



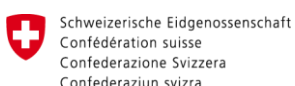
REPORT

PARTICIPANTS LIST AND WORK PLAN OF THE END-USER ADVISORY BOARD

Deliverable D1.1

2021-09-06, Revision 2.0

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1.1	2019-10-03	Update	HH Nap	Update with new members
1.2	2019-12-12	Update	HH Nap	Update with minutes of 2 nd EAB meeting
1.3	2021-6-9	Update	HH Nap	Updated with activities 2020-2021 / COVID-19
2.0	2021-6-9	Approved		

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Revision reviewed	Date	Remarks, Corrections	Reviewer	New Status
1.0	2018-10-19		M.Litzenberger	Reviewed

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EXECUTIVE SUMMARY

In order to guarantee active end-user involvement during the project, FreeWalker has established an end-user advisory board (EAB) of the national end-user organisations, representing different areas and nations within the provision of long-term care to people with dementia. This Deliverable presents the end-user advisory board for the FreeWalker project. In 2019, there was a change in the members of the EAB and a major business partner was included. In 2020 & 2021, no specific EAB meetings were organized, however, the ethical representatives were involved in online meetings on ethical issues and approval for the various end-user pilots and usability study. In this deliverable, the procedure for inclusion and involvement is discussed and results will be added after every EAB meeting/telco.

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1 INTRODUCTION

1.1 Scope of the document

This Deliverable 1.1 details the participants list and work plan for the end-user advisory board that will be involved in all phases of the FreeWalker project. The document can be used as a reference for the end-user advisory board meetings in respect to procedures, content, planning, and documentation.

1.2 Relation to other project documents

This document is related to a variety of documents and tasks in the FreeWalker project. The EAB will reflect on T1.2 User needs, Usability analysis and iterative user-centered co-design with D1.2. Furthermore, they will reflect on T1.3 System architecture and specifications with D1.3. The EAB will also reflect on the initial design of the mobile app user interface, defined in T2.1 with D2.1. The EAB should also support in providing feedback on the recruitment phase of test persons in T3.1 and the ethics approval of D3.1. In addition, for T3.2 – the preparation of the trial – the EAB has a major role in reflecting and advising on the protocols for the trials and in T3.4 on the evaluation phase (D3.2). The EAB will receive feedback on the evaluations in T3.5 and T3.6 by D3.5 and D3.6 and D3.7 based on T3.7. Finally, the EAB will provide reflections on T5.5 (responsible research & innovation and data protection management).

1.3 Contributions of partners

Partner	Chapter	Description of Contribution
VILANS	All	
MAS, Terz & tanteLouise	3	Providing participants for EAB

1.4 References

1.5 Acronyms and Conventions

Acronym	Explanation
AAL	Active Assisted Living
N/A	Not Applicable
EAB	End User Advisory Board
GA	General Assembly

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2 FUNCTION AND SCOPE OF THE EAB

The goal of the FreeWalker project is to integrate several proven components of AAL assistive devices and technologies to support independent living and freedom of mobility for people with dementia. These components consist of a GPS tracker of MOPAS, the CareCenter platform, end-user apps by CREAGY, and a logic engine developed by AIT. FreeWalker will consist of a flexible and versatile solution for guiding and monitoring people with dementia in the outdoor environment. A focus will be on supporting caregivers by providing emergency information in order to recover disoriented persons safely. The primary target groups in FreeWalker are people with dementia, living at home or in an intramural care setting, as well as their (in)formal carers. The aim is to promote persons with dementia and cognitive impairments to stay active and physically healthy by reducing the fear of going out.

To guarantee active end-user involvement during the project, primary, secondary and tertiary end-users will be involved from all participating countries in all phases of FreeWalker, an end-user advisory board (EAB), persons accompanying the design process by participating in co-creation sessions and test persons participating in the field trial. Personas will entail all relevant information on the most important end-users. These personas will be continue to be part of the entire project and will evolve with every user research activity.

The EAB will be prepared primarily for consultancy in:

- (1) Analysis and specifications,
- (2) Usability analysis and co-design
- (3) Field trial
- (4) Evaluation

In respect to reflection to user needs, the EAB will be involved in all phases of the project to monitor the actual agreement between needs established in Task 1.2 and the actual evolution of the FreeWalker solution during the iterative development. It will be especially focused on the field-trial and hold regular meetings, synchronized to the feedback loops, to make corrective proposals to the project general assembly (GA).

