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Improving patient-centeredness for older people in a digitalizing healthcare context

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Chapter



How to approach user-based testing of eHealth with older patients: insights from an expert-based workshop

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Abstract

Background: Involving representative participants in user-tests of eHealth is a central aspect of user-centered design approaches of (new) eHealth interventions. Older patients might especially benefit from these interventions. Yet, barriers exist that hamper adequate user-testing with this user group.

Purpose: To create awareness on how aging barriers influence the performance of user-based evaluation studies and to propose recommendations on how to perform user-tests of eHealth suited for older patients.

Methods: A consensus-seeking process was performed based on an expert workshop, where experiences and insights on how characteristics of older patients influence (usability) evaluation studies and user-testing were shared.

Results: In total, the experts provided nine recommendations for user-testing of eHealth with older patients. Three main themes were identified: 1) empathetic approach and trust-building; 2) new requirements to testing and study design and 3) adjustments to user evaluation methods for testing with older patients. The overview of recommendations gives support and advice on aspects needing attention at the design, planning and execution phase of user-based evaluations of eHealth with older patients.

Conclusion: The recommendations presented aim to support the performance of user-testing of eHealth interventions with older patients to ultimately enhance the usability and effectiveness of these innovations. Application of these recommendations in practice will enhance execution of user-testing studies on this matter, and ultimately lead to a better eHealth design quality. These recommendations are an important step towards building stronger evidence on usability of health innovations for older patients, key for sustainability of eHealth amongst this target group.

Keywords: user-based evaluation, methodology, elderly, eHealth, Think Aloud protocol

1. Introduction

To support the aging population, the interest and development of eHealth technologies for older patients is on the rise [1-2]. Such eHealth interventions, including mobile health (mHealth) and digital health devices, are increasingly being designed to assist older patients in independent living and self-management of (chronic) illnesses. These interventions may for example provide medication assistance by prompting alerts, provide self-care advice for diabetes patients, assist heart failure patients in monitoring their blood pressure, promote independent living as well as identify and alleviate fall risk factors [3-5]. In the development of such eHealth interventions, existing research recognizes the critical need to involve older end-users to ensure high usability and alignment of the eHealth intervention within the actual user context of the older patient [6-7]. Perceived usability and usefulness are of importance to allow for sustainability of eHealth interventions for older patients, as shown in a recent scoping review on mHealth advances by Matthew-Maich et al [6]. This review indicated that an intervention will not be used if it is perceived to be “more trouble than it is worth” [8-9], too time-consuming [10], unreliable [8], or generally burdensome [11-12]. Taken together, there is a potential of innovative eHealth interventions to support successful management of chronic conditions and health behavior. However, most publications mainly show case studies on pilot implementations or systems’ feasibility assessments [3], whereas especially regarding mHealth, usability barriers to sustainability have limited the number of successful and evidence-based interventions for older patients beyond this pilot or feasibility stage [6].

A range of usability engineering methods (UEM’s) can be applied to provide sight on the user interface and/or functional problems end-users encounter when interacting with a system. Involving end-users within UEM’s can be done by means of user-tests, in which problematic issues in the design of a tool or technology are identified by end-users. Amongst others means, user-tests can consist of usability tests, interviews and surveys. Using such UEM’s can improve eHealth, mHealth and medical device designs as these methods aim to align them with needs and characteristics of their user population [13], given that they are applied with participants that are representative to the intended user group of the eHealth intervention. However, a main challenge faced by research and development teams in performing user-tests with eHealth interventions for older patients, is to involve a representative group of older patient participants in user-tests. Examples of barriers that have been observed in previous research on this matter firstly report that it proves to be difficult to recruit older participants for user-testing within the project timeline [14], since older patients’ willingness to participate in such studies seems to be low. Secondly, age-related and disease-related barriers may pose limitations to include older patients for user-testing. Older patients often have multi-morbidity related physical and perception impairments, such as problems with the eyesight, deafness [15], or more severe disabilities related to stress induced factors that

could make inclusion of older patients difficult. Cognitive or physical impairments may also lead to being excluded from user-testing as patients might not be able to attend the evaluation sessions. Excluding older patients with these impairments is a major problem in performing accurate user-testing to assess the usability and effectiveness of eHealth interventions, since then these interventions are not tested with participants that are representative to their intended user group. This is especially of concern when these interventions are aimed at chronically ill patients, considering that important user-context issues such as the age-related and disease-related impairments, for example eye-sight problems of diabetes patients, which influence the eHealth intervention's use might then remain under-recognized.

