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PROMOTING ACTIVITY AND CUSTOMIZED HEALTHCARE

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Deliverable D1.1: Presentation of the outcome of an analysis (including on-site analyses) of the current use cases and practices at HUG, SK, ZZ, Lyngby and formulation of initial, concrete use scenarios (associated with task T 1.1).

Abstract: This deliverable report presents the outcomes of the analysis (including on-site analyses, stakeholder identification, identification of used assessment practices, patient profiles, personas, interviews with patients and stakeholders, etc.) of the as-is situation and practices at the use case partner's care settings and the formulation of first, initial use scenarios (including concrete application opportunities/experience maps for each setting, opportunities arising from transfer through institutions/settings, technological potentials and opportunities, etc.). To accomplish this task, an analysis framework was first developed (Month 1), then further analysis was carried out (Month 2), and finally conclusions were drawn (experience maps, scenarios, opportunities, etc.; Month 3). Key feature of the analysis was an in-depth analysis of more than 50 real-world end-user profiles. Based on the analyses conducted within this deliverable, the system vision will be detailed in T1.2, an in depth stakeholder analysis conducted, and requirements systematically elicited and formalized.

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Key expressions

- Activation:** physical and cognitive activation before an incident or way to keep patient as long as possible in a good baseline health state.
- Activities of Daily Living (ADLs):** classification into activity categories (e.g. dressing, bathing, feeding, etc.) which are necessary to maintain care independent living.
- Barthel Index (BI):** ordinal scale used to measure independent performance in *Activities of Daily Living (ADL)*.
- Berg-Balance-Scale (BBS):** a 14-item scale designed to measure balance of the older adult in a clinical setting.
- Care continuum:** Refers to the fluent transitions between pre-acute care, acute care, and post-acute care and to the natural way of *elderly citizens/patients* though health states, settings, care-need levels, and institutions.
- Contactless vital signs sensing and measurement:** sensors embedded in furniture, building interior and transfer/mobility devices.
- Dynamometry:** method to measure muscular power and ability of force production.
- Elderly citizen:** REACH target users, includes healthy people, people in need of care and patients.
- Electromyography (EMG):** electrical muscle function analysis.
- Electrophysiology:** measurement of the electrical conduction of the human heart, which allows to analyze the health condition of the most important muscle in the human body
- End-user profiles (EPs):** in depth analysis of real-world, potential REACH end-users.
- End-user:** elderly citizen that are supposed to profit from reach services and products.
- Energy expenditure measurement:** currently direct measurement is difficult and therefore indirectly measured over CO² emission, ECG or body composition.
- Evolutionary approach:** the REACH system should optimally be able to “assemble” and “dis-assemble” itself (e.g., from light frailty to more severe frailty and optimally back to light or no-*frailty*).
- Experience Flow (EF):** method for mapping an experience – from expectation, to first impression, then through discovery, usage and finally to memory. Usually part of an *Experience Map (EM)*.
- Experience Maps (EMs):** method to spot and contextualize the unmet needs of people and then translate these into innovation opportunities and directions.
- Fitness Furniture:** Without going to the gym the user can benefit from using the fitness furniture in a home or rehabilitation environment.

Frailty: not a disease but an umbrella term designating a multi-factorial syndrome like dizziness, sensitive skin etc. May include the loss of muscle strength, force, robustness, ability to perform *Activities of Daily Living (ADL)*.

Functional Independence Measure (FIM): uniform system of measurement for disability based on the International Classification of Impairment, Disabilities and Handicaps.

General Practitioner: provides treatment in early disease/impairment stages, provides treatment mainly to outpatient people

Healthy Life Years (HLYs): amount of time spent in a good health condition.

Hospital Anxiety and Depression Scale (HADS-D): used to detect anxiety and depression in patients with physical conditions.

Inpatient: Patient stays day and night in the hospital for a limited amount of time.

Longitudinal study: a study that takes longer than 2-3 weeks.

Long-Term Care (LTC): care received over longer period of time in particular in institutions such as nursing homes and hospitals.

Modified Ranking Scale (mRS): outcome scale for measuring the degree of disability or dependence in the daily activities of people with neurological diseases.

Monitoring and Assessment Framework for the European Innovation Partnership on Active and Healthy Ageing (MAFEIP): measurement system to identify health status and periods and success of interventions.

Muscle function analysis: basis for frailty detection; can be done by methods such as, *Body Composition Analysis, Electromyography (EMG)*, ultrasound imaging, and *Dynamometry*.

Outpatient: patient visits doctors, hospitals or similar for receiving treatment of care but stays not continuously (i.e. at night) there.

Patient: person that receives health care services.

Persona: exemplary, fictive model end user that characterizes a typical and potential REACH user group.

Platform approach: In REACH a digital platform and interior equipment modules should serve as digital/physical platforms that tie together a variety of products and services developed within REACH.

Portability of the system: the REACH system should be able to follow the elderly person through different life phases, institutions, and environments/settings.

Pulse oximetry: measures the oxygen saturation of the blood, as well as the pulse.

Rehabilitation: physical and cognitive *activation* after an incident or way to move patient from a certain (deteriorated) level of health state to a better health state.

Rehabilitation bed: center of life in clinics, rehabilitation settings and home care) shall become part of the solution.

Sensing furniture: allows the placement of a range of (medical) sensors that can be used to obtain a range of parameters relevant for early detection of risks in an unobtrusive manner in an environment or setting.

SF-36 health survey: measures and reflects experiences of the last week prior to the date of the survey.

System modularity: REACH will be modular in order to allow an adaptation to various use cases/scenarios and to be able to adapt/evolve over time with the user.

The Montreal Cognitive Assessment (MOCA): rapid screening instrument for mild cognitive dysfunction.

The Motor Function Assessment Scale (MFAS): examines 4 groups of 44 motor functions.

Time series approach: An analysis approach that exploits the temporal structure of data (in our case, *Activities of Daily Living* and health-related information) in order to extract meaningful statistics and patterns.

Use case: The four solution operators are in the context of T1.1 and this report called *use cases* since they reflect concrete application scenarios.

Wearables: wearable devices used to obtain temporal information from a person about physical activity, water intake, weight, emotions, and blood glucose levels in a seamless manner.

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1 Background and summary of tasks and activities

In the REACH project a sensing-monitoring-intervention system will be developed that can be placed in an unobtrusive manner in various care settings and living environments of elderly citizens. The system will be able (1) to use a set of sensors to detect selected vital signs, behavioral/care patterns, and health states, (2) predict – as early as possible - future health states, risks or events (loss of function, frailty, stroke, etc.) and (3) provide and coordinate proactively a set of customized services and products. Early intervention by REACH should allow that the time spent in a desirable health state (baseline health), and Healthy Life Years (HLYs) are increased and that the time spent in Long-Term Care (LTC) facilities is reduced. In that context, it will be shown that REACH can improve and speed up, on the one hand, the physical and cognitive rehabilitation of elderly citizens in deteriorated health states or suffering from a sudden incident, for example, by speeding up their transfer from acute care to rehabilitation to home care as well as their health state improvement within one of these institutions. On the other hand, it will be demonstrated that REACH can be utilized in home/ home care contexts to keep people as long as possible in a desired base-line health state, mitigate the risk of deterioration, and finally slow down or prevent deterioration.

In order to develop the mentioned features in a target oriented manner REACH, integrates various stakeholders such as knowledge providers (research, universities) technology providers (sensors, prediction, intervention mechanisms), multipliers (insurances, standardization organizations, etc.), and solution operators (clinics, rehabilitation centers, home and home care providers) into a joint development team. REACH will carry out the development of the mentioned features within four years, through nine work packages and in three iterative development cycles (phase 1: mock-ups and lab testing of single technologies; phase 2: mock ups and short term tests with sub-systems in real-world environments; phase 3: system prototype long term testing in real-world environment). The four solution operators (in the context of T1.1 and this report called “use cases” since they reflect concrete application cases for the REACH system) Geneva Hospital (HUG), Schön Klinik (SK), ZuidZorg (ZZ), and Lyngby-Taarbæk Municipality (Lyngby) that are part of the REACH consortium, in that context reflect two dimensions:

1. Health state dimension: the four use case partners represent the most relevant ways or transfer possibilities of elderly through various health states and institutions (e.g. from hospital to rehabilitation to home in case of a health state improvement; alternatively, from home to hospital/rehabilitation in case of a health state deterioration). The REACH system should be able to move with the elderly through the various health states/institutions.
2. System development dimension: the four use case partners represent the development strategy. Development will in the beginning phases of the project target the more “structured environments” (clinic/HUG; rehabilitation/SK) since here requirements are more obvious and system features are easier and faster to be verified and validated. These technically complex solutions can then in later project phases be stepwise (in an adapted and simplified form) transferred into the home care (ZZ) and smart home (Lyngby) use case contexts and open new markets in this fields for the REACH industry partners.

WP1 will in the first 14 project months (Milestone 2) detail the REACH concept and system design before in WPs 2- 5, the individual subsystems are developed and subsequent system integration and testing/demonstration are conducted (WP6). WPs

7, 8 and 9 are concerned with cross sectional topics such as usability, ethics, safety, security, business models and project management.

WP1 consists of four work tasks and will follow a systematic system development approach. First, as part of T1.1 (outlined in this deliverable report) the as-is situation of the four use cases will be analyzed, relevant problems and stakeholders will be identified and initial, concrete use scenarios will be formulated. Second, based on T1.1 in T1.2 the system vision will be detailed, a stakeholder analysis will be conducted, and as part of a “requirements engineering” process, requirements will be elicited and formalized. Then, in T1.3 requirements will be prioritized and selected, initial value proposition and product-service-system concept will be developed together with the stakeholders. Finally, in T1.4 the product-service-system architecture (modularity, standards, software architecture, etc.) will be detailed.

This deliverable report (Deliverable D1.1, due date: Month 3; related to T1.1) presents the outcomes of the analysis (including on-site analyses, stakeholder identification, identification of used assessment practices, real world profiles of elderly citizens, personas, interviews with “patients” and stakeholders, etc.) of the as-is situation and practices at the use case partner’s care settings and the formulation of first, initial use scenarios (including concrete application opportunities and experience maps for each setting, opportunities arising from transfer through institutions/settings, technological potentials, etc.). To accomplish this task first an analysis framework was developed (Month 1; see **Section 2**), then the analysis was carried out (Month 2; see **Sections 3 and 5**), and finally conclusions were drawn (experience maps, scenarios, opportunities, etc.; Month 3; see **Sections 3, 4, and 6**).

A key feature of the analysis was the in-depth analysis of real world “patient” profiles (the word “patient” can in this context also refer to elderly living at home with light disabilities or no problems but at risk; in this report “patient profiles” are thus referred to as “end-user profiles”). The real world patients/elderly citizens analyzed in this context state concrete, common examples and stand, moreover, exemplarily for other similar end-users. Furthermore, from the end-user profiles then “personas” (fictive example users) were generated. In this first step, for HUG 20 end-user profiles (EPs) and 5 personas, for SK 15 EPs (5 outlined in this report in detail) and 2 personas, for ZZ 14 EPs and 4 personas, and for Lyngby 6 EPs and 2 personas were subject of in-depth analysis. In case of HUG for the analysis of the EPs (planned in combination with personal test and interviews) due to national regulations an ethics approval had to be filed. Since it was not possible to obtain the ethics approval before the end of the task/deliverable submission it was decided that HUG’s EP analysis in the context of this task/deliverable is done based on patient data obtained within regular clinical practice, and that then (once ethical approval obtained) within the stakeholder analysis in T1.2 this is deepened and extended.

The remainder of this report is subdivided into 9 sections. **Section 1** describes the background and the tasks and **Section 2** the analysis framework. **Section 3** presents the analysis outcomes for each of the four use cases (HUG, SK, ZZ, Lyngby) and **Section 4** analyses based on this their commonalities and differences. In **Section 5** the outcome of an analysis of the technological potentials and application scenarios is presented and in **Section 6** the potential of the utilization of REACH in each use case and cross use cases and the technological opportunities are concluded. **Sections 7, 8 and 9** provide references, enclosures and appendices.

