Improving Acceptability and Implementation of ICT-based Healthcare Platforms for Older Adults with Dementia or Parkinson Disease: Qualitative Study Results of Key Stakeholders

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Abstract

Background: The management of Neurodegenerative Diseases (NDDs) in older population is usually demanding and involves care provision by various healthcare services, resulting in a greater burden to be placed on the healthcare systems in terms of both costs and resources. The convergence of various health services within the integrated healthcare models, enabled and adopted jointly with information and communication technologies (ICTs), has been identified as an effective alternative healthcare solution. However, its widespread implementation faces formidable challenges. Both the development and implementation of integrated ICTs are linked to the collaboration and acceptance of different groups of stakeholders beyond patients and healthcare professionals, with reported discrepancies in the needs and divergent preferences amongst these groups.

Objective: Complementing a previous publication, that reported on the needs and requirements of end-users in the development of the EU funded project Personalized Integrated Care Solution for Elderly “PROCare4Life”, the current paper aims to report about the opinions of other key stakeholders in the fields of academia, media, market, and decision makers, for improving the acceptability and implementation of an integrated ICT-based healthcare platforms supporting the management of NDDs.

Methods: The study included 30 individual semi-structured interviews, that took place between June and August 2020 in five European countries (Germany, Italy, Portugal, Romania, Spain). Almost all the interviews were done on the web, except for participants who asked to be interviewed in-person. In that cases the Covid-19 PROCare4Life safety procedures were applied.

Results: Two themes and five sub-themes were identified. Users’ engagement, training and education, and the role played by the media were identified as strategic measures to ensure acceptability of the ICT healthcare platforms. Whereas sustainable funding and cooperation with authorities were foreseen as additional points to be considered in the implementation process.

Conclusions: The gradual transformation and responding to the various needs of the end-users in the ICT-based healthcare platforms requires a shared dialog between different experts such as: researchers, policy makers, technology developers, and media experts. Addressing typical barriers for ICT adoption among older population such as technology complexity and digital literacy among the potential users, need to be considered by providing a tailored system. Future projects are required to plan and budget training measures for end-users, ensuring that the time needed for training on the technology is planned for. Furthermore, overcoming costs of technology adoption can be facilitated by offering tailored pricing models. A comprehensive research on the users’ needs shall comprise four main aspects: Identifying the challenges associated with illness; researching the digital skills and preferences of the target groups; adjusting the ICT functionalities to the real unmet needs of end users; and the inclusion other key stakeholders in the research.

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Improving Acceptability and Implementation of ICT-based Healthcare Platforms for Older Adults with Dementia or Parkinson Disease: Qualitative Study Results of Key Stakeholders

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The management of Neurodegenerative Diseases (NDDs) in older population is usually demanding and involves care provision by various healthcare services, resulting in a greater burden to be placed on the healthcare systems in terms of both costs and resources. The convergence of various health services within the integrated healthcare models, enabled and adopted jointly with information and communication technologies (ICTs), has been identified as an effective alternative healthcare solution. However, its widespread implementation faces formidable challenges. Both the development and implementation of integrated ICTs are linked to the collaboration and acceptance of different groups of stakeholders beyond patients and healthcare professionals, with reported discrepancies in the needs and divergent preferences amongst these groups.

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The study included 30 individual semi-structured interviews, that took place between June and August 2020 in five European countries (Germany, Italy, Portugal, Romania, Spain). Almost all the interviews were done on the web, except for participants who asked to be interviewed in-person. In that cases the Covid-19 PROCare4Life safety procedures were applied.

Results: Two themes and five sub-themes were identified. Users' engagement, training and education, and the role played by the media were identified as strategic measures to ensure acceptability of the ICT healthcare platforms. Whereas sustainable funding and cooperation with authorities were foreseen as additional points to be considered in the implementation process.

Conclusion: The importance of the UCD approach in ensuring the involvement of users in the development of ICTs has been noted. Addressing the most common challenges that hinder the acceptability and the implementation of ICT-based healthcare platforms, requires creating synergies among efforts from users, academics, developers, policy and decision makers. In order for the future ICT healthcare projects to base their development on a comprehensive understanding of their potential users, this paper outlined recommendations to be integrated when conducting research on users' needs. Comprising the following aspects: properly identify the particular challenges faced by the future user groups without neglecting their social and clinical contexts; make sure to search iteratively the digital skills of the future users and their acceptance of the proposed platform; align the functionalities of the ICT platform with the real needs of its future users; and involve key stakeholders to guide the reflection on how to bring the platform to its actual implementation in the future.

Keywords:

Acceptability; implementation; neurodegenerative; Parkinson disease; dementia; chronic diseases; health care technologies; older people; stakeholders; information and communication technology; ICT; user-centered design; co-design

Introduction

As the global population is ageing, the prevalence of neurodegenerative diseases (NDDs) such as Dementias and Parkinson disease (PD) has increased. In Europe, the overall prevalence of dementia in people between 60-64 is only 0.6% average, increasing to 40.8% among individuals in their 90's. It is estimated that the incidence of PD has doubled over the last 25 years, increasing faster than any other neurological disorder. Both dementias and PD are of a progressive nature, and contribute to major reasons for disability and dependency among older adults [1-3]. Furthermore, the management of the NDDs is usually demanding and involves various healthcare services, resulting in a greater burden to be placed on the healthcare systems in terms of both costs and resources [4-8]. The convergence of various health services within the integrated healthcare models, enabled and adopted jointly with information and communication technologies (ICTs), has been identified as an effective alternative healthcare solution [9-13].