When older patients are nevertheless included in user-tests, cognitive impairments pose further limitations to the performance of a well-known technique performed during user-testing: the Think Aloud protocol. This method provides a unique source of information on cognitive processes in many cases: it generates direct data on the ongoing thought processes during task performance [16]. As such, this methodology relies heavily on the cognitive capacities of participants, such as communication, attention and speed of comprehension, whereas it is exactly these cognitive capacities that decline with aging. These cognitive skills, especially attention, are deeply solicited by the Think Aloud protocol, preventing people with cognitive limitations such as older patients to have sufficient remaining attention for using the product under evaluation. These barriers to inclusion of representative older patient participants in user-testing and execution of these tests with them, might lead to solely considering the needs of (younger or more autonomous and less disease-dependent) patients who are more easily involved in user-testing. As a result, eHealth interventions might remain cumbersome and ineffective in use for (chronically ill) older and less autonomous patients.

Although the need for applying user-tests as a central aspect of user-centered design approaches in eHealth development and evaluation is thus clear, little attention has been paid to the above mentioned barriers of older patient participants and on how to adapt user-tests to such barriers. New evaluation studies and trials on eHealth interventions could benefit from an overview of methodological recommendations on this matter that can be applied within their eHealth development context. This paper therefore gives an expert-based overview of recommendations to user-testing UEM's that are adapted to user-testing with older patients with the ultimate aim to improve the alignment of the evaluated eHealth technology to older user populations.

2. Methodology - Expert workshop

A workshop was held during the 18th Medical Informatics Europe Conference, where health information technology (HIT) evaluation experts were invited to funnel the expertise on user-testing studies on HIT involving older patients. The workshop project was endorsed by the EFMI Working Group on Human and Organizational Factors of Medical Informatics (HOFMI). The aim of the workshop was to share experiences and insights on how characteristics of older patients influence user-testing, and to jointly propose methodological approaches via a consensus-seeking process to improve user-testing with older patients.

The level of expertise of the participants was assessed based upon the number of relevant experiences and publications in the field. Participants were divided in groups during the workshop, where each group contained multiple senior researchers to ensure a sufficient level of expertise per group. Each group addressed one main perspective in relation to older adults' involvement in user-testing, respectively: eHealth, mHealth and medical devices and was hosted by one of the authors. The groups were provided with a persona of a typical older patient (65+ years old) by the host. Each group discussed what participants' thoughts were on how to overcome barriers to user-testing with older patients and thus how to best approach user-testing with this population. In each group, participants started answering these questions by writing their answers on index cards, which were collected and pinned onto a pin board. Each participant explained for his or her cards what the answers entailed. The role of the host was to rekindle the discussions, as well as to help participants synthesize and structure their answers. Once all the index cards were collected and discussed, participants clustered them in a joint effort guided by the host. Each card stating a barrier was discussed among the participants regarding its relevancy to the usability methodology cards. For instance, whether the statement fitted with mentioned problems, or whether it represented a new idea that would provide a recommendation for adapting existing methodology or provide a new approach to HIT evaluation with older patients. A plenary discussion was then held by the groups' hosts on overarching themes and proposed recommendations on appropriate methodologies that were put forth by each group. The workshop was finalized by gaining consensus on the recommendations provided.

