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User involvement plan
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1. Introduction

1.1. The HAAL project

The HAAL project aims to develop a HeAlthy Ageing eco-system for peopLe with dementia and it is partially funded by AAL (Ambient Assisted Living) Programme. HAAL's main goals are to combine the consortium members' proven technology to create the whole bundle of care technology for every dementia stage and to commercialise the final bundle in the Netherlands, Italy, and Taiwan, see Figure 1. The main goal of the eco-system is to support people with dementia, their informal caregivers and the professional caregivers throughout all stages of dementia.

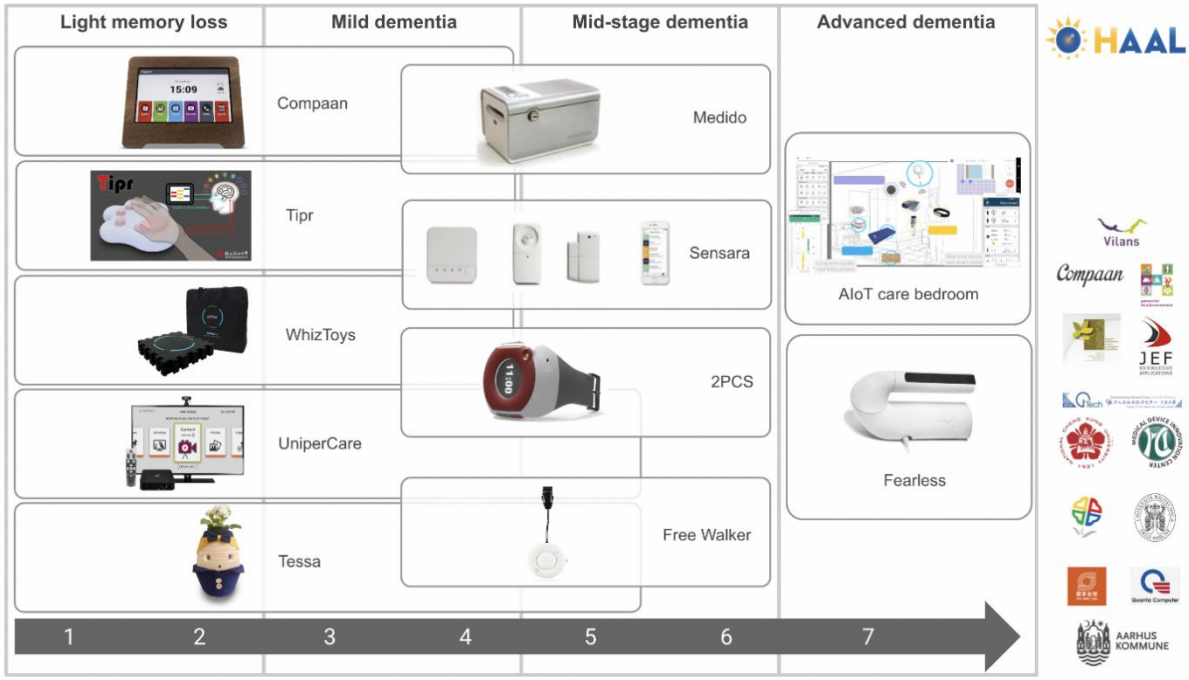

Figure 1. The first assumption of HAAL's care technologies throughout dementia stages based on the initial Description of Work

In the work package 2 (Co-creation and co-design of HAAL bundles), the first-phase aim is gathering user requirements and designing the ecosystem's structures for work package 3 (services and platform development). Within the complicated dementia care with multiple stakeholders, HAAL choose to actively involve stakeholders throughout the decision process.

After conducting desk research into different methods and the state of the art for user involvement in dementia care, Living Labs (LL) and co-design with people with dementia were chosen as the most relevant methodologies for the HAAL project.

1.2. Living Labs

The European Networks of Living Labs defines Living Labs (LLs) as user-centred, open innovation ecosystems based on a systematic user co-creation approach, integrating research and innovation processes in real-life communities and settings. Living Labs have five main elements: (1) multiple stakeholders and user involvement; (2) a real-life research

environment; (3) management; (4) a research protocol; and (5) challenges. (Brankaert & IJsselsteijn, 2019; Certification-D, 2020).

1. Stakeholders: It is recommended to collaborate with multiple stakeholders throughout the study. Within the dementia context, five groups of stakeholders were specified: user, organisation, ecosystem, society and research group (Certification-D, 2020).

2. Setting: Two Living Labs approaches are experiments in simulated environments or the actual real-life context of the participants. Although the simulated environment aims to be as realistic as possible (Certification-D, 2020), most literature recommends for the real-life environment. And this is also the case when researching with People with Dementia (PwD).

3. Management: Since organisations of research projects depend on a shared vision and goal for the living lab, it is encouraged for researchers to maintain the management and organisation (Certification-D, 2020). Among the management process, Brankaert (2016) pointed out that the strategic level deals with balancing the interests and contradicting opinions among different stakeholders.

4. Protocol: 'Innovate Dementia Living Lab protocol' (Brankaert, 2016) constructed five sequential steps when involving PwD: preparation, introduction, intervention, reflection and results and feedback. Preparation is a consideration for the most suitable set-up, evaluation method and participant selection. The introduction is a phase to introduce PwD to get to know the project and familiarise researchers with them. The intervention consists of introducing and performing the planned method when PwD is comfortable with the project. Reflection is gathering participants' opinions and insights of the products and evaluation method. Finally, results are analysed and processed.

5. Challenge: LL's challenges vary from the type of LL and the operating context. The two prominent challenges are ethical issues and sustainability (Certification-D, 2020). The ethical issues in researching with PwD included the topics of informed consent, comprehension of handed out information, and ability to express. It was advised that ethical issues should be listed for PwD and their caregivers to reflect on. And sustainability entails business-model creation to keep the continuity of the research by self-funding.

These five main elements are used in the HAAL project to conduct the research. Multiple stakeholders are involved: users, organization, ecosystem, society, and research group. The real-life research environment is online, due to COVID-19 restrictions in 2021, but as realistic as possible. Management is supported by balancing the interests and contradicting opinions among different stakeholders. The research protocol is the 'Innovate Dementia Living Lab protocol' (Brankaert, 2016). As the Living Lab Protocol calls for inclusion of all stakeholders, this entails co-creation with PwD. However, co-design with people living with dementia is a delicate process and different from the usual co-design and participatory design, so it should be studied in detail.

1.3. Co-design with people with dementia

Co-design or participatory design is a method promoting users to have a role in designing and making decisions alongside designers. Iterative co-design with end-users is needed to endure good accessibility, relevant benefits, and satisfactory use of these supportive technologies (Suijkerbuijk et al., 2020). Cognitive decline, issues of trust, and scarcity of resources are difficult challenges that limit the involvement of older adults in co-creation (Hendriks et al., 2015; Knight-Davidson et al., 2020). Especially in the case of health technologies, the lack of user involvement led to the failure of motivating the older adults to engage and interact with the final product (Suijkerbuijk et al., 2020). A systematic review (Suijkerbuijk et al., 2019) showed that most research involved PwD in the evaluative stage after the design was created because of the difficulty of involvement. Yet, they encouraged that the participation of PwD during the design process would be more successful.

Cognition and health conditions belonging to the group of older persons are a significant factor to achieve communication-based research, especially participatory design. According to American Psychiatric Association (1984), most people in mild to moderate dementia stages suffer from a deterioration of memory (such as amnesia), difficulties in language and communication (aphasia), the inability to perform purposeful movements (apraxia), and/or orientation in time and place (agnosia). These cognition impairments could directly reduce communication skill during the research sessions. Furthermore, the large majority of PwD might need to deal with physical ailments like impaired eyesight, hearing, or physical coordination (Harman, 1981; Lobo et al., 2000). Such functionality loss would also affect communication approach and the use of research artefacts. Thus, individual cognition and health conditions have to be taken into consideration.

Guideline for participatory sessions with people with dementia

Due to the sensitivity of the process, Hendriks et al. (2013) drew up ‘guidelines for participatory design together with persons with dementia’. The guidelines are worth reciting because they explicitly identify action steps in detail. The guidelines cover stages and topics on co-designing with older adults and include amnesia, aphasia, dementia and older adults in general conditions. Some suggestions are specifically intended for some specific cognitive condition. Thus, an additional annotation (de) identifies the suggestions specifically for people with dementia.

