Opportunities and challenges with My Kanta: first results from a focus group study about user experiences and opinions on the National Archive of Health Information

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This text presents some first results of a focus group study on how older adults (defined as aged 55-70 years) have used, experienced and perceived both the

This article is licensed under the terms of the CC BY-NC-SA 4.0 -license Persistent identifier: https://doi.org/10.23978/inf.76068 national Finnish electronic health record system Kanta and these kinds of services in general. Kanta produces digital services for both the social welfare and healthcare sector, and citizens can browse their own medical records and prescriptions through the My Kanta-pages¹. The aim of the study was to examine whether the service corresponds to the expectations of its users especially concerning usefulness and contents.

Previous studies have focused on perceptions of Kanta or other electronic health records (EHRs) among Finnish healthcare professionals (Nissinen, Soini, Leino, Hakulinen, & Saranto, 2018; Palojoki, Pajunen, Saranto, & Lehtonen, 2016) and pharmacists (Kauppinen, Ahonen, Mäntyselkä, & Timonen, 2017). In the autumn of 2015, a survey was conducted in 18 Finnish pharmacies on citizens' use of ePrescriptions and My Kanta (Lämsä, Timonen, Mäntyselkä, & Ahonen, 2017), but to the best of our knowledge, there are no earlier qualitative studies on how users, especially older adults, experience the My Kanta services. Comparable studies based on focus groups on electronic personal health records have, however, been conducted in, e.g., the USA (Dontje, Corser, & Holzman, 2014), where focus group interviews identified challenges with access, lack of perceived value, opportunities for improvement, and security concerns. In Germany, focus groups were used with cancer patients, persons representing patient support groups, physicians, and other healthcare professionals to study the patients' role in managing personal EHRs (Baudendistel et al., 2015). Papoutsi et al. (2015) combined a survey with focus group discussions with patients, health professionals, and researchers, in order to examine views about the security and privacy of EHRs in the UK. Another survey study in the UK showed purposes and consequences of using online medical records (Shah et al., 2015).

Method

Six focus groups with 24 persons in total were interviewed in May and June 2018. The participants constituted of seven men and 17 women in the ages 55 to 73 years (mean age 60.6 years). Three of the interviews were conducted in Turku and the other three in Oulu. The number of respondents in the groups ranged from three to five. The respondents represented a convenience sample; persons estimated to be within the chosen age range were contacted and invited to attend the interview. Snowball sampling was used for recruitment, as well. Informed consent was ensured from the participants. All but one of the group interviews that lasted between 47 minutes and 1 hour 31 minutes were conducted

¹ https://www.kanta.fi/en/what-are-kanta-services

by two interviewers respectively. The discussion was video- and audio-recorded and transcribed verbatim by two researchers who had themselves attended the interviews, one of them in Oulu and the other one in Turku. An interview guide was prepared in both Finnish and Swedish based on extensive literature review (Hirvonen et al., n.d.). The guide contained sections on uses (e.g., What is My Kanta used for, what type of use?), enablers or barriers (e.g., Is the information/content clearly presented, is the needed information found, does something lead to concerns?), and outcomes (e.g., Has the use lead to changes in behavior?). The participants were, furthermore, requested to give suggestions for what could be included in a good EHR service.

Results

We have started to analyse the data and some preliminary themes that rise from the analysis of the discussions in the focus groups include uses, challenges with access, concerns, opportunities for improvement, perceived value, and outcomes such as influence on behaviour, as presented in Table 1.

Table 1: Themes that were discussed in the interviews

Theme	Examples of topics that occurred in the focus group discussions
Uses	 checking and renewal of prescriptions making an organ donation testament preparations before and checking after medical tests or appointments using Google or other (medical) sources for additional information
Challenges with access (barriers)	hassle with bank access codesinterruptions in access
Concerns (barriers)	the use of medical terminology or latin low age limit for parental access to children's records security and privacy concerns (including sensitive or unnecessary information spreading within healthcare) seeing negative or frightening information before appointment with doctor feeling that doctors do not check the information before appointment rorrs in information (e.g. in prescriptions) insecurity about how to fill in the advance healthcare directive confusion when using several differing EHRs

Theme	Examples of topics that occurred in the focus group discussions
Opportunities for improvement (enablers)	specific information about vaccinations reminders for vaccination and prescription renewals information about blood group, allergies more complete dental health information and general cancer screening results possibilities for own input, feedback, chat service links to additional information or care instructions personalized appearance (incl. language choices) or information, e.g. AI-based health-promoting information better interoperability between EHRs fewer variations in amount of information in the epicrisis
Perceived value (enablers)	 all needed information gathered in one place nationwide availability ease of use possibility to check test results, monitor condition over time possibility to check who has seen information and when
Outcomes	 influence on health behaviour and managemen of personal health information raised interest in and better understanding of test results discussions or comparisons with others (friend or family)

Discussion

The presented themes based on the preliminary analysis show similarities with those found in earlier studies. Like American EHR users (Dontje et al., 2014), also these participants experienced challenges with access, lack of interoperability between EHR systems, and security concerns. The focus group study by Papoutsi et al. (2015) showed that security concerns included the risk of the information being hacked, being seen by others than those who need it, and containing errors, and similar concerns were identified in the current study. The current participants also discussed purposes and consequences of using My Kanta that seem to be close to those of British EHR users: checking test results, searching further information, preparing for appointments, making decisions, and monitoring one's condition (Shah et al., 2015). The problems with understanding the medical terminology that were mentioned have been a matter of concern in earlier studies, as well (Baudendistel et al., 2015; Dontje et al., 2014). In accordance

with results from a Finnish survey (Lämsä et al., 2017), the users were, however, in general content with the ease of use of the My Kanta-portal. We will proceed with a deeper qualitative analysis and findings from this analysis will be published in international scientific publications.

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