# “My Personal Doctor Will not Be Replaced with Any Robot Service!”: Older Adults’ Experiences with Personal Health Information and eHealth Services.

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# “My personal doctor will not be replaced with any robot service!” : Older adults’ experiences with personal health information and eHealth services

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**Abstract.** The ways of preservations of personal health and medical information vary, from digital to paper-based approaches. This study examines older people’s experiences on eHealth services, including benefits. A postal survey was mailed to a random population sample of 1,500 individuals aged 55-70. A total of 373 (25%) responses were received. The mean age was 63.2 (SD 4.7) years of which 225 (60.6%) were women. This study focuses on the open-ended questions on personal health information management and views of eHealth services. Data were analyzed using content analysis. Older adults’ experiences and attitudes are divided. The best possible eHealth service would contain versatile health information and combine information from different healthcare sectors. It would be easy to use and up-to-date, but would also allow the possibility to contact a real human being, such as via video connection. The findings reflect capabilities needed for personal health information management, relating to health information literacy.

**Keywords:** eHealth, health information, information experience, older adults, personal information management

## 1 Introduction

With age, the importance and relevance of health information usually increases noticeably. The information is preserved and managed in professionally maintained medical records, but also privately by patients. The ways of preserving vary, from digital to paper-based, but increasingly, medical records, and health services overall have turned digital. Reasons for preserving health records relate to both maintaining health but also to monitoring illnesses. For instance, we might want to or need to track possible changes in our cholesterol levels or compare what a doctor has written in medical care summaries of different appointments. We need to manage our own and, in several cases, our family’s medical information. These tasks are part of personal health information management [1].

As we are witnessing the digital transformation of healthcare, access to digital health services is becoming an increasingly important determinant of health. eHealth services

are often considered to promote patient empowerment by facilitating patient control and providing tools for self-management [2-4], which can support the shift away from the 'paternalistic' model of healthcare, where an expert makes decisions on behalf of a patient, towards a patient-centred, more transparent, approach [5]. However, not all favour digital services, especially among older adults. Negative views on digital health services can reflect attitudes towards digital technology [6] or appreciation of direct interaction with healthcare professionals, for example [7].

The topic of this study relates to personal health information management, digital exclusion, digital health equity, and emerging technologies. Our aim is to contribute to filling in the gap observed in a systematic review, indicating that in comparison to perceived usability and satisfaction, relatively little attention has been paid to examining people's experiences on eHealth services and their usefulness [8]. Furthermore, it has been stated that the knowledge of the elements playing a role in older adults' personal health information management is scattered and unclear [1]. For this study, the following research questions were set:

1) How do older adults currently store and manage their personal health information?

2) What kind of visions and perceptions do older adults have towards the future of eHealth services?

## 2 Previous research

### 2.1 The ageing population and health information

In Finland, people are covered by a universal public health and social care system. The constitution states that public authorities shall guarantee everyone adequate social, health and medical services. Healthcare and social welfare services are mainly funded by general tax revenues. In addition, private healthcare and social welfare actors provide occupational healthcare and complementary private services for citizens. eHealth services that are in common use across the healthcare sector include electronic prescriptions, a national health data repository and online patient accessible health record MyKanta. In 2022, MyKanta had 3.5 million users. More detailed account of the Finnish healthcare system can be found in a report of Finnish Institute for Health and Welfare [9]. In spite of the efforts to improve the integration of eHealth services, there are still problems with siloed information and systems not communicating with each other.

Finland ranks among the five fastest ageing populations worldwide. While the share of individuals aged 60 years and older was still 20 percent in 2000, it had increased to almost 28 percent by 2020 [10]. Researchers expect it to further increase to almost 35 percent by 2050 [10]. According to a large population-based survey in 2022, of the Finnish older adults 73% of 55-64 years olds and 52% of 65-74 year olds used the internet several times a day. In the younger age group, 95% and in the older 78% owned a mobile phone with a touch screen [11]. According to the statistics, 76% of those

belonging to the younger age group and 65% of the older age group had at the time of the survey searched information from the internet on health, diseases, or nutrition during the past 3 months [11].