3 THE EAB - PARTICIPANTS

The EAB is assigned to ensure that FreeWalker remains aligned with end-user needs and technology innovations during the course of the project as such that end-user needs will continuously be taken into account in the development and evaluation phases. The EAB provides important organizational requirements that are collected and refined in the iterative design, development and evaluation processes. At the time of writing, the EAB consists of four members and a chairman (representative of Vilans). A list of the members is presented below. The EAB will not make decisions on behalf of the FreeWalker project, but will make recommendations to the General Assembly (GA). The chairman and Coordinator will secure that recommendations from the EAB are properly recorded and communicated to the work package leaders. The Chairman may organize external peer reviews of project deliverables by members of the EAB. The EAB will meet via telco's at least every 6 months (see section 4 of a timeline). If needed, the Chairman can call more frequent meetings. The Chairman decides the agenda for the meeting in close cooperation with the coordinator. The technical Coordinator and the Project Coordinator participate in the meetings.

At the end of June, 2018, we established the following preliminary EAB (see 2018 table), consisting of four confirmed people from all participating countries. Two members of terzStiftung could eventually not participate due to language problems. This also holds for the nurses and informal carers. MAS is searching for the inclusion of a police representative and Nurse. The group will be further enlarged in during the project. For example, tanteLouise is trying to include a member from the client counsel. In 2019 it appeared difficult to organize an EAB telco from June to September 2019, due some changes in the composition of the EAB. We had to recruit new members which are presented in the 2019 table. Due to a business and commercial interest of Enovation (including Verklizan), we extended the EAB with a commercial partner to comment from a business perspective.

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2018 Organization	Country	Name	Function	short CV	Contact via
MAS Alzheimer Hilfe	Austria	Yvonne Roithinger	Expert Psychologist	1999-2005 Psychology at the University of Salzburg (Austria); 2006-2007 Curriculum 'clinical and health psychology' (AVM Austria), 2005-present Psychologist at the 'MAS Alzheimerhilfe' Austria	stefanie.auer@mas.or.at
tanteLouise	The Netherlands	Katja Drost	Location Manager	Katja Drost is a location manager at tanteLouise. She works since 2002 at tanteLouise, as an occupational therapist and also as a advisor for the board of directors on care processes and innovation.	Matthieu.Arendse@tantelouise.nl
terzStiftung	Switzerland	David Fuchs	Akademi Berlingen	David Fuchs works at the Academi Berlingen (Switzerland) as a project manager in the AAL project CareLink (similar to FreeWalker). Het has an academic background in humanities.	martin.bader@terzstiftung.ch

2019 Organization	Country	Name	Function	short CV	Contact via
Enovation (Verklizan)	The Netherlands	Johan Vos	Manager Product Management	Johan Vos has an MBA from Erasmus University Rotterdam and has many years of experience as a manager product marketing and worked for 14 years at Enovation. Enovation recently included Verklizan (UMO central) in their business.	h.nap@vilans.nl
tanteLouise	The Netherlands	Matthieu Arendse	Innovation Manager	Marsha is an experienced nurse at tanteLouise. She worked at SVRZ, the Admiraal De Ruyter Hospital, and Emergis.	
tanteLouise	The Netherlands	Marsha McCabe	Innovation Manager	Matthieu is an innovation and policy advisor at tanteLouise. He also worked as a teammanger at RIBW Brabant and at GGz Breburg.He has a	

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			Master in Health Sciences from Erasmus Universiteit Rotterdam.	
MAS Alzheimer Hilfe	Austria	Yvonne Roithinger	Expert Psychologist 1999-2005 Psychology at the University of Salzburg (Austria); 2006-2007 Curriculum 'clinical and health psychology' (AVM Austria), 2005-present Psychologist at the 'MAS Alzheimerhilfe' Austria	stefanie.auer@mas.or.at

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4 WORK PLAN AND TIME TABLE

Below a work plan is presented for the end-user advisory board (EAB). The EAB has an important role in the project by periodically reflecting on the progress and choices made for design. EAB members are invited for consortium meetings, which may be most convenient if they are in their own country (also in respect to the costs). At least once a year (every 12 months) there will be a telco and the EAB will receive messages and content no more than once a month to reduce workload. At the end of M5 (August 2018) the first EAB telco was planned to introduce the project, introduce ourselves and respond on the interface requirement document shared in M5 and the second took place in October 2019. The EAB will be prepared for consultancy in (1) analysis and specifications, (2) usability analysis and co-design, (3) field trials, and (4) evaluation.

