Deliverable 3.1

Joint methodology and guidelines for user involvement

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1 Task description

Task 1 (Lead: TU/e, participating: RZCC, PROGES, UNITBV, NWCAHSN):

Source: ENSAFE project plan

Joint framework methodology and guidelines will be elaborated by the task leader on the user involvement to accompany the product service development. This will follow the living lab approach and will be applied in all the pilot sites (adapted to the local infrastructure and healthcare services available at each pilot site).

Guidelines will include provisions concerning ethics and security mainly concerning the testing phase. Following this methodology, partners will select participants for the **co-production sessions** and the **real life testing** by narrowing down the survey group in a way to ensure a balanced representation and later comparison of the findings.





2 Co-production protocol

Take place before and after the live testing with a diverse range of stakeholders to be determined in each region. These sessions are workshops to be held with stakeholders to address important issues in the project.

Early stages: of a developmental nature, creating technology.

later stages: will be of an evaluative nature, reflecting on technology.

Relevant stakeholders: Needs to be defined. Example groups: Elderly, care professionals, business

etc.

1. Introduction of the Innovate Dementia project.

Overview of project partners, results so far, future plans

2a. Workshop Investigating Unmet needs.

The stakeholders provide feedback about several care questions posed by workshop organiser.

2b. Collective idea generation on unmet needs.

The stakeholders brainstorm briefly on the unmet topics and how to solve them..

2c. The stakeholders select the best ideas

The stakeholders provide a selection and feedback among several (potential) innovations/directions.

3. A general discussion on the main findings.

The meeting closed by discussing the main findings of the meeting and the project members of Innovate Dementia investigating future collaborations which each stakeholder.





3 User involvement protocol

Based on the literature, we propose a new in-context evaluation protocol (Figure 1) to be used in design-driven Living Labs for impaired users (Brankaert et al. 2016). This protocol is based on three home visits, each with a specific goal: introduction (Home Visit 1), intervention (Home Visit 2) and reflection (Home Visit 3). Thereby, we propose additional steps for a safe involvement of users, and the engagement of users through a community structure. These are covered in Figure 8.5.

In addition to the protocol phases we suggest a strong involvement of all relevant stakeholders throughout the process (User, Care, Industry and Research). In this way the different stakeholders feel involved and responsible in each of these stages.

For designers this protocol enables a holistic, safe and efficient way to engage with people with dementia and their context. By this they can evaluate their design proposals in a real-life context and gain insights for adjustment or redesign through this. Therefore such an evaluation should be seen as part of an iterative process, which will most likely be preceded or will be succeeded by additional iterations.

Living Lab protocol

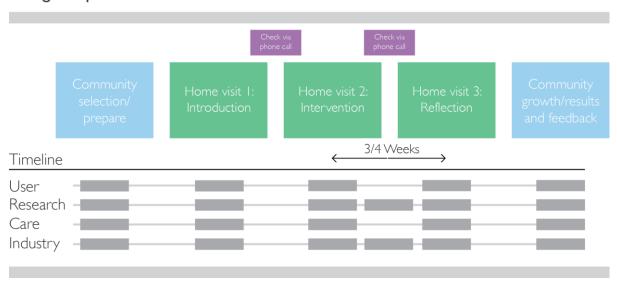


Figure 1 Protocol proposal for future involvement of impaired users.





3.1 Community selection/preparation

In this phase the study is set-up and prepared. We recommend that all relevant stakeholders are already included from this phase onward. In this way they might feel more ownership in selecting an intervention, the evaluation method and the context. Finally, when a community is built, it could support a selection of users who match a certain intervention. In this way, needs are better matched with interventions, and the results for stakeholders might improve.

3.2 Home visit 1: introduction

During this phase the users are visited with the main purpose of introducing the project and the rationale behind it. Depending on the abilities of the users, the intervention could also already be explained. Key in this phase is to allow users to get acquainted with the project and the process step by step.

3.3 Home visit 2: intervention

During this visit the intervention is brought and (re-) introduced; the users should already be familiar with the project. We advise that at least one familiar person (from Home visit 1) joins this visit. In this step the research method is explained as well, and from this moment the users can use the product or system for a limited period of time as they wish. Thereby, it has to be made clear that users cannot keep the intervention after the test period if this is not possible in the specific case.

3.4 Home visit 3: reflection

During the final home visit the researchers (and potentially the care or business stakeholder) collect the prototype used for the intervention and the data from the research method (again we recommend that one familiar person is present). They also reserve sufficient time ($^{\sim}$ 1 hour) to reflect with the users on their experiences and address queries related to the research method and the project in general. The agenda for this meeting has to be set together with the relevant care and business stakeholders, so that these partners gain reflective insights that are of particular interest to them.