With age, the importance and relevance of health information can be considered to increase noticeably [12]. Older adults experience an increased need to manage their health information for example, due to greater number of chronic diseases and medical visits. The active use of information has been associated with healthy ageing [12-14]. Issues related to health and well-being form a major category in the information needs of older people [15].

### 2.2 Personal health information management

Personal health information management is a process that involves creating, seeking, organising, and sharing personal health information to family, peers, and healthcare [16]. Active and coherent management has been linked to, for instance, patients' knowledge of their condition [17] and adherence to treatment [18].

The information management related focus of our study is on storing and maintaining information. A review by Kolotylo-Kulkarni, Seale and LeRouge [1] observed that, according to the analysed literature, older adults managed various types of personal health information using several kinds of strategies and tools. Personal health and medical information can be textual, numerical, and visual. It includes - clinical data such as lab results, patient generated data such as self-care logs, and general health and wellness data, such as online information on medication side effects or health education materials. Older adults also created information, for instance, by checking their weight as part of their morning routine [19]. According to the review by Kolotylo-Kulkarni et al. [1], strategies and tools for management included electronic approaches relating to computers and internet (for example, patient portals) and paper-based approaches such as printouts, calendars, or notepads. The handling of papers has been described using such words as tossing, filing, and piling. In many cases, a care booking was done "just in case" [20]. Some people rely on intangible objects such as their memory [20].

The consumer health information technologies, that help people to track and organise their health information within and outside of clinical settings, are not typically used by older people [20]. These technologies include, for instance, self-management monitoring systems and patient portals [20].

Patient-accessible services shape people's personal health information management behaviour by providing new opportunities [21]. For example, Turner et al. [20] found that older adults having a passive approach for managing health information described themselves doing little intentional seeking of health information. Especially people in good health did not necessarily think that there is any need to follow and keep track of health-related information. In turn, active information seekers tended to be more open to health portal use [20].

### 2.3 Older adults and eHealth services

Older age has been associated with perceptions of barriers to use of technology and readiness to use eHealth [6], as well as actual less use of patient portals or eHealth in general [22,23]. Based on studies on medical records, the oldest of older adults were the least likely to use digital records and the least prepared to manage clinical personal health information by using digital technologies (e.g., [21,24]).

In general, the attitudes towards digital technology can be negative among the older adults [6]. Furthermore, people might be anxious or nervous to learn and face new technologies. According to a study on challenges experienced by vulnerable groups (including elderly) in digital health services during the COVID-19 pandemic, the lack of strong e-identification or suitable devices were found to prevent access to eHealth services [25]. Perceptions of one's own skills, often related to age, are one of the most mentioned reasons for use or nonuse. Technical literacy, or lack of skills to use technology, was the most common barrier to use of telehealth among older adults in the study by Kruse et al. [26]. Despite perceiving digital health information as useful, Swedish older adults were found to be hindered by difficulties experienced when using technology [27]. Lack of technology skills [28], aversions against computers [29], lack of interest [30], lack of desire to use technology [26], or even computer anxiety [31] can be barriers to use. In addition, not only digital, but also medical and administrative competencies are needed [32].

According to Price and colleagues [33], older adults preferred a system that makes information interpretable and usable and provides advice rather than merely provides a storage for information. Luo, Dozier, and Ikenberg [34] found that ease of understanding the contents of electronic patient health records was positively linked to use. According to Eriksson-Backa et al. [35] also the high level of perceived everyday health information literacy, that refers to information literacy competencies in health setting, is positively related to positive attitudes to digital health services. The results emphasise the importance of everyday health information literacy as an enabler of the acceptance of digital health services.

