

CAREGIVERS' ROLE ON ICT FOR AFE

Green Paper | Four-step list of actions to maximize the engagement of caregivers at all stages of ICT life cycle and exploitation



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ABSTRACT

“Caregivers’ role in Information and Communication Technologies (ICT) development and exploitation for Age-Friendly Environments (AFE)” is the result of a Collaborative Work between members of Action Groups C2 (Independent living solutions) and D4 (Age-friendly buildings, cities and environments) of the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA) [1].

The analysis of existing approaches and challenges around this theme led to the development of a methodology composed of a four-step list of actions that should be addressed during the life cycle of ICT development projects in order to maximize the engagement of caregivers at all stages of development until the product reaches the market.

This easy-to-apply method can be used by different stakeholders during the development of new technological solutions and the validation of corresponding business models. The proposed guidelines do not require major adjustments to existing approaches but, by presenting a simple structure, can add significant benefits to the current practice and enhance the added value and market acceptance of the new solutions/products.

This document is the starting point for an open consultation between September and November 2018 on practices and policy recommendations to strengthen the engagement of caregivers in the development process of ICT-based solutions for AFE, leading to a Green Paper on the subject which will be the denouement of this collaborative effort.

BACKGROUND

The demographic old-age dependency ratio was established at 29,6% in 2016 and it is projected to increase to 51,2% in 2070 [2]. This means that in Europe we will have two working-age people for every person aged over 65 in 2070. The ageing population is the net result of decline in birth rates and increased life expectancy. The improvements in welfare and medical care are contributing to longer lives in European population; yet the increase in the number of life years does not immediately translate into an increase in Healthy Life Years (HLY)¹. The latter measurement is now recognized in the new World Health Organisation Work Programme as the main measure of health care success to assess the achievement of this major public health goal “*to live not just long but also healthy lives*” [3].

The main care models implemented to support older persons rely on formal and informal caregivers providing help and care in different living environments, from residential homes to individual houses.

Considering the context of demographic change around the world, the challenges for caregivers are increasingly demanding and the consequences on their physical and mental conditions are reflected earlier and have clear consequences on their level of productivity and absenteeism. In this sense, technologies have the potential to be essential tools to help older people to *Age in Place*, in a healthy and independent way, enhancing socialization and autonomous routines for

¹The Healthy Life Years indicator (HLY) is a European structural indicator computed by Eurostat. HLY measures the number of remaining years that a person of a certain age is expected to live without disability. It is actually a disability-free life expectancy.

as long as possible. Likewise, they also have a high potential for making caregivers' work easier and more effective in providing social and health care, facilitating their usual tasks, better managing the situation, their routines and relieving their burden as well as the stress symptoms associated to their work that make them feel depressed, emotionally weakened and isolated.

Additionally, technology has much to offer to the Silver Economy Market by opening new pathways to a more preventive and empowering approach to healthy ageing. These solutions, if designed and implemented in accordance with users' needs and wishes would have direct benefits for older persons in need of care and formal and informal caregivers themselves and also for the social health care providers as reported by several studies [4, 5]. Therefore, the involvement and participation of both older persons and caregivers in the design and development of technological solutions through a co-creation process that engages all relevant stakeholders, will have a highly positive impact on the success of the technological solution. This document will focus on the participation of caregivers in the development of ICT solutions and corresponding business models.

CHALLENGES TO BE ADDRESSED

A co-creation process around the development of technologies can include different actors and stakeholders and when it is related with ICT for older persons, the good practice should be to engage the older persons and their network (e.g. caregivers, family, relatives, neighbours, etc) from the beginning. Departing from this, once the co-creation process aims to develop an ICT solution for older persons as the primary end user [6], it is usual formal caregivers encourage and motivate older persons to get involved in the ICT development, providing inputs and feedback. But sometimes caregivers are not the final users of the technology - they are the secondary end users, so they do not feel fully engaged in this process. Several reasons can be described:

- Even though they understand the importance and benefits of the innovative technologies in older people's lives, they somehow struggle to adopt and integrate ICT solutions in their (caregivers) own routines, because change is always a challenging process.
- When caregivers are replacing the older persons interests in the co-creation process, acting as surrogates, it is difficult to keep them engaged and motivated at all stages, since their heavy burden in care tasks along with some lack of digital literacy and communication skills [4, 5] hinders their adherence to the assessment and validation of ICT.