2 Analysis framework: description of methods and guidelines

As part of an in-person meeting of all work task participants (SK, HUG, ZZ, Lyngby, DTU, Tu/e, Copenhagen, Philips, TUM) at SK in Month 1 (M1) an analysis framework was set up and it was decided that the analysis of the 4 use cases (SK, HUG, ZZ, Lyngby) shall for each setting follow these analysis items:

1. Identification of stakeholders: Identification of the most important stakeholders and their relations to each other to build the basis for an in-depth stakeholder analysis, workshops with stakeholders and a subsequent requirements elicitation in T1.2 and T1.3.
2. Assessment of individual abilities/disabilities of target end-users: for each use case the common elderly citizens/patient (end-user) assessment regimes must be identified and used to outline the abilities/disabilities of the end-users in each setting. For this analysis each use case partner due to practical reasons used its own assessment regimes (such as, for example, Barthel Index and Functional Independence Measure. For later project phases the assessment regimes of the four use case partners shall be harmonized to a certain extent towards the Monitoring and Assessment Framework for the European Innovation Partnership on Active and Healthy Ageing (MAFEIP).
3. Analysis of end-user profiles (EPs): In-depth analysis of selected (up to 10) real world target end-users which characterize the use case and are also considered as potential REACH end-users.
4. Semi-structured face-to-face interviews with target end-users to elicit information about their current situation as well as their expectations and concerns.
5. Definition of personas: Based on the assessment, profile analysis and interviews for each of the four use cases a set of model users (personas) should be generated and characterized. Personas shall in later project phases also be used to communicate needs and requirements to the other, more technically oriented project partners.
6. Experience Mapping: Collection and mapping of routines of end-users, processes, experiences and day schemes based on the outcomes of the analysis items 1-5. The framework should characterize typical “a day in the life” of an elderly citizen in a specific stage of healthcare. The method was exercised on the in person meeting in M1 at SK. The experience maps developed by each use case partner as part of T1.1 comprise preliminary drafts which will be extended and detailed in the subsequent work tasks.

The analysis framework is for now not considered a fixed, rigid framework but rather gives a set of guidelines that can be interpreted and adjusted by each use case partner (as mentioned above for later project phases harmonization toward the MAFEIP shall be achieved). The analysis shall characterize each use case (end-users, stakeholders, processes, treatments) and outline the as-is situation (T1.1) as a starting point for a concretization of the system vision and a requirements engineering process (T1.2-T1.4).

2.1 Stakeholder identification

Actors map is a commonly used method in service design. It represents the system of actors (stakeholders) and their mutual relations to provide a systematic view of the service and its context (**Figure 1**). It can be built based on the observation of the service from a specific point of view that becomes the center of the whole

representation; for example if the selected perspective is from the end-user (elderly citizen), the graph will show all the stakeholders starting from their relations with him.

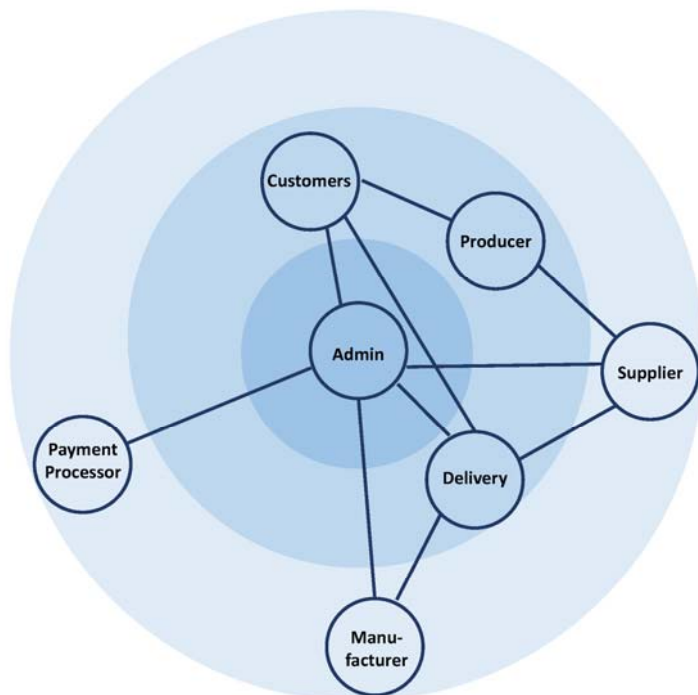


Figure 1: Actors map of an online food ordering service (adapted from *Actors Map*, 2016)

2.2 Methods to assess individual abilities/disabilities of end-users

The assessment method and scores outlined in this section can be used to characterize the end-users' level of (1) independence (2) mobility, (3) cognition, and (4) mental state. For the analysis to be conducted (**Section 3**) for each use case the appropriate method/s can be chosen. All scales are available in all major European languages, for simplicity only the German versions are referenced.

2.2.1 BI - Barthel Index

The BI is an ordinal scale used to measure independent performance in activities of daily living (ADL) with the following ten items (**Mahoney, 1965; Collin et al., 2009**):

Table 1: BI assessed dimensions

1	Feeding	0, 5,10
2	Bathing	0, 5
3	Grooming	0, 5
4	Dressing	0, 5,10
5	Fecal incontinence	0, 5,10
6	Urinary incontinence	0, 5,10
7	Toilet use	0, 5,10
8	Transfers (from bed to chair)	0, 5,10, 15
9	Mobility (walking/use of wheel chair)	0, 5,10, 15
10	Climbing stairs	0, 5,10

Performance items can be scored with 0, 5, 10 or 15, best overall score is 100. The need of support required to perform the respective item is used in determining the value of each item. Higher scores are associated with greater independence. The assessment should be performed by nursing personnel.

2.2.2 FIM – Functional Independence Measure

The FIM (**Black et al., 1999; Heinemann et al., 1994; Granger et al., 1993; Keith et al., 1987**) provides a uniform system of measurement for disability based on the International Classification of Impairment, Disabilities and Handicaps. It measures the level of an elderly citizen's/ patient's disability and indicates how much assistance is required for the individual to carry out activities of daily living. This test allows to dissect the nature of a patient's autonomy impairment and to provide well suited home care. The assessment contains 18 items including 13 motor tasks and 5 cognitive tasks (regarding basic activities of daily living). The tasks are rated on a 7 point ordinal scale that ranges from total assistance (or complete dependence) to complete independence. The scores range from 18 (lowest) to 126 (highest) indicating level of function. The assessment should be performed by nursing personnel.

Table 2: FIM assessed dimensions

1	Eating
2	Grooming
3	Bathing
4	Upper body dressing
5	Lower body dressing
6	Toileting
7	Bladder management
8	Bowel management
9	Bed to chair transfer
10	Toilet transfer
11	Shower transfer
12	Locomotion (ambulatory or wheel chair level)
13	Stairs
14	Cognitive comprehension
15	Expression
16	Social interaction
17	Problem solving
18	Memory

Table 3: FIM scoring criteria

No Helper Required	
Score	Description
7	Complete Independence
6	Modified Independence (patient/elderly citizen requires use of a device, but no physical assistance)
Helper (Modified Dependence)	
Score	Description
5	Supervision or Setup
4	Minimal Contact Assistance (patient/ elderly citizen can perform 75% or more of task)
3	Moderate Assistance (patient/ elderly citizen can perform 50% to 74% of task)
Helper (Complete Dependence)	
Score	Description
2	Maximal Assistance (patient/ elderly citizen can perform 25% to 49% of takes)
1	Total assistance (patient/ elderly citizen can perform less than 25% of the task or requires more than one person to assist)

2.2.3 mRS - modified Rankin Scale

The modified Rankin Scale (mRS) is a commonly used outcome scale for measuring the degree of disability or dependence in the daily activities of people with neurological diseases (**van Swieten et al., 1988**). The scale consists of the following 7 items:

Table 4: mRS item description

1	No symptoms
2	No significant disability. Able to carry out all usual activities, despite some symptoms
3	Slight disability. Able to look after own affairs without assistance, but unable to carry out all previous activities
4	Moderate disability. Requires some help, but able to walk unassisted
5	Moderately severe disability. Unable to attend to own bodily needs without assistance, and unable to walk unassisted
6	Severe disability. Requires constant nursing care and attention, bedridden, incontinent
7	Dead

The assessment should be performed by physicians.

2.2.4 BBS - Berg-Balance-Scale

The BBS (see for example, **(Berg et al., 1995; Scherfer et al., 2006; Liston and Brouwer, 1996; Stevenson, 2001)**) is a 14-item scale designed to measure balance of the older adult in a clinical setting. The scale is ordinal and ranging from 0 to 4, 0 indicates the lowest level and 4 the highest level of function, the maximum overall score is 56. The assessment should be performed by physiotherapists.

The scores are interpreted as follows:

Table 5: BBS score interpretation

41-56	low fall risk
21-40	medium fall risk
0-20	high fall risk

Item description:

Table 6: BBS item description

1	Sitting to standing
2	Standing unsupported
3	Sitting unsupported
4	Standing to sitting
5	Transfers
6	Standing with eyes closed
7	Standing with feet together
8	Reaching forward with outstretched arm
9	Retrieving object from floor
10	Turning to look behind
11	Turning 360 degrees
12	Placing alternate foot on stool
13	Standing with one foot in front
14	Standing on one foot

2.2.5 MFAS - the Motor Function Assessment Scale

The MFAS (range of scale 0 - 44) examines 4 groups of 44 motor functions: sitting, standing up and standing, walking, and functioning of the upper extremities. A patient who cannot fulfill any of the tasks scores 44 points **(Freivogel and Piorreck, 1990)**. The assessment should be performed by nursing personnel.

Table 7: MFAS item description

Sitting	
1	driving in a wheel chair from one room to another, unaided
2	Transfer wheel chair-bench over less handicapped side
3	Transfer wheel chair-bench over more handicapped side
4	Free sitting without any help (not leaning on the arm)
5	Like 4, additional free head movements
6	Like 4, additional free arm movements
7	Lift right buttock (+ right leg)
8	Lift left buttock (+ left leg)
Standing up and standing	
9	Standing up from the floor without assistance
10	Free standing for 8 seconds
11	Free rising from sitting to standing position (from 90° hipflex.)
12	Like 11, but without propping or pressing
13	Like 12, with right leg only
14	Like 12, with left leg only
15	Standing on right leg for 8 seconds
16	Like 15, left
17	Rising asymmetrically from low knees bend (crouching)
Walking	
18	10 m with auxiliary person + device
19	10 m unaided (with auxiliary device, without auxiliary person)
20	10 m unaided (without auxiliary device, without auxiliary person)
21	10 m barefoot
22	Walking 10 m, touching ground with one hand, turning and walking back
23	Like 22, touching ground with both hands
24	Climbing 5 stairs (with rail)
25	Walking down 5 stairs (with rail)
26	Like 24 (without rail)
27	Like 25 (without rail)
28	Running 20 m
29	Hopping 8 times with right leg (without break)
30	Like 29, with left leg
31	Tightrope walking 3 m forward (on long bench turned upside down, assistance for climbing)
32	Like 31, backward
Upper extremities	
33	Putting right hand on mouth
34	Like 33, with left hand
35	Reaching left ear with right hand across head (full elevation)
36	Like 35, with left hand
37	Bouncing a ball 8 times with right hand (from a standing or sitting position)
38	Like 37, with left hand
39	Holding paper with right hand (between thumb and forefinger)
40	Like 39, holding with left hand
41	Knocking with both hands alternatively on support (evenly/ with both arms propped)
42	5 knots in 20 seconds
43	Drawing a line without touching the margins, right hand (without interrupting)
44	Like 43, left hand

The MFAS is routinely performed by therapists at admission and discharge at the Schön Klinik Bad Aibling.

2.2.6 SF-36 health survey

The SF-36 (2nd edition, 2011, German version, 1 week) consists of 36 questions subdivided in 8 scaled sub-scores (**Bullinger and Kirchberger, 1998**). The overall score ranges from 0 to 100, lower values indicate more disability. In the REACH project two versions will be used, one filled in through the elderly citizen/ patient himself (self-assessment) and the second filled in by the caregiver (external assessment). The assessment refers to the experiences of the last week prior to the date of the survey (**Bullinger et al., 1995; Bullinger and Kirchberger, 1998**).

