"The support needs to be part of the system": designing inclusive eHealth applications for older adults with low eHealth literacy

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In the project "Got-IT", an online toolkit was developed to assist with the design of inclusive eHealth solutions targeting the promotion of healthy lifestyles among older adults (65+) with low eHealth literacy. The project consortium has used participatory citizen science as an approach to actively engage with the relevant stakeholders, including older adults with low eHealth literacy, eHealth developers, and secondary end users like eHealth professionals. We applied three different research designs, all centered on the active engagement of the different stakeholders, using the design of an eHealth app to ground the investigations. The outcomes of the Got-IT project align not only with the first objective of the AAL Programme ("better quality of life for older adults and their networks, by empowering the citizens to take care of their own health") but are also central components of citizen science as a whole, by actively engaging the different target groups at various levels of our research process.

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1. Introduction

In the project "Got-IT: a toolkit for inclusive and understandable lifestyle data visualizations in eHealth solutions", hereafter referred to as "the Got-IT project", a toolkit was created which was intended to support electronic health (eHealth) developers and other stakeholders on the journey of creating inclusive eHealth solutions. The approach of the toolkit is to first inform developers and other stakeholders in this field of the importance of an inclusive approach in the design process of eHealth solutions. Subsequently, information and recommendations are given on co-designing and testing such solutions to make them as accessible and inclusive as possible. The toolkit is thereby created as a living toolkit, embedded in an accessible online platform, meaning that the different sections can be updated and expanded to cover a variety of eHealth solutions and end-user groups [1].

As a starting point, the project thereby focused on older adults (65+) with low eHealth literacy, as a representative group of people who have limited access to eHealth solutions [1, 2]. EHealth-literacy is defined as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" [3]. Thus, people who lack this ability experience difficulties using, understanding, and interpreting applications and contents which promote a healthy lifestyle [1, 2].

2. Co-Creation in eHealth solutions

An area in which particular emphasis must be placed, considering the wants and needs of users, and thereby creating a design which is as inclusive as possible, is the area of eHealth solutions [4, 5]. EHealth, meaning "the use of information and communications technology (ICT) in support of health and health-related fields" [6] has long been an integral part of healthcare in Europe, and the trend is rising [7, 8, 9].

In addition to covering fundamental healthcare needs, eHealth solutions are often created to promote a healthy lifestyle and improve the quality of life of their users, e.g., older adults or people with chronic diseases. Thereby they are intended to, for example, enable the monitoring of health parameters (e.g., blood pressure, blood sugar, exercise), give information on health-related matters and disease prevention, promote a healthier lifestyle, and simplify processes of everyday life [10, 11, 12]. Looking at the bigger picture, eHealth solutions can help to increase health in the population, enable an autonomous life in one's own home for a longer period, and relieve the health system at many points [13, 14, 15].

However the advantages of eHelath solutions do not come to fruition if the target group cannot utilize certain functionalities of the product provided [16]. This is especially the case for older adults and people with chronic diseases—the target group of a substantial number of medical solutions—who are confronted with major problems when it comes to using eHealth solutions [16, 17, 18]. On the one hand, a majority of this age group lacks the technical skills to use such solutions without encountering hurdles. On the other hand, many lack the necessary health literacy to understand the information provided [17]. The result is that there exists a low

level of eHealth literacy, which is not a problem restricted to older adults, but concerns a large part of society. A lower eHealth literacy in a society can have drastic impact on the society, as it is particularly prevalent in the educationally deprived strata of society [17, 19], which generally have poorer health and chronic health outcomes as it is [4, 20, 21, 22]. Additionally, the affordability of new technologies is a problem [17, 18].

In sum, the result is that there is reduced usage of eHealth solutions in groups with lower socio-economic status (SES), older adults and people with low eHealth literacy in general [19, 23]. Thus, it becomes obvious that a failure to address the needs of these groups in the future development of eHealth solutions will only widen these identified gaps [19]. The aim must therefore be to make eHealth solutions accessible for everyone [4, 24] by further deepening the research on factors influencing eHealth use, such as eHealth literacy [25], and involving diverse groups of end-users in a co-creation process [23, 26].

