

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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The context

- The project: Taking Health Information Behaviour into Account –
 implications of a neglected element for successful implementation
 of consumer health technologies on older adults (HIBA)
- Academy of Finland 2015-2019
- Information studies at Åbo Akademi University and University of Oulu
- WP1: "How do older adults experience the usefulness, effectiveness, trustworthiness and privacy of e-health services?"





Aim

- To present 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 national Finnish electronic health record system Kanta in particular and these kinds of services in general.
- The study aimed to examine whether the service corresponds to the expectations of its users especially concerning usefulness and contents.



Earlier research

- In the USA, focus group interviews identified challenges with access, lack of perceived value, opportunities for improvement, and security concerns connected to use of electronic personal health records (Dontje et al. 2014).
- In the UK, a survey and focus group discussions examined views about the security and privacy of electronic health records. These concerns included the risk of the information being hacked, being seen by others than those who need it, and containing errors (Papoutsi et al. 2015).
- Another survey study in the UK showed that purposes and consequences of using online medical records included checking test results, searching further information, preparing for appointments, making decisions, and monitoring one's condition (Shah et al. 2015).

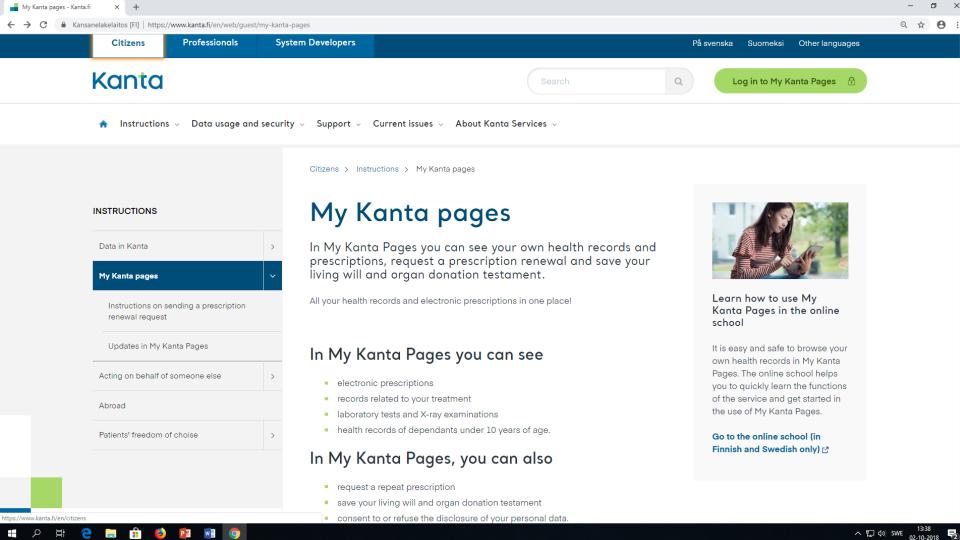




Kanta (Finnish National Archive of Health Information)

 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-pages. (Omakanta, Mina Kanta)







Method

- Six focus group discussions in May and June 2018.
- Three of the interviews were conducted in Turku and the other three in Oulu.
- 24 persons, seven men and 17 women in the ages 55 to 73 years (mean age 60.6 years).
- The number of respondents in the groups ranged from three to five.
- Convenience sample.
- All but one of the group interviews were conducted by two interviewers respectively.
- The discussion was video- and audio-recorded and transcribed verbatim by two researchers who had themselves attended the interviews.





Questions

- Uses (E.g. How is My Kanta used, which functions, how was the use experienced?)
- Enablers or barriers (E.g. Is the information clear and understandable? Is something perceived negatively?)
- Outcomes (E.g. What has followed the use? Is something done differently?)
- Suggestions for a good e-health service





Preliminary themes

- Uses,
- Challenges with access (barriers),
- Concerns (barriers),
- Opportunities for improvement (enablers),
- Perceived value (enablers), and
- Outcomes





Uses

The organ donation, that I ticked there. I do also have one of those cards but if it is better preserved there electronically. (O1_A)

Well at least I have these like reference values of lab results, if they have not been within the limits, then I have been using the library of Duodecim [Terveyskirjasto] or something quite much. Usually that. (O1 D)

Well I have actually quite recently started to check my prescriptions and diagnoses and test results and these kinds, followed up, checked what the doctors have written. (Å2_A)

- 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

No well it was, it threw me out a few times when I clicked on something and I was going to open something in a new window, and then it throws me out from everything just so ohoh, nothing! Then another bank access code had to be used and this so that...instead of giving an error message saying that you have to do this and this cannot be done, so just get out! (Å2_D)