The eight sections are:

1. Vitality
2. Physical functioning
3. Bodily pain
4. General health perceptions
5. Physical role functioning
6. Emotional role functioning
7. Social role functioning
8. Mental health

2.2.7 HADS-D - Hospital Anxiety and Depression Scale

The HADS assessment (German version (**Bjelland et al., 2002**)) is used to detect anxiety and depression in patients with physical conditions or (possibly psychogenic) physical complaints. The HADS is a fourteen item scale that generates ordinal data. Each item on the questionnaire is scored from 0-3, sub-scores are between 0 and 21 for either anxiety or depression. Higher scores are associated with more distinct anxiety/depression. Seven of the items relate to anxiety and seven relate to depression. The questionnaire should be filled in by the patient himself.

The items on the questionnaire that relate to anxiety are:

1. I feel tense or wound up
2. I get a sort of frightened feeling as if something bad is about to happen
3. Worrying thoughts go through my mind
4. I can sit at ease and feel relaxed
5. I get a sort of frightened feeling like butterflies in the stomach
6. I feel restless and have to be on the move
7. I get sudden feelings of panic

The items that relate to depression are:

1. I still enjoy the things I used to enjoy
2. I can laugh and see the funny side of things
3. I feel cheerful
4. I feel as if I am slowed down
5. I have lost interest in my appearance
6. I look forward with enjoyment to things
7. I can enjoy a good book or radio or TV program

2.2.8 BDI - Beck Depression Inventory

The BDI is a multiple-choice self-report inventory, one of the most widely used psychometric tests for measuring the severity of depression. It consists of 21 questions about how the subject has been feeling in the last week. Higher total scores indicate more severe depressive symptoms. Duration to complete the BDI is approximately 10-15 minutes (**Beck et al., 1961**). The questionnaire should be filled in by the elderly citizen/ patient himself.

The BDI scores are interpreted as follows:

Table 8: BDI score interpretation

0-10	These ups and downs are considered normal
11-16	Mild mood disturbance
17-20	Borderline clinical depression
21-30	Moderate depression
31-40	Severe depression
over 40	Extreme depression

A persistent score of 17 or above indicates that you may need treatment.

Table 9: BDI scoring criteria

1	
0	I do not feel sad
1	I feel sad
2	I am sad all the time and I can't snap out of it.
3	I am so sad and unhappy that I can't stand it.
2	
0	I am not particularly discouraged about the future.
1	I feel discouraged about the future
2	I feel I have nothing to look forward to.
3	I feel the future is hopeless and that things cannot improve.
3	
0	I do not feel like a failure.
1	I feel I have failed more than the average person.
2	As I look back on my life, all I can see is a lot of failures.
3	I feel I am a complete failure as a person.
4	
0	I get as much satisfaction out of things as I used to.
1	I don't enjoy things the way I used to.
2	I don't get real satisfaction out of anything anymore.
3	I am dissatisfied or bored with everything.
5	
0	I don't feel particularly guilty
1	I feel guilty a good part of the time.
2	I feel quite guilty most of the time.
3	I feel guilty all of the time.
6	
0	I don't feel I am being punished.
1	I feel I may be punished.
2	I expect to be punished.
3	I feel I am being punished.
7	
0	I don't feel disappointed in myself.
1	I am disappointed in myself.
2	I am disgusted with myself.
3	I hate myself.
8	
0	I don't feel I am any worse than anybody else.
1	I am critical of myself for my weaknesses or mistakes.
2	I blame myself all the time for my faults.
3	I blame myself for everything bad that happens.
9	
0	I don't have any thoughts of killing myself.
1	I have thoughts of killing myself, but I would not carry them out.
2	I would like to kill myself.
3	I would kill myself if I had the chance.
10	
0	I don't cry any more than usual.
1	I cry more now than I used to.
2	I cry all the time now.
3	I used to be able to cry, but now I can't cry even though I want to.
11	
0	I am no more irritated by things than I ever was.
1	I am slightly more irritated now than usual.
2	I am quite annoyed or irritated a good deal of the time.

	3	I feel irritated all the time.
12		
	0	I have not lost interest in other people.
	1	I am less interested in other people than I used to be.
	2	I have lost most of my interest in other people.
	3	I have lost all of my interest in other people.
13		
	0	I make decisions about as well as I ever could.
	1	I put off making decisions more than I used to.
	2	I have greater difficulty in making decisions more than I used to.
	3	I can't make decisions at all anymore.
14		
	0	I don't feel that I look any worse than I used to.
	1	I am worried that I am looking old or unattractive.
	2	I feel there are permanent changes in my appearance that make me look unattractive.
	3	I believe that I look ugly.
15		
	0	I can work about as well as before.
	1	It takes an extra effort to get started at doing something.
	2	I have to push myself very hard to do anything.
	3	I can't do any work at all.
16		
	0	I can sleep as well as usual.
	1	I don't sleep as well as I used to.
	2	I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
	3	I wake up several hours earlier than I used to and cannot get back to sleep.
17		
	0	don't get more tired than usual.
	1	I get tired more easily than I used to.
	2	I get tired from doing almost anything.
	3	I am too tired to do anything.
18		
	0	My appetite is no worse than usual.
	1	My appetite is not as good as it used to be.
	2	My appetite is much worse now.
	3	I have no appetite at all anymore.
19		
	0	I haven't lost much weight, if any, lately.
	1	I have lost more than five pounds.
	2	I have lost more than ten pounds.
	3	I have lost more than fifteen pounds.
20		
	0	I am no more worried about my health than usual.
	1	I am worried about physical problems like aches, pains, upset stomach, or constipation.
	2	I am very worried about physical problems and it's hard to think of much else.
	3	I am so worried about my physical problems that I cannot think of anything else.
21		
	0	I have not noticed any recent change in my interest in sex.
	1	I am less interested in sex than I used to be.
	2	I have almost no interest in sex.
	3	I have lost interest in sex completely.

2.2.9 MOCA - the Montreal Cognitive Assessment

The MOCA (full test, version 7, 2004, German version) (Nasreddine *et al.*, 2005) was designed as a rapid screening instrument for mild cognitive dysfunction.

MOCA assesses the following cognitive domains:

1. Attention and concentration
2. Executive functions
3. Memory
4. Language

5. Visuoconstructional skills
6. Conceptual thinking
7. Calculations
8. Orientation.

The maximum total score is 30; a score of 26 or above is considered normal. The assessment should be performed by personnel familiar with the MOCA.

2.2.10 MMSE - Mini-Mental State Examination

The MMSE is a screening score that is used to measure cognitive impairment. It is also used to estimate the severity and progression of cognitive impairment and to follow the course of cognitive changes in an individual over time. The MMSE test includes simple questions and problems in a number of areas: the time and place of the test, repeating lists of words, arithmetic such as the serial seven, language use and comprehension, and basic motor skills (**Folstein et al., 1975; O'Bryant et al., 2008**). Completion of the MMSE takes between 5 to 10 minutes. The assessment should be performed by psychologists or physicians.

The MMSE scores are interpreted as follows.

Table 10: MMSE score interpretation

24-30	Normal cognition
19-23	Mild cognitive impairment
10-18	Moderate cognitive impairment
≤ 9	Severe cognitive impairment

Table 11: MMSE scoring criteria

Max. score	Questions
5	"What is the year? Season? Date? Day? Month?"
5	"Where are we now? State? County? Town/city? Hospital? Floor?"
3	The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5	"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...); Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3	"Earlier I told you the names of three things. Can you tell me what those were?"
2	Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1	"Repeat the phrase: 'No ifs, ands, or buts.'"
3	"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1	"Please read this and do what it says." (Written instruction is "Close your eyes.")
1	"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1	"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.)



2.2.11 TFI - Tilburg Frailty Indicator

The Tilburg Frailty Indicator (TFI) was developed in line with the integral conceptual model of frailty (**Gobbens et al., 2010b**). Several other multidimensional instruments are currently available for measuring frailty in older persons, such as the Edmonton Frail Scale (**Rolfson et al., 2006**), the Frailty Index (**Jones et al., 2004**), and the Groningen Frailty Indicator (**Schuermans et al., 2004**). The TFI differs from these instruments in that the score on the TFI results entirely from self-reports and contains no questions on disability. Research has shown that frailty should be distinguished

from disability (Fried *et al.*, 2004). Frailty, in fact, is regarded as a pre-disability state (van Kan *et al.*, 2008; Morley *et al.*, 2006).

A recent cross-sectional study has shown that the TFI is easy to administer and also a reliable and valid measurement tool for assessing frailty (Gobbens *et al.*, 2010b). The TFI has good test–retest reliability, good construct validity, and good to excellent criterion-oriented concurrent validity for predicting the adverse outcomes disability, receiving personal care, receiving nursing and informal care, and mediocre for hospitalization and general practitioner (GP) visits. The concurrent validity of the TFI was also demonstrated by strong correlations with quality of life and relations among life-course determinants, disease(s), and frailty were also confirmed (Gobbens *et al.*, 2010a).

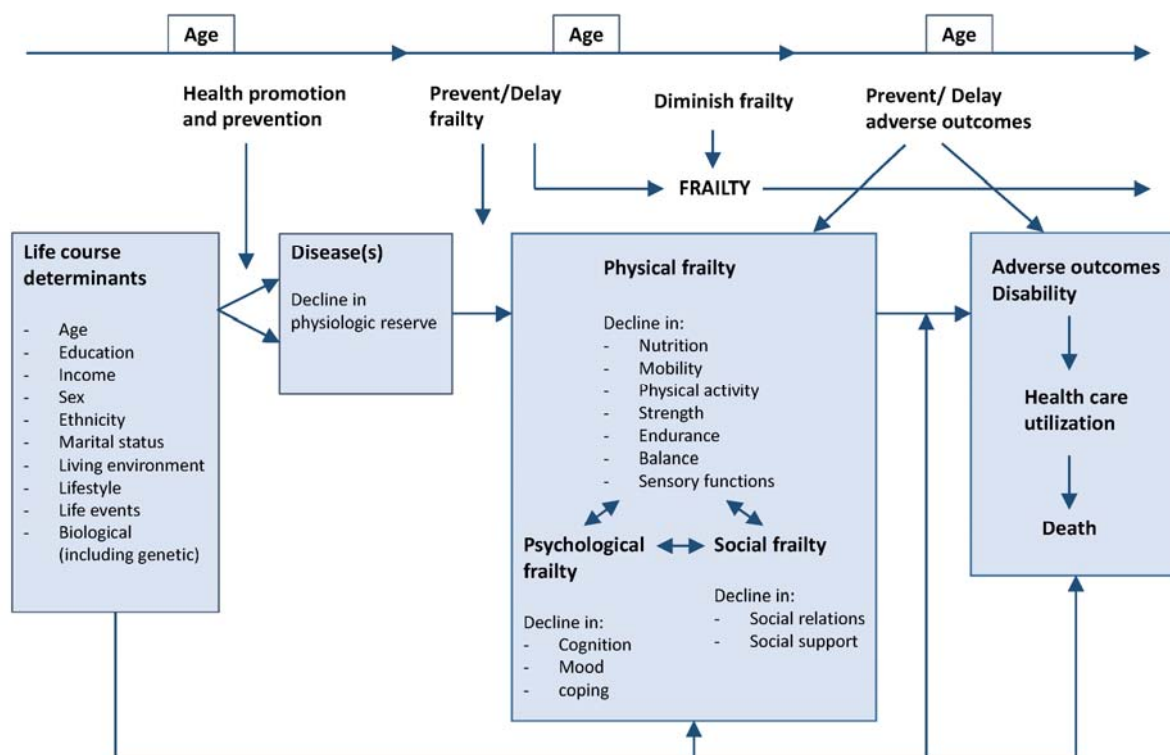


Figure 2: Integral conceptual model of frailty (adopted from Gobbens *et al.*, 2010a)

2.2.12 Monitoring and Assessment Framework for the European Innovation Partnership on Active and Healthy Ageing (MAFEIP)

MAFEIP is a *Monitoring and Assessment Framework* generated by the Joint Research Center of the European Commission to assess the evolution and impact of the *European Innovation Partnership on Active and Healthy Ageing (EIP on AHA)*. The main topic of MAFEIP is to facilitate and harmonize the monitoring of the overall outcome of the Action Groups within the EIP on AHA to allow a qualitative comparison with the EIP on AHA objectives (Boehler and Abadie, 2015). The superior objective of EIP on AHA is to increase the average healthy life span of European citizens by two additional healthy life years until 2020, accompanied by the *Triple Win* comprising the following targets:

1. Enabling EU citizens to lead healthy, active and independent lives while ageing;
2. Improving the sustainability and efficiency of social and health care systems;
3. Boosting and improving the competitiveness of the markets for innovative products and services, thus creating new opportunities for businesses.