3. Results

Table 1 shows the experience level of the workshop participants per expert group. In total 10 participants joined the workshop, of which 7 had a high level of expertise. Table 2 shows the themes that emerged during the group discussions, in which groups these themes were mentioned and which barriers to user-testing with older patients would be solved. Despite

the different topics addressed in each group, the resulting themes mentioned were similar across the groups. The results are therefore explained per main theme in section 3.1 to 3.3, respectively 'empathetic approach and trust-building', 'new requirements to testing and study design' and 'adjustments to UEM's for testing with older patients'.

3.1 Empathetic approach and trust-building

All expert groups mentioned it was especially important to have an empathetic approach towards the older patients throughout the whole scope of the evaluation project. This approach is of importance in order to build trust; if the older patients trust the evaluators it is more likely they will share their true experiences with the eHealth intervention. Aspects mentioned as part of this approach are: giving attention to the patients, listening to them and making them feel comfortable. It is important to understand that usability testing for older patients is a social experience, not just an experience where researchers get new information on for example an interface design. Experts agreed that such an approach would increase older patients' motivation to participate in user-testing and their genuineness in expressing experiences with the tested intervention.

3.2 New requirements to testing and study design

Experts coincided that setting additional requirements for the testing phase would benefit the quality of the test to be performed. In doing so, pre-testing would be a new phase in the planning and performance of the evaluation study. The experts expressed that pre-testing could lead to easier recruitment of older participants, more accurate inclusion and exclusion of older participants as well as provide sight on which contextual issues and organizational aspects might need to be (re)arranged to perform user-tests that are adapted to the aging needs of the participants. Overall, four add-ons to plan and perform a usability test with older patients were specified by the experts in the groups. A prerequisite foremost to older patient participation and stated by all expert groups was: 1) ensure pre (beta)testing. It is essential that the technology is 'bug' free, to prevent older participants' early withdrawal during a test. Even in testing during an early design phase, focus is needed on minimal complexity for older participants when interacting with the interface to prevent the burden of stress. Next, 2) to support older participants in feeling confident throughout the whole scope of the evaluation process, involvement of their family and caregivers in a contextual setting is considered useful. Having a family member or friend present during the test is likely to support the older patient and again will reduce stress and enhance comprehensibility of the evaluation tasks to be performed by participants. In addition, suggestions were given by the experts on performing certain methods in user-testing such as interviews or surveys with the family members as well, i.e. an interview with both a family member and the older participant present as well as interviews separate from each other. Direct involved caregivers such as nurses are additionally recommended to be part of the evaluation team: they are a consistent

factor and contact person for the older patient and can help in making older patients more comfortable during participation in user-testing. According to the experts an 3) intake meeting and 4) context analysis of patient characteristics that are specific to the actual use of the eHealth innovation may help to gain sight into the organizational aspects that developers need to take into account during the user-test. Experts mentioned that in performing such analysis, it could be helpful to use a theoretical framework that recognizes age-related and disease-related barriers possibly influencing eHealth's use, such the MOLD-US framework [15]. The MOLD-US framework, mHealth for older users, provides a visual and accessible overview of motivational, cognitive, physical ability and perception barriers to eHealth use; and more specifically to mHealth use. According to the experts it can be used as a guide to recognize these aging barriers in the context analysis.