Furthermore, since the caregivers will become the "new older persons" in the future, considering their experience and contributions is highly important for the development of useful solutions for ageing in place.

CONCEPT AND METHODOLOGY

Starting from the challenges identified in the reviewed literature and from the experience in projects related to ICT and Age-Friendly Environments, ***the outcome of this document can be translated into the concept presented in the figure below:***

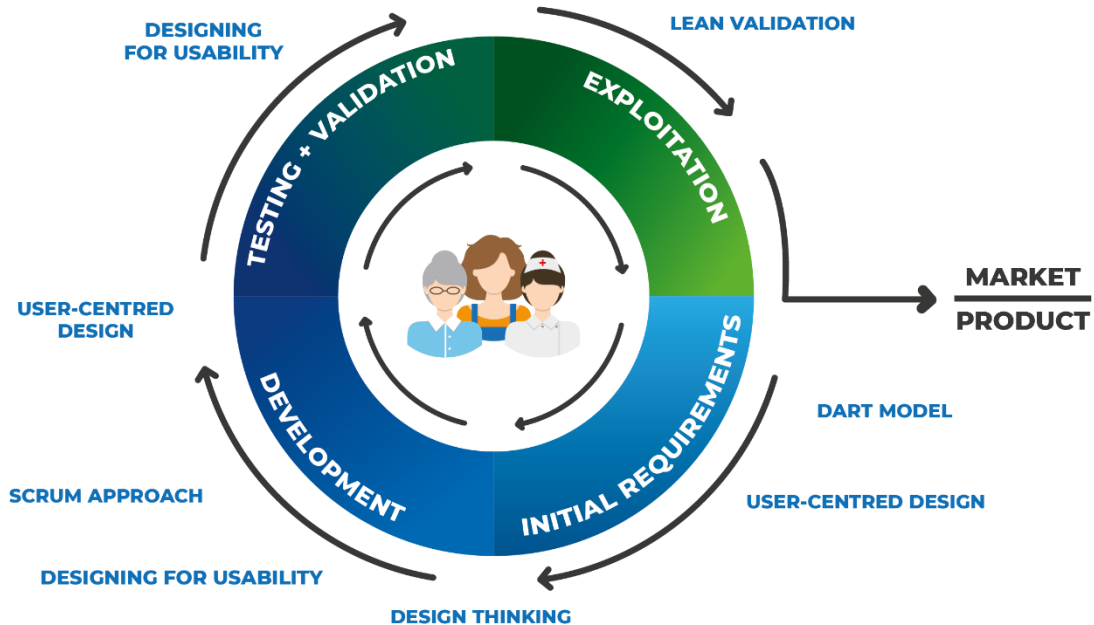


Figure 1: Caregivers' role on ICT for AFE (own elaboration)

This concept is grounded on three pillars:

1. The steps of ICT technology development and exploitation:
 - a. initial requirements;
 - b. development;
 - c. testing and validation;
 - d. exploitation.
2. The existing co-creation methodologies:
 - a. DART Model;
 - b. User-Centred Design;
 - c. Design thinking for social innovation methodology;
 - d. SCRUM approach;
 - e. Lean Validation.
3. The experience of the working group participants running ICT projects for Age-related challenges:
 - a. CARICT - ICT-based solutions for caregivers;
 - b. CITI-SENSE - Development of sensor-based Citizens' Observatory Community for improving quality of life in cities;

- c. E.C.A.R.E. - Community model for social isolation intervention of older persons;
- d. GrowMeUp - robotic system to support older persons carrying out their daily life activities;
- e. ICT4Life - ICT services for life improvement for the elderly and people affected by neurodegenerative diseases;
- f. Intent Care - educational technological resource for family carers;
- g. KWIDO_TELECARE - Multi device software platform for caring elderly patients at home;
- h. MOVECARE - Multiple-actOrs Virtual Empathic CARgiver for the Elder;
- i. TSBank - Time and Skill Bank for Active Ageing.

It intends to articulate these 3 pillars and to define a list of actions that could help the technical partners to increase the caregivers' participation in the different steps of development of technological solutions, thus facilitating their adjustment to the real user and market needs.

