patient and carer experiences of using health information on the internet.
- To refine and reduce the number of questionnaire items using expert and user opinion followed by statistical analysis.

The tool needed to be suitable for use across a range of health groups (for example, people with long term conditions, carers and those viewing websites aimed at changing health behaviour. The questionnaire also needed to be suitable for use with various styles of online information (for example, 'facts and figures' information, patient experiences information and discussion forums).



Laura Kelly, Sue Ziebland and Crispin Jenkinson

Development of the e-Health Impact Questionnaire (e-HIQ)



The assessment tool, referred to as the 'e-Health Impact Questionnaire' (e-HIQ), was designed to assess the impact of using health-related websites. This online self-report questionnaire consists of two independent parts which have undergone numerous stages of development. The use of existing literature, qualitative analysis, expert/patient opinion and psychometric analyses provide evidence of the validity and reliability of the measure.

Kelly L, Jenkinson C and Ziebland S. (2013). Measuring the effects of online health information for patients: Item generation for an ehealth impact questionnaire. *Patient Education and Counseling*. 2013 Dec; 93(3):433-8.

Kelly L, Ziebland S, & Jenkinson C. (in press). Measuring the effects of online health information: scale validation for the e-Health Impact Questionnaire. *Patient Education and Counseling*.

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The e-HIQ-Part 1 consists of 11 items asking about a person's general attitudes towards health-related websites.

The e-HIQ-Part 2 consists of 26 items asking about a person's views regarding a specific health-related website.

Both parts of the questionnaire have a five point response category for all items ranging from 'strongly disagree' to 'strongly agree'. A person's score for identified domains (or sub-scales) within the questionnaire can be calculated.

A summary score for each questionnaire part can also be calculated.

A translatability assessment of the e-HIQ was performed on questionnaire items to confirm cultural and linguistic suitability for translation in the future.

Use of the eHIQ

The e-HIQ demonstrates good psychometric properties and enables the measurement of the impact of using health-related websites across a range conditions. This tool has been used in the final work package, the randomised controlled trial which compared websites using 'facts and figures' to websites containing 'facts and figures' plus experiential information. It has been translated into other languages by members of DIPEX International. Since spring 2015 the questionnaire has been introduced as part of routine feedback on HealthTalk.org

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iPEX Briefing Paper 5 Work package 2a – Ethnographic observations

Background

The quality of online health material varies greatly. User-generated social networking sites, patient forums and reputation systems are proliferating. Patient experiential information is now offered in many forms – ratings, comments, blogs, discussion forums, interactive message boards, scripted vignettes, stereotypes and short films.

We know that the services available for people differs between conditions and that people respond to and use online PEx in very different ways. We also know that there is often a mismatch between what people do, and what they say they do, making this a very challenging area for academic study.

Given the diverse range of PEx online and the variety of experiential information sharing practices, in this work package we decided to focus specifically on the sharing of PEx in relation to Multiple Sclerosis (MS).

Objective and approach

Building on the conceptual literature review (briefing paper 2) and secondary analysis (briefing paper 3), the aim of this work package was to explore how PEx is constructed and exchanged in online MS-related support groups; and the ways people affected by MS (patients, family members and friends) respond to and interpret PEx-related information in these settings.

We used a combination of different methods, including: online ethnographic observations; targeted content analyses of forums and YouTube videos; telephone and face-to-face interviews with users and people working in relation to the provision of experiential information on the internet, such as web developers and forum moderators (n=24). During the course of the research we developed a specific interest in how PEx is sought and shared in relation to controversial theories and treatments.



Fadhila Mazanderani and John Powell

MS-related PEx on the internet

We found three main kinds of MS-related PEx and associated practices across the platforms we analysed:

- PEx focused on 'living with MS', practical information and support (e.g. coping with the illness, making life-style adaptations, managing benefits etc.).
- PEx used for creative and other forms of self-expression (e.g. poetry, autobiographic accounts, humour, artistic videos).
- PEx directly linked to healthcare and biomedical research, treatments, policy and practices.

