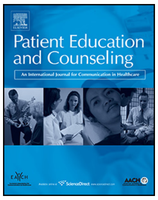
Patient Education and Counseling 93 (2013) 433–438

Contents lists available at SciVerse ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Measuring the effects of online health information for patients: Item generation for an e-health impact questionnaire

Laura Kelly [a,*], Crispin Jenkinson [a], Sue Ziebland [b]

[a] University of Oxford, Department of Public Health, Oxford, UK
[b] University of Oxford, Department of Primary Care Health Sciences, Oxford, UK

ARTICLE INFO

Article history:
Received 1 November 2012
Received in revised form 11 March 2013
Accepted 14 March 2013

Keywords:
E-health
Patients' experiences
Information
Secondary data analysis
Cognitive debrief interviews

ABSTRACT

Objective: The internet is a valuable resource for accessing health information and support. We are developing an instrument to assess the effects of websites with experiential and factual health information. This study aimed to inform an item pool for the proposed questionnaire.

Methods: Items were informed through a review of relevant literature and secondary qualitative analysis of 99 narrative interviews relating to patient and carer experiences of health. Statements relating to identified themes were re-cast as questionnaire items and shown for review to an expert panel. Cognitive debrief interviews ($n = 21$) were used to assess items for face and content validity.

Results: Eighty-two generic items were identified following secondary qualitative analysis and expert review. Cognitive interviewing confirmed the questionnaire instructions, 62 items and the response options were acceptable to patients and carers.

Conclusion: Using a clear conceptual basis to inform item generation, 62 items have been identified as suitable to undergo further psychometric testing.

Practice implications: The final questionnaire will initially be used in a randomized controlled trial examining the effects of online patient's experiences. This will inform recommendations on the best way to present patients' experiences within health information websites.

1. Introduction

UK health policy acknowledges the value of patient choice, self-care, and patient and public involvement [1–3]. In order to help people realize these ideals, the internet can be a valuable and accessible information resource. Research carried out by the Oxford Internet Institute has shown 71% of the UK population have sourced health information online [4]. Health-related websites have conventionally presented information in the style of scientific facts; however, experiences of health are increasingly exchanged by patients online and patients' experiences are often included on health websites. People's use of the web for sharing, collaboration and connecting gained pace with the advent of Web 2.0 and the use of platforms for social networking, personal blogs and multimedia [5].

Peer-to-peer information and support can act as a supplement to information provided by healthcare professionals. This 'experiential' information is now routinely incorporated into mainstream health websites and can be accessed on 'NHS Choices', national and local charitable groups and private company websites. U.S. research has found one in five internet users went online to find people like them, with the number rising for those with a chronic condition. Caregivers, those experiencing a medical crisis in the past year and groups experiencing change in their physical health (for example, changes in weight or smoking behavior) were also particularly likely to use peer-to-peer resources [6].

With the increase in internet use for health, however, the importance of establishing the impact health websites can have on the user becomes critical. It is important for health website developers and health care providers to understand the potential effects of the information provided through their websites and to understand the effect experiential information and internet discussion forums may have on users. In order to accurately evaluate the impact a website has on the user a valid and reliable instrument is needed. This paper demonstrates the use of secondary analysis and patient–expert refinement in the development of an item pool for an instrument to measure the impact of exposure to health websites.

Health-related measurement scales require a clear conceptual basis to inform item generation [7,8]. Involving the patient in the development of a self-reported questionnaire is important as they

---

* Corresponding author at: Health Services Research Unit, Department of Public Health, Rosemary Rue Building, Old Road Campus, Headington, Oxford OX3 7LF, UK. Tel.: +44 1865 289425.
E-mail address: laura.kelly@dph.ox.ac.uk (L. Kelly).

0738-3991/$ – see front matter © 2013 Elsevier Ireland Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.pec.2013.03.012

may highlight issues not found in the literature or considered irrelevant by health care professionals. Terminology can also become outdated or be interpreted differently among various populations and user involvement can ensure that a measures questions and response scales are understandable to patients [9–11]. It is widely acknowledged that the conceptual underpinnings of a measure must be explicit and empirically based [7–9,12,13]. With this in mind, we outline steps taken in the development of a generic item pool relating to the proposed instrument.

2. Methods

Several steps were taken in order to construct items relevant to the effects of exposure to health websites (see Fig. 1). Items were primarily informed through a review of relevant literature [14] and secondary qualitative analysis of narrative interviews relating to patients' and carers' experiences. Statements were selected to represent themes identified in the literature review and recast as questionnaire items. A period of item refinement through patient and expert review followed.