Previous literature highlighted the potential of ICTs offered in a wide variety of means, in supporting monitoring and managing health conditions [14]. For NDDs, ICTs have the advantages of improving patients' quality of life, quality of care, and reducing the healthcare costs [15,16]. However, its

widespread implementation faces formidable challenges [17,18]. Some of these challenges are related to technology complexity, resistance to change or low digital skills of the intended end users; and the costs associated with the deployment [19-21]. All of the aforementioned challenges are even complicated due to the fact that the integrated ICT healthcare solutions are linked to different groups of stakeholders, with reported discrepancies in their needs and preferences [22,24].

Alongside patients, caregivers and healthcare professionals, who are referred to as end-users. Implementation of ICT interventions involves other key stakeholders, such as policy makers, technology designers and healthcare managers. In fact, supporting successful implementation of technology for older adults requires extensive work on various levels: political, organizational, managerial, and scientific. Which in turn facilitate the required changes with respect to the healthcare systems and processes provision [18, 25]. Furthermore, engaging other stakeholders along the ICT development process helps to strengthen the likelihood that their current and future needs and requirements will be considered when advancing to real life adoption, that the implementation process is well coordinated minimizing disruption, as well as increasing the chances of aligning the process with the needs and priorities of all involved parties, thus ensuring a successful adoption and sustainability [26-30]. Regardless of the identified benefits, the actual involvement of other key stakeholders in both the development and implementation of integrated ICT interventions remains suboptimal [17].

Personalized Integrated Care Solution for Elderly “PROCare4Life” is a European funded project, that aimed to contribute to improving the quality of life and care of older people living with NDDs, through developing an ICT healthcare platform to be used among patients, caregivers, and healthcare professionals. User centered design (UCD) provision of the project started with the co-design and validation process, where future end users needed to be considered from the earliest stages. The needs and requirement fieldwork conducted by the PROCare4Life multidisciplinary team went beyond the inclusion of potential end-users, and extended to other key stakeholders involved in the different areas of NDDs healthcare process [31,32].

This paper complements a previous publication [33], that reported on the needs and requirements of PROCare4Life end-users in the development of an ICT-based integrated healthcare platform. The general approach of the study focused on identifying the aspects that the PROCare4Life should consider to achieve success in its acceptance, promoting its future usage, and the areas to be improved across all development phases since the initial ideation design of PROCare4Life. Aiming to shed lights on the opinions of other key stakeholders who took part in the study, in fields of academia, media, market and decision makers, we have conducted a further analysis of the data obtained from this complementary perspective. In the current paper we report the identified results of this analysis, including the participants’ opinions for improving the acceptability and implementation of an integrated ICT-based healthcare platform in NDDs.

Methods

Study design and setting

This study is part of a larger mixed-methods research that was conducted in 2020 by the PROCare4Life consortium, that aimed to identify the needs and requirements of its end-users and other key stakeholders in the development of an ICT-based healthcare platform targeting older people with NDDs and comorbidities. The study protocol and the results primarily related to the end-users are published elsewhere [32, 33]. The current paper focuses on the qualitative study that considered the opinions of the key stakeholders in the fields of decision making, healthcare market, academic and, media actors, who are involved in the healthcare of NDDs from five different

European countries (Germany, Italy, Portugal, Romania, Spain).
The study included 30 individual semi-structured interviews, that took place between June and August 2020. Almost all the interviews were done on the web, except for participants who asked to be interviewed in-person. In that case all the PROCare4Life COVID-19 distant procedures were applied [34].

Participants

Participants representing key stakeholders were included if they didn't have any conflict of interest with PROCare4Life objectives and consortium, aged ≥ 18 years and able to provide consent, and working or expert in any of the following four areas:
1. ***Market actors*** were identified as potential buyers and/or investors of the technologies and services piloted by the project (e.g., health care providers).
2. ***Policy and decision makers*** were identified as stakeholders who have the power to regulate or integrate project results into their scope, be it a country, region or organization (e.g., political representatives, people implementing change in healthcare provision, health related authorities).
3. ***Academia*** were identified as stakeholders from the scientific and cultural community, which can use project results and outcomes in future research (e.g., universities and research centers).
4. ***Media actors*** were identified as relevant media related, able to expand our reach to identified target groups, as well as to the general public (e.g., press).

All potential participants were approached by a member of the PROCare4Life team and received information about the project via email. Prior to the interviews, personalized video calls were also offered to the potential participants to explain more about the study aims and clarify any potential doubts.

Data collection and analysis

Individual interviews with open-ended questions were conducted, each one lasted between 30-45 minutes focusing on the following topics:

- Sociodemographic data
- Opinions regarding ICT-based healthcare platforms for older people with Dementia and PD, identifying possible facilitators, barriers, and implementation prerequisites
- Suggestions to be considered in designing an ICT-based healthcare platform, enhancing its marketing potential and acceptability by the targeted users.

Within the scope of an extensive research, it became apparent over time that the complexity and diversity of the gathered information posed a significant potential, leading to revisiting the data and conducting a further analysis. Collected data were recorded and transcribed verbatim according to the guidelines provided by the research team. In which, each interview was transcribed and revised by 2 researchers from each project site, using a transcription software (i.e., Parlatype). In case the interview was conducted in languages other than English, an additional translation step was concluded. Translation process involved native speakers from both the interview language and English language. A deductive-inductive qualitative data analysis was conducted, using MAXQDA software-version 20 [35]. The thematic analysis process [36] started with reading all the interviews by two researchers independently, and both took notes and documented them. The initial coding was then conducted, based on a framework derived from the question's categories in the interviews, and provided by the main researcher. A further open coding was done inductively. After that, two discussion sessions among the main researcher and two other involved researchers were held, as corresponding themes and illustrative quotes were identified and finalized.

