

Study protocol: Health talk Norway

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Abstract

This paper is a study protocol. "Health talk Norway" is a one year project where we will pilot a new and increasingly popular international methodology for qualitative research on people's health experiences; the DIPEX methodology, developed by the Health Experiences Research Group (HERG) at the University of Oxford. This study will explore if Norwegian research and dissemination on health experiences can be improved using the DIPEX methodology. At the core of the DIPEX methodology is a web site disseminating people's accounts of their health experiences. DIPEX has been founded to promote the spread of well-researched data on personal experiences of illness and health for the benefit of patients, professionals (both clinical and academic), health services, health care providers and carers. The methodology has been developed in the UK and has so far been adapted to 9 other countries, in Europe, Australia, North America and Asia. Results from the pilot will be of importance for future development of a Norwegian health talk web site, and support research infrastructure for qualitative research on health experiences.

Keywords: *health experiences, methodology, patients, qualitative, web science*

Introduction

In "Health talk Norway" we will pilot the DIPEX methodology of health experiences research [1, 2], developed by the Health Experiences Research Group (HERG) at the University of Oxford and the DIPEX charity (which owns and publishes the website www.healthtalk.org). This is a methodology for developing, producing and systematizing qualitative research on people's health experiences. The methodology has been developed in the UK, but is also applied by researchers in 9 other countries: Germany, The Netherlands, Canada, Japan, Korea, Australia, Spain, Israel and USA. The 10 national research networks are joined in the organisation DIPEX International. If the pilot is successful it is our aim to apply for a large-scale project that conforms to the DIPEX International standards, but conforms to the specific Norwegian context (as identified in the pilot) and join the network.

The aim of the research study is to explore if Norwegian research and dissemination on people's health experiences can be improved using the DIPEX methodology.

Background

In research focused on people's health experiences and aimed at understanding how patients live with their illnesses and

make treatment choices, the qualitative interview stands out with evident methodological advantages. Open-ended questions and the interview-researchers continuous work to remain un-biased allows for the informants to present in-depth stories [3]. In qualitative research interviews with patients, unexpected accounts and new angles that may differ from clinically centred understandings of illness can be revealed. Qualitative interview studies thus provide insights into how patients and the health-interested public actually reason; how they construct meaning around their everyday habits and health challenges. There is a growing body of interesting qualitative research on patient experiences, both internationally (for instance [4-6]) and in Norway [7-10]. However, small-scale qualitative research is met with challenges when it comes to dissemination and transferring applicable knowledge to general clinical practice, which is often case-based but maintains large-scale Randomized controlled trials (RCT's) as gold standard [3].

At the core of the DIPEX methodology is a web site in which extracts of patients and carers interviews (as text, audio, or video) data is systematically presented. The DIPEX database serves as research infrastructure, and the extracts presented on the web are easily accessible for both health personnel and the public.

The purpose of a more systematic, transparent and more broadly available presentation of people's health experiences is to reveal the potential of such data as well as being a direct source for patients and clinicians. An interest in patients' perspectives is necessary for the development of patient centred health care, which is underlined in contemporary health policies [11, 12].

The Internet is an important source for health purposes [13], and the use of online resources for peer-to-peer connection has been one of its most transformational features [14]. The inclusion of patients' experiences on health information websites is recommended because these are most likely to engage site users [15, 16]. Evidence suggests that patients use personal experiences in various ways to support their decision-making. A recent conceptual review concluded that patient experience is a key feature of e-health [14]. It identified 7 domains through which online patient experience could affect health; information, support, relationships, behaviour, experiencing health services, learning to tell a story and visualizing disease. France et al. [15] found participants' inclination to use personal experience information was moderated by assessments of personal relevance, the motives of information providers and the 'balance' of experiences presented. There is, however, a significant challenge that websites as well as other media sources using patient experiences, often present few anecdotal accounts, or focusing on heroic or exceptional testimonials.

In contrast, the DIPEX web sites are research based, and include excerpts from rigorously designed in-depth interviews with real patients and carers (cf. www.dipexinternational.org). The web sites are accessible by all, and a fully realized Health talk Norway will thus provide valuable input to fellow researchers, clinical workers, policy makers, carers and patients alike. If the experiences are collected as interviews, and analysed and presented as carefully selected illustrative clips (as in the Health talk/DIPEX model), they demonstrate the considerable and subtle variation in human response and can make information highly accessible to people with different levels of health literacy.

Methods and study design

Description of the DIPEX methodology

The website

Many health websites now include some patient experience data, but Health talk is a unique resource. On the UK site (www.healthtalk.org) there are over 80 sections, each of them based on a rigorous qualitative research study exploring the experiences of 40 or so people facing the specific condition, health or social care issue. Hence, each section within Health talk presents careful analysis of around 25 of the most important issues identified within these in-depth interviews, illustrated with around 250 video, audio and written extracts from the interviews. The site covers different conditions or health topics, including several major cancers, cardiovascular disease, mental health, epilepsy, rheumatoid arthritis, pregnancy, screening, sexual health and experiences of carers of people with dementia. The project aims ultimately to cover all major conditions and experiences of treatments [17].