Preparation

1. Search for and connect to existing groups and organisation
2. Get to know your target group [cognitive deficits] and become sensitive to their needs and situations
3. Get the consent of PwD at various moments throughout the research process (de)
4. Assess each participant in a formal way
5. Give a lot of time for general practicalities

Method

1. Address experiential aspects
2. Tune the methodology towards the person’s background, interest, and specificities (de)
3. Take into account the different impairments when working in a group
4. Take into account the difficulty in envisioning intangible concepts and abstract notions
5. Take into account the difficulty in comprehension and production of language (verbal and textual)
6. Adapt the participatory design to overcome memory impairments
7. Adapt to aid in following a chain of action and reasoning
8. Communicate about your project’s goal without intermediaries (de)

Moderator

1. Clearly explain the purpose of the events and the role of participants
2. Foresee enough time for getting to know each other, for repetition and constraint reviewing the different phases (de)
3. Minimise distraction and keep participants in focus

Tools

1. The location should hold an appropriate social status (de)
2. Take into account logistics and transportation
3. Make use of non-verbal elements (visual stimuli - object images or physical artefacts) (de)
4. Use distinctive contextual cues
5. Use fictive third-person stories to consult a person in an indirect way (de) - using the more euphemistic term 'memory problems'
6. Use easy to understand wording

Participants

1. Give a trusted caregiver an important role during sessions for aiding with the participation of PwD (de)
2. Work in small groups (6-8) (de)
3. Group participants by their deficits
4. Use a person without a deficit to get rid of general design problems
5. Give flexibility to participants because they might fail to stay on the research track (de)
6. Involve the informal caregiver in the process, but be aware of their influence and suggestion that is not actual opinion from PwD
7. Formal caregivers can make projection over one unique single case (de)

Analysis

1. Don't over-analyse the utterance of your participants
2. Be critical towards the representativeness of your participants

Apart from their involvement, the methodology should value and prioritise the suggestions and opinions of the older adults when collaborating with interdisciplinary stakeholders. Project eWare (Suijkerbuijk et al., 2020) was one example that the suggestions from PwD for more engaging and interactive functionalities were not met. This led to a problem motivating them to keep using the prototype during an Alpha stage. Although dementia includes the problems of short-term memory, PwD have clear emotional reactions to their direct experience. Thus, a user-requirement collection should recognise their emotion-based cognition which is the main motivation of adoption for adults with memory loss.

Motivational goal model

In a multi-stakeholder setup like the HAAL project, it is important to address the emotional wishes of PwD as important as practical wishes of others. A motivational goal model is one approach arising from goal models and agent-oriented methods described in Sterling, L. and Taveter K. (2009). The model intends to explore and evaluate the emotions of users as much as functional goals. It focuses on three questions: what should the technology do? (Functional goal), how should it be (Quality goal) and how should it feel? (Emotional goal). As a result, the model communicates the three goals visually and verbally, see an example in Figure 2.

According to Burrows et al. (2018) and Taveter et al. (2019), the motivational goal model could explicitly bring out, organise and communicate the three goals among multiple stakeholders. The focus on emotions is perceived as valuable and changes the conversation throughout the exploration, design, experimentation, and evaluation strategies (Taveter et al., 2019). As the process could go beyond functional requirements, Pedell et al. (2017) had discovered interesting and conflicting insights. For instance, while the older adults want social connectivity, their busy family members or professional caregivers want short replies.

Moreover, the older adults expressed the desire to 'truly feel cared about'. Here, hidden dissonances for healthcare technologies start to unfold and await to be solved.

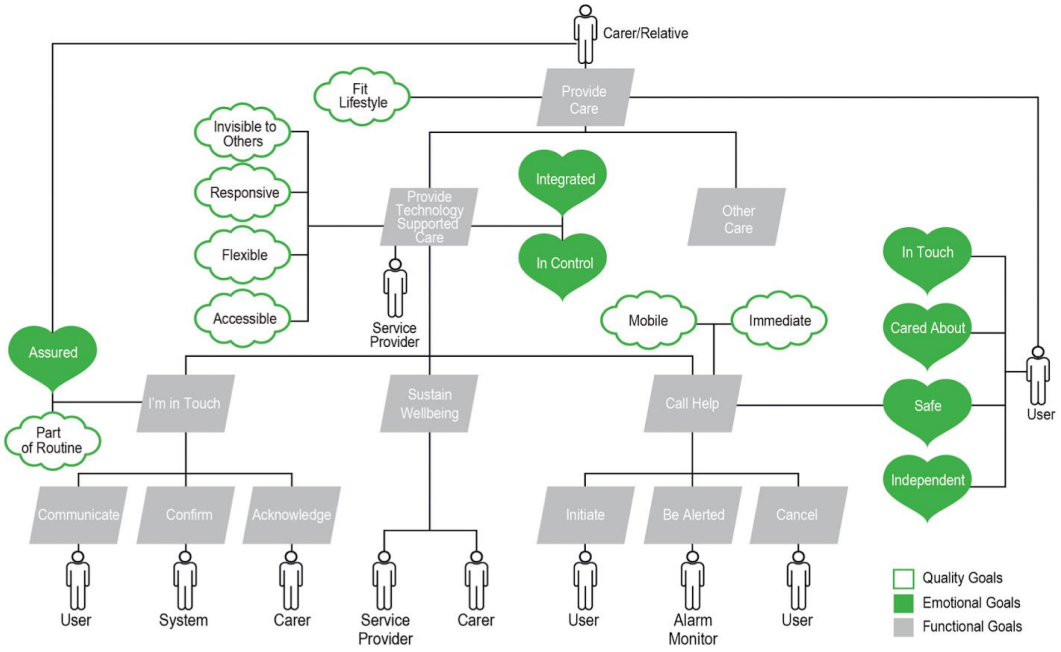

Figure 2. An example of a motivational goal model with Functional goals (kites), Quality goals (clouds), and Emotional goals (hearts)

Note. Pedell, S., Keirnan, A., Priday, G., Miller, T., Mendoza, A., Lopez-Lorca, A., & Sterling, L. (2017). Methods for Supporting Older Users in Communicating Their Emotions at Different Phases of a Living Lab Project. Technology Innovation Management Review, 7(2), 7–19.

2. User groups and external stakeholders

In the dementia care context for HAAL, user groups can be divided into three levels, see Figure 3. Primary end-users are people with dementia. The secondary end-users are informal caregivers or family members and care professionals. On the organisational level, the care community is the tertiary end-users because it is the major structure around dementia healthcare, which may differ per involved country (the Netherlands, Italy, and Taiwan). External stakeholders include technical stakeholders and the HAAL consortium members because their collaboration and comprehension in the HAAL direction has an immense influence on the outcome. And the researcher was also identified to be one stakeholder in this co-design.