According to a study by Turner et al. [20], older adults found that actual benefits of eHealth services include easy access to information about health, a more direct communication with health providers, and the possibility to make appointments online. Electronic personal health records have been found to be used specially to check test results, and for renewal of prescriptions and secure messaging with healthcare staff [34]. In a Dutch study, reviewing the medical record and checking appointments were perceived to be beneficial, but there were some problems concerning the interaction, for example, unresponsiveness of physicians to messages of patients [36]. In the systematic review by Hirvonen et al. [8], the use of eHealth services was divided into health management, social uses, and management of personal health information. Managing health included activities such as managing one's health in general, setting goals, planning, and scheduling, tracking one's own symptoms or behaviour, obtaining reminders or recommendations, and getting help in decision-making [8].

### 2.4 Empowerment, lack of physical presence and emerging technologies

Having online access to personal health records has been characterised as an important tool for empowerment [37]. Moreover, access to personal health records and information exchange between patients and medical professionals can result in patients getting more involved in their own care [38] and self-management [39], better attendance to self-care and informed decision-making, and improved trust between patients and medical professionals [40].

However, previous research indicates that, according to older adults, digital services are not viewed as applicable to all situations nor can they replace face-to-face services. For example, contact with healthcare providers via digital services was considered less personal [25], and lack of physical presence may affect patient communication and the patient-provider relationship. Admittedly, in a face-to-face meeting health care provider's touch can nonverbally express empathy and compassion, for instance [41]. This highlights the importance of digital empathy and "webside manners" [41].

People can also be unaware of existing services and their value and benefits [25]. Even if older adults tend to have more concerns and problems in using digital health services than younger individuals (e.g., [22,23,27]), they often find digital health services useful when they are aware of them (e.g., [42]). Moreover, need for and lack of guidance and support is another major hindrance of use of eHealth [26,32,43-45]. Need of guidance and not having been referred to eHealth services also hindered the use of a national patient portal according to a study by Kainiemi et al. [43].

The emerging technologies and practices associated with their use increasingly affect our society. Novel solutions will also be visible in the care of the ageing population. Remote health care has been associated with ensuring availability and access to cost-efficient and sustainable healthcare, but it also provokes discussion on topics like the lack of human contact. Furthermore, the field of artificial intelligence (AI) has shown rapid growth in recent years. AI has been introduced as a technology with the potential to transform medical practices, also relating to eHealth services [46]. The COVID-19 pandemic further increased the demand for remote healthcare services [47] but also for advanced AI-based applications and intelligent robot systems [48]. Robotics relate more generally to larger changes in medicine and healthcare but in the future are expected to be present for instance, in nursing homes. The current developments in AI have helped to expand the potential of robotics and the visions include, for instance, care, hospital, and assistive robots. As a whole, while technologies have a lot of potential to improve the efficiency and effectiveness of healthcare and access to health information, it has become increasingly apparent that their effectiveness depends on to what extent they leverage their anticipated benefits and enable access to information rather than mere systems [27].

## 3 Methodology

To examine older adults' ways to manage health information and views on eHealth services, a postal survey was mailed in 2019 to a population of 1,500 individuals aged 55-70 years, obtained from the national Population Information System of Finland. The sampling criteria were that the participants should be aged 55 to 70 by the end of 2018, have a permanent address in Finland, and be registered as speakers of the national languages Finnish or Swedish. A total of 373 surveys (25%) were received. The mean age of the final study population was 63.2 (standard deviation 4.7).

The questionnaire included both closed and open-ended questions on health information management, use, and views of current and future eHealth services, health information seeking and health behaviour. Both users and nonusers of eHealth services were encouraged to answer. The present study focuses on two open-ended questions of the questionnaire. These focused on personal health information management and visions of the future eHealth services.

In total, 345 respondents responded to an open-ended question on how they manage and keep track of the information relating to their personal health in their everyday life. Furthermore, at the end of our questionnaire, we asked them to imagine: "If there would not be any limits in resources or available technologies when developing a digital health service, how would the best possible service look like and what functions would it have?" Of the respondents, 159 answered this question. Of them, nine answered briefly "I don't know", leaving 150 more elaborate responses. Because most of the responses were fairly short, the qualitative data were analysed by using simple data-driven content analysis by colour coding to form themes in Microsoft Word. The selected citations have been translated from Finnish to English.