Ethical considerations

The study protocol was approved by local ethical committees in Germany, Italy, Portugal, Romania, and Spain. The organizations conducting this study enacted an additional data handling agreement prior to commencing any processing of personal data, according to legal regulations and following good practices in research.
Participation was entirely voluntary, and the participants had the right to withdraw from the study at any time, without giving reasons or experiencing any disadvantage. Adhering to standards of Good Clinical Practice and International Conference on Harmonization standards, once the study was fully explained, a written or digital informed consent was obtained from each participant before any study-related procedures.

Results

Participants

30 stakeholders completed the interviews (table 1), distributed as 6 media actors, 8 market actors, 8 decision makers and 8 participants who worked in the academic field. Most of the participants came from Germany (36.7%, 11/30) and Portugal (33.3%, 10/30). More than half of the participants were males 53.3% (16/30), and 46.7% (14/30) were aged between 46-65 years old. 40% (12/30) of the interviewees were PhD holders and had over 20 years of working experience.

Table 1: Characteristics of the participants across countries, and stakeholder sub-groups (n=30)

Characteristic	**Total, n=30**
Type of Stakeholder	**% (n)**
Media	20 (6)
Market actor	26.7 (8)
Decision maker	26.7 (8)
Academia	26.7 (8)
Country	**% (n)**
Germany	36.7 (11)
Italy	16.7 (5)
Portugal	33.3 (10)
Romania	6.7 (2)
Spain	6.7 (2)
Gender	**% (n)**
Female	46.7 (14)
Male	53.3 (16)
Age (years)	**% (n)**
18-30	6.6 (2)
31-45	26.7 (8)
46-65	46.7 (14)
66-75	16.7 (5)
Not reported	3.3 (1)
Education Level	**% (n)**
Post-secondary school	6.6 (2)

Bachelor degree	3.3 (1)
Master's degree	36.7 (11)
PhD	40 (12)
Not reported	13.3 (4)
Years of Experience	**% (n)**
1-5	13.3 (4)
6-10	20 (6)
11-20	23.3 (7)
Over 20 Years	40 (12)
Not reported	3.3 (1)

Evaluation Outcomes

Based on the data gathered and analyzed across the semi-structured interviews, our participants were largely aligned in suggesting some ideas when approaching the potential end users. Considering the possible measures in improving the acceptability and implementation of an ICT-based healthcare platform, we have identified two themes and five sub-themes (ST) presented as follows:

Theme 1: How to improve the acceptability of ICT health platform

In this theme the participants shared their opinions regarding aspects for improving the acceptability of the ICT-based healthcare platforms amongst end-users in the NDDs caring process.

Table 2 depicts the 3 STs identified, codes and sample quotations corresponding to this theme.

Table 2: Qualitative data analysis results: summary of STs, codes, and quotations corresponding to theme 1 (how to improve the acceptability of ICT health platform).

Subthemes	Code	Q ID	Interviewee profile	Sample quotation
ST1.1: User's engagement	Understand the users' needs	Q1.1a	Market actor-Italy	"All the aspects related to users' perception and experience should be taken into consideration in order to tip the perspective and generating a demand instead of an offer"
	User-center approach	Q1.1b	Market actor-Italy	"If the user-centered methodology work, it will be relevant to receive the feedback about the platform use from different users"
	Early involvement of the target users	Q1.1c	Academia-Germany	"I think the system has to be developed very closely with people from the target group and always be tested from the beginning. So, any approach should be discussed and worked out with older people and then I think that this access to the different methods needs to be considered"
	Conduct regular usability	Q1.1d	Academia-Romania	"This requires performing quantitative and qualitative research; quantitative in which you apply

	assessment			some validated questionnaires on quality of life or something else, and qualitative by means of interviews, such as this, you talk to the patient, if possible, with the family / caregiver”
ST 1.2: Training and digital divide	Digital illiteracy & resistance to technology	Q1.2a	Decision maker-Portugal	The barriers essentially have to do with the lack of knowledge. The digital evolution is constant and requires continuous training of all people in the health area. There is some resistance from the elderly to technologies”
	Provide education for end-users	Q1.2b	Academia -Portugal	“All people involved in this project should have the information about the main objectives of the project and about all the devices involved regarding the data. It's important to give them some education”
	Methods for training	Q1.2c	Market actor-Italy	“Healthcare providers can be informed through continuing education, webinars, seminars, and conferences”
		Q1.2d	Decision maker-Portugal	“Define methodology and concepts very well. Carry out pilot projects that give confidence to health professionals and disseminate results”
	Training	Q1.2e	Market actor-Germany	“I think people need to be trained as a prerequisite”
	Provide evidence-based data	Q1.2f	Academia-Germany	“To know about the acceptability and usability is super useful, whether it works or not, and to know which things work and which don´t work, so these results are super valuable for sure. I think you should avoid the issue of promoting your system, I don´t know if there is a risk of this and there could be a bias of being positive about the system, I think that can really help to be critical and have a self-criticism built in the way you report the results, and avoid trying to sell your system to the research community, and that can be a very strong point if you can minimize the risk of bias”
ST 1.3: Usage of Media	Which media channels preferred by the old population	Q1.3a	Media-actor-Spain	“If we follow reliability then our target group prefers the radio first, then newspapers, TV and internet the last. So, the perfect option for them it would be that their doctor would be talking about this kind of project

				in a local radio”
	Social media	Q1.3b	Media actor - Portugal	“Social media can be an entry point, a way to capture attention and visibility. More importantly, they allow to target users according to their profile”
	Create your own media channel	Q1.3c	Media actor- Germany	“You could also create a PROCare4Life group, so that the relatives can exchange information (…) But I think social media are a good thing in any case. But you also have to place the contributions well (….) Or you can actually create your own social media”

Q: quotation

ST 1.1: User’s engagement

There was an agreement among the participants that involving the potential end-users over the ICT for health development process, since its inception, is fundamental. This involvement should start from the beginning of the project, and during the design phase in a way that can create a need for the proposed platform rather than an offer (Q1.1a). Participants pointed out that adopting the user-centered design approach is essential (Q1.1b), which can ensure that potential end-users are involved from the early stages of the proposed platform design and throughout the implementation phase (Q1.1c). Furthermore, collecting and reassessing the user-experience and acceptance frequently via qualitative and quantitative studies needs to be incorporated and properly planned throughout the entire development phase (Q1.1d).