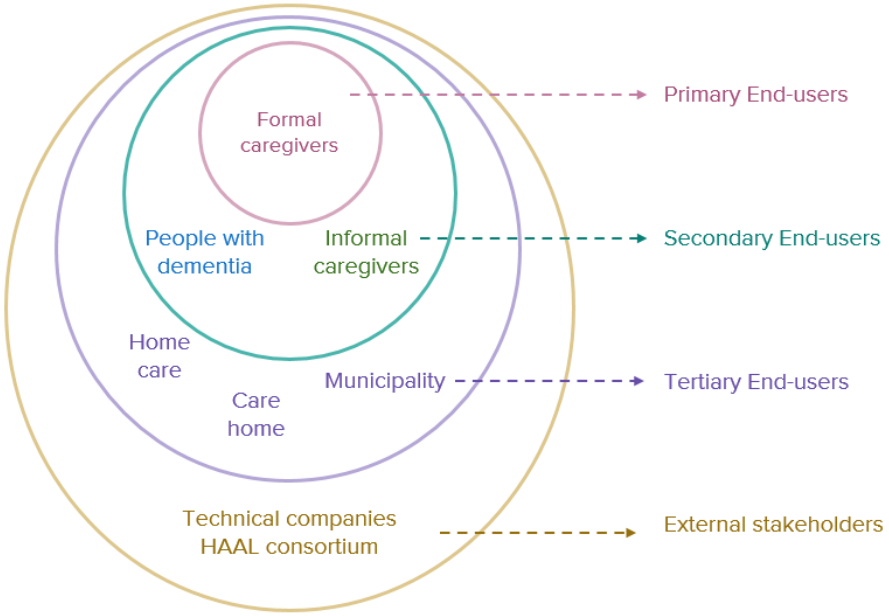

Figure 3. HAAL stakeholders include three levels of end-users and external stakeholders

2.1. People with dementia

People with dementia (PwD) vary between mild cognitive impairment (MCI) to severe stages of dementia. This intellectual deterioration can be measured using the Global Deterioration Scale (GDS) that defines seven cognitive decline stages and four stages of dementia (Reisberg et al.,1982). The PwD might can either live at home or in a caring home. However, because of their indication, the seniors receive some form of care support. The condition of PwD means that the seniors have at least MCI or memory problems. Having memory problems entails that those seniors are conscious of short-term experiences, but they have difficulties with recalling recent past experiences (e.g., more than five minutes ago). Moreover, dementia might affect comprehension, calculation, learning capacity, language, and judgement (WHO, 2021).

2.2. Informal caregivers

Informal caregivers are mostly family members or daily references of the people with dementia. Connections between informal caregivers and clients are private and not via a care

organization. Informal caregivers are concerned about the well-being of the PwD and they provide emotional or practical support regularly. Although it is easier to live nearby the PwD, informal caregivers do not necessarily need to live close by PwD. Informal caregivers are included in the HAAL project since they play an important role in the daily life of the PwD. Moreover, the informal caregivers can fulfil caring tasks to reduce the burden of formal caregivers. A good collaboration between informal caregivers and formal caregiver is needed as the informal caregivers can be the link between the client and the formal caregiver.

In Italy, migrant care workers are also accounted as informal caregivers. When family members could not provide 24-hour care for PwD, it is common for them to employ the migrant care workers for private caregiving. The migrant care workers would stay at the house of PwD and provide daily assistance throughout the week. The care workers are not specifically educated or trained for the medical purposes, but they could sufficiently help on household tasks and watch out for emergency cases. The case of migrant care workers is rare in Taiwan and is not very common in the Netherlands at all.

2.3. Care professionals/formal caregivers

Care professionals or formal caregivers are professionally responsible for dementia care. They are trusted agents for people with dementia and have direct contact with older adults and provide care and support when needed.

In the Netherlands[1], the relevant formal caregivers are district nurses and case managers. District nurses provide care and support for people with dementia living at home, that need it. Case managers would be assigned for people with dementia diagnosis and take part in long-term care provision. They will provide home care in the early and middle stages of dementia until the person needs more intensive professional care for daily tasks. Then, in the severe stage, when living at home forms a risk, the case managers would suggest the transition to a care home to receive professional caregiving.

In Taiwan, the care of PwD is first evaluated by the case managers of the long-term care management centres supervised by Ministry of Health and Welfare. The case managers are well-trained physicians, physical therapist, occupational therapist, nurse, and social workers. After the assessment, the case managers will arrange related follow-up care services for PwD. The follow-up care services include home care, day care centres, institutional care, group homes, psychiatric wards for the elderly, institutional respite services, etc.

In Italy, the formal caregivers are case manager, neurologist, psychotherapist, occupational therapist, and nurse. The case manager is responsible of the organizational aspects of care. The neurologist is a specialized medical doctor who diagnoses the disease and prescribes the treatment. The psychotherapist leads the intervention, whereas the nurses and the occupation therapists act as assistant. These professionals may be especially found in day care, but they are available in residential home care as well. People at severe stage of dementia are suggested to move to a care home.

[1] In a later stage in the HAAL project a new group of possible end users was added in The Netherlands, the alarm centralist who respond to alarms of frail elderly that they are responsible for.

2.4. Care Community

The care community may differ per country as it is built from organisations that provide care services, in this project particularly for people living with dementia. Care services are organized differently in every country.

In the Netherlands, elderly care is divided and managed regionally, and the care community can be divided into public and private sectors. Dutch municipalities are responsible for endorsing care support in public sectors. Hence, they are often involved in public decisions, which affect technology adoption in a local area. On the other hand, project managers from private care organisations also represent decision-makers for care services as they decide what type of care is given, and how, at the corresponding care organisation. Moreover, their roles are collaborating with external entities and managing internal resources. Concludingly, the focus of the care community representatives in the Netherlands is on organisational collaboration and central material provision to formal caregivers. Therefore, the care community representatives shall have decision power in putting technological solutions in place to some extent.

In Taiwan, before 2018, the service of long-term care is conducted by Department of Nursing and Health Care and Department of Social and Family. Although these two departments are both under the Ministry of Health and Welfare, the main decision-makers and workers belong to the two systems of social and health services, respectively. In September 2018, the Taiwanese government established the Long-term Care Department with the purpose of integrating social and health resources and providing better services to the people. Taiwan is still continuously rolling amendments to long-term care policies and resources. For the care of PwD, formal caregivers (such as decision makers in care institutions) or informal caregivers (such as family members) have decision-making power in implementing technological solutions in place to some extent.

In Italy, health and social care is guaranteed to all the citizens. The government of social-care is administered by local administrations. The welfare system is based on the universalistic model. It is financed by general taxation and direct contribution to the expenses of the service (ticket), but older persons (over 65 years) do not have to pay direct contributions. The Italian insurance system grants the gratuity of care in three sectors: first aid, primary medical care (family doctor and general practitioner), and hospital care. Concerning social provision of service for the older people, the organization is still underdeveloped and differently distributed throughout the country. Health care devoted to older persons has three main forms: health and social care at home, admission in residential structures of health care, and hospital care. Access to these services is based on the self-sufficiency level of the users and on the duration of the worst phase of the sickness or the disability. In particular, the system of health care at home is aimed to contrast chronic disease and functional decline and to ameliorate quality of life. Each region has organized in autonomy the service and the rule of access. The contribution is in proportion to income. Health and social care at home is a service organized by the local health district and the municipality to offer personal programme of care to older persons aimed to avoid hospitalisation. Two typologies of services can be offered: one composed of nursing and rehabilitation care, and another of more complex interventions of medical, nursing and social care. Residential structures can be devoted to the care of older people: with(out) disability, with the necessity of medical care, or with the necessity of nursing care. Other health services are: day hospital, day care centre, rehabilitation service, counselling for family, and geriatric assessment and continuity of care.

2.5. Technical stakeholders

In the first place, technical stakeholders will provide the technological products and/or services within the HAAL project. They conduct research and development on the

technological products and could either be small to medium enterprises (SMEs), researching groups, or commercialised companies. Representative persons of the stakeholders can lead the developing directions and they have a responsibility in integration of their products. Although the technical stakeholders do not directly provide care services, their product designs and decisions have an overarching influence on the way care is provided. Therefore, the technical stakeholders are involved in the co-design sessions to ensure feasibility of the HAAL-bundle. Moreover, they are involved to support on the developing features in case of a need for changes and adaptations to new user requirements.

2.6. HAAL consortium

HAAL consortium comprises working members from main collaborators in the HAAL projects. Each has diverse backgrounds and specialisations, from technical developers to experts in collaborating with end-users. In the whole HAAL project they need to develop the concept, technical execution, deployment, and commercialisation. They are also decision-makers for design direction, implementation prioritisation and task allocation. Thus, their mutual comprehension and agreement on the central concepts and directions would be an utmost factor for HAAL's achievement.

2.7. Researchers

Researchers in this work package 2 are central among all the groups. Their expertise is gathering user requirements and analysing the results. They are responsible for conducting and facilitating the co-design. In a separate co-design setup, they need to be a neutral central mediator among all the stakeholders who don't meet each other. Consequently, they shall make sure that functional and emotional requirements come through across the non-direct communication among several stakeholders.

Hereby, the roles of stakeholder groups in the co-design were established to clarify their unique contribution or expectations in the co-design series. This research has considered their characteristics, roles in caregiving and decision power on technology achievement. The summary of the roles is in Table 1.