Among the older adults 27.1% were 55 to 59 years old, 28.2% were 60 to 64 years old, 33,5% 65 to 69 years old and 11.1% were aged 70 or above. Most of the respondents were women (60.6 %).

## 4 Findings

### 4.1 Storing and maintaining personal health information and health records

An important aspect of personal health information management is storing and preserving personal health information. According to several respondents, storing the information in paper format is still typical among older adults. Papers were stored in a box at home, notes were kept in a notebook, and some also mentioned keeping a diary related to their personal health: "Medical reports in paper format, I do not use these documents with a computer." Digital information was also printed for preservation: "I arrange the sent epicrisis to a paper folder. Research results etc. I print information from MyKanta."

Paper and digital storage can also complement each other, and can serve different purposes: "I store part of the older health information in paper folders. The prescriptions are in Kanta.fi [MyKanta], vaccination information can be found in the vaccination

card. Prescriptions are renewed through MyKanta. I book doctor's appointments online. The latest medical information can be found from Kanta.fi." MyKanta was mentioned often and, in some cases, as the only response to the question of ways to manage personal health information. It plays a major role in managing records and information relating to personal health: "Both in paper and digital format, I always look what is written in Kanta, but the information is scarce."

Some respondents also pointed out that they use several digital services and platforms: "At home on paper and on my own computer, - occupational health's "Own health" pages, - medication in MyKanta database, - City's "Own treatment" database."

In their responses, older adults spoke about the reasons for storing personal health information and needs for checking the information. Preparing for doctor's appointments was a common reason for checking the information or taking the papers with them: "When going to a doctor. When tests and procedures have been made during several years. Changes in medication. The medicine that has caused allergy symptoms." The stored information was also compared to new pieces of information: "Prescriptions and renewing them, before doctor's appointment, lab results, medical reports, when a new symptom occurs, comparing older lab results to new ones."

Older adults did not only store information from the healthcare providers, but some did keep a record of their own measurements: "I use MyKanta, some of the doctor's reports are in paper folders, blood pressure results are on paper (self-measured). I handle information when I visit the doctor." In addition, articles and stories in magazines were mentioned to be worth saving: "I store them in paper format and on my computer: my own measurements (blood pressure, weight etc.), doctor's appointments and prescriptions. I follow and store articles that relate to my own health."

Over time the living environment, used services, and information needs can change, and this has its impact on managing personal health information: "Sometimes I take papers with me to the doctor because I have lived in several places." Significantly, making sure that the information will be available in the future may require actions from the individual: "I transferred my occupational health information from Mehiläinen [private health provider] to the public health centre, because these health problems continue and reoccur now when I am retired."

Interestingly, several respondents did not see reasons for storing personal health information. It was argued: "I don't keep any track – the doctor will tell you about the possible outcomes of the lab test results." Overall, maintaining information was not necessarily seen as easy: "Not in any way. Some things are on paper, but they are always lost somewhere." "I don't really keep any information. I will just mark in the calendar the date when some medicines are out, so that I know to fetch more. The receipt is in digital format and kept at the pharmacy. They will renew it if needed." Also others pointed out that medicines were the most central health-related thing they are concerned about: "I mostly follow the number of medicines in the medicine cabinet." One respondent gave an almost philosophical mortality-related answer: "I follow up my health status to an extent that I see if I get up from the bed every morning. If I can't make it, I am dead. Thus, I do not follow my information, it follows me."