ST 1.2: Training and digital divide

Digital illiteracy or lack of knowledge about using technological devices among patients, caregivers and healthcare professionals was reported as a barrier, some end-users tend to avoid or even reject using innovative technologies (Q1.2a). Fostering the knowledge of the potential end-users involved in the care process, through providing education about the proposed platform, including its benefits, devices integrated, and its usages is needed (Q1.2b). Education can be carried out using multimedia methods adapted to the target population. Information about the methodologies and concepts adopted in the design and development of the proposed platform might be relevant for some of the end users, mostly healthcare professionals, and managers. Some of the means to provide information to a wider audience might be completed through conferences or dissemination activities in order to provide them with evidence that is convincing for integrating the platform into their working routine (Q1.2c & Q1.2d).

Furthermore, providing training opportunities on how to use the technological devices is important, in overcoming the digital literacy barrier (Q1.2e).

At later stages, participants in the co-design activities can receive back reflections and sharing of the early or preliminary results obtained from the pilots conducted during the development process with potential end-users. This can be achieved providing evidence-based material regarding the strengths and limitations of the current version of the proposed platform (Q1.2f).

ST 1.3: Usage of the Media

Using media channels for advertising and promoting the proposed platform was discussed during the interviews. Participants highlighted the role of the media as part of the marketing strategy for ICT

healthcare platform. Elaborating on this ST, our participants referred to the heterogeneity of the target end-users when it comes to their media preferences. As older population prefer radio, newsletters, TV, and to a lesser extent internet-based media (Q1.3a).
On the other hand, social media was seen as an entry point that can capture visibility for the target end-users (Q1.3b). Therefore, some of the participants even suggested creating the projects' own media channel, where real stories derived from the pilot participants could be shared, agreeing that such content is powerful and could increase the acceptability among the older population and other user groups (Q1.3c).

Theme 2: Suggestions for facilitating the implementation of ICT health platform

In this theme, our participants elaborated on measures to be considered in the implementation phases of digital healthcare platforms. Both assuring the funding sustainability and the cooperation with different authorities were suggested, the identified two STs and sample quotations are illustrated in table 3.

Table 3*: Qualitative data analysis results: summary of STs, codes, and quotations corresponding to theme 2 (suggestions for facilitating the implementation of ICT health platform).*

Subthemes	Codes		Interviewee profile	Sample quotation
ST 2.1: Funding sustainability	Funding is an initial barrier	Q2.1a	Decision maker-Portugal	"The financial issue may only be an initial barrier. But it is all relative, it depends on the service provided. If it is really good, a service of excellence, it is no longer considered an expense and becomes an investment. We must have enough data to prove it and be seen as an asset, with results. The beginnings are always hard"
	Health and social systems should provide funding	Q2.1b	Decision maker-Spain	"It is not an easy task, but it should be financed by both the health and social systems"
	Third party fund	Q2.1c	Decision maker-Germany	"Applying for funds through projects"
	Provide different price offers	Q2.1d	Market actor-Germany	"In my opinion the price should be practically depending on the type of digital solution, it would have to be divided somehow. I can't demand the same price from someone who only uses one sensor as from someone who uses everything else. I think that would have to be graded according to the type of performance"
ST 2.2: Collaboration with authorities	Collaboration between local and general authorities	Q2.2a	Decision maker-Italy	"A more efficient and constructive cooperation between local decision makers and higher, national ones would facilitate the implementation of

				an integrated care system. Then, an informative action inside the hospital to raise awareness in patients and health-professionals about this kind of systems would be beneficial (..) Individual national organizations first, and then the regional ones, and their regulations, should be considered in order to put in place an integrated care system like this"
	Political and social co-operation	Q2.2b	Decision maker-Portugal	"Political will and bringing partners to the project. Having a strong and robust social network, which is the basis for developing such a project. There is a strong desire by the municipalities to work on a model of this nature"
	The importance of communication between different authorities	Q2.2c	Decision maker-Spain	"Communication channels. Right now, there is no communication channel between the health and social services, but there are no efficient communication channels between the health services themselves or between the social services either"

Q: quotations

ST 2.1: Funding sustainability

Our participants referred to financing issues as an initial barrier for implementing and maintaining an ICT-based platform running. However, positive results and benefits obtained through the development and implementation can contribute to overcoming this barrier (Q2.1a). In order to provide a sustainable funding for digital healthcare solutions, participants proposed several ways, such as the finance supported by the social healthcare systems and health insurance companies (Q2.1b), or as projects-based fund (Q2.1c). A software as a service funding model was also suggested, providing different customized packages that fit individual needs and usage patterns in affordable prices (Q2.1d).

ST 2.2: Collaboration with different authorities

Another suggestion that was repeated over the interviews, was to prioritize the cooperation with different authorities. For ensuring a successful implementation of digital healthcare solutions, participants pointed out the importance of bringing along local and regional authorities together. Local organization need to contribute to raising awareness of the expected benefits from such solutions before its implementation by the regional authorities (Q2.2a). Interviewees also mentioned with great alignment across participants that including the political and social partners together is one of the bases for developing and implementing digitally enabled integrated healthcare (Q2.2b). There is a need for creating communication channels between all the different sectors involved in the healthcare process and digitalization of the society, with an efficient collaboration between health and social care services (Q2.2c).