This highlights the huge variety of information that counts as PEx, but also shows how in practice distinctions between 'experiential' and other types of information, especially medical, are often blurred.

YouTube and the visualisation of PEx

YouTube has become a popular site for sharing patient videos. We conducted a quantitative and qualitative analysis of videos shared in relation to a controversial theory about treatment for MS. These videos combined people's everyday embodied experiences of living with MS, evidence of medical knowledge and tests, with highly visual representations of experience pre and post treatment. These videos are a powerful but often overlooked source of online PEx.

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From 'experiential knowledge' to 'experiential evidence'?

People affected by MS not only share individual PEx, they 'experiment' (e.g. with dietary regimes, medication and interventions), monitor and broadcast their responses online. In some cases these experiences are aggregated on different forums and sites and used to generate alternative forms of 'evidence' built on a hybrid of personal experience and medical knowledge (that may or may not be recognised as valid). These activities have consequences for healthcare practice and biomedical research as they can result in patients seeking treatments that have not been tested and approved, and even cause a break-down in trust between healthcare practitioners and patients.

Digital labour and the creation of online 'spaces of care'

Very little research has been conducted on the understanding of MS development and management of platforms and sites for sharing PEx. Rather than being neutral conduits, different sites and forums shape how and what PEx gets shared online. Ensuring these sites are 'safe' spaces often requires considerable work - often invisible and unpaid - from patients as well as from people formally employed as website managers, editors and moderators. As online services and platforms become an increasingly central part of contemporary healthcare it is essential that more attention is paid to the work that goes into the creation of online spaces of care. We suggest that this includes an awareness of what we have termed the aesthetics of online care. This signifies an ethically-sensitive balance between the degree to which an internet user feels attracted to, attached to and aligned with the purpose and values of an online space.

Mazanderani F., Powell J. 2013. Using the internet as a source of information about patients' experiences. In: Ziebland S, Coulter A, Calabrese JD, Locock L, editors. *Understanding and Using Health Experiences: Improving Patient Care*. Oxford: Oxford University Press, pp.94-103.

Mazanderani, F., O'Neill, B. & Powell J. 2013. "People power" or "pester power"? YouTube as a forum for the generation of evidence and patient advocacy. *Patient Education and Counseling*, 93 (3): 420-425.

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iPEX Briefing Paper 6

Work package 2b – Observational and experimental studies

Background

We wanted to find out how people view internet patients' experiences (PEX), including what makes an individual trust and engage with another patient's shared experience. We produced a set of guidelines and design principles for 'best practice' presentation of PEX on health information websites.

Objectives and approach

Acknowledging the diverse quality of online patient experience, our aim was to use observational and experimental studies to find out how people select from the various patient experiences available online. We wanted to understand how they used patient experience to support or inform their own health and life-style choices and also to assess how exposure to patient experiences might influence recall of health material and patient decision-making.

Key research questions

We addressed the following four research questions:

- What factors influence patient sampling of online patient experience and how do patients determine which sites and/or experiences merit further attention?
- Do patients' own sampling strategies bias their exposure to health information and advice?
- How does exposure to online patient experience influence decision-making and other health related outcomes?
- Does PEX offered in unstructured, unregulated settings lead to different sampling and outcomes compared to more structured sites?

Methods:

Participatory and exploratory workshops and focus groups designed to elicit patient opinion of existing sites.

Experimental studies that controlled for the design and content of PEX sites in order to assess health related impact.



Pamela Briggs, Elizabeth Sillence, Peter Harris

Engagement with patient experiences

People prefer credible, well designed websites from which they can examine the PEx in more detail. This involves an iterative process during which people discover who is making the contribution, and assess what is being said in a three stage process (detailed opposite). Patient coping strategies may change over time and this will be reflected in the nature of their engagement with online patient experience.

Key outputs and papers

Outputs include guidelines for the inclusion of experiential information in health information sites. These guidelines have been used to develop evidence based prototypes for the feasibility trials of websites based on patient experience.

Briggs, P., Hardy, C., Harris, P.R. and Sillence, E. (2014). Patient-led perspectives on ehealth: How might hyperpersonal data inform design? *Proceedings of HCIK, Korea*, ACM Press.