### 4.2 Imagining future eHealth services

The perceptions of eHealth services clearly differed between the respondents. Some of the respondents expressed their satisfaction with the available services and did not come up with any new ideas: “Difficult to say. I have not been using them much, but I have been satisfied with the services. I get to renew a prescription; I can book a time for an appointment to occupational healthcare. For me the system seems to be enough. Luckily, I am quite healthy and have not needed much.” Also, the MyKanta service was appreciated: “I am satisfied with the MyKanta service, it is a great improvement compared to the time before it.” On the other hand, some respondents articulated that they have no need for digital services: “Digital health services are not beneficial at all! PS. I am old school.” Or they even manifested clear resistance against the progressive technological transformation: ”My personal doctor or nurse will not be replaced with any robot service!”

The expressed worries included issues related to privacy and security, as expected: “The digital services are sufficient, but I would like to restrict the possibilities (of healthcare) of spreading the information / possibilities to read my information. For example, now, just checking information about my prescriptions tells too much about my diseases.” Additionally, a very timely concern relating to strong identification was stated: “National personal digital strong identification should be implemented first! Now we are all dependent on bank identification.”

Wishes and development ideas were brought forth. Some of them were more general, like: “Easy to use, understandable, safe.” As well as, ”clear, up to date, fixing mistakes should be easy and quick.” Many respondents considered the fast and workable connection as important: “Direct contact to healthcare professionals is the best!” “Possibility to contact healthcare professionals anytime from home.” The phone and video connections were also highlighted: ”Digital remote access e.g., via video connection. All markings and examinations. The results to MyKanta. Installations of digital services are fine. Phone services are also fine.” Video connection provides possibilities also for medical consultation: “Video connection with the doctor. For example, showing a suspicious mole could be easily done via a video.” The ageing and its challenges were pointed out in the responses: “Service that still works at the time when I do not understand anything about computers anymore.”

In the responses the continuity of the care-pathway and possibilities to influence were mentioned: “Same doctor taking charge (of the treatment) or possibility to change (the doctor) if needed!!! Customer oriented approach!!!” A customer oriented approach also included tailoring and personalization of the content provided: “Personalized instructions. If a person has some basic illness or weight problems, a digital service could offer instructions for eating, exercise, self-care etc. by considering all the person’s diseases, age etc., and residence and availability of services.”

The findability and the presentation of information were discussed: “All information in “the same place” and in an easily understandable format, plain language “easy-to-read” possibility.” Moreover, this viewpoint included easy access and aspects relating to usability and understandability: “Front page needs to be clear, no need for unnecessary clicks. Language should be understandable; pages should be easy to access (easy registration). But I still don’t think it is a good thing that everything is online. Meeting the doctor in person is the most important to me and that cannot take place

online."

Other responses also highlighted the importance of human contact and face-to-face connection for the ageing population: "For the young and those in working age, the technology is suitable and makes the service faster. Pensioners want personal service. It is not meaningful that elderly people living alone also attempt to use computers alone. Human contacts are important for them."

The aspects of prevention of loneliness and mental health problems were articulated and seen as major reasons for retaining the possibility of meeting the healthcare professionals in person: "Why digitally? Personal meeting would prevent loneliness!" "The development of mental health and substance abuse services in the manner that digital services would also include phone and face-to-face interaction. Through this kind of interaction lonely people's feeling of security and of being valued would increase. For elderly, the features of digital services should be easy to use. It should be remembered that older people are not interested in new things, like voice control of the services, but see the old ways as safe."

The aspects of AI and robotics did not come up as often as it might have been expected, but the reason for this could also be that these issues are not so much present in older adults lives (e.g., in media that they follow) as maybe for younger ones. The importance of human decision making was pointed out by one respondent: "The registered interpretations should always be based on the right conclusions done by a doctor/nurse ==> ability to listen!!" Moreover, only one respondent imagined positive opportunities with robotics: "Doctor robot, that would examine a person from head to toe in a flash and would tell what is wrong and what should be done."