Discussion

Principal Results

This study addressed strategies needed to improve the acceptability and implementation of an integrated ICT-based healthcare platform. Beyond the potential end-users (i.e. patients, caregivers, healthcare professionals), we brought in the voice of other stakeholders linked to the healthcare technologies in areas of market, decision makers, academia, and media experts. The majority of our participants identified the importance of the UCD approach in including the end-users in the development process, and exploring their needs. End-user engagement impacts the initial acceptability and the sustained usage of ICT healthcare solutions, as reported by Nadal et al. [37]. Hence, the early engagement of end-users starting from obtaining their feedback regarding the design, and moving to regular usability assessment throughout the development and implementation process is needed.

Despite the acceptance that have been shown towards ICT solutions by older populations, their families, and healthcare professionals [33, 38, 39], participants in the current study stated that the lack of knowledge about the benefits and the design of technology, accompanied with the complexity in using and managing technology are common challenges for ICT adoption in NDDs healthcare. Providing education about the design, aims, and benefits of ICT-based solutions was therefore proposed. Additionally, conducting conferences, workshops, and other dissemination activities to inform the potential end-users about the proposed solutions were suggested as education activities, that support overcoming these challenges and facilitate the adoption of ICT in the healthcare [40-46]. Furthermore, providing continuous training for all the potential end-users is needed, and shall be considered from early stages of the development. In particular, this holds for digital platforms which include multiple devices. Tailored training programs shall consider the various digital skills of its intended end-users, aiming to simplify the design, and thus increase its acceptance [47]. On the other hand, participants from the scientific field pointed out to the importance of reflecting on the usability results obtained from the target users, and making these data available for the public. This finding complements other evidence reported that, validating and assessing digital interventions via trials that involve older adults is critical, and impacts the acceptance and health decision making [48].

Another important finding was considering the role of the media channels. Our participants stated that media contributes to: informing the potential target groups about the innovative ICT platforms; raising awareness and; fostering a positive attitude towards the available ICT solutions. Similar to previous literature, these contributions support acceptance and successful implementation of ICT solutions in healthcare [49,50]. While the usage of social media has increased rapidly across various age groups in recent years [51], our participants highlighted the heterogeneity of preferences among older people with chronic diseases. Traditional media channels such as radio or TV were considered the first choice, that should be used when approaching this target group. It is also noteworthy that some of the participants recommended creating a media channel dedicated to each project, where personal narratives, success stories, and challenges faced by end-users are shared.

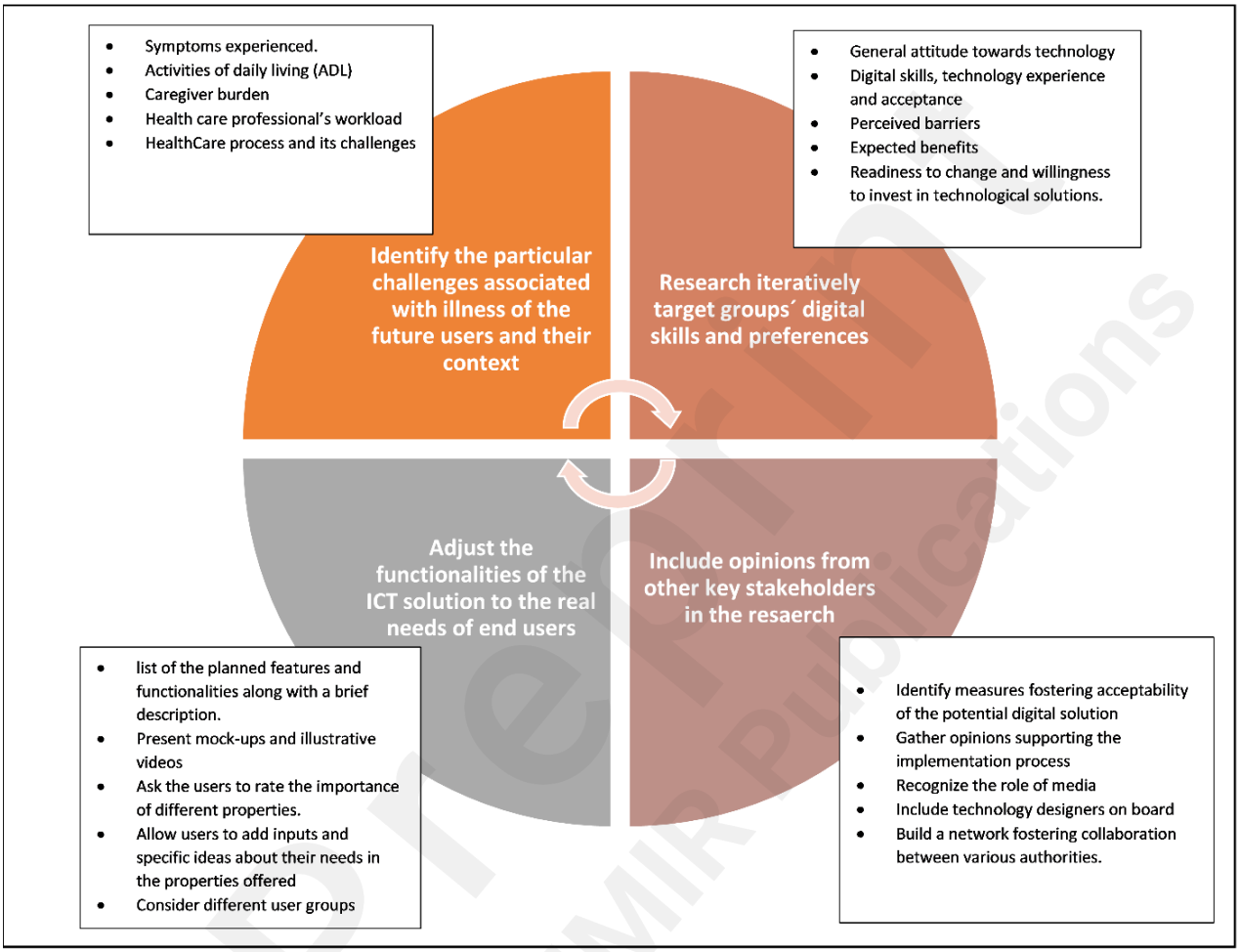
Similar to a wide body of research [52, 53], our participants referred to costs and sustainable funding as common barriers to the implementation across digital healthcare domains. Facilitating these barriers would require a collaborative multidisciplinary work on various levels, such as co-operation between social and health systems. Some of the participants voiced out the need for providing different pricing models, that are both personalized for the user needs and affordable. In line with