3.3 Adjustments to UEM's for testing with older patients

Experts mentioned several adjustments of current used-based evaluation methods to improve testing with older patients. First, conduct a usual user-test yet adapt the instructions and locations for testing to the older patient participant. These adjustments focus on recognizing cognitive barriers of older patients by adapting the length of the test and the set-up of the test. For example, instead of having one longer usability test session in which several tasks are evaluated, a set of multiple short sessions can be performed. Where each session consists of one brief task, followed by a brief interview to obtain relevant information from the participant on that task. Usability evaluations likewise can be performed in a set of several evaluations in for instance a week's time. This allows for an unrushed execution of usability tasks. During the evaluation(s) it can be emphasized multiple times that any interaction the participant has with the intervention is correct; explaining that the design of the intervention is being tested instead of how well the older participant uses the intervention. Experts further stated that is important to frequently emphasize why the older patient's involvement in this type of research is important. In doing so, the social impact can be explained and the difference between (the scope of) the research project and care activities can be addressed in more detail. Older patients may not be aware of this difference and may have trouble understanding research activities. Another adjustment, related to the comfort of older patients, is to explicitly explain them why the evaluation might be recorded and to only record after patients' consent while avoiding recordings of patients' faces. Other recommendations here related to the location of the evaluation. As a golden standard it was described that evaluators should go to the homes, the usual physical environment, of the older participants to perform the evaluations or to shadow the patient there for a short period of time. If this is not possible, it was mentioned to perform user tests in 'living labs', laboratories fully equipped with camera and microphone to observe the behavior of the participants and whose layout reproduce the setting of an older person's physical environment. For example, living labs can consist of older people equipped apartments or even elements of cities that closely mimic or represent

how older people experience that environment. Performing evaluations at settings that are unfamiliar to older people or look like a (clinical) lab or office atmosphere, should be avoided.

Other adjustments aim to adapt the user-testing method to allow for collective testing. These main additions were related to the social aspects older participants experience when acting as participants in usability evaluations. In the Think Aloud usability evaluation, the participant get user-tasks to perform in the eHealth intervention, such as 'go to appointment schedule and find the time of a hospital appointment'. The participants then needs to verbalize the interaction steps he/she is taking in the eHealth intervention to perform that task. This is done individually by the participant, which might put the older participant under pressure and also might not coincide with their actual use. Therefore, as a variant to an individual user-test including the Think Aloud method, the 'peer discovery' method was suggested. In this variant, the older patient participant can interact with the technology together with a family member or caregiver. The idea behind this approach is that they can help each other during the Think Aloud as they would in their personal context. When peers work together they express their impressions, frustrations, and thought processes more naturally; therefore, this variant yields a clearer picture of how a technology is used and where users struggle. In relation to this, experts mentioned the concept of 'peer community' user-testing as an addition to UEM methods. In this variant the older patient participant can use the technology together in a group setting with other older patient participants, again to stimulate a more natural expression of their impressions, frustrations, and thought processes in interacting with the eHealth intervention. Lastly, suggestions were given to use a different method than user-testing: shadowing, observing an older patient's use of the evaluated eHealth technology in his/her own environment for a period of time. Experts expressed this may give more accurate sight on their daily interactions with the eHealth intervention as well as causes to moments when the technology is not used.

Table 1: Overview of workshop participants' experience per group

Workshop group	Title	Amount of papers published (author/co-author) in field of user-testing in healthcare
1) eHealth	Professor	> 80
	Senior researcher	> 20
	Junior researcher	-
2) mHealth	Professor	> 80
	Professor	> 80
	Senior researcher	n.a.
3) Medical devices	Professor	> 30
	PhD candidate	< 5
	Senior researcher	< 5
	Junior researcher	-

Table 2: Themes and recommendations on user-testing with older patients, applicability in phase of test italicized.

No	Theme/sub-theme	Mentioned in group	Key elements mentioned by experts	Addressed barriers
1.	Empathetic approach and building trust <i>Total scope of project</i>	eHealth mHealth Medical devices	<ul style="list-style-type: none"> - Trust of participant towards evaluators of importance - Making participants feel comfortable - Prevent stress of participant during evaluation 	Patients' motivation to and genuineness in expressing experiences
2.	Pre-testing and study design <i>Pre-test phase</i>			
2.1	Beta testing	eHealth mHealth Medical devices	<ul style="list-style-type: none"> - Analysis of beta eHealth technology on alignment with intended user goals (possibly through observations) - Perform a beta test to ensure eHealth technology is bug free 	Patients' motivation to test and continuity of testing
2.2	Involving family and caregivers	mHealth Medical devices	<ul style="list-style-type: none"> - Recruitment of participants via family or caregivers - Include family and nurses as part of participants in evaluation interviews (together and separate of older patient participants) 	Recruitment of patients
2.3	Intake and older participants' capacities and skills	eHealth Medical devices	<ul style="list-style-type: none"> - Intake meeting at home of participant before test 	Aging barriers to inclusion or exclusion of patients
2.4	Analysis of patient characteristics and context specific to user-test	eHealth mHealth Medical devices	<ul style="list-style-type: none"> - In-depth needs analysis of participants' social context and physical environment - Assessment of cognitive, perception and physical abilities - Specify user- and organization requirements needed for usability evaluation 	Aging barriers to be recognized in organization of user-test