Table 1
Roles of stakeholders in the co-design series in the HAAL project

Stakeholders	Roles in the co-design series
People with dementia	• Validating the concept of ageing at home • Giving emotional and experiential feedback on the ecosystem • Giving emotional and experiential feedback on the platform • Suggesting or expressing what they think might be better • Finding a comfortable spot for themselves
Informal caregivers	• Validating the concept of ageing at home • Giving emotional, functional and qualitative feedback on the ecosystem • Giving emotional, functional and qualitative feedback on the platform • Suggesting or co-designing • Finding a comfortable spot for themselves and their cared person
Care professionals	• Recruiting older adults and caregivers for participation in HAAL • Generalising and finding compromises on visionary concepts • Giving individual opinions on technology adoption • Giving emotional and experiential feedback on the platform • Representing of the informal/formal caregivers
Care community	• Recruiting formal caregivers or case managers for participation in HAAL

	• Generalising and finding compromises on visionary concepts • Giving organisational opinions on technology adoption • Representing of the informal/formal caregivers
Technical stakeholders	• Ensuring feasibility • Supporting on the developing features (in case of changes and adaptation according to new user requirements)
HAAL consortium	• Understanding the results from all co-design session • Sharing their experience and knowledge on their specialisations • Developing the direction of the integration solutions
Researchers	• Facilitating several sessions • Sharing results and knowledge from one group to another • Representing the non-participating end-users in the sessions • Prompting non-functional questions

3. Method and plan

This work package 2 has divided work plans into 5 tasks: *Desk research, Co-design series, MoSCoW analysis, Meaningful try-outs* and *Report.*

3.1. Desk research

The aims of the desk research are to conduct literature review on research in the dementia contexts and plan the research plan. The literature review covers methodologies to conduct design research for stakeholders in dementia care contexts. In addition, research is conducted on responsible technology, or ethical considerations for technology adoption for people with dementia or healthcare sectors. The result of this first section is shown in this planning document (DP2.1).

3.2. User need research

The aims of the Co-design series are to validate the vision of the HAAL care technology bundle, to gather their requirements and to explore essential elements for the integration with all stakeholders. The underlying vision of HAAL project supports people with dementia to live independently at their home as much as possible; the concept is called ageing-in-place. The validation is important across varying contexts in 3 countries. User requirements depicts high-level concepts that the stakeholders need/want/wish in the technology integration. The approach and analysis would follow the Emotional Goal Model, to support not only functionality but also quality and emotionally satisfaction. And finally, essential elements for the integration are the details in technology experience and interaction. In action, co-design series include focus groups and interviews with the stakeholders.

3.3. HAAL device demonstrations

The aim of the HAAL device demonstrations (based on the method of meaningful try-outs) is to receive feedbacks from end-users through HAAL device demonstrations direct trial. Ideally, the end-users adopt each technology in their own home/living setting for 2 weeks – which allows more in-depth opinions on actual usage. And at the end of each trial, participants will discuss 1 to 2 out of 7 perspectives: functionality, usability, involved stakeholders, communication, organisation, environment and supplier. Due to Covid-19 restrictions, alternatives of on-site demonstration could be sending the technologies or showing the technologies in a physical form without longitudinal uses. And because of the varying possibility to technology set-ups and the number of involved technologies, each country could conduct meaningful try-outs with different technology that is fitting to their contexts and needs.

3.4. Prioritisation survey

The aim of prioritisation survey (based on the MoSCoW technique) is to gather quantitative information that sets priority on the project. In the MoSCoW analysis, participants rate the use case of technology combination by importance levels (Must, Should, Could, and Would) on a digital questionnaire. They also must explain their rationales on their rating on criteria that are derived from earlier co-design sessions. The participants include both the HAAL consortium members and targeted users. Ideally, the targeted users would rate the technologies before and after the meaningful try-outs, to verify their assumptions/imagination of the technologies.

3.5 Annotation interview

These interviews will be combined with the HAAL device demonstration. The aim is to give meaning to the different data that is gathered by the HAAL devices. Participants are asked to share what data they find meaningful in their work, and how to find data on the wellbeing status of a PwD.

3.6 Co-creation series

This co-creation series aims to answer which type of information should be displayed on the HAAL platform with dashboard, as well as in which manner this information should be visualised (e.g., grouping of information and graph type). Additionally, it will address how recommendations should be displayed. These series are related to the Responsible Innovation work – as we aim to explore which role Artificial Intelligence (AI) could take in the HAAL platform. This research question explores which level of AI involvement is expected and acceptable as well as how the interaction with AI should be displayed.

3.7 Report

The aim of report is to elaborate the results from all the earlier sessions. This includes analysing the results from three countries and transforming the user requirements and feedbacks into designs of the HAAL solution. The HAAL consortium also intends to submit a symposium, with at least six scientific papers. The results from WP2 would also be contributing to the papers.

These five tasks are not distinctively separated from each other linearly. As estimation, the Desk research takes 3 months. The user need research takes 7 months. Prioritisation survey takes 4 months, and the technology demonstration including the annotation interviews takes 2 months, excluding the preparation time. And finally the Report task takes 2 months until the end of Month 12 (M12). Afterwards the WP will focus on conducting the co-creation sessions and Responsible Innovation research.

Conceptually, the work process iteratively goes through the steps of ‘Innovate Dementia Living Lab protocol’ in both small and big scopes. The small scope is in a regional level – HAAL partners conduct the studies parallelly in their own countries. And the big scope is in the international level – concerning the sessions with technical partners and HAAL consortiums and the analysis of results from three countries in one body.

In a small scope, researchers prepare a workshop with questions/artefacts introduce and co-design during the workshops, reflect the results and feedback after the workshop and restart. The small scope includes iterative communication with all end-users. Due to the language barrier, cognitive abilities and the number of stakeholders, the sessions of stakeholders are conducted separately based on user roles for the communication convenience and cooperation feasibility.

In a bigger scope, the prepared workshops are conducted in all the three countries, the results and feedback come back to the centre and each region conducts the next workshops. The primary goal of international involvement is to understand differences and similarities in needs and wishes per region/country. Vilans, Silver Lining & Yuan Ze University, and INRCA are responsible partners in conducting sessions with care community, care professionals, informal caregivers and people with dementia in the Netherlands, Taiwan and Italy, respectively.

To ensure the smooth collaboration in WP2, Vilans facilitates bi-weekly meeting for WP2 to give updates on the progress and support each partner to go through the Co-design process. For example, Vilans presents the concepts of Living Labs and Co-design with stakeholders and people with Dementia to all stakeholders, see Appendix A. Besides, Vilans also provides supports on the methodology of each sessions and report templates with expected questions among the consortium members, see Appendix B.