what has been reported by Frishammar et al. 2023 [39], providing opportunities for flexible and personalized pricing models is only possible through the active collaboration between developers and policy dimension in the digital healthcare section. Therefore, the majority of the participants highlighted the need for bringing relevant authorities together when developing and implementing successful ICT healthcare solutions for older people. Furthermore, finding a medium for communication is critical. This is of great importance, as communication among various authorities is crucial to guarantee a cross-disciplinary collaboration, in which ICT solutions will be put to work effectively [17,18].

Recommendations for the research on users' needs

Stemming from evidence reporting that starting the development process with comprehensive study on the users' needs, can prevent or better manage the uncertainty and skepticism of some of the target users towards the technology [54]. In this context, we propose recommendations for a comprehensive methodology to be adopted in studies on users' needs in ICT-based healthcare solutions for dementia and PD, and when the development process adopts the UCD approach. These recommendations are derived from the findings of the current paper, and other results from our research on end-users needs reported elsewhere [33]. As there is an overlap between our findings and those from previous research as well [55], it is also relevant to consider these recommendations when targeting older populations with other chronic diseases. The recommendations are grouped in one model that covers four aspects (see figure 1), and explained as follows:

Figure 1: A model for the research on users' needs, covering 4 main aspects, along with proposed topics to be investigated corresponding to each aspect. The model is to be used by projects that aim to develop ICT-based healthcare platforms that adopt UCD approach, and target older people with NDDs and other chronic conditions.



Identify the particular challenges associated with illness of the future users and their context

One of the main aims when conducting research on users' needs, is to identify the specific challenges faced by the potential users and how they are being tackled. Older people with chronic conditions, in particular those with NDDs face everyday problems that also affect their relatives and families. There is a large heterogeneity of situations, linked to the cognitive and mobility capabilities of future end users. Therefore, future studies should focus on the actual functions and abilities rather than the diagnosis, and study the individual disease experience and evolution. Enabling a better understanding of the influence of concrete symptoms on everyday life abilities and mental abilities, rather than focusing on the overall diagnosis and medical symptoms alone [56]. From our findings, looking only at the diagnosis could be misleading. For instance, while (71%) of our participants from the patients were diagnosed with Parkinson, which is a motor disease in nature. However, based on in-depth analysis, both personalized memory support and reminders were mostly required as functionalities to be included in digital healthcare solutions.

Furthermore, dementia, PD and comorbidities, have implications that are beyond the people diagnosed with these conditions, extending to other end-users' groups, namely: healthcare professionals and caregivers. Therefore, identifying these groups' needs and problems, such as caregiver burden and the healthcare professional's workload, is also important for the research team to consider in the ICT design and development processes.

Research iteratively target groups´ digital skills and preferences

Digital skills vary greatly across the different end-user's groups, and thus there is not one solution that fits all. Therefore, when developing an ICT-based healthcare platform, it is important to consider the previous technology literacy and the digital abilities of the intended end-users, together with their social support to use technology [57]. From PROCare4Life, we recommend investigating the user technology experience and acceptance as an integral part of the research on users' needs. Applying both objective and subjective measures, we argue that this step could support ensuring inclusivity of the digital solution developed.

Another important aspect, is identifying the barriers that might hinder the intended users' adoption of the specific digital solution. Acknowledging those barriers at early stages of the development might support the developers to accommodate the solution, and provide alternatives when eventual barriers might be identified. For instance, in our research and owing to privacy concerns, most of the potential end-users did not accept the usage of in-depth cameras. Identifying this, the projects' development team created a modular system that worked with and without cameras, depending on the end users' preferences. Additionally, the technical team worked on updating the code with the in-depth cameras and the real-time software to avoid the storage of any patient's images. Meanwhile, when developing a digital platform that includes various devices (smartphones, wearables, cameras), we recommended exploring the acceptance of each one of the devices integrated among the intended target groups, hence, reducing the risk of the devices being left unused.

Furthermore, another recommendation is considering exploring the participants' opinions regarding the expected benefits, and how far are they willing to invest in the technology being developed. Recognizing these facts as early as possible supports the developers in aligning the design of the technology with the reported expectations, and making it more relevant for the intended users.

Adjust the functionalities of the ICT solution to the real needs of its future end users

Similar to other studies, our research on users' needs identified that personalization and ease of use are often discussed features in connection to technology [58-61]. Transforming those needs and the realization of personalized technical features, shall be derived from a proper research on the needs of the end users. Otherwise, there is a risk that the developed technologies are only integrating assumptions, limitations and biases of the research and development teams. Questions such as, What do elderly people living with chronic diseases need; How can technology contribute to those needs; Which functionalities and features needs to be integrated, must be researched considering the different targeted end-users' groups.