3. Co-Creation with Older Adults

Our empirical approach to creating the toolkit focused on integrating all stakeholders as experts in their field. We achieved this by involving older adults with low eHealth literacy in the design-process of an eHealth application-mockup and collecting the experiences, and the lack thereof, of developers in designing eHealth applications. Another important aspect of our project was gathering the experiences of those who provide older people with a direct (social) support system, (e.g., health professionals), when new eHealth-applications are being introduced.

The co-creation process in the Got-IT project took place in the Netherlands and in Austria. In both countries, we recruited co-design teams of 11 people each. We invited participants according to the following inclusion criteria: aged 65 or older with low eHealth literacy, cognitively able and legally competent, having access to electronic devices, such as a smartphone, tablet, or computer, and being able to use the electronic device. This resulted in seven female and four male participants per country. The average age of the participants was 74 in Austria and 69 in the Netherlands. After a recruitment phase, we had four co-creation sessions in each country with older adults with low eHealth literacy, where the visualizations of the app were iteratively developed and subsequently tested. The co-creation workshops ranged from collecting visualizations (session 1), discussing visualizations (session 2), and hands-on (re)designing visualizations (session 3 and 4). Their contributions addressed—amongst other things—the amount of information on the screen, colors and symbols used, font size and privacy issues.

We also investigated the experiences of eHealth developers designing eHealth applications for people with low eHealth literacy through an online survey (n=42). It was concluded that in general eHealth literacy does not play a large role in their development processes yet, but there is a large interest in co-design with end-users with low eHealth literacy.

Because older adults with low eHealth literacy often rely on the support of secondary end-users (e.g., care professionals or their extended family), we also conducted three focus-group discussions (n=9) with professionals working directly or indirectly in the field of healthcare (e.g., medical doctors, nurses, physiotherapists, psychologists). The experts stressed that simplicity, inclusivity, and motivation are key factors for a successful implementation of an eHealth application [27].

4. Discussion

A lot of research has been done on people with low eHealth literacy, focusing especially on age, gender, and SES. But there lacks a holistic and intersectional approach to address the target group in all its complexity. Looking only at singled-out socio-economic variables in terms of individual cases is not enough to engage with this target group to enable them to increase their eHealth literacy.

To empower the target group of people with low eHealth literacy to engage with eHealth-solutions, thereby increasing the benefits for their health, research needs to not only be done with the target group in mind, but even more so it must involve the target group in the process of creating guidelines for eHealth-developers. In other words, citizen science needs to be done by the people—the different stakeholders—on all levels of the research process within the empirical studies [28], as was done in our project.

The focus-group discussions with the secondary end users in the field of health care showed the importance of involving as many stakeholders as possible to broaden the perspective on the topic. Especially when working with older clients and patients, care-providers need to be as involved in the process of introducing digital health-solutions as the patients and clients themselves. Care-providers are the ones who can foster and support patients'/clients' self-confidence and empower them to familiarize themselves with technology and health information that might be alien to them at first.

The results of the qualitative research point to six main recommendations concerning (not only) eHealth-developers: 1) The motivation to use eHealth solutions should be high with all parties involved. Stand-alone solutions are not ideal. Treatment-related medical eHealth-solutions gain attractiveness for the user and the secondary end-user, if 2) more interfaces are provided to make the planning and overview of treatments manageable in an easier way for the patient as well as the health-care provider. Inexperience with new technologies as well as socioeconomic factors (e.g., age) create a barrier for people with low eHealth literacy to efficiently engage with eHealth-solutions. Therefore, 3) the provision of a sustainable support-system at every stage of the introduction of an eHealth-application is necessary. Health is a complex topic. Health information should therefore be delivered in an understandable but still 4) evidence-based and current manner. Also, especially considering the target group within this project (65+ years) and their financial means (e.g., when living in a retirement home), it is important to keep 5) the costs of a digital solution within an affordable price-range for the target audience. When describing people with low eHealth literacy one should always be aware that they are a diverse group of people. Thus, 6) designing eHealth-solutions in an inclusive, accessible, and non-discriminatory manner is important [28]. Including and involving all stakeholders in the research process and in the development of the toolkit should be made a priority. Collaboration with the different target groups, as well as applying a co-design approach as we did in our co-creation sessions, seems to be a very beneficial strategy. Raising awareness on this topic, also for developers of eHealth applications, is important (for more information visit: https://www.got-it-toolkit.eu).

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