

## Promoting Patient Voices on the Internet

Ethical considerations about web-based dissemination of research on patient narratives

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**Abstract**—Web-based promotion of qualitative research has a potential to reform traditional scientific dissemination, as well as it challenges ethical norms of research participation and anonymity. In this poster, we discuss ethical considerations of web-based dissemination of qualitative research on patient narratives through video recordings. Including subjective un-anonymized patient stories in research dissemination to inform and support, might have benefits for the field of science, patients, health professionals and the general population. However, ethical norms and guidelines for anonymity needs to be considered with care when promoting patient voices on the Internet.

**Keywords**—ethics; patient narratives; qualitative methods; video recordings; Internet.

### I. INTRODUCTION

There is a growing body of qualitative research aimed to explore in depth how people experience and manage their illness or health challenges [1][2]. The Internet provides new opportunities for dissemination of such research, within not only the established field of science, but also to lay people, health professionals and the general population. However, ethical norms and guidelines for anonymity needs to be considered with care when promoting patient voices on the Internet.

The traditional way of disseminating research has been through academic channels, such as conferences and scientific journals. In line with ethical norms and guidelines for scientific practice, the voice and the story of the informant usually is anonymized in written publications, striving for anonymity and the protection of privacy. Internet opens a new avenue of public dissemination for qualitative researchers, challenging the established ethical norms and guidelines.

In Norway, all health research projects involving patient and health information need to be evaluated by the regional committees for medical and health research ethics, who assess whether the project plan include a detailed strategy for handling data and ethical reflections with regard to patient involvement.

In this poster, we will exemplify some of the ethical considerations with regard to web dissemination of patient narratives using our project “Helsesnakk.no” (“Health talk Norway”) as case. In this project to begin in 2016, we will

develop a Norwegian website, to disseminate qualitative research on peoples’ experiences of health and illness, through use of video- or audio-recorded in-depth interviews with patients and family carers [3]. The purpose is to share information based on qualitative research to inform and support people who suffer from similar illnesses or health challenges, as well for the benefit for caregivers, health professionals, students and the public. In “Health talk Norway”, researchers interviewing people about their health experiences, analyze the interviews using thorough scientific methodology, and select and distribute short extracts from the results on the website. The extracts may appear on the website as videos with texts (transcripts), as audio with text, or as anonymous text. In the following, we concentrate on the video clips since they are most sensitive regarding patients anonymity in research. The aim of this poster is to discuss ethical consideration of web-based dissemination of qualitative research on patient narratives through such un-anonymized video clips.

The poster is organized as follows; Section II describes the various methods of web-based dissemination of the research. Section III discusses ethical considerations of dissemination of patients’ narratives using video recordings. The conclusions are presented in Section IV, and the acknowledgement closes the poster.

### II. VIDEO-RECORDED NARRATIVES ON THE WEBSITE

The informants are recruited based on their diagnosis or medical condition. Before the interview, they receive written information about the study. Moreover, they must sign an agreement selecting which of the following forms they agree to be interviewed for dissemination on the website: video-recorded with picture, sound and written text; audio-recorded with sound and texts; or audio-recorded for dissemination only in anonymously text.

The interviews are transcribed, and the informants have the opportunity to read the transcripts and remove parts or sections. A process of analyzing the data material follows, and the researchers carefully select illustrative video clips for the website according to the informants’ consent. Video clips are uploaded using the Vimeo service, with settings blocking all access to the videos except when played through the domain “Helsesnakk.no.” The process follows standard research norms. The informant may withdraw his or her

consent and have the extracts published on the website removed at any time. However, it may not be possible to remove all existing copies from circulation.

### III. ETHICAL CONSIDERATIONS OF PATIENT VOICES

Traditionally, in qualitative research researchers are striving for anonymity. Dissemination of video clips from the interviews at the website implies that the informants' names will not appear, but because we can see their faces, these stories cannot be anonymized. Such a break with the traditional way of disseminating research prompts the need to pay extra attention to the ethical considerations.

Thorough information about the study and the web dissemination is important. Hence, we must be sure that the informant gives written consent and is clearly capable of giving consent. As researchers, we need to be "objective" with respect to patient involvement, introducing the opportunity to participate in the research without pushing. Our experience is that recruitment for video-recorded interviews is more difficult than for audio-recorded interviews. Informants who sign up for the website might take on a whole range of attitudes from skepticism to total openheartedness as they tell their stories.

Published materials on websites will be visible to the public, family and friends for years. Young people grow up, and their attitude toward being on the website might change. Their stories might affect how people evaluate them, i.e. some are at the beginning of their work careers. The researcher must pay attention to factors such as age, how people talk about others (relatives, health professionals), and whether they are too openhearted in telling their stories. Should we limit these stories or should we let them speak? What is the most "correct" consideration to ensure ethics?

The website aims to communicate a maximum variation of health experiences. This means that we might receive stories from informants who want to be a public voice for tabooed, shamed, or sensitive themes. They might be eager to use their stories to inform or help others, to break taboos in society, or to promote voices we are seldom able to hear. In the methodological literature addressing ethical considerations, it is an ongoing discussion of the dilemma between the benefit and the risk associated with research participation about sensitive issues or for vulnerable populations [4][5]. Instead of causing distress for the informants, a growing body of research have point out that research participation might be educational, enriching, therapeutic or empowering for vulnerable populations [4]. Nevertheless, research addressing health and illness experiences, potential sensitive topics, and to select clips to be published on a website requires particular awareness. This will imply a researchers' good judgement about people's capabilities, their basis for consent, and how thorough the information given about the study. Does the researcher need to protect some voices? Will it be ethically correct to publish, or unethical not to publish the stories, since the informants have shared their stories for the purposed of

being published on the website? Not being identified as the data source or given opportunity to face a distinctive health condition can also cause disadvantages for a person or a group for example by maintaining of taboos or "invisibility" [6]. It is argued that in some cases the default of anonymization might be replaced by a careful liberation, together with the informants, of how to handle the issues of identification and confidentiality [6].

### IV. CONCLUSION

The Internet holds a potential to reform traditional research dissemination. The expansion of the Internet allows us to reach out broader and faster, not only to the scientific community, but also to the general population. For qualitative researchers, interested in peoples' health experiences, the use of the Internet as dissemination channel impose some new ethical considerations. Whilst the researchers' obligation to ensure informant anonymity has previously been the accepted norm, new technology is now challenging this ideal. When establishing a web site for disseminating insights based in research on patient narratives, anonymizing the individual stories will not always be the ethical thing to do. Rather one can claim that anonymizing the informant in this kind of research dissemination will contribute to silence and hide the patient voice from scientific, as well as public discourse, and thus be un-ethical. Including subjective un-anonymized stories in research dissemination must however be handled with care. Hence, informed consent and the right to withdraw at any time are fundamental.

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