Sets of potential outcome indicators were already specified for quality of life and sustainability of health systems. MAFEIP is not a rigid tool and will be adapted and further developed to the users' needs and expectations (**European Commission, 2015**).

2.3 Analysis of real world end-user profiles (EPs)

The functionality of the REACH system should accommodate end-users' needs. In hospital settings a lot of information is generated through a multitude of caregiver. Therefore collection, evaluation and quantification of relevant data is crucial to develop a suitable system. The best way to visualize the needs of end-user groups is by creating models (personas) based on data of various patients with different deficits. SK, for example, concentrates on two major deficit categories, motor deficits and cognitive/speech deficits, and generated from 5 EPs analyzed finally two personas, one with focus on motor deficits and one with focus on cognitive deficits. To ensure that every aspect regarding the pathologies represented by the personas is covered, SK screened the data from 10 additional end-users with the respective pathologies.

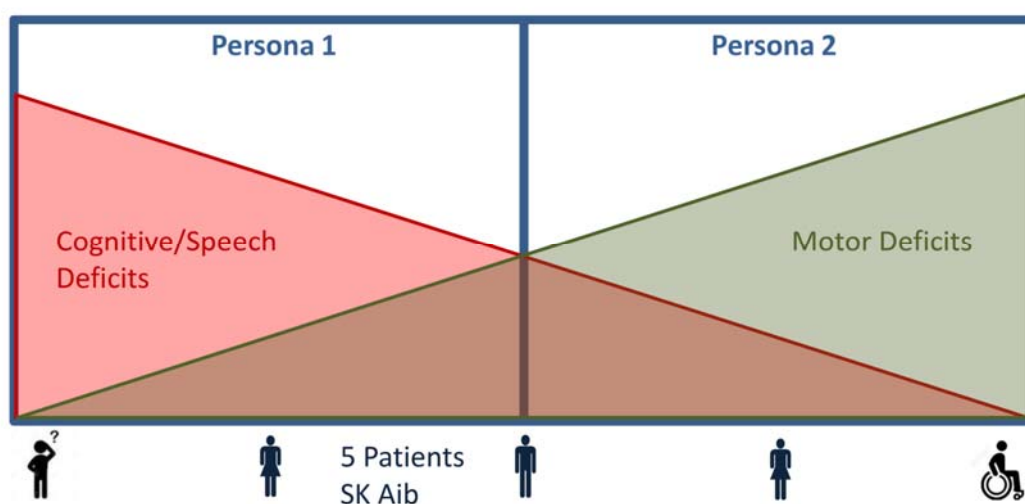


Figure 3: Focus of deficits in personas model

In the context of the analysis of EPs data on the following items will be collected and analyzed:

1. Demographics
2. Diagnosis
3. Relevant complications
4. Neuropsychological limitations
5. Movement disorders

To follow the REACH objective providing comprehensive mobilization, the needs of each persona shall be structured and assigned to all respective phases of the day.

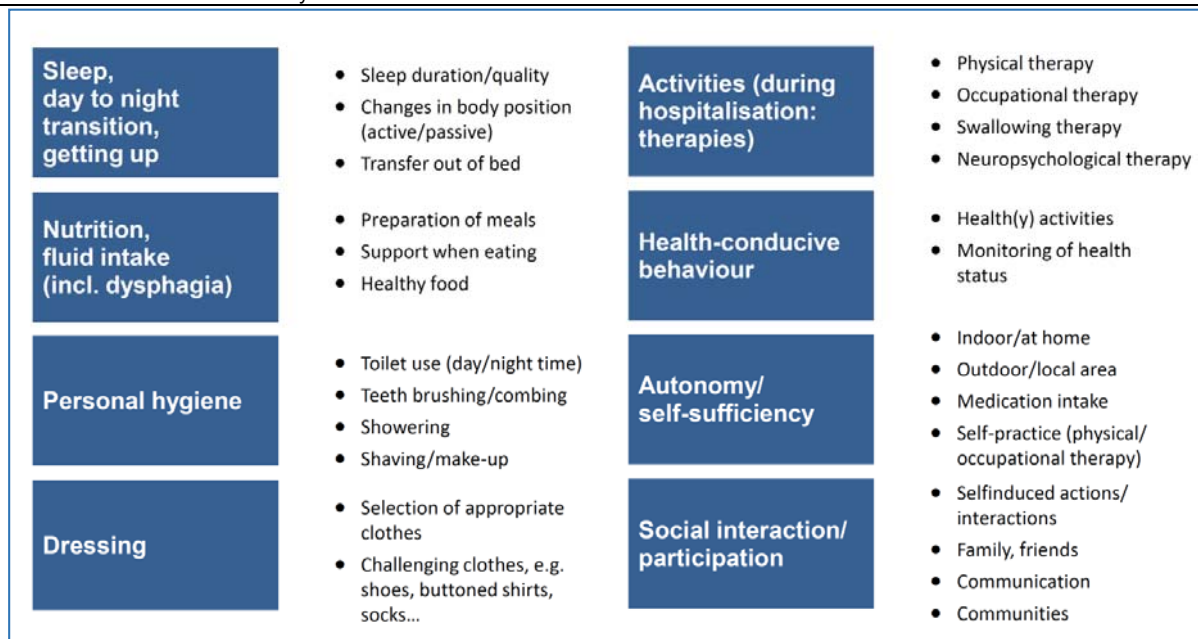


Figure 4: Phases of the day in the clinical setting

In addition to the demographic and clinical elderly citizen/patient characteristics, expectations from caregivers or therapists will be added to the respective phases of the day.

2.4 Interviews

The purpose of the interviews to be conducted in T1.1 was to contribute information from each of the 4 test sites for the elaboration of use cases. In particular, interviews shall elicit from elderly citizens/patients, their families and their professional caretakers their attitudes, expectations and concerns about 1) Monitoring, 2) Activity nudging; and 3) Privacy issues (associated with 1 and 2). The purpose of the interviews was not to collect data for a scientific paper. Each interview was expected to last 30-45 minutes, depending on the social talk during and after introduction, of course.

Interview Guideline:

1. Format: Semi-structured interview. Face to face interview set up preferred. May be replaced by or supplemented with focus group interviews or (for instance staff interviews) interviews in pairs or small groups.
2. Interview participants:
 - a) An adequate sample of elderly citizens/patients. Inclusion criteria: 65+, receiving some amount of care either personal or nursing. (N ≥ 6, try to sample both couples and singles, old and not so old citizens)
 - b) An adequate sample of relatives to elderly citizens/patients as above (N ≥ 6)
 - c) An adequate sample of professional care givers – nurses, nurse assistants (N ≥ 6)
3. Introduction: You will introduce yourself and explain the purpose of the study. Explain that all information your participants will provide is confidential and no

use will be made of this that can be used to identify any person(s). Write this down in advance in the language of the interview¹.

4. Demographic data: for each interviewee (participant) please record:
 - a) age,
 - b) gender,
 - c) cohabitation/marital status,
 - d) type of home situation (we only need to know if they live in sheltered home or live by themselves while still receiving some amount of care)
 - e) extent of care service per week (how many visits per day/week on average)
 - f) uses (yes/no) the internet/www regularly (by PC, tablet or smartphone)

5. Themes: For several of the themes you (obviously) need to explain, however, briefly what the issue is about and exemplify this. When you introduce sensors, you may bring a picture along for illustration (explaining that the idea is to mount a few of these sensors in the citizen's home in places to be agreed upon).
 - a) Theme 1: Collection of data from in-home or wearable sensors for monitoring health status - ask about and seek elaboration of the participant's views about the
 - A1. Usefulness of sensors (in-home and/or wearable that may alert caregivers if the sensors detect an event (fall, lack of movement during daytime) or a marked change in behaviors.
 - A2. Usefulness of family members or other informal caregivers. Can they have the same access to events and/or changes in activity, if the citizen permits this?
 - A3. Acceptability of the above – ask about concerns that caregivers will be able to see changes in activities
 - A4. Acceptability of the above with respect to family/informal caregivers

 - b) Theme 2: Prompting/ nudging to engage in physical activities – ask and seek elaboration of the participant's view about
 - B0. Do you wish to engage in (a bit) more physical activity than you currently are engaged in (dancing, bowling, walking, hiking, swimming, and if not: can you imagine that you at a later time might need some encouragement to increase your physical activity?
 - B1. Usefulness for yourself of having prompting via technology (in-home and/or wearable) to engage in a specific activity AND having feedback via the sensors of activities engaged in or not
 - A3. Acceptability of allowing (some of) your formal caregivers to monitor your activities retrospectively - concerns that caregivers will be able to see when you skip your “prescribed” activities?
 - A4. Acceptability of the above with respect to family/informal caregivers

¹ Your interview is not intended to collect any personal health data: therefore, we need not to prepare an informed consent form for our interview participants to sign. If you receive personal health data, please do not collect this.

If you need to keep a record of the names or other identifying information about your interview participants, you must make sure that you do not store such information in the files or folders in which you record results of the interview.

2.5 Defining personas

The purpose of personas (**Pruitt, J. and Grudin, J., 2003**) is to create reliable and realistic representations of your target users of the intended products and services. These representations should be based on qualitative and some quantitative user research. As a result, personas are fictional, generalized characters representing the real and potential customers with various needs, objectives, and behavior patterns. They can help understand customers better. According to (**U. S. Department of Health and Human Services, 2015**), there are a few important steps when making personas.

1. Conduct user research by answering the following questions: Who are your users and why are they using your products and services? What are their behaviors, assumptions, and expectations?
2. Condense the research by looking for themes/characteristics that are specific, relevant, and universal to your products and services and their users.
3. Brainstorm by organizing elements into persona groups that represent your target users. Name or classify each group.
4. Refine by combining and prioritizing the rough personas. Separate them into primary, secondary, and, if necessary, complementary categories. You should have roughly 3-5 personas and their identified characteristics.
5. Make them realistic by developing the appropriate descriptions of each personas background, motivations, and expectations. Do not include a lot of personal information. Be relevant and serious; humor is not appropriate.

Personas generally include the following key pieces of information:

1. Fictional name
2. Job titles and major responsibilities
3. Demographics such as age, education, ethnicity, and family status
4. The related goals and tasks they are trying to complete
5. Their physical, social, and technological environment
6. A quote that sums up what matters most to the persona as it relates to relevant products and services
7. Casual pictures representing that user group

It is important to organize persona information in an easy to read, logical format. Examples of persona can be found via (**U. S. Department of Health and Human Services, 2015**).

2.6 Use scenario elaboration by Experience Mapping

The method and the description in this section are partly adopted from “*Experience Flows Understanding people and their experiences to deliver meaningful innovations*” (**Philips, 2014**).

2.6.1 General description of the method:

- a. Making sense of context: Experience Maps (EMs) are one of Philips’ most useful tools for creating people-centered solutions. They help to spot and contextualize the unmet needs of people and then translate these into innovation opportunities and directions. This is done by consolidating vast amounts of qualitative and quantitative information and knowledge into a visual

- that makes immediate sense to everyone. Using multiple perspectives on a particular issue or topic ensures that a holistic insight into the total user experience is created.
- b. Mapping the experiences: Philips developed the Experience Flow (EF) as a way of mapping an experience – from expectation, to first impression, then through discovery, usage and finally to memory. The poster shows the journey a person or people make through their experience of a place, their interactions with people, and a product or service over time. Besides providing detailed insights from an elderly citizen/patient perspective, the process of creating a flow also helps a team to adopt and understand multiple perspectives and approaches to a context.
 - c. Gathering user insights: Using people-centered research, the team works with the project's target group to uncover what they think and feel as they experience the specific topic over time. This can be done in a number of ways, which include holding formal and informal interviews, workshops with stakeholders, asking individuals to write down their experiences in a diary or by using online ethnography, and shadowing them as they go about a typical day. The team keeps an open mind at every stage of the process. When doing fieldwork it is best to refrain from talking about the desired solution or direction. Instead, aim for talking about the experiences and the issues in their context.
 - d. Identifying issues: Using the current and real experiences captured during fieldwork, the team starts putting together an EF poster and issue cards. This helps to visually pinpoint problems or gaps, and serves as a basis for identifying opportunities across the EF in a collaborative workshop. The team uses the poster to walk through the journey as if they were the person or people concerned. Then they discuss, challenge and enrich the journey by spotting areas where the person's needs are not being met.
 - e. Going deep: The EF approach is not exclusive to Philips. Some other organizations have developed similar tools, which they call a Journey Map or a Customer Journey. But Philips is one of few companies to go as deep into the emotional and practical experiences of the people they design for by carrying out extensive field research, and then distilling that understanding in a way that makes sense to others. This depth makes the EF invaluable when seeking to truly understand the needs of a specific target group. As an example, biopharmaceutical company AbbVie hired Philips as a consultant to create an EF about elderly citizen/patients with rheumatoid arthritis, and found the results were a long way from what they were used to. "The difference between a Philips EF and a normal customer journey report is like the difference between reading a thesis about a person and seeing that person in real life situations," says Senior Brand Manager at AbbVie.