## 5 Discussion and Conclusions

Older adults' ways to manage their personal health information including the extent to which they use digital health services are divided. Fears, trust, and motivation, as well as general everyday life information practices and routines, guide their experiences and behaviour with digital health services. Without any limits in resources or available technologies when developing a digital health service, according to the respondents of this study, the best possible service would contain versatile health information and combine information from different sectors of healthcare. It would be easy to use, clear and up-to-date, but would also allow for the possibility to contact a real human being, a healthcare professional, for instance, via video connection.

The findings of our study support the observations by Kolotylo-Kulkarni and colleagues [21] about the multiple types of personal health information being managed and the use of several kinds of strategies and tools. Among the Finnish older adults participating in this study, paper-based approaches were still popular and digital tools were mostly seen as complementary. Papers were stored in a box at home, notes were kept in a notebook, and some also mentioned keeping a diary related to their personal health. One respondent pointed out that he is "old school" and another that "older people are not interested in new things, for instance, voice control of the services, but see the old ways as safe." Also problems relating to paper-based approaches were mentioned

by pointing out that the papers are “always lost”.

In many cases, preservation was obviously done “just in case” or for being able to compare the results and information to the older ones. Many checked information before a doctor’s appointment. This kind of preparation for interaction with healthcare professionals has been also observed in previous studies (e.g., [36,49,50]).

Intangible objects, such as trusting one's own memory was not explicitly mentioned, as in the study by Turner et al. [20], but some of the respondents appeared to trust that healthcare providers will take care of the information and tell them if something needs to be known. A medicine cabinet was mentioned as a tangible object that “reminds” when medicines are about to run out and the prescriptions need to be renewed. Some of the respondents also created information related to health. They followed and kept a record of, for example, their self-measured blood pressure or weight, as in the study by Michelson and colleagues [19]. Some also collected and saved articles or stories relating to health.

While, for many, eHealth services, including communication via video calls, enabled more convenient ways to manage personal health information, they were not viewed as replacements to all paper-based approaches or face-to-face services. Like in the study by Kaihilainen et al. [25], many of the older adults in this study highlighted the value of the physical presence of a health care professional and the need for personal contact. The aspects of prevention of loneliness and mental health problems were articulated and seen as major reasons for retaining the possibility of meeting the healthcare professionals in person. Moreover, it has been stated that lack of physical presence may affect patient communication and patient-provider relationship [41].

The topic of our study relates to digital equity. According to our findings, the services should be inclusive, in other words, people should have the opportunity to choose from digital or face-to-face services. Several older adults were not interested in their personal health information or in managing it. For them, digital services might lower the threshold for contacting healthcare providers and motivate managing personal health information. The actual benefits of eHealth services include easy access to information about health, a more direct communication with health providers, and the possibility to make appointments online [20]. A major implication of the present findings to systems design is to focus on helping users with tasks they find arduous and especially when new services are expected to act as substitutes, to be sensitive also to their less apparent, non-medical social and emotional affordances and functions. One of the critical topics for future inquiries is to develop a better understanding of how people manage their personal health information as a whole in relation to specific ehealth services. A comparison between younger and older adults’ personal eHealth management would also be interesting.

The findings might also reflect capabilities needed for personal health information management relating to health information literacy. With hindsight, the aspects of AI and robotics did not come up as often as it might have been expected. Likewise, only one respondent visualised positive opportunities of robotics. Evaluation of AI technologies, as well as, communication and collaboration with AI, are competencies that are defined as AI literacy. In the future, also older adults will need these capabilities for feeling inclusive, secure and in control of their interactions with AI-enabled services. All things considered, the impact and possibilities of intelligent technologies should be investigated together with older adults.

Lastly, we want to highlight some issues relating to our study. The citations chosen to represent the answers were from broad number of participants. They were translated from Finnish to English by the authors. The research questions could have been phrased also differently. Asking people what they would like to have can be challenging and especially the second survey question could have been a more concrete and precise one. The survey was conducted before COVID-19 pandemic and it might have changed the eHealth management practices of older adults. Therefore it would be interesting to repeat the survey now, after the COVID-19 pandemic and compare the results.

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