After having identified the challenges and the proposed objectives, the theoretical and experimental framework is described. It is based on desk research that identifies the most common steps of the ICT development lifecycle and the most common co-creation methodologies used in Age-related ICT, grounded on a literature review on this matter. Elaborating on the results of the desk research, the discussion between each step and related co-creation methodologies is described in a theoretical framework and complemented with examples of good practices implemented in ICT projects for age-related challenges. Consequently, its outcome is the list of actions to strengthen the caregivers' participation in the different steps of the innovative technological solutions' co-creation.

The collaborative work which led to the development of the above concept and the present document followed a methodology inspired in the "Mobius loop" [7] which is organized in three iterative steps: (1) Discovery (research to define what is the problem to solve or idea to pursue); (2) Options (desk research to identify potential solutions and good practices); and (3) Delivery (elaborate a document for public consultation and dissemination, collect and integrate feedback into a green paper and assess the impact).

THEORETICAL & EXPERIMENTAL FRAMEWORK

This section addresses the theoretical and experimental frameworks that will relate each co-creation methodology selected with the main four steps of the ICT development process [8] and the lessons learned from good practices implemented in several European projects to design, develop, test and validate ICT solutions for ageing well.

Based on the knowledge, experience and contributions of the partners participating in this collaborative work, some projects and methodologies considered to have been good examples of co-creation were selected and they will be further detailed and used as examples in this section and further on the document as the four steps of ICT development are discussed.

Initial Requirements | Theoretical & Experimental Discussion

The first inputs when starting the development of a solution should be based on the main challenges, needs and preferences felt by the older persons and their caregivers. Once the needs have been clearly identified, the development process begins with the definition and then design of the system where the associated requirements are specified as much as possible to ensure the solution matches the expectations that all involved parties. The literature says that all parties should be involved at this stage of the process, mainly who will use the technology in the end, since they have crucial information about their needs and how they expect them to be answered by the solution under development.

Theoretical Framework

Prahalad and Ramaswamy [9] propose to analyse the co-creation value through the **“DART” model**, an acronym that stands for four components: Dialogue, Access, Risk/Benefit and Transparency. For the scope of this document, the Dialogue component seems to be an important concept to take into consideration during the initial requirements. The communication between the end user and the different stakeholders in a project is a process to be observed by action and reaction promoting the creativity, innovation and mutual learning during the period where the developers/designers are gathering needs and expectations from the end users, trying to map them in terms of technical requirements and specifications.

According NDWE T., Jumbam N. and Isabirye N. (2017) the **“User-centred design” (UCD) approach** is a methodology that involves end-users throughout all stages of the development paying attention to stakeholder organizations’ business objectives and the end-users’ needs, sociocultural circumstances, characteristics, attitudes, preferences and other user attributes [10]. Although this is a methodology to take into consideration throughout all theoretical framework of this document, regarding the initial requirements step the authors suggest that finding a suitable methodology to identify initial requirements is needed so that developers can meet the end users’ expectations, creating a shared knowledge relationship that will bring value to the whole ICT development process.

Finally, the **“Design thinking for social innovation” methodology** [11] could provide an important insight to this stage of the process. According to Brown and Wyatt (2010), it is not enough to ask end-users what they want. They suggest technical partners to also implement tools enabling the collection of complementary information, since they may not be expressed spontaneously by end-users or not be understood/interpreted the same way by designers or developers who are used to a different – namely: more technical – language.

Experimental Framework

According to the experience of several participants in this collaborative work involved in research projects [12 - 20] which aim to test and validate ICT technologies for Age-related challenges, some good practices have been identified to collect data relating to initial requirements:

On the one hand, if the caregiver is the end user of the technology, it is important to limit the length of questionnaires and interviews, particularly for the informal carers, to avoid having

negative effects on the results of the data collection (e.g. important drop-out rates). On the other hand, it is important to consider their digital literacy level [21], so that an adequate protocol is developed accordingly. It is suggested also to use group techniques, since the informal and friendly context disinhibits the participants exchanging more opinions and ideas, in a natural way. In case the caregivers are not the end users of the technology (e.g. the end user is an older person), it is important to invite caregivers for the initial requirements gathering, since they could act as a moderator of the discussion regarding the group techniques and their presence makes the end users feel more comfortable and confident to share their expectations. Once the requirements gathering is finalised and translated to the technical requirements and specifications, the caregivers can be asked to review it to make sure that the requirements list is well prioritized and can be a good practice.