Sillence, E., Hardy, C., Harris, P. and Briggs, P. (2014). Modelling Patient Engagement in Peer-to-Peer Healthcare. *23rd International World Wide Web Conference*, April 7-11, Korea.

Sillence, E., Hardy, C., Briggs, P. & Harris, P.R. (2013). How do people with asthma use Internet sites containing patient experiences? *Patient Education and Counselling*, 93(3): 439-43.

Sillence, E., Hardy, C., Briggs, P. & Harris, P.R. (2013). Online Health Information and Patient Adherence. *Journal for Patient Compliance*, 2 (3), 24-26.

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Key messages

We developed a PEx engagement framework involving a three stage process: a gating stage, an engagement loop, and finally an outcome stage. A user can exit the PEx or website at any point in the engagement process.

1. The first stage – gating – is largely concerned with whether the user trusts the parent website. If the user is aware of the site or organisation (reputation), believes the site is impartial, and likes the look and feel of the site, they will be more inclined to engage with the PEx.
2. The second stage of the engagement process – the engagement loop – addresses four questions the patient asks of the material:
 - Who is sharing the experience? Is the PEX from someone like me or someone I know?
 - What is shared? Does the PEX offer the right mix and amount of information, support and advice?
 - How does it compare with my own situation? Does it reflect my own knowledge and experience?
 - Can I share my own experiences – telling my own story and adding my voice to the others?
3. In the third stage, patients assessed the outcomes of PEX engagement as: learning about their condition, understanding the practicalities of managing their condition; helping them deal with health services, managing expectations, motivating themselves using positive stories, comprehending the seriousness of their condition or outlook, and developing supportive relationships with others.

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iPEX Briefing Paper 7

Work package 3a – Development and testing of patient experience web interventions for exploratory trials

Background

The feasibility trials required the development of six new websites. As with the rest of the iPEX programme, we examined three exemplar conditions: asthma, smoking and caring for someone with multiple sclerosis (MS).

Each project was informed by a literature and field review and by the appointment of a specialist advisory panel comprising researchers, clinicians, lay persons, representatives from the voluntary sector and other stakeholders.

Objective and approach

Our objective was to develop 6 websites on three conditions which could be password protected for the duration of the randomised controlled trial.

We used established qualitative research methods to explore the experiences, information and support needs of people in each of the three exemplar groups. The research methods were based on those used in projects already conducted by the Oxford Health Experiences Research Group. The comparator (facts and figures) sites incorporated NHS Choices information.

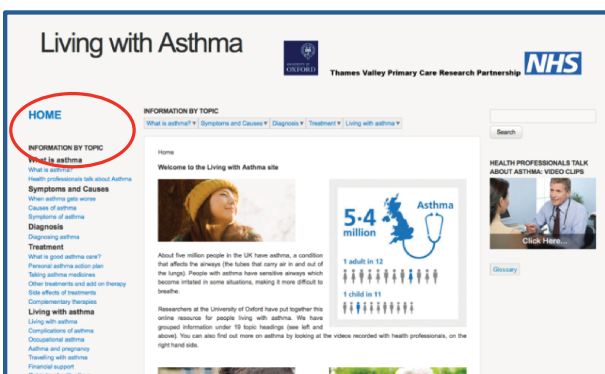
We developed multimedia websites featuring experiential information (intervention) or facts and figures information (comparator) for three exemplar health issues, using guidelines, developed in this programme, for how best to present experiential information online.



Laura Griffith, Susan Kirkpatrick, Nicolas Hughes and Ruth Sanders

Selection of health conditions

We selected the three health conditions to allow us to compare different aspects of exposure to facts and figures and patient experiences. Our aim was to provide transferable lessons for the use of patient experiences across other care settings and conditions. The topic summaries from the experiential sites did not map precisely across to the comparator sites. Information derived from patient experiences has a different emphasis. The summaries which formed the basis of the intervention websites were entirely informed by what was important to the study participants.



