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

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Scientific summary

Use of patient experience in health-care decision-making

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Scientific summary

Background

Health organisations remain committed to giving reliable and timely health information to the public and patients. Traditional health information has been based on facts and figures and not on the experiences of patients. Many different types of patient experience (PEx) are available online in health information sites, social networking, reputation systems (an approach borrowed from e-commerce) and online support groups. PEx may support and inform people but there have also been concerns that decisions about health care might be adversely affected if people identify with powerful stories that are not relevant to their circumstances.

Aim

The aim of the programme was to find out whether, when and how the NHS should incorporate PEx into online health information.

Methods

We set out to understand the mechanisms through which PEx might influence health, develop tools to measure the effects of these interventions, explore how PEx is used and test prototype websites on the following exemplar groups: people who wanted to give up smoking, people with asthma and carers of people with multiple sclerosis (MS). The programme used mixed methods and was delivered through three work packages (WPs): WP1 comprised a conceptual literature review, a secondary analysis of existing qualitative data and the development and testing of a new questionnaire to measure the effect of PEx; WP2 comprised an online ethnography and observational and experimental studies on the effect of PEx in an internet café-style environment; and WP3 comprised exploratory pilot trials to explore the feasibility of comparing new website interventions with information-only websites.

Results

Work package 1: conceptual framework

Work package 1a: conceptual and literature review

We conducted a broad literature review to identify theories and mechanisms of action that could help to explain the potential consequences of PEx. The review suggested that access to other people's experiences of a health condition could affect health outcomes both positively and negatively through the mechanisms of information, support, affecting relationships, providing ideas on how to use health services, influencing behaviour change, learning to tell the story and visualising illness and its effects. These seven domains formed a conceptual framework through which PEx could affect health. This framework informed all of the subsequent WPs, including the development of the measurement tool.

Work package 1b: secondary analysis of narrative interviews

The secondary analysis was used to gather evidence about how and why information based on real experience is sought and used, and to select quotations from interview transcripts which illustrate participants' views on their use of the internet for health information. The findings were used to provide an item pool for the e-Health Impact Questionnaire (eHIQ) measurement tool.

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Work package 1c: develop and pilot assessment tool

Trials to evaluate the impact of online PEx need to identify the most appropriate outcomes to measure. The range of outcomes is potentially large and may be addressed, in part, by existing measures. However, as research on online patient experiential information is in its infancy, there was no valid and reliable assessment tool to capture the health effects of using websites which contain PEx. We developed the eHIQ to assess health-related websites. The tool comprises two independent parts which have been rigorously tested. Part 1 (11 items) assesses general attitudes to health-related websites. Part 2 (26 items) concerns a specific, recently visited website. The eHIQ demonstrates good psychometric properties and is suitable for use across a range of health groups (e.g. people with long-term conditions, carers and those viewing websites aimed at changing health behaviour) and is also suitable for use among various styles of online information (e.g. factual or experiential information and discussion forums).

Work package 2: observations in natural and experimental settings

Work package 2a: explore the exchange of patient experience on online communities, using ethnographic observations and telephone interviews

Through a content analysis of online settings, ethnographic observation of online activity and telephone interviews, we studied how people living with MS and those who care for them seek out others' experiences, how they share their own experiences, and how this affects their understanding of MS, their relationship with health-care practitioners, their health-care decision-making and their general well-being. We found three main kinds of MS-related PEx across the platforms: (1) PEx focused on 'living with MS', practical information support and coping, (2) PEx used for self-expression and creativity and (3) PEx linked to health-care and biomedical research, treatments and practice. The study highlights that the distinctions between 'experiential' and other types of information, especially medical, are often blurred.

Work package 2b: observational and experimental studies to find out how people use, search for and select patient experience

Acknowledging the diverse quality of online PEx, we have conducted three studies using observational and laboratory-based methods to discover how people find and use PEx to inform health and lifestyle choices. The first study was expanded from that stipulated in the proposal and included, in addition to the asthma and MS carers elements, two further elements on people who wished to stop smoking. The second study, which focused on people with asthma and MS carers, involved the recruitment of additional patients and a more detailed comprehensive interview. From these studies, we developed a three-stage model of patients' peer-to-peer engagement online (gating, the engagement loop and outcomes) through which people discover who is making the contribution and assess what is said, with different consequences. The framework was used to generate web design guidelines which describe how best to present PEx online. These were used to develop the prototype websites for the WP3a exploratory trials.

The third study involved a sample of smokers and sought to examine the effect of (1) message type (i.e. PEx vs. information only), (2) perceived similarity of author and reader (based on gender) between the reader and the author of the PEx on the participant's readiness to accept the message and (3) palatability of material in terms of pre-existing beliefs (attitude towards quitting by using or not using aids and support). A longitudinal approach examined the impact of these variables on behavioural intentions and actions 2 weeks and 3 months after exposure. We found little effect of gender matching and observed a PEx effect in men only. Men found PEx preferable in terms of both mood and message believability, but it mattered little whether the experience seemed to come from a man or a woman. PEx did not affect message knowledge or website evaluation, as measured by the eHIQ, in either sex. Men showed increases in quit attempts and decreases in nicotine dependency over the 3-month period. Women also showed decreases in nicotine dependency over this period. There were also some significant effects of condition on nicotine dependency. Health information expressed in a way that was preference consistent led to higher levels of engagement with online content.

Work package 3: evaluation of online patient experience prototype interventions

Work package 3a: prepare prototype online patient experience interventions

We developed six prototype multimedia websites featuring either experiential information (intervention) or factual information (comparator) for the three exemplar health issues. We used established qualitative research methods to explore the experiences, information and support needs of people in each of the three exemplar groups. The design and presentation of patient experiential information on the site were developed in accordance with the WP2 guidelines. The comparator websites were based on non-experiential material from NHS Choices, presented in a similar design to that of the intervention sites.