Moreover, considering Groeneveld et al. [22] findings, it is important also to consider the potential conflict that could emerge within and between the user requirements and those of the (in)formal caregivers. The latter have the perception of dissonance related to the need of having a relief and time to relax and reduce their burden on one side and, at the same time, the need to control and monitor the safety the persons they care for with the help of ICT functionalities. This study highlights the importance to engage also the local stakeholders' community into the design process. Neighbours, general practitioners and social workers should play a relevant role in bridging the gaps, ensuring a closer help and connection among older people and informal caregivers, when needed. The suggested approach is to map the multi context of life where the ICT solutions are foreseen in a broader way rather than having in mind only the end users and informal caregivers' viewpoints.

Discussion

There is no doubt about the importance of the communication component across all the innovation process. However, it is on the initial requirement stage that it has a significant role to engage and strength the information sharing between the potential users and the developers/technical team. Regarding the traditional requirements gathering techniques from (in)formal caregivers, the experience of implementing projects suggests increasing the length of the protocol and complement the individual data collection with group techniques. Even when they are not the primary end-users of the technology, it is crucial to engage with (in)formal caregivers from an early stage, so they can complement the gathering of requirements with their owns .For example, design thinking for social innovation [11] methodology worked with formal caregivers to better interpret their cultural and functional needs by asking them to make small videos about their needs and aspirations. It allowed the developers to collect complementary information that helped them prioritizing the list of resulting requirements.

Furthermore, it is useful to consider the contextual use of ICT when the initial requirements are collected using a community-based co-design that embraces the social relationships among older people, informal caregivers and other relevant health and social actors to reach the appropriate use of technology.

Development | Theoretical & Experimental Discussion

Once the needs and expectations from the end users are collected and translated to a detailed technical requirement and specification list, a schedule is made, and the development phase is implemented mainly by the technical partners in order to execute all technical work needed [23].

Theoretical Framework

Again, **User-Centred Design** [24] is an important methodology to consider at this stage. Implementing an iterative process involving users throughout the design and development stage is crucial, since it makes possible to have a continuous analysis and feedback collection from the user, as often as necessary and to make sure the solutions are being developed in the right way from the beginning.

As Gould and Lewis (1985) indicate in their paper **Designing for Usability: Key Principles and What Designers Think** [25], the third principle focuses on the importance of iteration. Developing the product in an iterative way, enabling a process of cycles of design, test, measurement and redesign, starts a dialectical process between the users and the designers and developers that ensures the solution is permanently adapted according to the users' feedback.

The development process of an ICT application for AFE is complex. Therefore, maximum flexibility and appropriate control is required. **SCRUM** [26] is an approach that enables development teams to operate adaptively within a complex environment using imprecise processes. The SCRUM approach assumes that the analysis, design, and development processes in the Sprint² phase are unpredictable. A control mechanism is used to manage the unpredictability and control the risk. Flexibility, responsiveness, and reliability are the results.

In the agile **SCRUM** world, instead of providing complete, detailed descriptions of how everything is to be done on a project, much of it is left up to the SCRUM software development team³. This is based on the fact that the team will know best how to solve the technological problem they are confronted with. This is why in SCRUM development, a sprint planning meeting is described in terms of the desired outcome (a commitment to a set of features to be developed in the next sprint) instead of a set of Entry criteria, Task definitions, Validation criteria, Exit criteria (ETVX) and so on, as it would be provided in most methodologies. SCRUM relies on a self-organizing, cross-functional team. The SCRUM team is self-organizing as there is no overall team leader who decides which person will do which task or how a problem will be solved. A team is cross functional, meaning every stakeholder is needed to take a feature from idea to implementation.

² is a regular, repeatable work cycle in SCRUM methodology during which work is completed and made ready for review. TECHOPEDIA website. *Scrum Spirit definition*.

In <https://www.techopedia.com/definition/13687/scrum-sprint> acceded on 17.06.2018.

³MOUNTAIN GOAT SOFTWARE website. *Scrum Definition*.

In <https://www.mountaingoatsoftware.com/agile/scrum> acceded on 17.06.2018.