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Key messages

The six websites (three intervention sites and three comparator sites) and the associated data collection portal were constructed with the assistance of an external specialist web development team. The look and feel of the websites was identical.

All websites included topic-specific video material from health professionals.

The patient experience sites contained a series of topic summaries for each health condition, each of which contained video, audio, and text excerpts from interviews with people with experience of the conditions, talking about their personal stories. The intervention websites harness the full range of personal experience of a condition from diverse individuals, and provide this in discrete, searchable topic areas which can be consumed as videos, audio recordings, or written transcripts.

The facts and figures sites were based on material from the NHS Choices website.

Versions of the 3 experiential sites were published on www.healthtalk.org in early 2015, after completion of the feasibility trials.

Publications

Hughes, N., Locock, L. & Ziebland, S., 2013. Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis. *Social Science and Medicine* 96: 78-85.

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iPEX Briefing Paper 8

Work package 3b – Feasibility randomised controlled trials

Background

The sharing of online patient experiences could bring health and social benefits in a number of ways. One of our interests was to explore whether the value of these experiences can be harnessed as an intervention. We developed prototype websites which were either based on patient experiences (the interventions) or which only contained 'facts and figures' (comparators). All the websites had the same 'look and feel' and were designed in accord with the guidelines developed during this programme (see Briefing Paper 6).

Objective and approach

A series of exploratory trials in three health conditions were undertaken to assess the acceptability, feasibility and effect on self-report and process measures of patient-experience based websites, in comparison with matched health information websites that did not contain experiential information.

We recruited people with asthma, smokers who wanted to quit, and people who were family or friends of someone with MS. We wanted to see whether hearing about other people's experiences of managing their chronic illness (asthma) might increase confidence to self-manage; whether hearing about other people's stories of giving up smoking might change people's motivation to quit; and whether hearing carers' stories, might make other carers feel more supported. For each of these studies we asked half the participants (chosen at random) to look at the intervention (experiences) site, and the other half of participants to look at the comparison (facts and figures) site. Both groups were given two weeks to look at the sites, and we asked them to fill in questionnaires before and afterwards.



Rafael Perera, John Powell, Sue Ziebland and Andrew Farmer

Measures

All participants were asked to complete questionnaires, which included questions on:

- General demographics
- Internet use and ability
- Health status (SF36)
- Health literacy
- Social support
- MOS Social Support Survey
- E-health impact questionnaire (e-HIQ)

There were also measures specific to participants in each of three exemplar conditions.

Key messages

It is feasible and acceptable to produce patient experience based websites which adhere to guidelines derived from theory and best practice. These multimedia websites capture what it is like to experience a condition, and we know this sort of information is valued and requested by others.

It is also feasible and acceptable to develop a comparison website with the same design features but without the experience-based content.

It is possible therefore, to test the value of such a patient-experience based intervention (versus a 'facts and figures' website) in a randomised trial. We were able to survey users before and after their use of the sites and ask them questions about their personal characteristics, their health experiences, and their use of the internet and other sources of help.

We were able to demonstrate that we could easily recruit people with asthma through GP records, and (to a lesser extent) identify people who smoke and want to give up, to a trial of an online information resource. Carers of people with MS were harder to recruit.

After two weeks 75% of participants filled in their follow-up measures.

Many of the people who took part did not use the allocated websites very much, if at all. This is common to all studies of online interventions.

We found no differences in terms of the effects of the experience-based website or the comparison website, between the two groups of participants. Both types of website were well received as judged by their e-HIQ assessments.

We question whether allocating people to look at a particular website over a two week period reflects how people actually use this kind of information in practice. We know people search and browse for online information and also interact with others both online and offline. Any one piece of information is rarely viewed in isolation from other sources of help.

Our qualitative work showed that people have a range of personal preferences for different types of information, and everyone wants (and needs) facts and figures. Experiential information from others in the same situation is not an alternative but an addition, and may incorporate facts within it. Future work needs to not only allow for the iterative nature of information behaviour but also to not isolate personal stories from the rest of the 'information landscape'. It needs to consider the timing of the 'exposure to information' and what 'exposure' really means in this context.

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