Work package 3b: conduct exploratory trials of online patient experience interventions

As originally proposed, we evaluated the feasibility and acceptability of using three PEx prototype websites intended to improve health outcomes. In addition, we compared self-report and process measures with a comparator website. We ran three separate pilot randomised trials, one for each health condition under the governance of a single trial protocol and analysed by condition. The trial researchers were blinded and we maximised allocation concealment from participants by only informing them that they would receive one of two kinds of information (complete blinding of participants was not possible given the nature of the intervention). We found that we could easily recruit people with asthma through general practitioner records and, to a lesser extent, identify people who wanted to give up smoking. Carers of people with MS were harder to recruit. In the three conditions (smoking cessation, asthma and caring for someone with MS) we randomised 87, 148 and 42 participants, respectively. At final (2-week) follow-up, retention rates were 75%, 82% and 86%, respectively. Usage of allocated websites was low. The median numbers of logins to the websites were 2, 2 and 4; the median numbers of page views were 10, 15 and 27.5; and the median total duration on site was 9.5 minutes, 17 minutes, and 31.5 minutes, respectively. We captured self-report measures of condition-specific outcomes, health status and attitudes of users towards health websites. There were no reported adverse events or harms.

Qualitative interviews were conducted with 30 trial participants, purposively selected to represent the different conditions and both arms. Participants who were interviewed were content with the way that the trial was run and did not find the questionnaires, reminders or log-in requirements burdensome. The interviews provided evidence for all seven domains identified through the conceptual review and demonstrated the highly individual way that people integrate information for their own information landscapes, drawing on facts, figures and experiences at different times in relation to different needs.

Conclusions

Our conceptual literature review established the theoretical underpinnings for the study and guided our understanding of the potential positive and negative consequences of looking at other patients' experiences online. We found that there was no validated outcome measure that could be used to compare the effects of a 'facts and figures' and 'PEx' website, and so we set about developing and validating a new measure, the eHIQ, for this purpose. The ethnographic studies and detailed internet café laboratory observations helped us to understand the various ways in which PEx is used in online support groups and how patients use and respond to a variety of different types of health information websites that present PEx as single stories, testimonials or 'maximum variation' samples. These studies fed into the development of a three-stage model of peer-to-peer engagement, which informed new guidelines. These were used to devleop prototype PEx websites for three online feasibility trials.

In the final WP, we demonstrated the feasibility and acceptability of a patient-experience based website intervention. We showed that this could be evaluated in a randomised trial, compared with a 'facts and figures' website, although it was very hard to recruit participants who were carers of people with MS.

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Our findings raise questions over the nature of participant engagement with the websites, with low actual usage of the interventions in this trial. A 'phase II' pilot trial approach of a 2-week allocated 'exposure' to a 'dose of information' is also very different from how information sources are used in everyday life. Our findings suggest, therefore, that future work needs to understand how to embed such interventions in people's everyday lives. The qualitative interviews with trial participants underlined that everyone wants and needs facts and figures and that online experiential information is not seen as an alternative to facts, or to care from a health professional, but is used in addition to other sources of information, support and expression. In practice, some people will prefer only facts and figures but others may like to see shared experiences for an additional source of information that fulfils a rather different purpose. Finding measures which accurately capture the impact of this is not straightforward.

Recommendations for research

The National Institute for Health Research (NIHR) and academic community may benefit from research in the following areas (in order of priority).

1. Future intervention research evaluating online health interventions should reflect the way in which people use the internet in everyday life. This is challenging within the specification of a randomised trial. People search, browse, digest and comment on multiple information sources to varying degrees, within a landscape of other sources of help and advice, and with varying personal preferences for types of information. Although it is *possible* to package an online health information intervention in the same way as a 'dose' of a medication, and to administer an exposure by allocating or denying access to the intervention, researchers need to consider critically whether or not this reflects real information-seeking behaviour. Further theoretical and methodological work is, therefore, needed to consider the issues of 'exposure' and 'dose' in the context of online health information interventions. This present programme of work makes a significant contribution to this area; the Medical Research Council (MRC) new guidance on developing and evaluating complex interventions, and the recent additional MRC guidance on process evaluation, can help to systematically examine these issues in future work.
2. Future intervention research evaluating online health interventions should examine and explain issues of engagement and use and seek to identify how to increase engagement. In common with many online trials, ours showed that actual usage of the website intervention was low (in terms of numbers of logins, numbers of page views and duration on site) for both the intervention and the comparator sites. Further research is required to understand the nature of engagement with online interventions and the determinants of this. The reliability of tracking data should also be assessed.
3. Future research should harness qualitative methods, including online ethnography and offline interview research, to further explore how and why people use online sources of experience-based health information, and what effect this may or may not have on subsequent behaviour and health and social outcomes in different conditions. In particular, studies might consider who chooses to share experiences online, who is influenced by these, and to what extent online sources of PEx (both solicited and unsolicited) are representative of patients' experiences more generally, and, indeed, what *representative* means in this context. Areas of particular interest are online patient activism, especially regarding contested illnesses and treatments, and online comments on health services (including reviews and ratings).
4. Future studies evaluating health information websites should make use of the eHIQ, which we have demonstrated to be an acceptable, valid and reliable measure for examining individual attitudes towards websites presenting different types of information.
5. In designing online interventions which harness PEx, researchers should note the guidelines on intervention design. We demonstrated that these guidelines can be successfully applied in building three intervention and three comparator websites.
6. The seven domains (identified through our review) have been demonstrated to be a valid conceptual basis for research on how online PEx affect health and should inform research in digital health.

Trial registration

This trial is registered as ISRCTN29549695.

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