2.1. Secondary data analysis

Secondary data analysis, the reuse of data originally collected fo another research purpose [15], was carried out using interview transcripts held in the Oxford Health Experiences Research Group (HERG) archives. At the time of the study the HERG database included 60 narrative interview collections relating to patient and carer health experiences. HERG interviews are recorded using digital video and/or audio recording equipment and collections typically aim to achieve a sample with 'maximum variation'. The HERG collections have been used for a number of other secondary analysis studies, including studes of how people talk about using the internet [16,17].

HERG interviews are conducted using an open ended narrative structure followed by a semi-structured interview [18]. Participants are asked about sources of health information or support, including the internet. Interview transcripts were reviewed to identify incidences where participants discussed having used websites which contained factual health information or experiential information. Of the 203 interviews sampled, the analysis reported here was based upon 99 transcripts where use of the internet was discussed in some detail ($n = 99$, 48.8%).

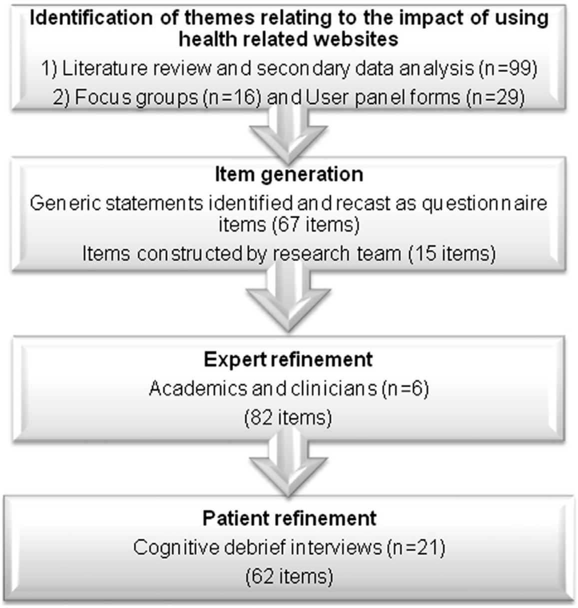


Fig. 1. Steps taken to develop item pool.

Access to the interview archive meant that our analysis was not limited to a population with a specific condition, demographic profile or role (i.e. carer or patient). Rather, a range of socio-demographic variables and illness categories were chosen to compare and contrast effects amongst conditions.

2.1.1. Analysis

Interview transcripts were analyzed using a modified version of the "Framework" method, an analytical approach developed by the UK based National Centre for Social Research [19]. Framework analysis is systematic and involves five stages: (1) familiarization with the data gathered; (2) identifying a thematic framework; (3) indexing the transcripts according to the thematic framework; (4) charting the data to allow within-case and between-case comparison; and (5) mapping and interpretation of data [20–22]. Many of the themes that were expected to be raised during analysis had been identified in the literature review [14] which explored the potential effects of seeing and sharing experiences online. The secondary analysis sought to gain a deeper understanding of existing ('anticipated') themes found in the literature whilst being mindful of any new ('emergent') concepts which arose.

Indexing took place within NVIVO and charting was carried out using EXCEL. Charting the data involved lifting the data *verbatim* to facilitate the use of participants own words when forming items. Themes were checked for applicability across three condition groups and three different types of health websites to ensure its suitability for inclusion in a generic item pool.

2.2. Confirmatory sources

Two sources of data were used to check the themes identified for the measure: (1) Focus group transcripts ($n = 16$) from research carried out on trust and online health information in Northumbria University (see [23] for methodology) and; (2) Comment forms ($n = 29$) completed by members of an internet user panel consisting of lay persons using local primary health care services. The user panel comment forms asked people to list the potential advantages and disadvantages of using the internet for health information. Comments were collated in a single document to compare issues raised with the themes previously identified. Using more than one data source provided 'data triangulation' to enhance rigor within the research [24].

2.3. Representation of themes and identifying generic statements

Each theme identified through the analysis was represented by relevant statements (in the form of verbatim quotes) from the HERG transcripts. Statements were arranged according to the theme in a tabulated summary which identified the health condition from where it originated. This allowed each statement to be traced to its origin throughout the iterative process. Statements which could be answered by people across health conditions (i.e. generic statements) were identified. The authors recast statements as questionnaire items and removed duplicate items.

2.4. Expert refinement

Items were reviewed by an advisory board consisting of six clinicians and academics with interests in the field of e-health. Reviewers were asked whether items were answerable to those exposed to websites containing: (1) experiential health information, (2) standard 'facts and figures' health information and; (3) patients online health forums. Reviewers were also asked to