Experimental Framework

According to the experience of the working group participants involved in European research projects [15] which aim to test and validate ICT technologies for e-related challenges, two good practices could be extracted:

1 - Implement an inclusive user-in-the-loop⁴ during the development process permits that the system meets their needs as close as possible. According to the different stages of the technology maturation level, different types of users should be considered to test and provide feedback, according to their skills and abilities. If the technology maturation level is too low, the user test should be run in the lab, developed by developers/integrators; when it is more matured it should then be run in real life environments to be tested by the secondary end-users (the caregivers) and only later going to the primary end-users (the older people). Doing it in this way, on the one hand, developers will receive a concrete feedback that allows them to deliver a more realistic technology to the end-users; on the other hand, the technology will be delivered when all mandatory requests are checked by its caregivers, so that the level of requirements from the end user can be also managed in a proper way.

2 - Due to unforeseen technical problems during the development stage, it is important to design an alternative scenario in order to make sure that the main goals/functionalities of the technology will be able to be tested by the end-users [13] and the expectations initially created will not be fully broken. Therefore, providing a clear and transparent explanation about the possible failure risks from the beginning is also important to keep the caregivers and older persons clearly informed, so they could feel more confident during the whole process.

Discussion

Although literature indicates this step of the ICT life cycle as a complex and challenging one, being more focused on development issues, it is clear that end-users need to be engaged during this stage in an iterative process, so that they can follow and provide feedback.

When the technology is tested following this framework, the developers do not need to wait for the testing period to solve small issues that are crucial to user acceptance. This iterative process also allows the developers to save time and money since they are collecting early feedback to deliver a technology as mature as possible for the testing period. On the side of the users, they don't feel frustrated by dealing with low Technology Readiness Levels (TRL) and therefore to test technologies that may still have major flaws. Participatory and co-design processes can generate high expectations on the side of potential end-users who may have difficulties in adjusting their requirements to the state-of-the-art solutions in different ICT areas. Inviting them to participate in the validation later in time will also allow them to already experiment more matured products that they may easily assess as they can already integrate them in their daily routines and activities.

⁴ having the user following the all development workflow, intervening with small tests, if needed.

Test and Validation | Theoretical & Experimental Discussion

Once the technology is developed, implemented and integrated from the technical point of view, end users will test and validate it in a real environment. This step could be a challenge because of the existing gap between the expectations of the users, how far their requirements have been considered and developed and what TRL was achieved. The results and feedback collected at this stage are a very useful tool, so that the technology may be improved according to their feedback. This is an iterative stage and depending on the evaluation results, some technical refinements might need to be implemented, tested and evaluated again until the validation is ended. It is important that all critical requirements are achieved at this stage, to avoid much more hours/costs refining the technology at a later stage.

Theoretical Framework

There is a wide range of literature focusing on the importance of **User-Centred Design** (UCD) and its relevance in the testing and validation phase of a product. Gould and Lewis' (1985) paper [25] is today still valid and offers a clear overview of the three principles relevant for UCD: early focus on users; empirical measurement using prototypes and iterative design. The authors make the difference between understanding potential users and identifying and stereotyping them - the importance is to get the designers to work in close contact with the users by performing interviews or exchanges with and observations of users as appropriate methods to be applied prior to design. Empirical evaluation methods are also recommended to be used during the users' interactions with the tested prototypes and their performance and reactions should be observed, recorded and analysed.

Experimental Framework

According to the experience of several working group participants involved in European projects [12-13, 15-19] that aim to test and validate ICT solutions for Age-related challenges, during the test and validation in real environment stage, some good practices could be extracted:

1 - Besides the protocol that formalizes their participation, it should be provided to users and carers practical, clear and friendly information (videos, infographics, schemes) about the main objective of the innovative technology, the involvement required, all ethical and privacy issues related with their participation and the data collected, stressing the importance of their participation for the success of the technology in the market. All these could make the difference in their engagement.

2 - The training session is an important step to have successful ICT validation process. Making a session where the technical developers together with a trusted person (e.g. formal caregiver) could provide a clear and simple explanation of the aims of the technology, the practical issues that need to be tested and evaluated and the conditions in which the testing will take place (when, what and how the test/validation is expected to be carried out). When the caregivers are not the primary end-user of a technology, it is important to highlight the benefits of the solution for the older person as well as to clarify the benefits secondary end-users (that may be caregivers) will achieve in terms of burden, quality of life, etc. if the technology is proven to be

of added-value. It also stimulates caregivers to engage older persons to be active during the testing and validation period.

3 - Creating a team during the ICT testing period that we can refer to as “innovation ambassadors” is also a way to motivate and engage them informally during this period.