How to make and use EFs for REACH: To support the collection and mapping of elderly citizen/patient experiences and opportunities for use cases in the REACH project, we advise to conduct the following selection of activities at least to some extent. These are abstracted from a more extensive set of guidelines on Experience Flows, but given the level of experience and amount of resource available, the following procedure should help with capturing the most important aspects.

2.6.2 *Frame the project*

1. Clearly define parameters: The target elderly citizens/patients, region, challenges, timing, core team and deliverables are defined by the team. This may seem obvious, but many projects fail at this first hurdle.

2. Create the experience framework: This rough generic model is the starting point, mapping out what is already known about a topic. The framework is filled with the team's existing knowledge. For REACH, the framework could be "a day in the life" of an elderly citizen/patient in a specific stage of healthcare (rehabilitation, transition, home care, etc.), with the timeline on a horizontal axis. This is similar to what was exercised in a T1.1 task initiation meeting in February 2015 at SK. The vertical axis has the different layers of insights. For the application in REACH, we suggest to use the following layers:

- Mood and elderly citizen/ patient experience: Describe how the elderly citizen/patient feels and experiences the specific events, activities and interactions throughout the day.
- Equipment and facilities: Indicate the technology and facilities used. This can be rehabilitation equipment, but also communication technology to talk to their family.
- Social contacts: The interactions with friends, family and other people are an important part of peoples' lives. Depending on the context, personality and technology available, people may engage in different types of social contact and activities, as well as experience them in different ways.
- Medical professionals and stakeholders: Indicate which medical professionals and/or institutions are involved at certain points during the day. It is valuable to also capture the experiences, concerns and pains experienced by these professionals.

2.6.3 *Contextual stakeholder research*

1. Formal and informal interviews: Helps understand people's rationale and thoughts. In the short time period available in the project, we suggest to use a semi-structured interview approach, probing for behaviors, attitudes and experiences. Use a why-why-why approach to gain deeper understanding of the underlying reasons and motivations. If possible for REACH it would be optimal if not only elderly citizens/ patients are interviewed, but in some cases also their partner, medical staff, and other stakeholders (see point 3 and 4 above).
2. Shadowing and observation: Helps the teams to see what people do and use in a more objective manner. This may be different to what they say in interviews.

2.6.4 *Map the experiences*

In this phase the research is reviewed and patterns and areas of interest are identified, and the Experience Flow created and developed. It maps relationships between activities, context (environments/spaces), people, and experiences over time. The focus is on needs in context rather than solutions, including comments like "I find it quite annoying that", not "I want a product to..." The aim is to see issues in a positive way, as opportunities rather than problems. Please note that it is important to also try and map any dilemma's that may be experienced by the stakeholders in the experience map. Do not forget to make transitions between activities, stakeholders and contexts explicit. It is often in these phases, moments and situations that opportunities or design spaces arise.

2.6.5 *Explore opportunities in workshops*

People from different backgrounds are brought together as a team to work out how relevant each of the statements on issue cards are for different personas in different phases of the Experience Flow. This often leads to multiple opportunities identified along the day-journey of an elderly citizen/patient, including the involvement of other stakeholders. Optionally, these issue cards can be further discussed with the target

group and stakeholders to further enrich the understanding of particular issues and concerns. Individual issue cards, or a cluster of cards can be translated into particular use cases to be addressed by the consortium.

2.6.6 *Tools to deepen understanding*

1. **Personas:** Descriptions of fictional characters, based on a combination of qualities, lifestyle patterns, needs and desires of the researched people. These personas are used to test various topics (how do they cook, how do they prepare for a hospital visit, how important is style for them?). Personas help make the work more people-focused. It's easier to design for 'Sue' than it is for 'the target user' (also see **Section 2.5**).
2. **Stakeholder maps:** A simple mapping that shows how multiple groups of people relate to one another in a specific context over time. The best example here is elderly citizens/patients, their families, doctors and nurses in a hospital. This map is put next to the Flow as a reference to the bigger context in which the Flow is only a part (also see **Section 2.1**).

3 Analysis and description of use cases

The use cases hospital/transition (HUG), rehabilitation (SK), home care and homes (Lyngby and ZuidZorg) cover different care settings which the elderly citizen (in the context of HUG and SK also referred to as “patient”) passes through during the course of a health deterioration, care or recovery process. Not all use cases have to be passed through by each elderly citizen. Elderly citizens who recover quickly can be directly discharged to their home. Only if impairments at the end of the hospital stay are hindering the elderly citizen from an independent life, rehabilitation is indicated. Home care is needed when the elderly citizen (and his/her family) cannot accomplish ADLs. Rehabilitation, activation, and physical therapy and training are also needed for almost healthy elderly citizens to reduce the risk of health deterioration. This normal development may be altered by complications and adverse events. Some scenarios are overlapping and can be found in more than one use case.

Table 12: Primary and secondary attributes of use cases

Use case	Primary Attribute	Secondary Attribute	Main Topic
HUG	Transition between use cases	Acute care Rehabilitation	Prevention of readmission and increased need of care
SK	Neurological rehabilitation	Acute care (Stroke Unit, ICU)	Rehabilitation
ZuidZorg	Home care	Meet and greet center	Avoiding nursing home/hospital admission
Lyngby	Home care Homes	Smart Home	Avoiding nursing home/hospital admission

3.1 Use case 1: Geneva Hospital (HUG)

HUG will in the context of REACH focus on the transition between use cases and health states of end-user (in particular involving its geriatric unit, and rehabilitation and home care specialists), represent in the REACH care continuum an acute care setting, and will aim at the prevention of readmission and need of care.

3.1.1 Description of use case, focus and target users/elderly

The Directorate General for Economic and Financial Affairs expects a 350% increase of health costs by 2050, in a context of limited economic expansion. Increase in LTC, due the global ageing of the population, is recognized as a major determinant of this inflation. REACH is a technological product that aims at limiting admissions in LTC by promoting the autonomy, the physical condition and the literacy of geriatric-aged elderly citizen (in the context of HUG called “patients”) with cognitive or physical impairment. It will use furniture-embedded or worn sensors to identify abnormal health patterns, propose recommendations, and eventually apply them with a particular focus on motivation. HUG now is in the conceptualization phase and proposes to focus on the hospital to home transition.

Hospital to home transition is increasingly recognized as a critical period in the continuum of patient care, where notably high numbers of adverse events and hospital readmissions may occur (**Baker et al., 2004; Bowles et al., 2002; Bull et al., 2000; Forster et al., 2003; Heggstad, 2002; Naylor, 2000; Naylor et al., 1999; Naylor et al., 2004; Naylor and McCauley, 1999; Pohl et al., 1995; Rich et al., 1995; Riegel et al., 2004; Schultz, 1997; Siu et al., 1996; Waite et al., 1994;**

Weinberger et al., 1996). Among other interventions, application of innovative eHealth strategies such as REACH could act on the determinants of these adverse outcomes and improve the quality of care. Accordingly, HUG proposes to focus the use case on this context with the overall aim to facilitate the hospital to home transition and the home care, thereby limiting hospital readmissions.

In accordance with the REACH concept, the target population will consist of patients 65 years old or older, with functional and/or cognitive impairment, hospitalized in the geriatric hospital of Geneva (Hôpital des Trois-Chêne), with need of home care after discharge, and with home care provided by the public Institution genevoise de Maintien A Domicile (IMAD). The IMAD supports more than 19.000 persons per year. Specific scales described in the assessment methods part will enable HUG to state the degree of physical and cognitive impairment more precisely. In order to further define the use case, HUG must aim at better understanding regarding the needs of the target population and their partner.

For that purpose, key questions were stated:

1. What are the demographic and medical characteristics of the patients?
2. What are patients', families' and care-givers' expectations and fears about REACH?
3. What are the determinants of hospital readmission?
4. For hospitalized patients, what are the determinants of long-term care versus discharge with home-care?

The analysis of patient profiles will help to answer the first question, and, to some extent, the third and the fourth ones. The interviews of patients, family members and care-givers will help to answer the second question. Finally, expert interviews, literature review and eventually a dedicated study will help to answer the third and fourth questions. In order to work on the literature review regarding questions 3 and 4, Prof. Armin Schnider, head of the neurorehabilitation division at HUG, met with stakeholders Prof. Jean-Luc Reny, head of the Hôpital des Trois-Chêne.

The main conclusions of these stakeholder meetings were that:

1. Falls, heart failure and cognitive impairment were the most frequent problems associated with hospital readmissions.
2. Anxiety by relatives, dangerous situations linked to cognitive impairment (patients may forget to eat or to turn-off the cooking plates), or every situation that needs the continuous presence of care-givers (which is in many cases not possible) are the main limiting factors to provide care at home versus long-term care in a nursing home.
3. Accordingly, REACH features should target these problems.

A definitive use case can only be provided after answering fully to our four key questions. However, HUG proposes here a prototypical use case to allow a more concrete representation that could be useful for further reading of this report:

1. A geriatric-aged patient hospitalized at the Trois-Chêne Hospital (3C) is identified as lacking autonomy (defined by the MMSE, FIM BBS) by the medical doctor, nurse or physical therapist in charge.
2. Alternatively, the patient reads a brochure about REACH and speaks to the care team.

3. The potential benefits resulting from the implementation of REACH are discussed during the weekly-held social meeting where nurses, occupational therapists, social workers, doctors, physical therapists and liaison nurses are present.
4. The product is then presented to the patient and/or his/her family by a member of the care team that can come from a variety of different professional categories depending on which REACH module is considered (i.e. physical therapist for motor rehabilitation, MD for a module involving treatment adaptation etc.).
5. The patient and/or his/her family give or not his/her informed consent for the implementation of one or more REACH modules.
6. Upon approval, and if the remaining hospitalization time allows for it, the module (from the existing HUG pool of REACH devices) is first installed in the rehabilitation setting by a trained HUG technician, and the patient and care-givers start to train with it.
7. If necessary, an on-call REACH technician is able to fix minor technical issues.
8. REACH-associated medical issues are discussed with the care team during the round (as would be medication side-effects) on a daily basis.
9. After 3 days, the patient chooses whether or not to install the system at home.
10. In the case the patient accepts to install the REACH system, the liaison nurse contacts the REACH technician from the IMAD.
11. The patient is discharged and arrives home where the REACH smart furniture is already installed and where it helps to facilitate the care transition. Features that may contribute to improve the hospital to home transition may include (this is the critical part that will be adapted once the definitive use-case outline will be available):
 - a. Physical therapy aimed at limiting falls: Continuation of exercises started in the hospital, monitoring and adaptation via REACH that would also be able to create reports for the physical therapist. Some innovative features such as virtual reality could be integrated.
 - b. Fall detection and alarm: REACH movement sensors may be used to detect a fall or an absence of movement and alert care-givers or family members.
 - c. Promotion of treatment observance: The treatment plan could be integrated into to REACH and associated with a reminder system that could improve patients' observance. Sensor: intelligent pill box. Effector: reminder via the REACH interface. IMAD and GP could get access to and modify the treatment plan via REACH.
 - d. Suggestion of treatment adaptation based on sensed parameters: increase of the diuretic doses following an increase in body weight for patient with heart failure; increase of the basal evening insulin following an increase of the morning fasting blood glucose levels.
 - e. Monitoring of context-associated critical parameters (blood pressure after a hypertensive crisis, O2 saturation after a respiratory failure) that could be collected via IMAD nurses or sent to the IMAD/GP.
 - f. Regular brain exercise: Cerebral training program could be performed through the REACH interface and feedback would be provided using monitoring of the scores and/or the brain electric activity via an easy-to-use, dry, electroencephalogram cap.
 - g. Meal reminder and planning: Data from sensors aiming at measuring the food intake could be used to plan and eventually help to prepare adequate meals.