1. Analysis and specifications

In Task 1.2 user interface requirements and specifications will be gathered to be used in the development of the FreeWalker interfaces and interaction styles. Furthermore, in Task 1.3, the system architecture will be specified and in T2.1 the user interface designed. The end-user board (EAB) will reflect on the preliminary and final outcomes of these tasks, first in M5 and then in M8. Vilans will provide the EAB members a summary of the results in a clear, concise and easy to understand summary (in EN, or else translated by end-user organization from EN to national/local language). The EAB can respond directly to the WP manager Vilans for questions and comments. We will also organize a telco in M5 and M8 to discuss their comments plenary.

2. Usability analysis and co-design

The user needs, usability analysis and iterative user-centered design will be performed in Task 1.2, from month 1 to month 8. User needs will be collected based on existing requirements data and during 6 co-design sessions with a total of 36 end-users. The EAB will receive a clear, concise and easy to understand methodology/script to reflect on before the focus groups and co-design sessions take place. The EAB will receive the methodology (on the co-design sessions in M7) by email and may respond to the document with suggestions in track changes or approve the methodology as it is (within 2 weeks).

3. Field trials

The field trials are described in detail in WP3 (DoW). The EAB will be involved in the recruitment strategy in the organization they work for (tanteLouise, MAS, and terzStiftung). Recruitment starts from M1 in respect to (in)formal carers, although people with dementia will be recruited from January 2019. Furthermore, the preparations will be done for the trial in Task 3.2 (including ethical approval). WP1 leader Vilans will share the procedure document for recruitment in M4 and the preparation of the trial (concise and clear) with the EAB by email in M8 (including informed consent form and information flyer). Again, the EAB can respond in track changes or approve procedure as it is (within 2 weeks).

4. Evaluation

In FreeWalker there will be approx. 20 months of evaluations from Month 13 to Month 33. The EAB already replied to the field trial design and during the evaluation we will organize at least 2 telco's per year to reflect on the evaluation findings. Furthermore, they will receive a concise and easy to read summary of project results during the time of the evaluation to keep them involved and motivated.

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Table 1. Timeline of EAB involvement (more in-between telco's are possible)

→								
Month of project	July 2018	August 2018	July 2019	October, 2019	July, 2020	March 2021		
<i>EAB Members will be invited to join Consortium Meetings, in particular in their own country.</i>								
Activity	Welcome, FreeWalker information, Methodology Co-design by email	First EAB telco. Reflection on specifications and analysis. System architecture and specifications will be shared. Methodology on co-design & recruitment document shared with EAB by mail.	Evaluation Telco + summary of project results via mail. -> Had to extended.	Second EAB telco. Evaluation Telco + summary of project results via mail.	Evaluation Telco + summary of project results via mail. [CANCELLED DUE TO COVID-19 -> focus on lock-down and outbreak within the care homes / organizations]	Final FreeWalker meeting – possibility for EAB members to come. [EAB members receive a summary of the findings when available]		

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4.1 First EAB telco

In FreeWalker, the first EAB telco took place on 31 of August 2018. The members received an overview of the work that has been performed and the plans. Furthermore, before the meeting, all FreeWalker partners had the possibility to prepare questions for the end-user advisory board. These were sent one week before the actual teleconference meeting. The agenda at the first meeting included first an introductory round by the members of the EAB. This was followed by a short presentation by the Chairman on the FreeWalker project, the progress, and the plans for the upcoming months. After that, we went through the questions of the FreeWalker partners. This was followed by feedback from the EAB members on the document that was sent with the progress and future plans:

Report on End-User Advisory Board Telco – FreeWalker

31-8-2018 (10:00-11:00 CET)

Present:

EAB Advisory Board

- Yvonne Roithinger (MAS, Austria)
- David Fuchs (Akademi Berlingen, Switzerland)



Project participants

- Klaus Dittrich (AIT)
- Stefanie Auer (MAS)
- Henk Herman Nap (Vilans)

We started with an introduction and get to know each other. All advisory board members received a document beforehand with information on the project and progress. Henk Herman Nap gave a 20 min. presentation on the project goals, architecture and progress.

Yvonne Roithinger (MAS): I am psychologist and work with Stefanie. Experience with people with Alzheimer's disease. Role at MAS: working with social worker. Near with people with dementia, Diagnosis. Evaluation. Needs. A little bit up to date on FreeWalker project.

David Fuchs (Terz): Academi Berlingen (Switzerland) near German border. Work as a project manager. AAL project CareLink (similar to FreeWalker). Academic background in humanities. Academi Berlingen is an end-user organization. CareLink -> tracking system for people with dementia. Platform for carers to exchange information. First year finished and ahead of FreeWalker. Highly relevant to exchange experience and information during the phases.