4 - The inclusive user-in-the-loop process described earlier is also a good practice to consider during this stage, since several test periods are needed until the validation is ended.

5 - Providing feedback to all participants to the testing and validation phase and sharing with caregivers the testing results and all further work is recommended, so they can understand the outcomes of their contribution. It can take the form of a dedicated session where participants to the testing and validation phase are asked to present some of the results to the stakeholders.

6 - Since several periods of tests may be needed and depending on the scope of the tests, the caregivers and older persons who collaborate in previous phases should not participate in this testing phase to avoid any bias.

Discussion

The literature references highlighted in this section are widely known. Having a focus on user engagement at this stage of the process, it is very important to collect reliable conclusions about the usability and usefulness of the technology. The feedback collected will provide crucial information to evaluate the technology and probably more test sessions/periods will be needed until a final version is accomplished, according to the iterative process suggested by Gould and Lewis or the UCD approach.

However, the iterative process between testing, results and the decision to test it again or go to the market is not so clear. A suggestion to keep user engagement could be to provide caregivers (even when they are not primary end-users of the solution) clear and user-friendly information about all steps composing the testing and validation period so they can fully understand what is expected from them and from the older persons; once the conclusions of the tests are met, it is recommended to show them in a simple way the issues that still need to be solved. A concrete preparation of the test period evaluation also influences the engagement level of the users – besides using questionnaires as it is more usual, it is also important to track the motivation and the routines of the users, since the information provided in the evaluation process may also envisage the results, for example due to recent events in their lives.

Exploitation | Theoretical & Experimental Discussion

The value of insights from caregivers has been used to assess the potential of innovative technologies for AFE so far. In parallel with the progress achieved in the previous phases, parallel to the ICT development it is also important to develop a successful business strategy capable to bring the innovation into the market. And this effort should start from the initial requirements stage, being consolidated after the test and validation phase. In fact, this discussion is a challenge for the whole society and there are still many questions to be answered. For the scope of this document, the issues of relevance are related to the product related business model, the collection of intentions about the user's willingness to pay and the identification of potential funders, considering the variety of contexts where technologies for AFE can be used.

Theoretical Framework

According to the **Lean validation approach** [27] a group of questions should be taken into consideration. The author suggests exploring and investigating if users are somehow available to pay for a solution that can meet their needs and preferences. In order to collect insights that could answer these questions, Lean recommends carrying out specific experiments: (1) to implement a competitor analysis to understand if in the future someone is trying to meet the same users' expectations and how they are doing it; (2) to carry out a customer survey/interview to collect useful information about how they expect the product could answer their demands, what it means for them and their availability to pay; (3) to compare two versions of the solution to determine which one performs better; (4) to implement a pre-selling action supported by online platforms and media channels to find out if the customer is willing to pay and/or who can be the potential funders of the solution in the future.

Experimental Framework

According to the experience of several working group participants involved in European projects that aim to test and validate ICT solutions for Age-related challenges, some good examples of exploitation plan/business strategy could be extracted for this section of the document:

1 – TSBank [20] project developed a service that matches volunteer service with needs. The purpose is to focus on specific areas, for example tourism, where older adults can provide services, share their experience, keep active and at the same time get their contributions recognised and rewarded. In terms of exploitation strategy, this project has led to the development of the silverskills platform [28] that was the outcome of a validation effort, based on a mix of business model canvas and lean experiments. This work involved many older adults in Switzerland and in Romania, and the use of focus groups and working prototypes⁵ from the beginning was instrumental to keep the caregivers (responsible for guaranteeing the adherence of older adults and for acting as their surrogates) engaged during the two iterations that were planned in the development process.

⁵Following the "Minimum Viable Product" (MVP) approach which is one of the cornerstones of lean experimentation.

2 - ICT4Life [16] is a project focusing on the development of an Integrated Care Platform to support Parkinson's and Alzheimer's disease patients, their caregivers and relatives and the social and health professionals that care for them. The ICT4Life platform exploitation requires an integrated care approach on the target care scenario with the involvement of the patients and their caregivers in the care process. This project involves the end-users during an iterative testing process before the pilots, gathering their feedback on the technology and its potential application in daily care processes thanks to focus groups and questionnaires. During the pilots, a survey for wider target groups was carried out supported by multimedia information for respondents. All this process enables the project to make an analysis from a qualitative and quantitative point of view supporting better information for the project exploitation plan.