- h. Smoke alarm: Smoke detectors may alarm fire workers in case of a fire. Cooking plates could be automatically turned off after a period of inactivity or after an ignored reminder. These are already existing, yet very useful, systems for people with cognitive impairment that could be easily integrated into REACH.
- i. Continuous monitoring of ADLs coupled with pattern analysis and prediction algorithms that may indicate early worsening of cognitive or physical impairments, trigger distance or face-to-face evaluation, and may help avoid hospital readmission.
- j. Collaborative tools that may facilitate the interactions between the patient and the formal and informal caregivers with the aim of improving social or medical support.

12. If patients have to be readmitted to the hospital, REACH may send collected information (last parameters, current treatment for example) to the hospital caregivers.

3.1.2 Stakeholder identification

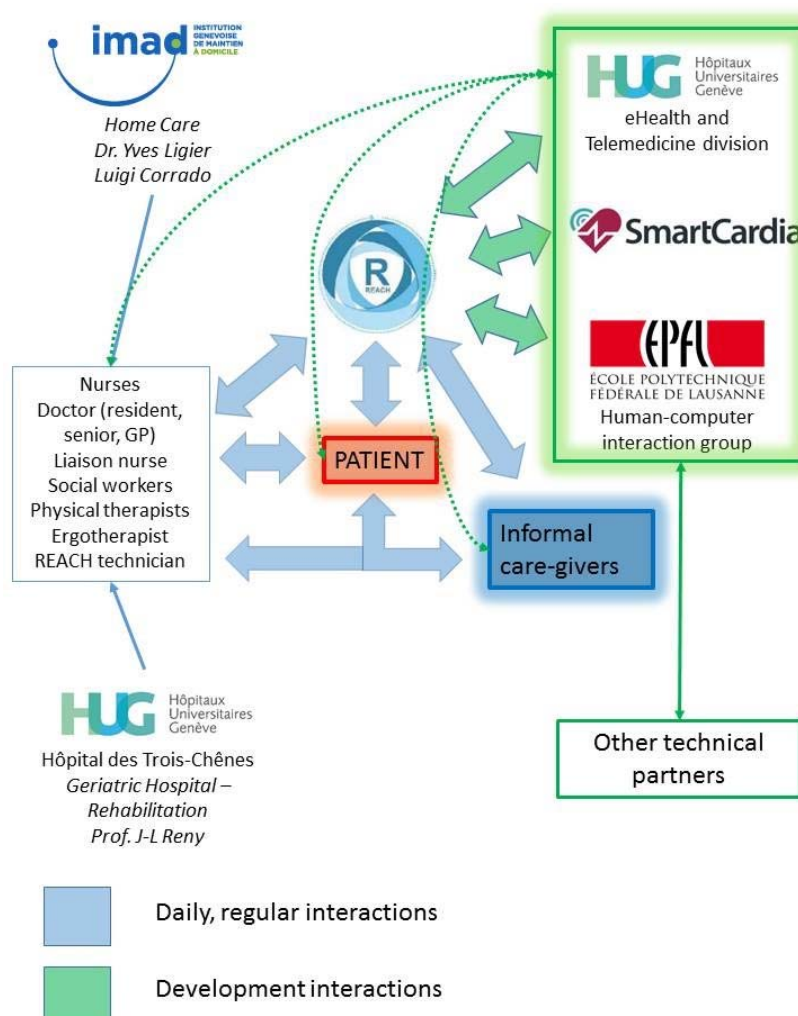


Figure 5: Stakeholder identification at HUG

This figure identifies the main stakeholders interacting daily with REACH and patients in our use case (blue arrows and boxes). It also identifies stakeholders involved in the development phase of REACH (green arrows and boxes). On a daily basis, patients, the REACH system and care givers will mutually interact promoting home

care. The development team of REACH will promote user-assisted development by frequent contacts with patients and caregivers.

3.1.3 Assessment method

Regarding the suggested scales, the MOCA (for cognitive impairment), the Barthel Index (for the overall autonomy) and the BBS (for risk of fall) are well suited to our use case. However, our collaborating center, the Hôpital des Trois-Chênes, routinely uses the also well recognized MMSE for cognitive assessment and the FIM for autonomy assessment. In order to use tests that are both already available in the medical records and well suited to HUG's use case, following assessment methods were chosen: MMSE, FIM and Berg Balance Scale (see also **Section 2.2.4**). These scales are used to define the HUG use case target population. In order to enroll patients that have some degree of cognitive and/or physical impairment but that are still able to interact with a technological interface, it is suggested to use the following cut-offs in the context of the HUG use case:

1. 21 < MMSE < 27: corresponding to a level of cognitive impairment that allows interacting with a human-machine interface and using the patient capacity of discernment.
2. 64 < FIM < 120: corresponding to an autonomy impairment that allows interacting with a human-machine interface and eventually gaining benefits from REACH functions.
3. 20 < Berg Balance Scale < 40: corresponding to a patient needing assistance to walk.

3.1.4 Analysis of real-world end-user profiles

In order to better understand target population in the context of the HUG use case, we have designed a study which is described below. To be in accordance with the Swiss legislation, HUG was forced to submit this study to the Geneva state ethical committee. Please see the application file joined to this in **Section 8** as part of the enclosures. HUG is currently still waiting for the approval of the ethical committee. Accordingly, results of the analysis of personal patient profiles and of the interviews and will be considered therefore as part of the stakeholder analysis in T1.2/D1.2.

HUG plans to recruit patients corresponding to the outline target population (65 year-old or older, hospitalized at the 3C with a planned discharge with the help of the IMAD, with physical or cognitive impairment as defined in the assessment methods part) and to extract medical and demographic data from their medical records. Recruited patients (potential REACH end-users) will also participate in a semi-structured interview that will assess their expectations and fears regarding REACH as proposed in **Section 2.4**. Moreover, HUG will also interview the patients regarding the use of REACH for the hospital to home transition. Finally, interviews will include questions about patients' needs regarding REACH on particular times of the day as suggested by the analysis framework in **Section 2** (for instance, early morning, morning, lunch, afternoon, evening, night). Formal and informal care-givers from recruited patients will also be enrolled for similar interviews. This design will allow HUG to:

1. Define the dominant medical and demographic profiles of our target population.
2. Define patients' and formal and informal caregivers' expectations and fears regarding REACH in our particular use case setting.

3. Eventually reveal a link between a particular patient profile and distinct expectations or fears regarding REACH.
4. Extract patients' needs according to a 24 hours cycle.

3.1.5 Interviews

HUG is currently still waiting for the approval of the ethical committee. Accordingly, results of the analysis of personal patient profiles and of the interviews and will be considered therefore as part of the stakeholder analysis in T1.2/D1.2

3.1.6 Defining personas

As HUG is currently waiting for the analysis of patients' profiles and the interviews, HUG designed these personas (**Figures 6-10**) on the basis of meetings held with experts (description of use case, focus and target users/elderly) and their personal experience.

CARDIOVASCULAR DISEASES

Demographic data

Mr. Roberto Dos Santos

73 years old, married, 3 children (50, 47 and 45 years old)

Retired Taxi-driver, fond of motorbike mechanics

Regularly uses an iPad to surf on the internet and play games. Do not like when technology is too complicated



Main medical issues

Heart failure secondary to

- Myocardial infarction in 2009
- Hypertension
- Multiple hospital admissions for acute heart failure

Type II diabetes treated by insulin

Chronic renal failure

Heavy tobacco use (2 packs per day)

Overweight

Conditions of living, autonomy and home care

Live with his wife in an apartment on the 4th floor without elevators. His children frequently visit but are not implicated in health problematics.

His wife takes care of the household, shopping and meal preparation because he is too breathless to help. He still takes care of the paperwork and tries to tinker motorbikes. He is able to go buy his cigarettes 250 meters from home but if he needs to go further, he takes the car because of his breathlessness.

He is helped by the IMAD nurses once a week for preparation of treatment and surveillance

of clinical parameters. Although washing himself is becoming hard, he refuses further help.

Expectations and fears regarding REACH

He is open to a system such as REACH but it needs to respect his autonomy and privacy as soon as he decides it.

He also expects an easy-to-use system that works all the time without the need of specific maintenance.

He would particularly appreciate that REACH helps him to avoid frequent hospitalizations for acute heart failure, diabetic decompensation or hypertensive crisis.

He would appreciate innovative strategies to stop smoking and that promote physical rehabilitation through a gaming interface.

He believes that sharing recorded data with care-givers could help him but that the system must allow him to clearly choose what he shares.

His wife would appreciate that in addition to limit hospitalizations, the system could help him to achieve a better physical condition.

Quote

“Le travail c'est la santé” = “Working is health”

Figure 6: Persona for patients with cardiovascular disease

FALLS

Demographic data

Mrs. Geneviève Duret

79 years old

Widow, her husband deceased 5 years ago

One son, 50 years-old living in the US

Former Professor of English Literature

Uses regularly an eBook reader

Knows how to use a computer but prefers books



Main diagnostic and comorbidities

Primary osteoporosis with multiple fractures:

- Right femoral neck with total hip replacement in 2013
- Right radius treated by osteosynthesis in 2009
- Multiple vertebral compression fractures treated by cimentoplasty

Multiple falls in a context of:

- Fear of falling
- Pain
- Poly-medication
- Visual impairment due to age-related macular degeneration
- Polyneuropathy and cerebellar syndrome due to past alcohol abuse and B12 vitamin deficiency

Conditions of living, autonomy and home care

Lives alone in a small villa and is able to cook and perform paperwork.

IMAD helps her once a day to wash herself, deliver meal, control clinical parameters, and once a week for house holding and shopping.

She barely leaves home because of fear of falling

Expectations and fears regarding REACH

Even if she says being happy reading books, she would really enjoy being able to go out on her own and avoid hospitalization. REACH should help her in that.

She would like the system to motivate her to do rehabilitation exercises and rewards her progress to decrease her fear of falling. She also would appreciate to share her progress with her son and care-givers.

She would find funny that the system may communicate with her in different manners (auditory, visual, etc.).

She defends strongly privacy and wants to be able to decide what kinds of data are shared.

Despite the geographical distance, her son would feel safe if her mother had a system to alert care-givers in the case of a fall

Quote

“Home, sweet home”

Figure 7: Persona of patients with tendency to fall

MILD DEMENTIA

Demographic data

Mrs. Germaine Janvier

82 years old

Widow, 4 children (60, 56, 54 and 50 years old)

Former seamstress, still doing frequent knitting

Has never been so much interested in computer and internet



Main diagnostic and comorbidities

Mixed dementia: Alzheimer and vascular, CDR1 stage (MMSE 23)

Regressive Ischemic cerebral stroke in 2009:

- Right motor hemisindrome
- Aphasia

Hypertension

Hypercholesterolemia

Atrial Fibrillation

Conditions of living, autonomy and home care

She lives alone in a ground-floor apartment.

IMAD helps her daily to wash herself, dress-up, take her medication and delivering her meals.

She has delegated all of her paperwork to the oldest son. Her two daughters alternate to spend some time with her and do shopping. The youngest son come to drink a coffee every day to ensure everything is fine.

She uses a stick to walk inside the house and across the neighborhood. She sometimes uses public transports.

Expectations and fears regarding REACH

Mrs. Janvier is not really interested in technical matters but is open to something that may help her to gain autonomy and reassure her children.

She stopped cooking because her children were worried she may forget to turn off the hotplates and she would really appreciate REACH could allow her to cook again.

She is afraid not to see her children anymore if a system like REACH will be available to ensure her safety.

She would probably accept to do regular brain exercises if that could increase her autonomy and if she was sufficiently motivated.

She doesn't want a technological system directing her life.

Her children would all be reassured if a system such as REACH could detect falls, automatically turn-off cooking plates and improve physical conditions to allow her to safely walk in the neighborhood.