- hassle with bank accesscodes
- interruptions in access

But when there is this problem like for us too that, for example, now for the child we just got him/her the first bank access codes, that is, he/she cannot log in there him/herself as underaged, either. (O3_C)

My sister is a physician and she complains that terribly often it is so that they, for example, cannot give, write a prescription electronically. These things all break. (O3_B)





Concerns

One thing that I thought about a bit was these reports and diagnoses and, and descriptions of interventions and those things, so there they use like this medical terminology ... so even if you read it and can take part of it you don't understand it. (Å2 A)

Well how is it, during the current data protection era, is it easy to break into, that is one of the small fears, but I don't know if it is, personally I don't see it as a very serious problem that well some disgusting net criminal will take a look at my information, that get a life. (O2_C)

That do the bioanalytics inform when they have done them [blood tests] that if they see there that what an awful value, that do they immediately inform the physician before it is added to My Kanta so that he/she can be in touch with the patient or is it just that the poor patient or customer stares at his/her screen and is like terribly worried and waits for the doctor to call, when the given call time is in two weeks, that... (Å1 B)

- 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





Concerns (cont.)

Yes and that you could check the level of care from there like well, for example, when I have hypothyroidism there are sometimes those situations where the prescriptions have been a bit erroneously written and then how it has been balanced, that it influences quite many things in me that well weight control and well, sleeping and... (O2_A)

But this living will, it felt a bit too complicated to start thinking about because I think it was an open text field and then you have to think it through quite thoroughly before you start expressing yourself (Å3_B)

- feeling that doctors do not check the information before appointment
- errors in information (e.g. in prescriptions)
- insecurity about how to fill in the advance healthcare directive/living will
- confusion when using several differing EHRs



Opportunities for improvement

[...] But really this vaccination thing so that is actually better if it is electronic because if you don't have the card with you when you go and take a shot, then.... (O3_D). And you don't remember when, or at least I don't remember (O3_A)

But this municipal [dental health information] is not available in My Kanta, that for example the one from the city of Turku, it's not there, I have checked (Å3 E)

- 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

And I thought that could there be a section where you could like yourself add some information like when you for example have taken a vaccination sometimes you can add the date, that you could gather kind of your own archive there. (O1_A)





Opportunities for improvement (cont.)

Well, could it contain like a link to the terminology? Because there are for example these abbreviations and even me, who have studied the subject a bit, even I didn't know all. So I had to get out of there and start searching. (O2_C)

Yes, personalization, that is personalization of the browser was it in...Firefox...you could add your own flowers or something like that in the background. The appearance is quite boring. And the fonts are small (O3_D).

- 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

Yes and now I have to say that I am very happy that these services exist, or this service exists, because [...] I have some chronic diseases and you don't always have the strength to keep track on like all those printed paper prescriptions, so this is really tremendously convenient. (A2 B)

Well of course they are critical things that another physician really can see what has been done elsewhere and of course you yourself, if your papers happen to be a bit messy on some table you can then find them there in Kanta... (O3 D)

- all needed information gathered in one place
- nationwide availability
- ease of use
- possibility to check test results, monitor condition over time
- -Using it [My Kanta] is easy. (Å1 D)
- -Yes it is not more complicated than anything else. (Å1 A)
- -If you know how to behave in the bank you can do it there, too. (Å1 D)

possibility to check who has seen information and when

> There is this kind of listing that this doctor has seen these and these things...for example he/she has somewhere checked this [information] produced by some other service provider. (O3 C)





Outcomes

Well of course it does [influence] on health choices when you, well, should have a surgery and, and you should loose weight before that, so it does influence. (O2_A)

Well perhaps this that well that these, all these prescriptions and epricrises are floating around in envelopes at home, when it is gathered in one place it is very good, because I am not that good at keeping my papers in order. (Å2_B)

Well, in principle doctors reel off say some test results and from there you can like absorb something that he/she says. And now when you look at some blood values so it shows, for example, all limits. So now I learned a little like that, to mirror them that are they within normal limits or not. (O2_C)

- influence on health behaviour and management of personal health information
- raised interest in and better understanding of test results
- discussions or comparisons with others (friends or family)





Conclusions

- The presented themes based on the preliminary analysis show similarities with those found in earlier studies: the participants experienced challenges with access, lack of interoperability between EHR systems, and security concerns.
- The current participants also discussed purposes and consequences of using My Kanta that seem to be close to the EHR users elsewhere: checking test results, searching further information, preparing for appointments, and monitoring one's condition.
- The problems with understanding the medical terminology that were mentioned have been a matter of concern in earlier studies, as well.
- 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.











Questions? Comments?