3 - The E.C.A.R.E. Project [14] objective is the analysis and application of techniques and tools for the reduction of social isolation and psychological, physical and relational difficulties of older persons living in their own home or in a home made available to them by the public administration. The pilot is being implemented in four sites through a "Personas" tool. It works as a grid analysis of the potential senior profile also in terms of personal relationships, especially with relatives and informal caregivers that could be engaged into the project as a remote supervisor connected to seniors by ICT solutions. Considering the main needs and critical points that will rise from the items of the tool, the delivery of E.C.A.R.E. ICT platform will be highly customized in terms of functionalities and senior connections with relatives, neighbours and care provider organizations. The empowerment of users and the opportunity to make them more in control about its life will lead care-provider organizations to define a range of prices that should be aligned with the "value-for-money" that users are willing to pay along the time. This last point it still to be an open issue that will engage Public Authorities and the Health System into the discussion about if and how they are able to deliver economical contribution to users in a mix of public/private payment that will foster the demand of eHealth services.

4 - The Aarhus Municipality has a policy strategy [29] implemented that aims to test and validate innovative solutions that may improve the quality of life of their ageing citizens, by trying to keep them healthy and autonomous at home. The Municipality invested on a Primary Task Centre for Assisted living technology in cooperation with other departments within Health and Care and relevant external partners (research/academia, companies and end-users) to seek, test, develop and implement welfare technological solutions, which can provide the citizens increased self-reliability and independent living, can improve working conditions, increase efficiency and improve economy for the municipality and growth and jobs for companies. The main strategy is investing on technology from the test and evaluation stage to the public procurement and full-scale implementation in case of success. Although this is an investment priority for the Municipality, it is a complex methodology since it is not possible to use a unique evaluation methodology for all technologies and it is very hard to use case studies from other countries, since the workflow from each country varies a lot.

Discussion

The literature related to the exploitation plan is very well known and has been consolidated in the different sectors of the economy. However, with regard to its success in the Silver Economy Market, we can admit that there is no methodology/model that serves all the strategies and that it is necessary to consider multiple variables when designing the business strategy. From the research described above, which is only representative of its vast size and complexity, it is possible to conclude that the involvement of caregivers at this stage is still crucial, now from a different point of view - as a potential consumer/client.

The literature suggests the implementation of a customer survey and pre-selling actions using online tools to capture detailed information about the consumption preferences. The combined implementation of existing methodologies is also a good practice already implemented in European projects, and the focus groups or interviews with caregivers and other target audiences (including the wide public) have been referenced as a very important source to support the definition of business plans. Finally, an aspect to consider at this stage is the sustainability in the market.

In this section, examples of exploitation plans were mentioned in collaboration with local public entities and private entities, in order to optimize the sustainability of the technologies of AFE in the future, since as the effectiveness for people and for the economy is demonstrated, it is necessary to implement a strategy that fairly shares the cost between different actors.

LIST OF ACTIONS

Based on the Theoretical and Experimental Framework discussion a list of actions is suggested to be addressed during the life cycle of ICT for AFE projects, in order to maximize the engagement of caregivers at all stages.

INITIAL REQUIREMENTS

1. Refine the protocol and complement the individual data collection with group techniques (e.g. focus group, thinking aloud, informal interviews). ☐
2. Structure a protocol according to the digital literacy of the respondents. ☐
3. Even though caregivers are not the (only) final users of the technology, include them from an early stage, so they could complement and validate the data collected. ☐
4. Accompany the caregivers for a period of time in their daily routines to better understand their workflow to acknowledge what the key functionalities of the technology should be. ☐

DEVELOPMENT

5. Implement an inclusive user-in-the-loop methodology; depending on the different stages of the technology maturation, different categories of users should be considered to test and provide feedback. ☐
6. Identify a person of trust for older people to be able to rely on a surrogate if they feel the need to. ☐

TEST AND VALIDATION

7. Provide clear and user-friendly information (videos, infographics, schemes) with the main aims of the technology, the involvement required (when, what and how) as well as ethical and privacy issues. ☐
8. Organize a training session between developers, end-users and their network with the support of previous materials to clarify the process and answer questions. ☐
9. Create and promote a "innovation ambassadors" team to promote adhesion to the innovative solution and collect essential feedback from caregivers and older persons end users. ☐
10. Share friendly information about the validation results and the further work that is still to be done, so that participants to the co-creation of the solution (both caregivers and older adults depending on who was involved) can understand their importance in the process. ☐