Feedback on FreeWalker Project

In respect to ethics:

David Fuchs: One thing that gets to my mind. Be Aware of the Ethics submission and recruitment. It is very important. Hard process. It takes a lot of time. In Switzerland it is difficult to recruit people with dementia. Informed Consent. Do you want to recruit people from care homes? There is always a drop-out rate. Progress of disease. How fast? Just starting ethical approval with CareLink. Ethics application: the procedure and regulation is important. How is the process going? In some countries not necessary? **Henk Herman:** Can we use it. Use template of Interlinks? **David:** Yes, we can. Very good. Study proposal in discussion now at CareLink.

In respect to insurance:

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Yvonne Roithinger: Insurance? Do we have an idea on insurance. When there is an accident? Who is responsible? Is MAS also involved. **Henk Herman:** Maggie Ellis (LSE) had a good talk on insurance before at AAL or EKTG. **Stefanie:** -> insurance. CoTrain, need to make a contract. Send out people, huge issue. High Risk! Rate is very high!! **Klaus:** we adapt to their common life. **Stefanie:** Due to this device they are motivated to go outside. Clinical trial. Burden the care giver whenever they walk with them. **Henk Herman:** Sign by dementia people? **Stefanie:** Ethical committee will not sign this.

In respect to the inclusion criteria:

David Fuchs: while reading the inclusion criteria. Do you have Interviews planned? Is the information they share reliable? In CareLink we conducted interviews. In Switzerland we already had interviews. We did not get a lot of insights (unreliable data from people with dementia). They interviewed them in Belgium - different experience. Always interview them together with a care professional.

Yvonne Roithinger: GDS staging, MMSE 20-28 (still possible to get expertise from the person dementia). Reformulation of primary client or caregiver. **Stefanie** -> Open formulation, we want to learn from this system. Field trial is not a conclusive study. Again, person is in danger to be lost should be out the inclusion criteria.

In respect to questions of Ivengi:

- Cancel a calendar item -> no reflections yet
- Arrived at destination? -> will send reflections via email
- What to do when person not arrived?
- Notification should go to the informal & formal caregiver (AIT, Klaus). EAB members agreed.
- Who can edit a safe zone? Care organization? Yvonne Roithinger: think in stages (GDS, 2 has not dementia, subjective feeling). GDS 5 not (no traffic, cannot navigate in traffic). Various stages.

4.2 Second EAB telco

In FreeWalker, the second EAB telco *will take place* on the 11th of October 2019. The members received an overview of the work that has been performed and the plans. Furthermore, before the meeting, all FreeWalker partners had the possibility to prepare questions for the end-user advisory board. These were send one week before the actual teleconference meeting (see set of questions below). The agenda at the second meeting included first an introductory round by the members of the EAB. This was followed by a short presentation by the Chairman on the FreeWalker project, the progress, and the plans for the upcoming months. After that, we went through the questions of the FreeWalker partners. This was followed by feedback from the EAB members on the document that was send with the progress and future plans:

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Report on End-User Advisory Board Telco – FreeWalker

11-10-2019 (10:00-11:00 CET)

Present:

EAB Advisory Board

- Yvonne Roithinger (MAS, Austria)
- Matthieu Arendse (tanteLouise, The Netherlands)
- Johan Vos (Enovation)
- Marsha McCabe (tanteLouise, The Netherlands)



Project participants

- Martin Litzenberger (AIT)
- Henk Herman Nap (Vilans)

We started with an introduction and get to know each other. All advisory board members received questions from the partners beforehand and links to online material with information on the project and progress.

- Katja Drost (tanteLouise): Manager elderly home. At Vissershaven they already work with GPS tracking and safe zones.
- Matthieu Arendse (tanteLouise, The Netherlands): Innovation Advisor, in particular AAL projects on testing.
- Johan Vos (Enovation Group, The Netherlands): Management Team, information and eHealth Business.
- Martin Litzenberger (AIT, Austria): Coordinator FreeWalker
- Johan van der Leeuw (Vilans, The Netherlands): Senior Advisor Vilans, involved on business modelling and head of BM in FreeWalker.
- Henk Herman Nap (Vilans, The Netherlands): Expert eHealth Vilans, Involved in multiple AAL projects (coordinator of 2) and leads EAB and co-design of FreeWalker.

Usability

Matthieu: discussion on end-product. Is it really needed? It should not be an additional product, should be with high usability, integrated in the work process. FreeWalker should make work easier, it should save time.

Johan Vos: very important that it is not an extra system. Connected to UMO central/certified. First step is connection with UMO.