Interviews, analysis and presentation of interviews on the website

In the UK, the interviews on the healthtalk.org are generated and analysed by experienced social science researchers most of whom are based in the HERG within the University of Oxford's Department of Primary Care Health Science. Interview transcripts are analysed by the qualitative researcher responsible for the data collection in collaboration with a research "buddy" or supervisor who have familiarised themselves with all the interview data. Attention is paid to emergent (i.e. unexpected) themes as well as those that were anticipated [1, 2] using the method of constant comparison. This approach ensures that the researchers write summaries on the issues that are important to the participants— not just the ones that health professionals and researchers may think are important. To ensure the quality and balance of the material included in the section, each summary is prepared by the researcher, checked against the interview data by a second researcher (the research buddy/supervisor) and reviewed by at least one suitably qualified member of an Advisory Group before final editing.

Evaluations of the methodology

The UK-website has been evaluated with patients and as a teaching resource. In 2012, the site received about 2 million visits and 55 million hits, representing growth of 37 per cent over 2011. The website has won several awards, and was highly commended, e.g. in the British Medical Journal (BMJ) Book Awards (2005) and the Health Service Journals Award (2005). Ann McPherson, the co-founder of Healthtalk (formerly DIPEX) was awarded the BMJ Health Communicator of the Year award in 2011.

The DIPEX methodology is thoroughly based in well-known quality standards for research interview techniques and dissemination. The DIPEX web site will thus be a valuable supplement to other Norwegian web sites built for and about patients, e.g. web based hospital education courses for patients or www.helsenorge.no. A DIPEX site will provide information on everyday health experiences from the patients and carers, and to health care professionals or other patients, carers, researchers and policy makers.

Aim, research question and methods

Aim and research question

The aim of the pilot is threefold, in non-sequent order: First, to study, translate and if needed adapt the DIPEX methodology to a Norwegian health care context. Secondly, to assess the feasibility of a DIPEX web site in a Norwegian health care context, with emphasis on patient interests and ethical requirements, and thirdly to establish a network of qualified researchers in Norway, who already work in the field of people's health experiences. The overall objective can be operationalized into the following research question:

"Can Norwegian research and dissemination on health experiences be improved using the DIPEX methodology?"

Methods/Work procedures

As this project is a pilot of a methodology, we will describe our work procedures in this section. The section is structured according to the project aims:

Study and translate the DIPEX methodology

To be able to study and translate the DIPEX methodology, the project research team will attend courses in the DIPEX methodology at University of Oxford and participate in necessary translations of material using the dual focus approach to translation (18).

The DIPEX methodology will be tested in two series of interviews. Five patient interviews are already planned for in another research project at the host organisation Norwegian Centre for Integrated Care and Telemedicine (NST). These interviews will be oriented towards experiences from being a patient at a hospital surgical department. There will be three or more interviews with patients recruited through collaboration with other departments at the University Hospital of North Norway (UNN).

Assess the feasibility of a DIPEX web site in Norway

The feasibility report will include several sections. There will be a section reflecting on overall methodological considerations, comparing the DIPEX methodology with other qualitative work procedures. This also includes ethical considerations, based on the discussion that will then have taken place with the Norwegian regional ethical committee (REK). The feasibility report will also include assessment of required expertise, and technology assessment; i.e. of the web technology and of audio and videotaping equipment. The report will include advices for organisational anchoring of the research network and of editorial responsibility for the web site. There will be judicial assessment of lawfulness. We will also suggest a name for the Norwegian research network/web-site.

Building the network

The project research team consists of members whom are well established in Norwegian health sociology. The planned research network will be built successively, based in existing collaborations.

Discussion

The purpose of Health talk Norway is to contribute to the practical collaboration in health care. If successful, it will add valuable research based knowledge to be implemented in practical daily work in health care, and contribute to reach policy goals of patient centeredness and extended inter-institutional collaboration on patient treatment [11, 12].

Further, through gathering and systematizing qualitative research on people's health experiences and disseminating these, this project paves the ground for the social aspects of the doctor-patient encounter to be better grounded in existing (social) scientific knowledge, in line with the ideals of "kunnskapsbasert praksis" ("evidence based practice") in Norwegian health care work and education.

Through its ability to reach patients and the lay public via the web, the project also has an evident public health potential. At www.dipexinternational.org (downloaded 20.05.2015) we can read that: "DIPEX International's mission is to promote the spread of such research [rigorous research into people's experiences of major illness and health-related conditions] throughout the world for the benefit of all those dealing with health issues, including not only patients and carers but also health and social care professionals, providers and educators. Online, accessible publication of the results of robust qualitative studies provides a unique perspective on the very different ways that people deal with health issues. They educate those facing similar health challenges and remove the oft-felt sense of isolation. Clinicians and health service providers have increasingly recognised the importance of putting patient experience at the heart of service design and commissioning."

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