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Appendix A

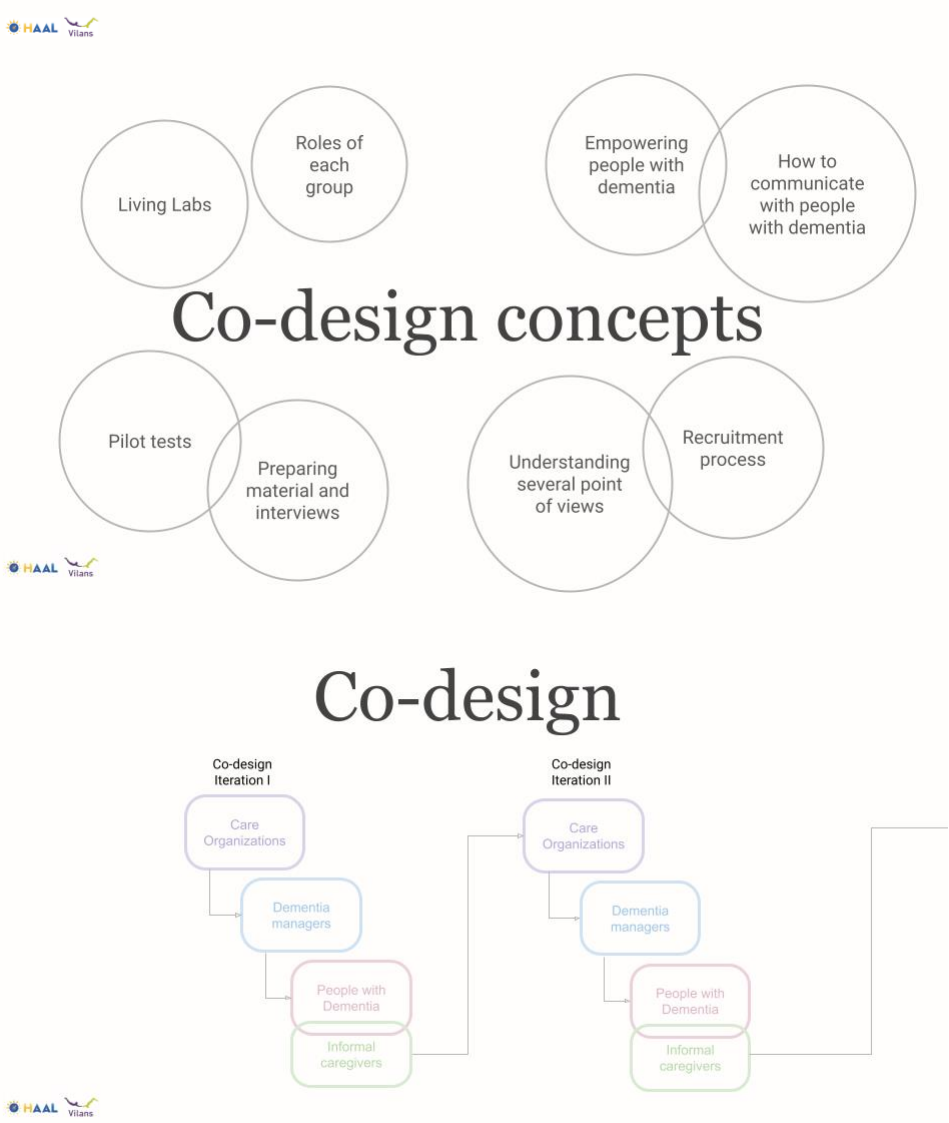
HAAL: co-design methodology

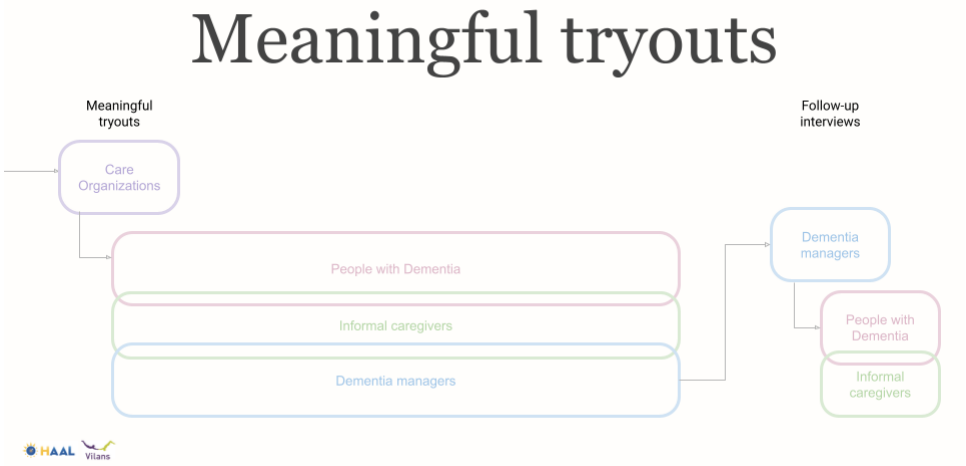
Sharing know-how with the consortium members

Agenda
- Co-design concepts
- Methodology

Why co-design?

"some older people perceived that their feelings were not being taken into consideration"


Goal?
"Getting guidelines for making a central platform for technology integration"
Living Labs
Roles of each group
Empowering people with dementia
How to communicate with people with dementia
Co-design concepts
Pilot tests
Preparing material and interviews
Understanding several point of views
Recruitment process
Co-design
Co-design Iteration I
Care Organizations
Dementia managers
People with Dementia
Informal caregivers
Co-design Iteration II
Care Organizations
Dementia managers
People with Dementia
Informal caregivers


Meaningful tryouts
Meaningful tryouts
Follow-up interviews
Care Organizations
People with Dementia
Informal caregivers
Dementia managers
Dementia managers
People with Dementia
Informal caregivers

Methodology
Recruiting participants
Preparing material for the session
Conducting pilot tests
Facilitating co-design session
Analysing result

HAAL: co-design with PWD

Explanation for the co-design series with PWD

Agenda

- Objective
- Guidelines
- Before the session
- During the session
- After the session

Co-design with PWD and their family members

4 people with mild cognitive impairment
4 informal caregivers (family members)

Objectives

1. Validating long-term care at home
2. Making a 'Can-do' list for an older adult
3. What can technology help you? {co-creation}
4. User requirement on the ecosystem

Guidelines for co-design with PWD

1. Give a lot of time for general practicalities
   a. Foresee enough time for getting to know each other, for repetition and constraint reviewing the different phases
2. Tune the methodology towards the person's background, interest and specificities = The more you know about them in advanced, the better you can prepare for them.
3. Take into account the difficulty in envisioning intangible concepts and abstract notions
   a. Use easy to understand wording
   b. Make use of non-verbal elements (object images or physical artifacts)
   c. Address experiential aspects

Guidelines for co-design with PWD

5. Minimize distraction and keep participants on focus
6. Use fictive 3th person stories to consult a person in an indirect way - using the more euphemistic term 'memory problems'
7. Give a trusted caregiver an important role during sessions for aiding with the participation of people with dementia
8. Be aware of caregiver's influence and suggestion that is not actual opinion from people with dementia

(Hendriks et al., 2013)
https://link.springer.com/chapter/10.1007/978-3-642-40483-2_46

Appendix B

Template for a session with care community

This is a template for user-research sessions. The black texts are outlines for the sessions and questions. The grey texts are only short examples of possible results. Please add results based on your contexts and number of participants. All coloured instructions shall be removed after finishing.

DESCRIPTION OF THE PARTICIPANTS AND THE STATUS OF THE COLLABORATION (Example: This session was the first time XXX had direct contact with HAAL and the care organization only had a flyer of the project as introductory information.)

The first meeting was intended for getting to know each other's situations for further collaboration. The main topics of the first session include HAAL project introduction, current tech situation, use case for integration and long term care planning.

**

DETAIL OUTLINES OF THE SESSION {60 min}

1. **Introduction:** welcoming and introduction to the workshop {3 min}
    a. Agenda of the session
    b. Informed consent for the recording (screen recording for an online setup and video recording for a physical setup) - and starting to record
    c. Round-table introduction (facilitators and participants)

    Project introduction: Informative introduction to the HAAL project and its plan {7 min}

    Current tech situation: Asking the participants to explain what technologies they are using for dementia care {15 min}
    a. What is the current situation of dementia care technology?
    b. What opportunities and improvements do you see?

    Use case for integration: Asking the participants to express opinions about potential scenario or case for HAAL technology bundles {15 min}
    a. What possibilities do you see in the integration of the various HAAL technology?

    Long-term care planning: Asking the participants to elaborate on their current approach of planning long-term care for people with dementia {15 min}
    a. What platforms do you now use for long-term care plans/files?
    b. What kind of information is relevant//potential for your management?

    Conclusion: Thanking for participation and asking if they might be interested in joining in the future workshops {5 min}

**

Facilitators: (Example: Henk Herman Nap and Piyakorn Koowattanataworn from Vilans)
Participants: (Example: 1 participant from XXX (NL), 2 participants from XXX (NL), 2 participants from XXX (NL), and 2 participants from XXX (NL))
Date: (Example: 03.06.2021)

Participants

(Example: Participant 1 is from XXX and she has introduced XXX for digital daycare. They are working towards offering a digital provision of daycare for all their clients.
...
Participant 5 and 6 work for XXX and has developed XXX tablet for 8 years. They are one of the suppliers of technologies in this project.)