Quote

"Useful things are simple"

Figure 8: Persona of patients with mild dementia

CEREBRAL ISCHEMIC STROKE

Demographic data

Mr. Bernard Winter

72 years old, widower, 1 daughter, 3 grandchildren

Retired marketing director in a pharmaceutical company

Love watching movies and is a sport fan



Main medical issues

Recent cerebral ischemic stroke with:

- Motor and sensitive right hemi-syndrome
- Aphasia
- Two falls in the hospital setting

Atrial fibrillation

Hypertension

Conditions of living, autonomy and home care

He lives alone on the second floor of a country-side apartment. Had no help before but since he has come back from the hospital, IMAD helps him daily to wash himself, to dress-up and delivers his meals.

He is still doing his paperwork and can still enjoy watching movies and sport on TV.

However, moving has become difficult, even with his stick and he is afraid of falling. He remains home most of the time.

His daughter does his shopping, helps him to walk in the neighborhood but is worried that he may fall again and that stroke may reoccur. She wonders if placement in a social health institution would not be appropriate but

would like her father to remain home as long as possible.

Expectations and fears regarding REACH

Bernard would really like to do his best to recover his physical condition and would like REACH to allow this.

Bernard does not think he would need that much motivation to be active but would appreciate to monitor his progresses and to be able to perform different types of exercise with REACH.

He would also appreciate a function to improve his speech.

REACH needs to be a tool for him, and not the opposite. However, he is not too much concerned about sharing data with caregivers and family.

His daughter would like to REACH to make Bernard safe. For her, the most important feature would be to alert caregivers in case of a fall or a new stroke.

Quote

“Sport is health”

Figure 9: Persona of patients with cerebral ischemic stroke

INFORMAL CAREGIVERS – DEMENTIA AND FALLS

Demographic data

Astrid Summer

50 years-old

Married, 3 children (15, 18 and 20 years old)

Investment advisor in a big company

Uses high technology on a daily basis



Health problematic

Her mother is suffering from frequent falls that have induced many fractures in the past, despite a maximal presence of the IMAD. Her mother was also diagnosed with mild dementia five years ago and her condition has worsened over the last year. Since then, she passes by her mother's home every single day to ensure everything is fine.

Astrid is herself in good health but it is difficult for her to manage her family, her job and her mother care. She is afraid that she won't be able to continue that way for a long time and that she will be forced to propose long-term care to her mother.

Expectations and fears regarding REACH

Astrid would appreciate that REACH may increase her mother's safety by:

- Detecting falls and alerting care-givers
- Helping her mother to follow her medical treatment
- Motivating her mother to do regular brain exercise
- Increasing her mother's balance and physical condition to prevent falls
- Detecting fire and alerting fire workers
- Automatically turning-off cooking plates after a certain time
- Proposing her adequate meals and reminding her to drink and eat

On the other hand, Astrid would like REACH to:

- Respect her mother's privacy whenever she wants it
- Allow her mother to choose what data will be shared with family and care givers

Quote

"I wish there were 28 hours in a day"

Figure 10: Persona of informal caregivers for patients with falling tendency and dementia

3.1.7 Experience mapping

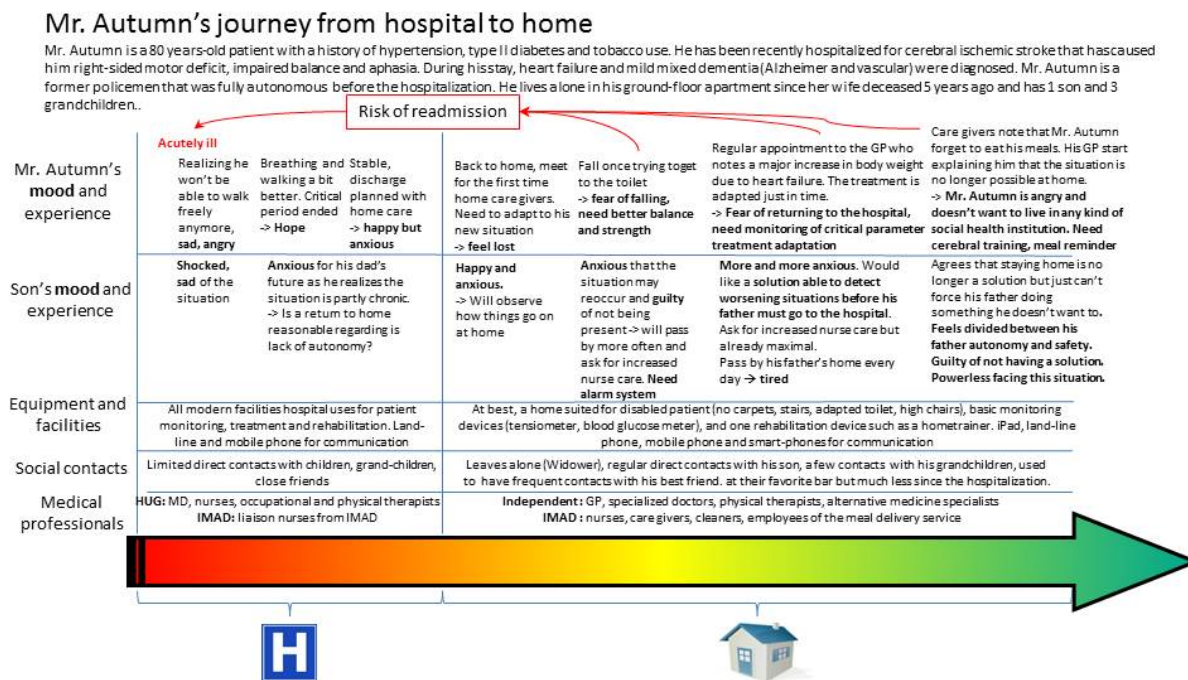


Figure 11: Experience mapping transfer from hospital to home

Mr. Autumn is an 80 year-old patient with a history of hypertension, type II diabetes and tobacco use. He was recently hospitalized for cerebral ischemic stroke that has caused him right-sided motor deficit, impaired balance and aphasia. During his stay, heart failure and mild mixed dementia (Alzheimer and vascular) were diagnosed. Mr. Autumn is a former policeman that was fully autonomous before the hospitalization. He lives alone in his ground-floor apartment since his wife deceased 5 years ago and has 1 son and 3 grandchildren.

In the following his journey from hospital to home is briefly described:

1. The first days in the hospital were quite difficult as Mr. Autumn learned he probably won't be able to walk freely anymore and that he was suffering from a heart problem. Still, his condition improved and he began to regain hope and even happiness when he learned he will be discharge soon. Nevertheless, he was anxious regarding the idea of living alone and sick. His son felt the same: he was happy that his father was going home but feared a lot regarding his father's safety.
2. Arrived home, Mr. Autumn was first happy to find his personal environment untouched and was reassured of seeing the care-team. However, he progressively felt stressed because he needed to adapt to his new situation. Moreover, the care team was present only half an hour per day and he had to take care of his self alone the rest of the time. He couldn't see his best friend as often as before because of his mobility limitations. The only regular visit he had was from his son that was worried about his father living alone. He had sometimes his grandchildren on the phone.
3. A few days after his arrival home, Mr. Autumn accidentally felt going to the toilet. Fortunately, the care team passed by his home 20 minutes after the fall to get him back on his feet, but this episode marked him. Since then, the fear of

falling was more and more present. He wished that he could engage in an activity increasing his physical condition and balance.

4. After some weeks, Mr. Autumn went to a regular appointment with his GP. A major increase in his body weight due to insufficient treatment of his heart failure was noted. The diuretic treatment was adapted just in time to avoid hospital readmission. Mr. Autumn was afraid he will once need to go back to the hospital and would have liked his treatment to be adapted frequently. However, his GP and the nurses were overloaded with work and, accordingly, were focused mainly on emergency situations.
5. Thereafter, the care-team noted that Mr. Autumn was forgetting to eat his meals and was becoming frailer. Mr. Autumn's GP started explaining him that the situation was no longer possible at home. With many regrets and guilt, Mr. Autumn's son was progressively thinking the same and was feeling divided between maintaining his father's autonomy or safety.
6. Since then, Mr. Autumn has clearly refused to go to any kind of social health institution.

3.2 Use case 2: Schön Klinik Bad Aibling (SK)

SK will in the context of REACH focus on physical and cognitive rehabilitation. Rehabilitation aims at reducing the impairment and handicap of patients/elderly citizens and thus improving their independence from nursing. Rehabilitation is organized according to medical specializations (neurology, orthopedics, cardiology, psychosomatics, etc.) or age (pediatric or geriatric rehabilitation). The treatment is based on relearning and exercising of prior abilities.

3.2.1 *Description of use case, focus and target users/elderly*

SK is a neurological rehabilitation hospital for severely affected patients with a small unit for acute neurology patients. About 25% of the patients are transferred from neurology, 20% from neurosurgery departments mainly from Upper Bavaria, the most densely populated district of Bavaria (4.2 million inhabitants) with its capital Munich. That means that 55% of the patients are transferred from non neurological departments, mainly intensive care units - anesthesia, internal medicine and surgery because patients have a primary non neurological diagnosis like cardiac arrest, severe infection or accident, which may be cured faster than their neurological consequences or complications so that neurological symptoms prevail at the end of the stay in the acute hospital.

An intensive care unit in SK with 85% of ventilated patients can accept patients directly from other intensive care units but, of course, also patients are treated who suffered a complication in the own hospital and therefore need intensive care. A focus of the intensive care unit is weaning from the respirator (with a high success rate of 90 to 95% taking into consideration that the patients transferred for this treatment constitute a negative selection). In addition to intensive care treatment patients get rehabilitation treatment, i.e., physiotherapy with a focus on mobilization out of bed and verticalization, occupational therapy with a focus on activities of daily living, neuropsychology and speech therapy focusing on establishing contact with the cognitively impaired patients. The largest and economically most important unit in SK is "early rehabilitation" (in Germany formerly named Phase B), where patients

simultaneously get medical treatment and rehabilitation. Patients are severely affected and therefore still need hospital treatment and usually are very dependent on nursing support (Barthel Index 30 or lower).

Patients may be transferred from the own intensive care unit or directly from other hospitals or the own acute care ward to early rehabilitation. Besides medical diagnostics and treatment patients get rehabilitation treatment in a 1 to 1 relationship, i.e., 1 therapist treats only 1 patient at a time: for the mobilization of a (heavy) patient even more than 1 therapist may be necessary. For diagnostics and treatment in rehabilitation the hospital has 125 therapists who are organized in departments of physiotherapy, occupational therapy with a focus on activities of daily living, speech therapy (including articulation and diagnostics and treatment of swallowing) and neuropsychology with a focus on improving cognition. A large part of the training in the activities of daily living (washing oneself, teeth brushing, clothing, toileting etc.) is also done by the nursing staff. According to the German health care regulations each patient in "early rehabilitation" is entitled to get 300 min. therapy time per day on the average of the stay in this rehabilitation phase. So a very intense treatment and high number of staff for these very severely affected patients is ensured.

To avoid that patients who improved during "early rehabilitation" have to be transferred to a conventional rehabilitation clinic SK also offers "continuing rehabilitation" (Phase C for patients with a Barthel Index of 35 to 65 and who do not fulfill the criteria for the necessity of hospital treatment any more) and "conventional rehabilitation" (Phase D with a Barthel Index of 70 to 100 points). In these rehabilitation phases the therapy started in "early rehabilitation" is continued and adapted to the increasing performance of the patients which usually means that part of the treatment may be done in groups of similar affected patients and no longer in a 1 to 1 relationship.

The neurological diagnoses of the patients include the whole field of neurology with ischemic stroke being the most frequent followed by cerebral bleeding including subarachnoid hemorrhage, degenerative disease (mostly Parkinson's), critical illness polyneuropathy/myopathy, encephalopathy, hypoxic brain damage and traumatic brain injury. As these diagnoses are more frequent in the elderly the average age of the patients is 63 years, with the largest group between 65 and 75, and a small group of mainly male traumatic injury patients aged 20 to 25 years.

For rehabilitation treatment SK has invested into a large number of equipment for training gait, arm function, visual and acoustic perception, recording of speech and swallowing performance. SK is in close contact with many manufacturers of this equipment and has conducted numerous scientific studies on the success rates of apparatus assisted treatments. Nevertheless rehabilitation training may be further improved by newly designed equipment as intended in the REACH-project. The intention of SK is to continue rehabilitation as long as this treatment improves the performance of the patient, i.e., his/her independence from nursing care and finally his chances for reintegration into his/her former social and (for younger patients) professional situation. Therefore the progress of the patient is monitored continuously. Medical doctors, therapists and nurses meet in weekly conferences and discuss the problem of each patient and decide on the therapies for the next week. Of course, the whole staff is in close contact with the patient and his/her needs during the whole process and also with the patient's relatives especially if the patient is neuropsychologically impaired and cannot express his/her will and wishes.