We recommend conducting interactive discussions with future end users, providing explanations to them, and relating symptoms to functionalities as a way for supporting them verbalizing their needs. Initiatives such as showcasing interface mock-ups and demonstrating various technical features, using illustrative videos or screenshots of the design and functionalities throughout the development

process, foster collaborative design and co-creation of the digital solution. This, in turn enhances its future acceptance and usability by incorporating adjustments whenever challenges are encountered by the research team or end users. Our suggestions align with previous research [62,63] that have reported the difficulties that most of the end-users, particularly older patients, face when imagining how the desired functionalities are to be integrated into digital solutions.

Include other key stakeholders in the research on users' needs

UCD approach and co-design are common terms in the development of technologies for older populations, with the first aims to involve users in the development process, whereas the second brings together different stakeholders to collaborate to the creation [64,65]. While both terms have been recommended to be adopted when developing ICT-based healthcare platforms [31, 66], only few studies have reported the actual usage of their principles [67]. In PROCare4Life research, the importance of including other key stakeholders beyond the end-users has been recognized. In fact, bringing in voices of experts in areas linked to the future exploitation of ICT systems, such as scientific research, market, policy, and media, not only have proven to enrich the research on user needs and to foster the overall UCD approach, but has also anticipated the exploitation the future implementation of the ICT-based platform. Also, based on our findings, this dialogue with experts brings valuable ideas to be considered in the efforts to develop a well-accepted digital solution, and facilitate the implementation process in the medium and long run.

Stemming from the growing role that media plays in the recent years, shaping the awareness of many people in digital healthcare, the importance of bringing media experts on board in future research needs to be stressed out. It is also important for technology designers to take part in such research studies, as they have been referred to as another fundamental stakeholder in digital healthcare solutions, whose needs and preferences need to be identified and accounted for [68].

Strengths and limitations

The study was affected by the restrictions associated with COVID-19, and the contingency measures. For practical and safety reasons, most of the interviews were conducted on the web. Video calls were set up to reduce the distance between the interviewee and interviewer at times of social distancing due to the COVID-19 pandemic. Whenever possible, English language was the language used. However, participants were free to decide for using their native language, as selectively translating and transcribing the interviews was conducted later during the data analysis process. No language barrier was reported during those interviews. The flexibility to conduct both remote and in-person interviews, when necessary, demonstrates the study's adaptability to changing circumstances. This aspect highlights the strength of the methodological approach.

The involvement of highly experienced experts from various disciplines and a variety of countries within the European Union, had brought diversity of knowledge, expertise and perspectives. Including professionals from diverse backgrounds such as media, market actors, decision-makers, and academia was essential for obtaining a comprehensive understanding of the elements impacting the acceptability and implementation of ICT-based healthcare platforms in the context of NDDs. Including the perspective of media professionals was instrumental in shaping public perceptions, potentially contributing to increased acceptance and understanding of the platform's benefits.

While the diversity of experts and the quality of their experience strengthened the validity and relevance of the findings obtained in the framework of this study, thereby solidifying the robustness of the obtained results. However, the lack of representation of technology experts or designers

among interviewees was a main limitation of the current study. Aiming to investigate the technical perspectives, our methodology relied on the experience brought by the different key stakeholders' groups included, and the technology experts who are active in the PROCare4Life consortium. Nevertheless, future studies need to bring in the voices of technology designers and experts, and to make sure that their needs and ideas are well represented in research on users' needs.

The thematic analysis along with the deductive-inductive approach in the current study, used a framework derived from the question's categories in the interviews rather than using other existing technology acceptance models (e.g., TAM, UTAUT-2). This is mainly due to the fact that these models focus primarily on the user, and applying them require the users to actually test or use the technology before acquiring their opinions [69-71]. Considering the aim of our study of involving other related-stakeholders, and that the study took place at an early stage of the development process of the platform. The decision to utilize the deductive-inductive yielded mostly consistent results, and were in line with findings from literature.

The research on users' needs intended mainly to support and guide the development of the PROCare4Life platform, meaning that questions and discussions regarding the specific design of the PROCare4Life were integrated in the study guidelines. This might be interpreted as a limitation for generalization of our results, and in turn the recommendation proposed. Nevertheless, the questions included in the study were mostly general, and those were the ones we have analyzed in our current results. Furthermore, we could demonstrate alignment of our results with literature, and even point out to the importance of considering the specificity of every project in our recommendations.

Future directions

Gangas et al (2023) recently published a paper highlighting the lessons-learned from the pilot 3 of PROCare4Life [72]. The paper emphasized that, developing multidisciplinary collaboration is effective in identifying and managing challenges related to the ICT platforms, both in the development and implementation phases. Aligning with our results, we argue that responding to the various needs of the end-users in ICT-based healthcare platforms, requires a shared dialog between different experts such as; researchers, policy makers, technology developers, and media experts. Addressing barriers for ICT adoption among older population, such as technology complexity and digital literacy, is possible by providing a tailored platform. Future projects are required to plan and budget for personalized training measures for end-users, ensuring that the time needed for training on the technology is planned for. Furthermore, overcoming costs of technology adoption can be facilitated by offering tailored pricing models, that accommodate the idiosyncrasies implicit in reimbursement systems unique to regions or countries. However, considering the importance of maintaining a sustainable funding for digital health solutions, a specific research needs to be conducted to identify the various existing funding opportunities, and to explore other ideas with different stakeholder's groups.

The role the media plays in shaping the public awareness including older population, has been noted in the current study. However, the precise impact of this role on the acceptance of ICT among older people with chronic conditions, needs to be further investigated. More studies should test and report results, considering which media channels and strategies to be used and their effectiveness, what type of content to be incorporated, and finally how can the messages be crafted and tailored for this target group.