Current tech situations

Questions: What is the current situation of dementia care technology? What opportunities

and improvements do you see?
SUMMARY OF ANSWERS
(Example: Both the participants from care organisations are involved in daytime activities or daycare, in which clients participate in daytime activities at the physical care organizations. This means that the results don't include the perspectives of visiting home care or care home service.)

SPECIFIC ANSWER FROM EACH PARTNER
(Example: XXX: In the daytime activities, they are testing tablet screens (XXX and XXX). And in other care departments, automated medicine dispensers (XXX), and lifestyle monitoring (XXX) are being used.

The daytime activities service at XXX has just started with digitisation at that moment. So she didn't have much experience and it was difficult for her to indicate any problems or possible improvements in the system at the moment. Although home care and care home services are more engaged in technology adoption, she didn't know much about departments other than the daycare. Besides, XXX has an innovation department, which is open for more experiments. Current experiments are with Virtual Reality and Robots.)
RELEVANT QUOTE AND THE SPEAKER (Example:'Yes, we are still searching which form of digital means meets the needs of the clients [people with dementia]' - Participants 1 from XXX)

A use case for HAAL technologies

Question: What possibilities do you see in the integration of the various HAAL technology?
SUMMARY OF ANSWERS
(Example: All participants from the care organizations found the presented products interesting. A participant from XXX expressed a clear interest in trying wearable products and games for physical activities/rehabilitation. First, she expressed her interest for Freewalker, because more people are inside due to Corona. Moreover, she expected that WhizPads and ARm-PETs could be suitable for daytime activity service.)
RELEVANT QUOTE AND THE SPEAKER (Example:'WhizToys, I am sure, could be an added value. Because people find it such a shame they cannot go outside as they don't know the way.' - Participant 2 from XXX)

SPECIFIC ANSWER FROM EACH PARTNER
(Example: Likewise, a participant from XXX found these household technologies interesting. Because XXX moves toward supporting people to live longer at home with informal caregivers and providing long-term care at home. The reason was rooted in the rising number of the elderly and the heavy shortage of professional nurses. She believes that digital daycare could support professional caregivers.)
RELEVANT QUOTE AND THE SPEAKER (Example:'I naturally see that they can live at home for as long as possible with the support of the carer, that a form of digital daytime activities is only part of it.' - Participant 1 from XXX)

Long-term care planning

Questions: What platforms do you now use for long-term care plans/files? What kind of information is relevant//potential for your management?
SPECIFIC ANSWER FROM EACH PARTNER
(Example: Both of the care organisations are using ONS, a digital patient record provided by Nedap Healthcare. The system stores information from clients from ONS and we can do the district nursing planning. It covers home care (Intramurale zorg) and daytime activities. It also covers a wide range of target groups, for example, GGZ (Mental health care), intellectual disability and the elderly.

Besides, Caren Zorgt is another platform for informal caregivers. It is connected to a client file from ONS. And according to a participant from XXX, Sensara is connected to both ONS and Caren Zorgt.

When Sensara sensors detect unusual behaviours, the signal is sent to both platforms. Although Compaan indicated that its portal can be connected to ONS for scheduling a meeting, XXX is not using the function at the moment. Because they are only using Compaan at daycare.)
RELEVANT QUOTE AND THE SPEAKER

Conclusion

SUMMARY OF PARTICIPANT'S PERSPECTIVES TOWARD USING CARE TECHNOLOGIES IN CAREGIVING AND THEIR REQUIREMENTS FOR THE TECHNOLOGIES.
(Example: Care departments in XXX and XXX use care technology to a different extent. While care homes or nursing homes have used and integrated care technology in the system, daycare just started digitizing at the moment. Consequently, daycare was searching for more technological options that would fit the client's needs. Both of them were using ONS from Nedap for client management, including dementia planning.

In conclusion, they perceive digital solutions as a tool to support human care and are searching for suitable interventions. In general, they support the ageing-in-place concept, which aligns with the HAAL projects. They expressed a clear interest in the HAAL technologies and would like to see more details about them. Besides, XXX is looking toward a social approach to dementia. The approach is to take care of the disease but also the impact on the personal environment of people with dementia and their loved ones. And user requirements from the care community can be summarized in a list.

- **Holistic:** Technology should serve several fields of life - social, mobility, etc.
- **Integrated:** All of the tools should work in an integrated manner. This implies the integration among devices and toward the existing central system for client management.
- **Preventive:** Intervention that would prevent disease progression is the most added value, especially before the symptom develops from the early stage. The digital service should start from the beginning stage when they reach the district nurse.
- **Ageing-in-place:** The technology supports clients to stay in their accommodation as long as possible.
- **Domestic:** The solutions should include domestic care with digital communication. This means the devices should also be at home, rather than only at the care institutions. By this, technology will help to decrease the workload for professional caregivers in nursing homes.)

Template for a session with care professionals

This is a template for documenting user-research sessions. The black texts are outlines for the sessions and questions. The grey texts are only short examples of possible results. Please add results based on your contexts and number of participants. All coloured instructions shall be removed after finishing.

DESCRIPTION OF THE PARTICIPANTS AND THE STATUS OF THE COLLABORATION (Example: This session included project managers and dementia case managers from XXX and XXX.)

This session was the first (or second) time that formal caregivers knew about the HAAL project. The main topics of the first session are project introduction, HAAL technologies, central platform, and prototype.

**
DETAIL OUTLINES OF THE SESSION {60 min}

1. **Introduction:** welcoming and introduction to the workshop {3 min}
    a. Agenda of the session
    b. Informed consent for the recording (screen recording for an online setup and video recording for a physical setup) - and starting to record
    c. Round-table introduction (facilitators and participants)

    Project introduction: Informative introduction to the HAAL project and its plan {7 min}

    HAAL technologies: Aftering showing the HAAL technologies on videos, asking for participants' opinions/interests toward specific technologies {15 min}
    a. What is your opinion about these HAAL technologies?

    Central platform: Asking for their user requirements for the central platform that integrates several technologies {15 min}
    a. How can it help you in healthcare?
    b. Within which care processes/actions?
    c. How do you want to experience it?

    Prototype: Showing an example of an interface for displaying client's information to caregivers and giving them options to construct a new interface. Asking for their user requirements on the central platform. {15 min}
    a. What do you think about it?
    b. What is missing?
    c. What could be improved?

    Conclusion: Thanking for participation and asking if they might be interested in joining in the future workshops {5 min}

**

Facilitators: (Example: XXX, XXX and XXX from Vilans)
Participants: (Example: 2 participants from XXX (NL), 4 participants from XXX (NL), 1 participant from XXX (NL), and 1 participant from XXX (NL))
Date: (Example: 13.07.2021)

Participants

(Example: Participant 1 is a project leader for integrated care in XXX and XXX, which are districts around XXX, a capital city in the Netherlands. In the past, she was in a project that implemented some technologies like the Compaan, lifestyle monitoring, and GPS trackers. From that project, they set up the Dementheek in XXX, where clients can rent and try technological solutions.)

Current tech situations

Questions: What is the current situation of dementia care technology? What opportunities and improvements do you see?
SUMMARY OF ANSWERS

(Example: XXX introduced Compaan for digital daycare for all clients (not only older adults). They also introduced Lifestyle monitoring for older adults at home.

XXX started digital daycare with the Compaan during covid in 2019-2020. Because they found that people were still scared to come after 1st lockdown. A case manager from XXX (participant 2) uses Compaan and personal alarms with GPS. At the moment, she was working on implementing an automatic medication dispenser, Thelma, and XXX was also trying to use social robots, Tessa. However, the case manager expressed concern about the lack of technological support that made it difficult to be adopted. Nevertheless, the case manager from XXX indicated her interest in domestic services for PWD, especially in Lifestyle monitoring. Another interesting experience she shared was that one client has bought their own personal alarm with GPS and this works well.)