Matthieu: at tanteLouise we use smart phones with notifications. Devices integrated. For care personnel the background is not important, only the frontend. Eurocom is the system integrator at tL and they use TraxPlay for the GPS tracking. **Usability** is important and **Reliability**. In FreeWalker we need to integrate this in the Alpha and Beta testing (usability & reliability).

Business Modelling

Johan Vos: intelligence should be the USP of the platform. Johan Vos will check with NAAST, to which extent they offer something similar as FreeWalker.

Matthieu & Katja: connection to agenda is the USP. Relieve care-givers and make it more time-efficient. Dynamic safe zone on usual habits could be useful. Inside tracking more important than outside? Is it safe to use? Do we have enough overview over the individual situation. In the end it is about acting. How they act? Connected to the client agenda. The agenda of the client is always leading. At tanteLouise they use ONS from NEDAP. Interesting to

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focus on risk analysis and make choices about the zone for the end-users. Whenever you receive warnings, you want to know about choices you have. So, make choices about the alarms (extend with 30 minutes? With 60 minutes?).

Katja: USP, it should be a personalized solution. Risk analysis for alarms. System help for personalized decision making.

Ethics

Matthieu: monitor safety only when leaving the safe zone, or whenever at risk. Only for data & specific items.

Henk Herman: how is it decided if and when somebody is under 'surveillance' of GPS tracking?

Katja: consent is provided at location Vissershaven for all clients (because they live at that location). For location 'Hof van Nassau' it is decided with the family by means of consent forms. That they use the data & GPS, and the possible risks.

Question from Martin: what are the types of parameters already used at tanteLouise? What do you use know for providing 'freedom' to clients? **Katja** will look into it.

Answers of Roland Sperling (MAS) Questions to EAB:

- How important for market success do you see the direct connection of a FreeWalker solution to other existing care solutions? As an example think of existing care management systems, but also technical measures such as door-lock systems already in place in some facilities.

For the market success, a direct connection of a FreeWalker solution to other existing nursing documentation systems in nursing homes is very important. The caregivers can already deal with the existing system and immediately receive information about the whereabouts of their residents or alarms, provided they leave the safe zones.

In this context, it should be noted that caregivers in nursing homes do not constantly sit in front of a computer and usually do not have a smartphone for their work, which means that there must be useful devices for this area.

- We believe that FreeWalker needs to be used and get used to already in an early stage of CI, to be used and useful in the more progressed, severe stages. How do you think we can best motivate clients to adapt FreeWalker early when the personal feeling of being in need of help is not yet so strong?

In order to accept offers of help, it often requires good approval by trusted persons, which may be the attending physician, a carer or a relative. As dementia progresses, disability decreases, but empathy is often retained. Thus, when relatives express concern for the person, the willingness to accept help or allow support is often greater.

- Other than in fixed geo-fence solutions FreeWalker will produce a "personalized" safe zone (called the "green" zone) from the clients habits, that will be available to check/see for the carer/relative. How critical is this with respect to data protection and ethics? Should a final product have an option to "obscure" this personalized zone in some way (e.g. show just a circle without the zone details) from the carer/relative, at least for low risk clients?

In my opinion, the exact position may only be apparent to another person as soon as previously defined safe zones are left or an alarm situation occurs. Before that, it does not matter exactly where a user is.

- What data (in terms of history of an alarm case) should / should ~~NOT~~ be visible in the FreeWalker portal for the caregivers?

Exact location, possibly different health data, telephone accessibility of the user

Acceptance/usability

- Which technical requirements are necessary for end user organisations (which device: PC, tablet, ...)

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Compatibility with existing PC programs (care documentation), possibility of sending SMS or other acoustic alarm on mobile devices (often cordless phone, no mobile or smartphone)

- Which technical skills are required from caregivers
No special technical skills of the caregivers are necessary as they are familiar with the existing system
- What may be the workload for the organisation if they use FreeWalker? Every minute update or just then when something is wrong?
an update only if something is wrong
- Besides the alarm function: what should be implemented too? Medicine alarm, heart rate, blood pressure?
Heart rate, blood pressure, blood sugar, respiratory rate

5 CONCLUSION

This deliverable, D1.1, is a running document and the conclusion will follow at the end of the project. The procedures and planning is described in this deliverable. Most importantly, the results from the various EAB meetings are iteratively presented and communicated with the FreeWalker GA. The EAB meeting of 2020 was cancelled due to other priorities among the EAB members and end-user partners relating to COVID-19. The company Enovation took a different course in business from 2020 and resigned from the EAB. In 2021, whenever available, the remaining EAB members will receive the results from the clinical and usability evaluations.

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