EXPLOITATION

11. Understand with the caregivers, since the beginning, what business models are possible (namely: directly paid by the end-user of the solution or regulated market) to adjust the solution to a feasible exploitation strategy. ☐
12. Define experiments that can be easily deployed to test the solution (or part of the solution) and validate assumptions made in the development process. ☐
13. Run focus groups with caregivers to validate assumptions and get caregivers active in the business model validation process. ☐
14. Adapt the business cases to each country or region, according to the profile of each region, culture and preferences (e.g. welfare system, family structure, cultural habits, etc.). ☐
15. Combine different methodologies to gather feedback from different type of potential customers. Engage them with easy to understand online surveys in order to gather their willingness to use the technology in their lives. ☐

CONCLUSION

The main objective of this collaborative work was to identify and propose a set of actions that could highlight and enhance the contribution and involvement of caregivers throughout the development process of innovative ICT for AFE solutions. The final result highlights the importance to engage end-users (both direct users that may be either older persons themselves or caregivers and indirect or irregular users that may be informal carers, relatives, etc.) during all stages, and also how challenging it is to keep them engaged and motivated during the whole process.

In order to support the technical teams in the difficult task of guaranteeing a constant contribution from caregivers during all steps, especially when they are not the primary end user of the technologies, the present document **“Caregivers’ role on ICT for AFE”** was developed. It is based on a three-fold concept composed of: (1) the steps of an ICT development and exploitation project, (2) a set of selected co-creation methodologies and (3) feedback from experienced D4/C2 EIP-AHA Action Groups partners⁶ running ICT Age-related projects.

Theoretical and experimental framework were developed to highlight the similarities between the selected co-creation methodologies and concrete practices already implemented and tested in projects related with the engagement of caregivers in the Aged-related ICT process, for each step of the lifecycle of the projects. The outcome of this discussion originated a four-step list of actions that can be used by different stakeholders during the development of new technological solutions that could correspond closer to their needs by including the contributions of caregivers.

Although the discussion under this document was made step by step, the contributions of caregivers for the life cycle of projects should be faced as an iterative process and flow according to the development progress achieved so far or should be repeated until a mature user readiness level is achieved. This will allow saving time and money since technical teams are collecting early feedback to deliver a solution as mature as possible to the testing and validation period and in line with end users’ expectations. Also, the importance of the implementation of co-creation methodologies throughout this cycle is clearly demonstrated, explaining how they could fit in more than one step of the cycle.

Among the list of actions, it is clear that having an accessible and constant communication with caregivers and older persons during all stages is a crucial way to deliver a solution closer to their needs and with the potential to reach the market successfully. The recommendation is to adapt traditional data collection techniques to this process. Especially when the caregivers are not the final users of the solution it is important to engage them in the process, so they can complement the information collected with their perspective of secondary end-user. This document also recommends their participation during the development of the exploitation plan once the solution is technically validated, in order to collect insights as potential customers.

In addition to the advantages of implementing this list throughout all phases of technology development and exploitation, we believe the involvement of caregivers in an ongoing basis can also be beneficial to decrease the lack of digital literacy and health literacy in society. Consequently, their contribution to the product development process will contribute to increase

⁶A list of partners having contributed to this collaborative work is available in acknowledgement section at the beginning of the document.

their belief in the benefits of using technology in the lives of older people and thus contribute to a stronger and more sustainable Silver Economy in the future. In order to maximize the sustainability of these products in the future, it is necessary to implement a strategy that fairly shares the costs and benefits between the different stakeholders, where a common agenda between local and regional authorities, health and care social providers and private entities should be implemented according to the profile of each country and target group.

This document portrays the result of internal discussions that took place between the members of the EIP-AHA C2/D4 Action Groups from April to July 2018. This document, referred to as a green paper, is a tentative report and consultation document that lists good practices and proposes an approach for the involvement of caregivers in the development of innovative –ICT solutions for AFE. This green paper aims to promote a debate and discussion on this topic and will be open for public discussion to collect comments and recommendations that will contribute for its improvement and will lead to a White Paper on this subject. The White Paper will be the final result of this collaborative work.

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