RELEVANT QUOTE AND THE SPEAKER (Example:'We are working with a digital medication dispenser, and we are trying to use the social robot but it doesn't really take off yet. I'm personally interested in lifestyle monitoring but it lacks in support to implement this broadly.' - Participant 2 from XXX))

HAAL technologies

Question: (Aftering showing the HAAL technologies on videos) What is your opinion about these HAAL technologies?
SUMMARY OF ANSWERS
(Example: Participant 1 pointed out that lifestyle monitoring can be used for people at home very well, especially for supporting informal caregivers. Her organisation set it up in a project and informal caregivers were very happy. In the beginning, it took some time to get used to it, because the informal caregivers were waiting and anticipating an alarm. But when they are used to it, it can be of a lot of added value. Besides, she also suggests early technology adoption. She hinted that it can be beneficial when they move to a nursing home if you give Compaan early enough. It can be very helpful for contacting the family when you live in a nursing home.)
RELEVANT QUOTE AND THE SPEAKER (Example: 'I would like to add that for lifestyle monitoring, they talked about the intramural setting but it is also very appropriate for situations at home, especially to support informal caregivers. We implemented it in a project in which informal caregivers were very happy with it. ' - Participant 1)

Central platform

Questions: How can it help you in healthcare? Within which care processes/actions? How do you want to experience it?
SUMMARY OF ANSWERS
(Example: From the beginning, Participant 6 from XXX disclosed concern that they were struggling with moral dilemmas. For example, privacy concerns with lifestyle monitoring. She was interested in HAAL's consideration of ethical perspectives and possible solutions. A facilitator in the HAAL project pointed out that one of the work packages of the project focuses especially on ethical concerns. Additionally, Participant 7 suggested that HAAL should also include Slimotheek. Because it has a lot of tools available. At that moment, they were busy with making a portal that describes all the technologies and they wanted to add videos. So she saw a direct relationship with this HAAL project. Participant 2 thought that the central platform would be used for risk signalling, the collection of data, as support for informal caregivers and professionals at a distance. Case managers could benefit from the notifications and collected data, which would be turned into insight and appropriate action. For example, a decline in nightly unrest. Currently, they use the information provided by informal caregivers. But not everyone has a partner or informal caregiver. From the ones that do, the informal caregivers are often overburdened and they don't know available solutions. Moreover, it depends on the stage of dementia when you start with innovations and what you can use them for. One possible fitting innovation for nightly unrest could be a music pillow.)
RELEVANT QUOTE AND THE SPEAKER (Example: 'Now we have to use information from the informal caregiver that, in case of nightly unrest is pretty overburdened. and who knows, using this technology we might be able to introduce new interventions.' - Participant 2)
(When asked if there is information missing at the moment regarding the status of the client,

Participant 2 would like more information on daily behaviours. She is curious to know what a person is doing, if the person sits a lot, and how much they move (through Lifestyle monitoring). This information doesn't have to be notifying alarms, but more monitoring over time.
'For example lifestyle monitoring, what does a person do during the day, in general? Do they sit a lot? And if they move, how much do they do that? That kind of stuff.' - Participant 2
Participant 8 talked about a recent report indicating that people with early dementia fall between several care streams (district nursing, case management, WMO care). It's unclear where the older adults should be because there is a lot of risk in the household which leads to escalations in a lot of cases. He questioned, "How can you get rid of those escalations?". Regarding financial reasons, he thought that funds should rather be spent on circumventing those escalations.)

Prototype

Questions: What do you think about it? What is missing? What could be improved?
SUMMARY OF ANSWERS
OPTIONAL: Creating a sketch of the user interface from their suggestion during the session to make the same clear image of their requirements
(Example: Participant 2 thought the designed prototype (Figure 1) looked good, practical and giving a good overview. Additionally, she would like a notification if there are discrepancies in the situation. After the facilitator made a new interface for notification (Figure 2), she suggested that the notification should have a colour of the application (e.g. Sensara notification = purple) and no notifications would be necessary if behaviours are normal.

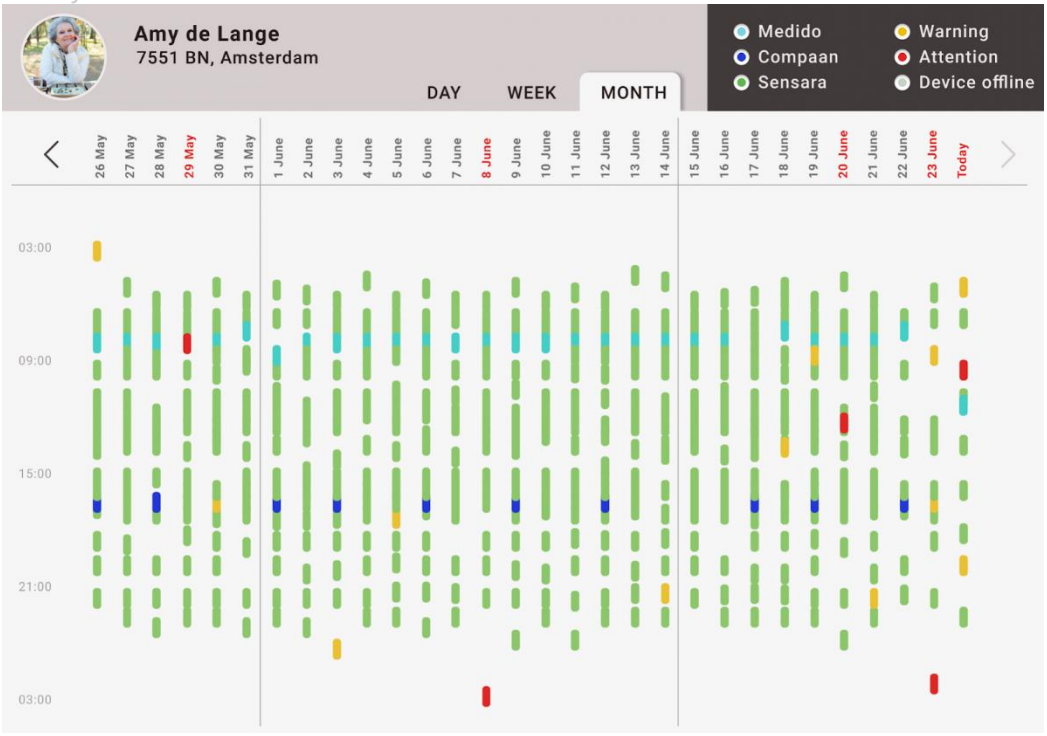


Figure 1. A design interface, showing an overview of a person in a month for formal caregivers

Figure 2. A proposed interface, notifying formal caregivers of behavioural status

Participant 1 raised the topic of a collaboration among formal caregivers. This includes the question of an authorised caregiver who would get a notification and documenting reacting actions to the notifications. The central platform should allow the continuity of care to clients and make it work for the whole care team. A senior facilitator proposed that the researcher would study an existing connected platform, "Hello Zorg", because they have provided solutions for using innovations in teamwork.

'If you have multiple people in the same situation, working for the same client. Can they all receive access to this app or how does this work? Because for example at Amy's, possibly 3 caregivers show up. How many people have access to this [the system]. Because if you want to provide this continuity of care and you get a warning then you should do something with the warning. How can you make the system in a way that it works for a whole team?' - Participant 1

Participant 3 would like to connect blood saturation measurement to the central platform and have notifications when the measurement indicates risk. In the current situation, one caregiver is assigned to look up the saturation number and report it. However, some caregivers are not very precise in reporting the measurement. Thus, she saw an added value if the central platform could give a pop-up notification when the measurement is alarming

Finally, Participant 1 visioned that in the future the professional caregiver has to look into the reported information, to identify an essential piece of information, and to act responsibly to the information. She strongly implied that the task of reading digital reports is an important job and it should not be optional anymore. Consequently, the central platform should be well arranged as well.

'That you look very thoroughly at what do you need, and how you're going to use appropriately. And indeed with a team, that at a certain stage it won't be voluntary anymore, but instead a way of working. But for that, it needs to be clear for everyone, because otherwise one person will feel very responsible when they have the application on their phone when the others do not.' - Participant 1)

Conclusion

SUMMARY OF PARTICIPANT'S PERSPECTIVES TOWARD USING CARE TECHNOLOGIES IN CAREGIVING AND THEIR REQUIREMENTS FOR THE TECHNOLOGIES AND THE CENTRAL PLATFORM

(Example: Case managers perceived the importance of giving services at clients' residences, aligning with the innovation manager in a previous session. As technology could be a potential solution, a strong connection for technical support has a direct impact on the adoption rate in real life for the case managers.