3.5 In-between checks

To streamline communication, we added additional checks in between the home visits. One of these checks is set before the second home visit to improve protocol efficiency and communication. The second check, which should be scheduled during the intervention study, is designed to address issues that might have come up so far. However, we can also anticipate other purposes, or a higher quantity, for the checks depending on the specific user (and their impairment), the complexity of the research method, and the length of the study.

3.6 Community growth/results and feedback

We added community building to the proposed protocol. This is new; however, it has been experienced as positive so far in our project after the GoLivePhone® study. The users feel engaged with the project because their efforts go beyond a single research project. They are asked during "Home visit 3" if they want to join the community and, if they do, are added to the community list. In our case, the members of the community get updates concerning developments and publications via a newsletter. In addition, they are invites for focus groups that are organized twice a month. The first indications suggest that users feel involved and connected, and they even recruit new users from their own communities (via sport clubs, hobby associations, etc.). Finally, the results of the Living Lab cases are processed in this phase and provided to the relevant stakeholders. We discuss with these stakeholders how to continue the collaboration.





4 Stakeholder roles

In the protocol proposal (Figure 8.5) each of the four stakeholder types should be included in each of the protocol steps as indicated by the grey blocks.

Initially end-users only participated in the field studies as participants or co-creators. However over the course of the Living Lab cases we found value in involving them earlier to also support in the study setup, and later to reflect with us on the results. Over time this active involvement of participants grew into a community. This allows for users to be involved beyond a single Living Lab case. Additionally, the Living Lab benefits as a community ensures participants are more easily available.

For the care stakeholders their role initially was solely to prepare and select participants during the evaluation. This grew over the course of the Living Lab cases to a more engaging role in which they as care stakeholders take interest in the reflection (Home Visit 3) and results to improve their own services and research. In addition, they benefit most from the community structure and therefore take responsibility to maintain this through meetings and newsletters.

For the business or industry stakeholders the implementation and evaluative results of the design are most important. This still fulfils their primary purpose. However, by involving them early in the process, during the preparation and introduction of the intervention, they gain ownership of the evaluation and have influence on the study design. As such the results are more valuable for them and their expectations match better.

For the role as researcher, in our case as design researcher, the study allows for a direct engagement of users with a design proposal in context. By this the design researcher gains insight into the usability and successfulness of a design proposal and the factors that influence this. Naturally the design researcher takes the leading role in such design-driven Living Lab studies and enables the involvement of the other stakeholders to benefit the design and from the design.

In the end, there are contradicting interests between these different stakeholders. For example, between business stakeholders and care stakeholders concerning the importance of value versus revenue. Or between researchers and business stakeholders related to objective research and a positive outcome of the research. We recommend that in such stakeholder collaborations it is the role of the (design) researcher to balance these interests. And t oensure a balanced gain in value for all of the stakeholders to make the collaboration beneficial for everyone.





5 Adaptation to the ENSAFE case

For the in context evaluation of the GoLivePhone system in connection with additional services such as the GAIA system and UNIPR sensor system the protocol needs to be specified and adapted.

The goal of this evaluation is to evaluate on the one hand the usability and acceptance of the GoLivePhone system and the potential impact on the care system. In this specific attention to the service extension are paid. In this evaluation we use data from the participants directly (diary study) as well as data from the system directly (GLP). For this it is important to include a baseline measurement.

In this evaluation we want to focus on an implementation pilot. This means that we don't test the system, but that we want to implement the system into the care system and see how it adds value in a realistic context with realistic stakeholders.

Therefore the protocol looks as following:

Protocol:

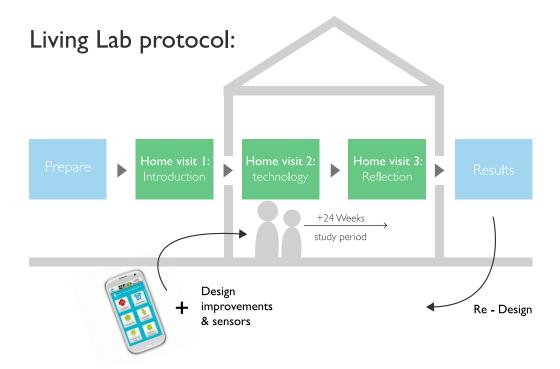


Figure 2: In context protocol adapted to the GoLivePhone system.