No.	Theme/sub-theme	Mentioned in group	Key elements mentioned by experts	Addressed barriers
3.	Suggested adjustments to UEM's for testing with older patients <i>During test phase</i>			
3.1	Peer discovery	mHealth	<ul style="list-style-type: none"> - eHealth technology is used together with a peer (i.e. family member) 	Patients' motivation to test
3.2	Peer community session	Medical devices	<ul style="list-style-type: none"> - eHealth technology is used in a group session with other older patient participants 	Patients' motivation to test
3.3	Living lab	eHealth Medical devices	<ul style="list-style-type: none"> - Resemble physical environment of patients to perform test (if test cannot be done in actual home) 	Diminishing contextual barriers influence on results of test
3.4	Adapted instructions and guidelines	Medical devices	<ul style="list-style-type: none"> - Attune evaluation set-up to cognitive capacities of participants - Have brief tasks, each followed by short interview - Perform several short evaluations in for instance a weeks' time - Record only relevant information and explain why evaluation is recorded - Emphasize importance of participants' involvement 	Diminishing cognitive barriers influence on results of test Patients' motivation to test
3.5	Shadowing	mHealth	<ul style="list-style-type: none"> - Observe how patients' uses eHealth technology in own environment for a period of time 	Diminishing contextual barriers influence on results of test

4. Discussion

The recommendations provided in this paper to user-testing with older patients, aims to support evaluators, healthcare professionals, decision makers, software developers and other HIT stakeholders in performing user-based evaluation studies of eHealth interventions for older patients. The overview gives support and advice on aspects needing attention at the design, planning and execution phase of these evaluations. The recommendations in the overview have been developed through a consensus-seeking process during an expert workshop in which experiences and insights on how characteristics of older patients' influence user-testing were shared. By sharing these expert experiences and by exposing current issues on this matter, this paper aimed to contribute to creating awareness on aging barriers influencing the performance quality of user-based evaluation studies. The recommendations in this paper further aimed to raise the level of quality of user-based evaluation studies and thus to contribute to the accumulation of the scientific evidence base for eHealth interventions.

4.1 Benefits of proposed recommendations to redesigns

The recommendations can be applied to any eHealth user-based evaluation involving older patients to support a user-centered design. Insights from user-centered design processes with older patients may improve various design aspects that are especially relevant for perceived usability and usefulness of a product by older people [17]. For example, the presentation of information can be adjusted in such a way that is easily readable and interpretable by older people. This includes how to best present texts, buttons and icons as well as their dependencies; creating a clear distinction between texts, buttons and icons. Further, the navigational levels of an interface design can be adjusted such that it is compatible with older people's cognitive capacities. Another important design aspect of older people's technology use is related to how they should use a device to enter and review data, for example minimizing the number of steps to take in doing so and ensuring consistency in input/output features [17]. This is particularly relevant for minimizing older patients' burden in obtaining an overview of multiple data devices or sources, such as data from multiple healthcare organizations, and maximizing the interoperability between eHealth interventions and medical devices used by older patients. In addition, older people indicate that they prefer clear instructions and support in using technologies and eHealth [17-18]. It is highly assumable that applying the recommendations of this paper to user-testing with older patients, can improve insights on how to best design these aspects of information presentation, navigational structure, interoperability design and clarity of instructional support for older (chronically ill) patients. To assess the validity of the recommendations on this matter, as well as on their clarity and completeness, we encourage researchers and eHealth developers to report on how they integrated these recommendations in their application and use in user-tests with older

patients. We advise to involve a multi-disciplinary team in doing so; not only consisting of Human Factor researchers and eHealth IT developers, but also of healthcare professionals and geriatricians. Especially the latter can provide more sight on the older patient population and may provide in-depth knowledge on the age-related and disease-related barriers as mentioned in the MOLD-US framework [15]. This is relevant to possibly expanding the identified issues of this population to user-testing and further developing the overview of recommendations to solve such issues.

