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*Published in:*

Proceedings of the Association for Information Science and Technology

*DOI:*

[10.1002/pra2.818](https://doi.org/10.1002/pra2.818)

Published: 22/10/2023

*Document Version*

Accepted author manuscript

*Document License*

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[Link to publication](#)

*Please cite the original version:*

Eriksson-Backa, K., Enwald, H., Hirvonen, N., & Huvila, I. (2023). Involving Older Users in Design of Patient Accessible Electronic Health Records: Exploring the Potential of Open-Ended Questions. In *Proceedings of the Association for Information Science and Technology* (Vol. 60, pp. 576-580). (Proceedings of the Association for Information Science and Technology). Association for Information Science and Technology. <https://doi.org/10.1002/pra2.818>

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Postprint of Eriksson-Backa, K., Enwald, H., Hirvonen, N., & Huvila, I. (2023). Involving Older Users in Design of Patient Accessible Electronic Health Records: Exploring the Potential of Open-ended Questions. *Proceedings of the Association for Information Science and Technology* 60(1):576-580. <https://doi.org/10.1002/pra2.818>

# Involving Older Users in Design of Patient Accessible Electronic Health Records: Exploring the Potential of Open-ended Questions

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## ABSTRACT

Despite older adults being one of the most important groups of users of eHealth services, including patient accessible electronic health records, these are claimed not to be designed to suit older users, and to not necessarily fulfill their information needs. User-centered design methods often utilized when developing eHealth services have also been claimed not to work well for older adults. This paper suggests an alternative way of collecting ideas and feedback on eHealth from older adults, by including open-ended questions in the data collection of larger studies on eHealth information behavior. When data are collected by methods like focus group interviews and surveys, older adults can be requested to envision an eHealth service that suits their needs. Results from studies in Finland are presented, and show that current eHealth services do not fulfill all information needs of older adults, as answers to the question in both focus group interviews and surveys contain practical suggestions for additional and more comprehensible information, easier ways of searching for needed information, and alternative channels for communication. Open-ended questions can be a cost-effective and timesaving way to help in the design and development of patient accessible electronic health records and other types of eHealth services.

## KEYWORDS

eHealth, focus groups, older adults, service development, surveys

## INTRODUCTION

Older adults are generally thought to benefit from eHealth solutions such as patient portals (e.g. Wildenbos et al., 2018), but older age groups might not use eHealth applications if these are not perceived to fulfill the users' needs or the users experience difficulties in using them (Vergouw, 2020). In library and information science, the aim of research is generally to come up with solutions to fulfill information needs of users or potential users, be it of existing or planned services, systems or products within these. This has been at the core of the field at least since the early 1980s, when Tom Wilson published his much-cited work on information needs and user studies (Wilson, 1981). Later, Mark Hepworth (Hepworth, 1997) underlined the need to understand the consumers in the context of design and development of electronic information products and services. The focus of research has often been to suggest how knowledge of users' information behavior can be useful for designing information systems in various contexts ranging from archeology to health. Yet, information behavior researchers have often failed to reach out to systems developers, for various reasons (Huvila et al., 2022). Rytönen and colleagues (Rytönen, Kinnunen & Martikainen, 2022), however, found that Finnish software developers working with information systems within social and healthcare were positive towards end-user input, as they considered feedback useful, but cooperation with users was restrained by lack of established methods for cooperation and necessary resources. In addition, the end-users the software developers considered important to work with were mainly health professionals or people in decision-making positions, not laypersons. Comprehensive user-centered design of new systems is, in addition,

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*86<sup>th</sup> Annual Meeting of the Association for Information Science & Technology | Oct. 29 – 31, 2023 | London, United Kingdom. Author(s) retain copyright, but ASIS&T receives an exclusive publication license.*

usually time-consuming, and there is room for other and faster methods to examine users' needs and preferences. This paper suggests involving older laypersons in innovating eHealth services that suit their needs, and presents findings from a larger study on eHealth information behavior of older adults in Finland.

## **MOTIVATION**

The focus of this paper is on patient accessible electronic health records (PAEHR). While electronic health records are records and systems maintained by health professionals and official agencies (Comandé, Nocco & Peigné 2015), a PAEHR is a service that is provided by an online system and that grants patients continuous access to their medical health data from either electronic health records or other systems related to health (Essén et al 2018). The value of PAEHRs lies mainly in the possibility to check test results, and for renewal of prescriptions and secure messaging with healthcare personnel (Luo, Dozier, & Ikenberg, 2021). Reviewing one's medical record and checking appointments are also perceived to be beneficial (Wildenbos et al., 2018). Frustration with technical issues related to access, temporal unavailability of information, or limitations in the available contents, on the other hand, possibly limits use. Limitations in the available content can be an issue especially for those who want to know more about particular aspects of their health or treatment such as, for example, test results (Shah et al., 2015). Timeliness can be a problem when the content does not become available fast enough. For example, it is often requested that test results are quickly available. Usability issues, such as difficulties with the login process, form additional barriers to use (Shah et al., 2015; Wildenbos et al., 2018).