Regarding the HAAL technologies, one participant expressed a strong interest in Lifestyle monitoring and daily behaviours. The information about daily movement and activeness at home is now missing

and it is very important for professional health analysis. In addition, another participant revealed from her indirect experience that Lifestyle monitoring is very helpful for informal caregivers.
The proposed interface of the central platform that shows an overview of the digital report was appreciated by case managers. Suggested improvements are alarming notifications about urgent discrepancies, collaborative features among professional caregivers, and ethical concerns of personal disclosure.)

Template for a session with people with dementia and informal caregivers

This is a template for user-research sessions. The black texts are outlines for the sessions and questions. The grey texts are only short examples of possible results. Please add results based on your contexts and number of participants. All coloured instructions shall be removed after finishing.

DESCRIPTION OF THE PARTICIPANTS AND THE STATUS OF THE COLLABORATION (Example: This session was the first time that researchers have direct contact with the participant with dementia and his/her informal caregiver. They were recruited through care organisation partners; XXX and XXX .)

The first meeting was intended for getting to know personal needs from both PwD and informal caregivers, and co-design technological solutions that fit their wishes. The main topics included validating long-term care at home, making a 'Can-do' list for an older adult, co-creation and gathering user requirements on the ecosystem.

**

DETAIL OUTLINES OF THE SESSION {60 min}

1. **Personal self-introduction:** Introduction to facilitators and participants {3 min}
    a. Possibly using a self-intro album (The older adult could prepare an object/image that describes him/herself to reduce upfront stress to find words.)

Short project introduction: Introduction to HAAL and co-design process {3 min}
    a. Brief explanation to the HAAL project
        i. "This HAAL project wants to combine technologies for caregiving, so older adults can age at their home. In this research, we focus on your feelings and thoughts on what you need as you age."
    b. Informed consent
        ii. "You can stop or quit this session at any time. And we would like to record this session but we will not share your name or any personal information. Do you feel comfortable with the condition? [If you have any questions, please let me know.]"
    c. Two sides:
        iii. "This session focuses on what assistance you would like to have. And we would like to know opinions from both people with dementia and their family members. So we will encourage both sides to speak up."

Validation question {5 min}
    a. Asking for their opinions about ageing in places
        i. "What is your living situation at the moment?" (Live at home, hospitals, or home care?)
        ii. "What is your opinion toward home care?"
        iii. "How do you feel about living at your own residence as long as possible?"
        iv. "How about a time when you might need part-time assistance?"
        v. "What do you think about help from technology? / What do you think about staying at home with technological help?"
        vi. "Would you prefer this to going to a care home?"

Can-do list: Discovering retained skills and care technology they want {25 min}
    a. Playing a board game with objects on daily basis: seeing what they can do {10min}
        iv. "Now, we would like to discover what you can do. We will go through pictures of scenes. You can look at the items around each and let us know what you can do and how you feel about it."
    b. Getting helps from the caregiver to expand the can-do list {5 min}
        v. "Are there any additional actions you would like to add?"
    c. Discovering their needs(High-Level) {10 min}
        vi. "What more do you want to do? What do you miss doing?"

Future workshop: Brainstorming technological solutions together {20 min}
    a. Depicting 2-3 problems they mentioned or expressed enthusiast about
    b. Placing technological objects on the picture
        vii. "So regarding the __ action you want to do, How can technology help you to __?"
        viii. "What should it do?"
        ix. "How should it feel?"
        x. PWD might not know the technology, and ask what they can be used for. You can let them know that it depends on what you need. Researchers could propose ideas and

ask the questions.

Re-summarising into an emotional goal model {5 min}

a. What should technology do to help you?
b. How should it help?
c. How should it feel when doing it?

Conclusion {2 min}

a. Thanking the participants
b. Asking if they would like to participate in the next session

**

Facilitators: (Example: XXX)
Participants: (Example: 1 participant with dementia, 1 informal caregiver, 1 case manager from XXX (NL))
Date: (Example: 10.10.2021)

Participants

(Example: Participant 1 is diagnosed with mild dementia. She is now living at home with her partner, Participant 2, who is the main informal caregiver at the moment. The item she chose for herself was a coffee mug, because she liked drinking and tasting coffee.)

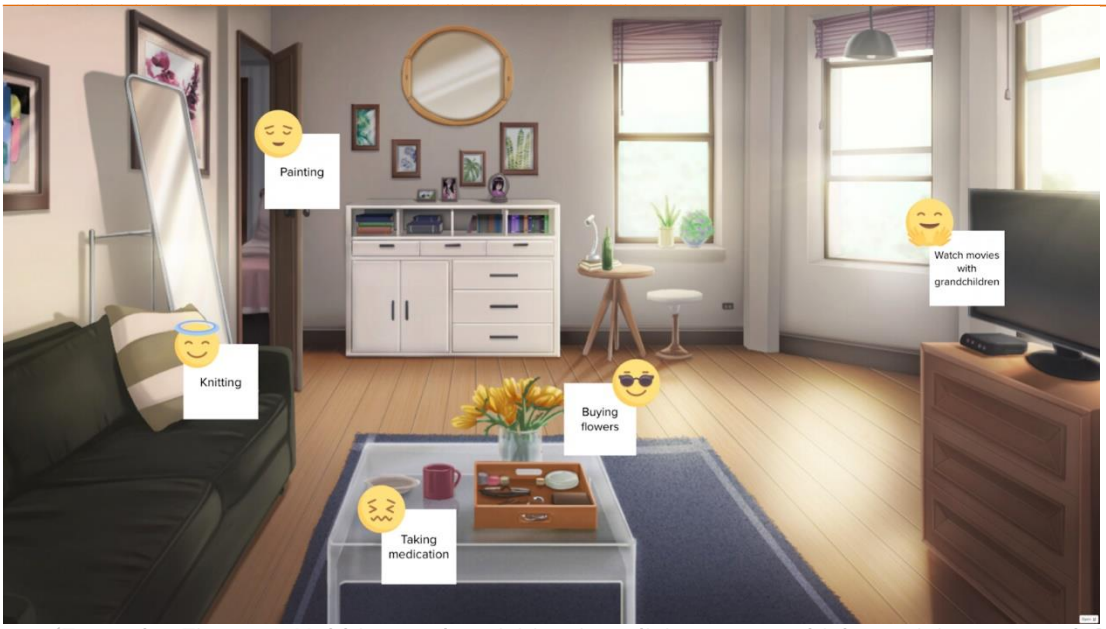
Validation question

Questions: What is your opinion toward home care? What do you think about help from technology? / What do you think about staying at home with technological help?
SUMMARY OF ANSWERS
(Example: -)
SPECIFIC ANSWER FROM EACH PARTNER
(Example: -)
RELEVANT QUOTE AND THE SPEAKER (Example:'' - Participant 1)

Can-do list

Question: Based on scenery images, what actions can you do?
SUMMARY OF ANSWERS
(Example:-)
RELEVANT QUOTE AND THE SPEAKER (Example:'' - Participant 2)
IMAGE FROM THE CO-DESIGN SESSION

Question: What more do you want to do? What do you miss doing?
SUMMARY OF ANSWERS
(Example:-)
RELEVANT QUOTE AND THE SPEAKER (Example:'' - Participant 2)
IMAGE FROM THE CO-DESIGN SESSION



(Example: Figure 1 Hobbies and activities in a living room which participant 1 and 2 helped constructing together)

Future workshop

Questions: How can technology help you?
SUMMARY OF ANSWERS
(Example: -)
SPECIFIC ANSWER FROM EACH PARTNER
(Example: -)
RELEVANT QUOTE AND THE SPEAKER (Example:'' - Participant 1)

IMAGE FROM THE CO-DESIGN SESSION

(Example: Figure 2 A reminder watch to notifies the user what time to go home and a tablet that helps garden management)

Conclusion

**SUMMARY OF PARTICIPANT'S PERSPECTIVES TOWARD USING CARE TECHNOLOGIES IN

CAREGIVING AND THEIR REQUIREMENTS FOR THE TECHNOLOGIES.**
(Example:-)