Conclusion

The data obtained from the current study highlighted the importance of the UCD approach, in ensuring the involvement of the users in the development of ICT platforms and integrating their needs. However, addressing the most common challenges that hinder the acceptability and the implementation of ICT-based healthcare platforms, requires creating synergies among efforts from users, academics, developers, policy and decision makers. In order for the future ICT healthcare projects to base their development on a comprehensive understanding of potential users, this paper outlined recommendations to be integrated when conducting research on users' needs. Comprising the following aspects: properly identify the particular challenges faced by the future user groups without neglecting their social and clinical contexts; make sure to search iteratively the digital skills of the future users and their acceptance of the proposed platform; align the functionalities of the ICT platform with the real needs of its future users; and involve key stakeholders to guide the reflection on how to bring the platform to its actual implementation in the future.

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Data availability

The data sets generated during and/or analyzed during this study are available from the co-author author (MM) or the corresponding author on reasonable request.

Authors' Contributions

This paper was conceptualized by MA, MM, and MB. First draft was prepared by MA. MM, CL, PG, EB and MB reviewed the draft and contributed substantially to the results and discussion sections. All the co-authors reviewed and approved the final version of the manuscript.

Conflicts of Interest

"none declared".

Abbreviations

ICT: information and communication technology
NDD: neurodegenerative disease
PD: Parkinson disease
PROCare4Life: Personalized Integrated Care Promoting Quality of Life for Older People
ST: subtheme
UCD: User centered design

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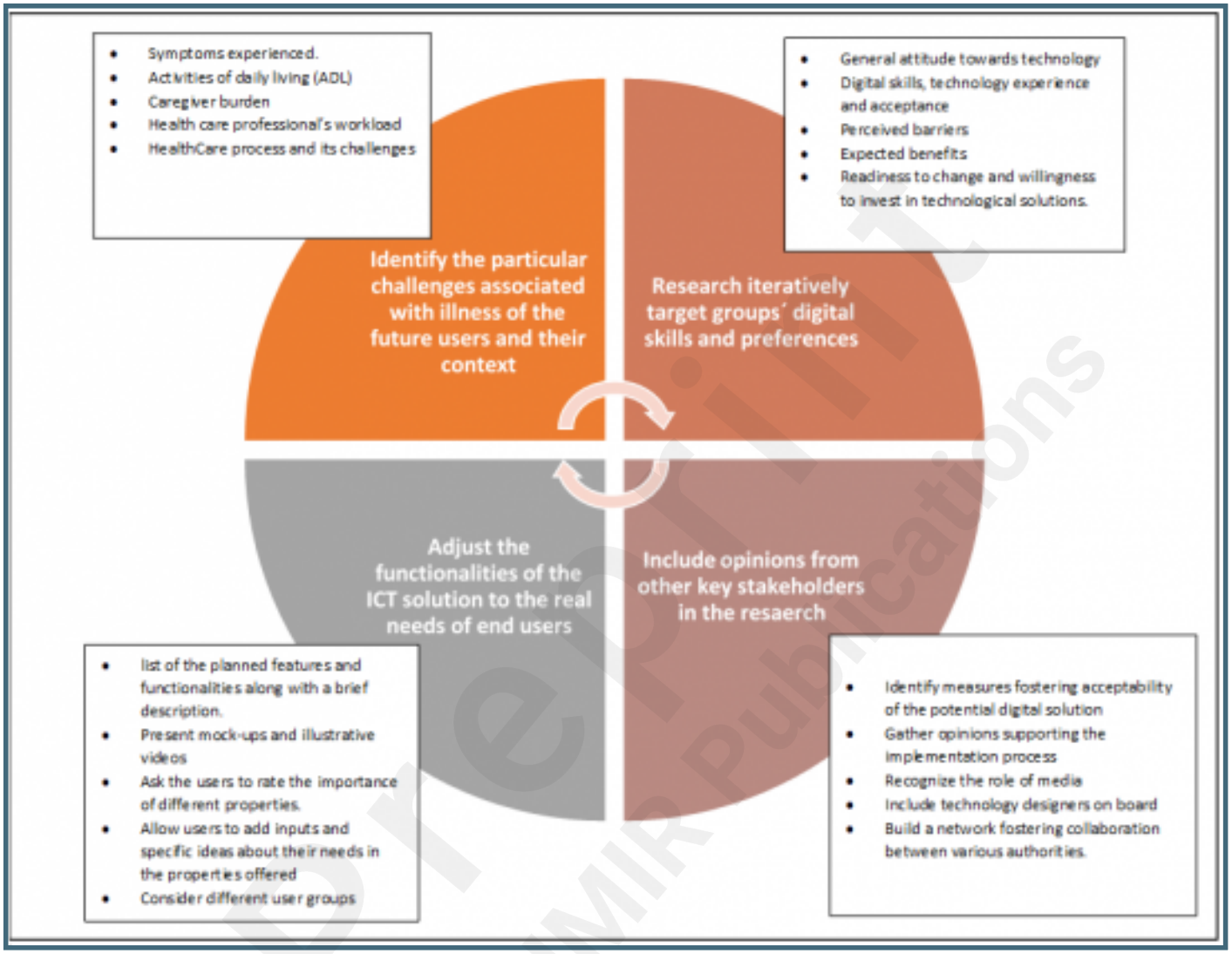
Supplementary Files

Figures

A model for the research on users' needs, covering 4 main aspects, along with proposed topics to be investigated corresponding to each aspect. The model is to be used by projects that aim to develop ICT-based healthcare platforms that adopt UCD approach, and target older people with NDDs and other chronic conditions.



Related publication(s) - for reviewers eyes onlies

The study protocol that was published in JMIR research protocols journal in 2021.
URL: http://asset.jmir.pub/assets/c8655b535fb29efdf76c1f2de2de3c23.pdf

The first results paper, published in JMIR formative resaerch in 2022.
URL: http://asset.jmir.pub/assets/d8cb0b0a409f1bc500baf51060a18d30.pdf