Older adults are perhaps the most important group of PAEHR users. However, it is claimed that health technologies fail to be designed in a way that meets the expectations of those in older age groups (Wildenbos et al., 2018). Stojmenova et al. (2012) feared that if users are not involved in the design of eHealth services, this might influence how well they accept and adopt these services. In order to involve end-users, user-centered design has been considered crucial for eHealth design, for example, to increase user satisfaction and technology adoption (van Velsen, Ludden, & Grünloh, 2022). Gould and Lewis (1985) describe user-centered design as a situation where designers study users and what they need to do with technology. For this purpose, users need to work with existing prototypes, and the technology should be tested and possibly redesigned several times during the process. Over the years, new approaches have been introduced to address this issue, including activity-centered, community-driven and economic design approaches, and citizen science and participatory action. Researchers who have worked with user-centered design, have also expressed concerns about, for example, sampling bias, limited and biased end-user input, overreliance on end-user input, that end users are only a subset of those who should be heard, and that ethical, societal and political aspects are missed out (van Velsen, Ludden, & Grünloh, 2022). In addition, this approach requires time and effort. Stojmenova et al. (2012), on their hand, claimed that conventional user-centered design did not work well with older adults, due to various factors, such as lack of familiarity with technological terminology. It is, hence, motivated to try out other methods.

## **AIM**

Drawing on earlier research showing the importance of involving end-users in development of eHealth applications, and existing problems in doing so, this paper explores how (potential) users can be involved in development or improvement of PAEHRs in a way that is simpler than the user-centered design approach. We suggest using a method based on asking users open-ended questions on what their ideal eHealth service or application would look like, and which features it would have, as a part of focus group interviews and surveys examining eHealth information behavior more extensively.

## **METHODS**

As part of a larger Finnish research project aiming at connecting health information behavior research and development of health technologies for older adults, two sets of data were collected separately. The methods were in part overlapping with those used in user-centered design; focus group interviews and surveys (Stojmenova, Imperl, Žohar & Dinevski, 2012). Focus groups have been described as a good way to examine needs, wishes and opinions on eHealth (Kip et al., 2022). Suggestions developing during the discussions in the focus groups can be more in-depth, and more varied than those in surveys, as more people with more ideas are involved in the discussion, whereas the answers in surveys are generally the output of one single person, who has to write down the answer that can be quite short and not much elaborated on. Questionnaires are, hence, not suggested to be the sole method for collecting data, but triangulation has been suggested (Kip et al., 2022). On the other hand, the number of survey answers is much larger and can give more variation. In contrast to previous mixed-method studies such as that by Papoutsis et al. (2015), where survey results were later discussed in focus groups, these particular studies were conducted separately, and the survey questionnaire was, in fact, developed based on the focus group interviews that were conducted first.

Focus group interviews were conducted with a convenience sample consisting of 24 persons aged 55-73 years divided into six groups, and printed questionnaires were sent by mail to a nation-wide sample of 1,500 Finnish

persons aged 55-70 years. This sample was randomly drawn from the population register system of Finland. In total, 373 responses were obtained. In both cases, the participants were asked to discuss or respond to questions surrounding their health information behaviour, with a special focus on the Finnish National Health Archive Kanta and its portal My Kanta, yet not limited to it. Stojmenova et al. (2012) were concerned that older adults are not familiar with eHealth systems and hence cannot express their wants and needs. In this study, some experience of the My Kanta portal was a requirement for inclusion in the focus groups, whereas the survey participants may not have had such experience. On the other hand, occupational healthcare and municipalities in Finland generally have their own PAEHRs that were possibly familiar to most participants in the selected age group. Open-ended questions have been described as “any question where the respondent’s answers are not limited to a set of predefined response options” (Singer & Couper, 2017, p. 117). The following open-ended question was included in both studies: “If there would not be any limits in resources or available technologies when developing a digital health service, what would a best possible service look like and what functions would it have?”. In the focus groups, the question was asked at the end of the interview, whereas it in the survey was placed in the middle of the questionnaire, and altogether 160 respondents answered the open-ended question in the questionnaire. Focus group discussions were recorded and transcribed verbatim, and for both interview transcripts and survey responses, the content analysis was inductive.

## **RESULTS**

The responses provided to the open-ended question in the focus groups showed both similarities with and differences from the answers in the questionnaires. Overall, the suggestions in the focus groups were more in-depth and detailed than many of the written answers in the questionnaires, which were generally shorter than the spoken ones in the focus groups, and some were a mere “I don’t know” or short expressions of being satisfied with the current services. However, most survey answers did contain practical suggestions. As the focus group participants were given the open-ended question at the end of the interviews, they had already previously discussed several additions or improvements, and sometimes struggled to come up with additional new ideas, but the support from other group members helped to stimulate the envisioning, and some features that are not currently available were suggested. The suggestions were categorized into five categories: access to service or care; access to information; personalized content; communication channels, and; control of information.