4.2 Proposed recommendations aiding representative project management

Some of the recommendations emerging from this expert workshop relate specifically to project management of user-based evaluations. Recommendations mentioned, such as performing a thorough beta-test, undertaking an intake meeting and an assessment of older patients' capacities and skills, observing or shadowing the participants and having multiple test moments, are especially labor as well as time intensive. Furthermore, an intake meeting to assess older patients' capacities and skills might give sight on their limitations to participate, such as mobility issues when participating in user-tests and evaluations on location. Often these issues are encountered during the execution of the project, leading to higher expenses and/or a delay in the project timespan. The recommendations given in this paper can therefore help in the set-up of a representative project management plan at the initial phase of a new eHealth development. For example, by taking these recommendations into account in listing the staffing resources and budgetary aspect of a project proposal, such as allowing the budget to reimburse taxi costs of participants, aids a more accurate estimate of project costs. Regarding the length of a project involving end-users in user-centered design processes, previous research has shown that the contribution of end-users significantly altered the ultimately designed technological intervention from the initial prototype. Yet as a consequence of end-users' involvement, it took longer than expected to develop the intervention [19]. User-testing with older patients requires more time than user-tests with younger populations due to the added elements during the preparation and execution phase of the test, such as the intake meeting or performing several test sessions instead of one. It is thus likewise important to allocate a sufficient timespan in the initial project proposal to iteratively redesign the intervention based on the end-users insights gained through the user-tests. Paradoxically, both financial resources and sufficient development time is scarce in eHealth development projects. We nevertheless want to make a plea for investing finances and time for the involvement of older end-user participants in a user-centered design process. This can improve the quality of user-based evaluation studies leading to accurate redesign solutions, ultimately improving the success rate in uptake of the eHealth intervention for this target group.

4.3 Challenges of proposed recommendations related to standardization in user-testing

The proposed recommendations in this paper make an important contribution to the performance of UEM's for a specific user population. These insights on how to approach user-testing with older patients can lead to more accurate insights resulting from such tests, improving eHealth designs for older patients as well as the project management approach to involve patients in the development of eHealth, as is described in section 4.1 and 4.2. Nevertheless, the proposed recommendations are challenging to standardization in user-testing. User-testing research, specifically usability research, is strengthened when scientific requirements are met that aid reproducibility of the user-test, such as a standard means to execute the research or using validated usability questionnaires to gather data [20]. As this paper argues, requirements of standardized user-testing in eHealth pose constraints and limitations to older patient participants, resulting in less valid and valuable data on usability of the eHealth technology under evaluation. Yet, by not complying with scientific requirements of standardization in eHealth user-testing, a comparison overtime and with other eHealth technologies on usability for older patients may become problematic. In user-testing studies with older patients we suggest paying special attention to finding the balance between scientific constraints of user-testing and barriers in older participants' participation. Future research is therefore recommended on how to empirically compare standardized user-test results of eHealth in which older patients participated with user-tests performed via these recommendations on performing user-tests with older patients.

5. Conclusion

A comprehensive overview of recommendations to user-test evaluations of eHealth with older patients has been developed by means of experts insights. The overview contains nine recommendations, related to the pre- and execution phase of user-test studies. These recommendations facilitate eHealth evaluators and stakeholders in eHealth development regarding recruitment as well as in- and exclusion of older participants to user-tests. Further, the results of such studies will become more robust when the recommendations are applied, contributing to an important step towards evidence-based eHealth for older patients.

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