### **Access to service or care**

In the surveys, one of the most often mentioned ideas included 24/7-access to health care. In the group discussions, there were suggestions about possible improvements in access to the service, for example, in case one helps elderly parents who are not able to log in themselves, and also in the surveys there were suggestions for improved alternatives for authentication. Furthermore, the possibility to make appointments was mentioned. In the surveys, some even envisioned a robot that could promptly perform a thorough examination and come up with a solution.

### **Access to Information**

In both the focus groups and surveys, there was a wish that all information from different care providers could be gathered in one place. Sometimes the used services did not fulfill information needs, as some participants wished for additional information on one’s condition or a vocabulary of medical terminology in order to understand the language of the contents. In addition, a well-functioning search function that would give access to needed information was mentioned in the surveys.

### **Personalized Content**

In one focus group, the participants discussed adding a health-promoting function, possibly by utilizing artificial intelligence to provide recommendations for eating or exercising to the user based on test results. In similar fashion, survey responses contained suggestions for personalized information, for example, in the form of recommendations for eating. Another focus group discussed reminders for check-ups at certain ages. There were also suggestions for a possibility to personalize the look of the service, for example, making it more pleasing to the eye or easier to read.

### **Communication Channels**

One of the most common ideas in the surveys was the possibility of contact via video connection. Participants also requested channels for interactivity that were more varied than the current ones, including chats. In the focus groups, a section where the users themselves could add some possibly important information was discussed. Another suggestion was the possibility to give feedback or comments on some medication.

### **Control of Information**

Ideas that occurred only in the focus groups were related to having some control of the contents, such as the possibility to remove obsolete information like treatments in youth that are no longer of any use in older age and a possibility to monitor one’s own test results, for example through figures showing test values over time. In addition,

information on vaccinations, blood type and allergies, to prevent possible trouble in case one is taken into care and is unable to inform about possible allergies, was mentioned.

## DISCUSSION AND CONCLUSIONS

Our results can be directly useful for the design of eHealth services, or further development of existing PAEHRs in terms of the practical suggestions made by the study participants. The answers to the open-ended questions show that variations in information behavior are important to consider; older adults have needs for both more varied information and other communication channels than the PAEHRs they currently use can provide. Users may also need to feel that they have some control over their information. Our results remind of those showing the benefit of secure messaging (Luo, Dozier, & Ikenberg, 2021), frustration with access, or needs to know more about one's own condition (Shah et al., 2015), but also bring up new suggestions. Open-ended questions elicit variation in the answers. Users' concerns are not necessarily focused on mere usability issues and testing of existing features, often of a certain service or application, that is often the focus in user studies (e.g. Cornet et al., 2020; Gould & Lewis, 1985; Stojmenova, Imperl, Žohar & Dinevski, 2012). By using open-ended questions, respondents are allowed to innovate freely and propose ideas that go beyond specific services; hence, the answers can also be useful for informing the development of multiple types of services. As it has been found that lack of resources hinder cooperation between end-users and software developers (Rytkönen, Kinnunen & Martikainen, 2022), and user-centered design approaches usually include several phases such as planning, designing, testing and evaluating, requesting longer time spans and hence more resources (Cornet et al., 2020; Gould & Lewis, 1985; Stojmenova, Imperl, Žohar & Dinevski, 2012; van Velsen, Ludden, & Grünloh, 2022), the option of including open-ended questions in larger studies related to eHealth information behavior can be a cost-effective way to provide developers with useful feedback. The approach can be termed as a form of citizen science (van Velsen, Ludden, & Grünloh, 2022) with a major benefit of not requiring a recruiting of end-users at certain points of time at certain places, or the effort of testing existing services thoroughly multiple times (Cornet et al., 2020; Gould & Lewis, 1985).

There are, however, possible limitations with relying on answers to open-ended questions. Envisioning an ideal service might be challenging, not the least in the middle of an otherwise mostly structured questionnaire, but at its best, it can also be a quite rewarding and interesting task. As questions are generally open-ended in interviews, including focus groups, answers to the intended topic might be given already in other parts of the interviews potentially diminishing the need for a specific question on design or development. On the other hand, the answers in our focus groups were more in-depth and managed to elaborate service features in more detail than many of the answers in the survey. In this sense, collecting data through different methods might be the most useful solution, as also Kip et al. (2022) suggest. Other limitations of this particular study include the small number of participants giving suggestions with only 160 out of 373 survey participants responding, and of them, many merely answering that they did not know what to suggest. Not obtaining specific answers is also a disadvantage, which, on the other hand, also occurs in user-centered design studies especially with older adults, despite their focus on a specific service (Stojmenova, Imperl, Žohar & Dinevski, 2012). There might also be challenges in reaching out to those who can implement the suggestions. In order to provide software developers with suggestions provided through the open-ended questions, researchers in the library and information science field should, furthermore, strive to approach developers more directly to share their findings, instead of merely presenting or publishing them for an academic audience.

## ACKNOWLEDGEMENTS

The studies were conducted within the project Taking Health Behaviour into Account: implications of a neglected element for successful implementation of consumer health technologies on older adults (HIBA), funded by the Academy of Finland (grant 287084).

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