SK is also in continuous contact with the insurances paying for the treatment. The medical insurance companies pay for intensive care and "early rehabilitation" and in the elderly also for "continuing" and "conventional rehabilitation". If there is a good chance for reintegration into professional life the national retirement insurance company pays for "continuing rehabilitation" and "conventional rehabilitation". The insurance responsible for the patient gives its consent to the continuation of rehabilitation on the basis of regular reports of the hospital which have to be transmitted on the average every 4 weeks. The reports include a description of the present medical symptoms of the patient, the treatment done so far, its effect, the symptomatology expected to be improved and the therapeutic measures planned.

The end of the rehabilitation in SK may have the following causes:

1. *Rehabilitation was successful*: the personal aims of the patient and his/her relatives have been fulfilled. Inpatient rehabilitation is no longer necessary, outpatient rehabilitation may be sufficient to treat remaining deficits.
2. *Rehabilitation has not been or has only been partly successful*: Improvement of the patient is missing or is very small over several weeks, so that the patient, his/her family or the insurance company paying for the treatment are no longer willing to continue the treatment or the staff of SK does not see any realistic chances for improvement.

Before the end of the treatment SK has to assure that the patient gets the support he needs immediately after hospital discharge. As the medical status of patients varies widely a very detailed individual planning of supportive measures has to be done in advance:

1. If the patient is discharged to his/her home, he/she may be able to take care of him/herself alone. For younger patients a professional rehabilitation may be necessary.
2. If the patient cannot fully support him/herself, it has to be assured that relatives care for him/her or a professional nursing service is organized. The apartment especially bathroom and toilet may need adaptation to the handicap of the patient. Also some technical aids (hopefully improved by REACH) that the patients may need (like special nursing bed, wheel chair etc.) have to be organized (including financial planning with the health insurance) and have to be delivered before the patient returns home.
3. If a discharge to his home is not possible, the patient usually is discharged to a nursing home. The selection of the nursing home has to be done on the basis of the deficits of the patient (there are patients who need assistance with breathing by continuous ventilation) and on the basis of the residence of family and friends to assure social contacts. Also the financial situation of the patient's family has to be taken into account as the nursing insurance usually does not cover the full costs of a nursing home.

Of course these decisions have to be prepared by the whole staff and discussed with the patient, his/her family and his/her legal representatives. So the discharge process involves numerous persons and partners within and outside the hospital.

3.2.2 Stakeholder identification

Figure 12 shows all relevant individuals, groups or organizations which may have some interest or concern in the patient. We grouped the stakeholders based on their

origin and function. The functions referred to under the topic “function provider” are placeholder for various persons.

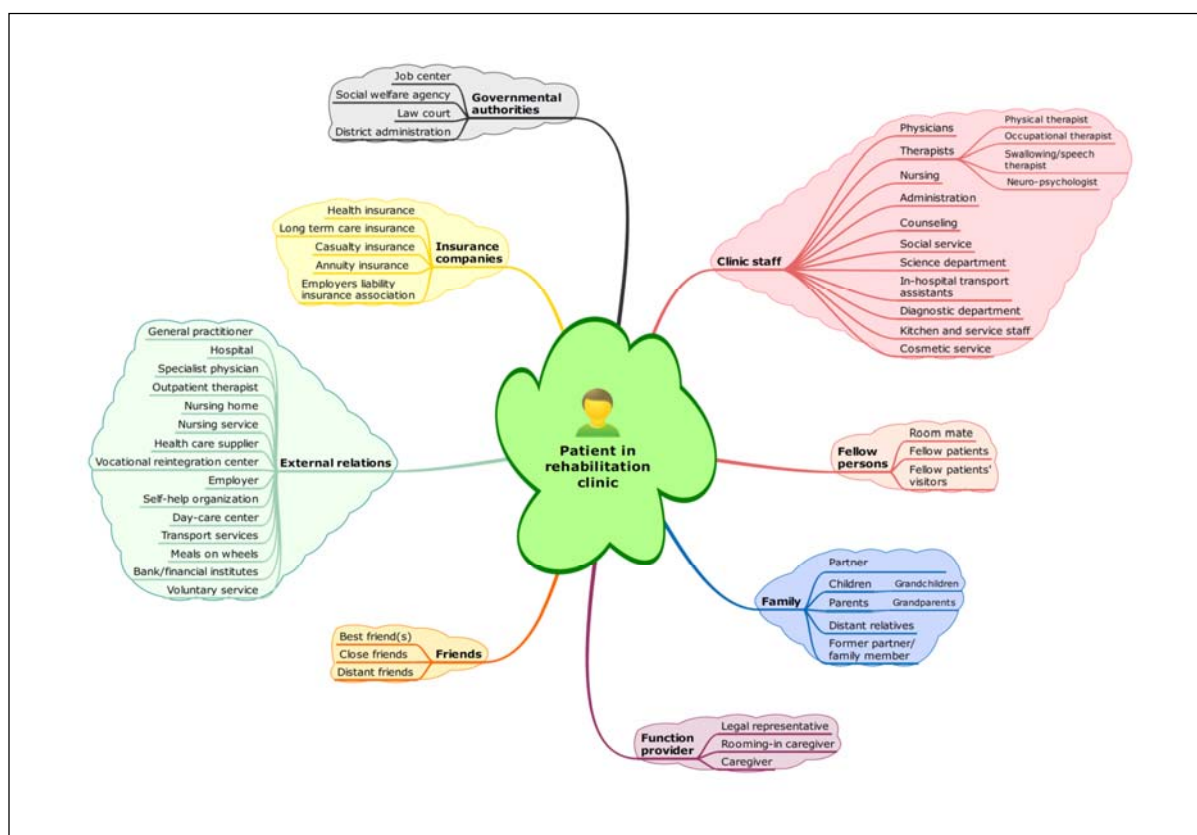


Figure 12: Stakeholder identification for patients in rehabilitation clinic

3.2.3 Assessment method

All information about patients were collected from the clinic information system, therapy reports, routinely performed assessments, and process analysis. The assessments were used in the clinical routine to generate a status analysis after admission and before discharge and to document the progress during rehabilitation treatment.

With regard to the brief time span from task defining (Feb 16, 2016) until submission date SK decided to use only data generated in clinical routine processes and therefore was able to forgo without ethics committee approval. The appropriate ethics committee (EC of the Bavarian State Medical Association in Munich) committee meets only every four weeks, and the completed proposal has to be sent in at least two weeks before this actual date.

The patients and – where applicable – their legal representatives were verbally informed about the use of patient data in pseudonymized form. After all questions have been satisfactorily answered and all concerns addressed and resolved the patient and the legal representative signed the informed consent form. The consent form was verified and released by the data protection officer of the SK.

Results from the following standardized assessments were used to generate this report:

- BI – Barthel Index (see **Section 2.2.1**)
- mRS – modified Rankin Scale (see **Section 2.2.3**)
- BBS – Berg Balance Scale (see **Section 2.2.4**)

- MFAS – Motor Function Assessment Scale (see **Section 2.2.5**)
- BDI – Beck Depression Inventory (see **Section 2.2.8**)
- MMSE – Mini Mental State Examination (see **Section 2.2.10**)

Furthermore we discussed with therapists and nurses to verify information provided in their reports, e. g. patient's therapy goals. For the stakeholder identification hospital routines were tracked and involved departments were interviewed about internal and external persons, departments and organizations which might get in contact with the patient.

The following departments/employees were contacted for information about stakeholders:

1. Therapists
2. Nurses
3. Physicians
4. Social Service
5. Administration (e. g. Therapy planning, Accounting department)
6. Diagnostic department

We generated two personas based on the data of five patients which represented the following neurological pathologies:

1. Single stroke
2. Multiple strokes
3. Alzheimer's disease
4. Parkinson's disease
5. Critical illness polyneuropathy

Data from 10 additional patients with corresponding pathologies but without consent to process their data in pseudonymized form were analyzed to ensure that the personas cover every aspect of patients' issues.

One persona represents patients with severe motor deficits and minor cognitive deficits, and the second persona represents patients with severe cognitive deficits and minor motor deficits (see **Figure 3**).

3.2.4 Analysis of real-world end-user profiles

		Pat.1	Pat.2	Pat.3	Pat.4	Pat.5
Evaluation from therapists		uncertainty in new situations and surrounding conditions; needs motivation and memo to keep appointments	slowed movements and reaction times, slowed speech production; rush and flurry movements in critical situations (body transition, sitting down, using walker); is aware of those situations but not able to handle appropriately	high risk of falling leading to fear of independent walking	neuropsychological deficits; memory deficits: unable to recall therapy knowledge in following therapy sessions or to non-therapy situations; - hand coordination disturbed; Neglect to left side leading to complications and delay in use of walking aid; spatial orientation deficit; needs transportation service from patient room to therapies; unable to read clock; unable to recognize route; limited mobility and pain due to orthopedic diagnoses (dorsal immobilisation of lower thoracic spine); fear of falling	physiotherapy: transfer from wheelchair to bed/chair; hypersecretion leading to therapy breaks; reduced pulmonary capacity
Most important therapy goal		acquire self-management strategies to handle disease, negative emotions (anger, depression, ...) of self and partner and family; strategies to structure a day	independent walking, pain reduction left arm and increase ROM	independent lifestyle, improve hand writing ability or pc writing (office work is an important part in life)	independent ambulation, driving a car (realistic self-evaluation: long-term goal), grasping and manipulating objects (problems with goal directed movements)	extubation of feeding tube, reduction of hypersecretion, independence in ADL and dialing phonenumber; increase motor functions upper extremity (open bottles or yoghurt cup; unpacking food; holding items with paretic hand; operate music player)
Phases of the day:						
Sleep, day to night transition, getting up	Sleep duration/quality	sleep problems (no deep sleep, agitated); sleep medications not wanted; stands up to fill in cross words; wants to talk but tries to avoid to bother others with her problems at night	sleeping problems due to uncontrolled urinary incontinence; tries to change diaper on her own which is demanding and negatively affects sleep		sleeping problems (no deep sleep); uses sleep medication; fear of falling; needs bed rails during night	normal sleep behavior
	Changes in body position (active/passive)	independent	independent	needs assistance; bed with handle	independent	independent in bed; difficult in wheelchair due to hemiparesis
	Transfer out of bed	independent	with assistance of one person; risk of falls	fully dependent	dependent with help from husband	dependent; needs help from caregiver
Nutrition, fluid intake (incl. dysphagia)	Preparation of meals	setting the table and preparing breakfast	fully dependent; risk of injury while cooking due to balance and motor deficits (based on experience)	fully dependent	fully independent; assists in minor activities (i.e., cleaning vegetables); husband prepares breakfast and makes sandwiches and coffee	motor deficits with problems to cut food and lift items; buys convenient and frozen food
	Support when eating	independent	needs assistance with cutting food; eating possible with adapted cutlery (spoon or fork)	independent with adapted cutlery	problems with cutting and using a knife; needs assistance with cutting food and pouring beverages	per os: independent with adapted cutlery, but supervision due to dysphagia needed. Most nutrition via PEG
	Healthy food	prepares simple meals for husband and herself; problem: she is vegetarian but husband not; cooks 2 dishes; focus on simple meals not on balanced diet	fully dependent in grocery shopping; get's fresh food if wanted	important: wants to have fresh ingredients (wife goes grocery shopping)	simple diet; often prepares cold food	
Personal hygiene	Toilet use (day/night time)	independent	need assistance with toileting; uses diaper during night time	to bathroom with wheelchair; transfer to toilet per moveable shower chair; handles necessary; problems: body transitions in stance; drop trousers while holding on to handles	independent during daytime; requires assistance from husband during night time; drug-induced vertigo	dependent; needs help from caregiver
	Teeth brushing/combing	independent	independent teeth brushing and cleaning the face; needs assistance with grooming and hair washing	independent	needs assistance with cleaning of partial denture; combs hair independent	cleaning of dental prothesis: dependent
	Showering	requires some assistance with hair; vertigo with fear of falling in bathroom; requires stand-by of one person	partly independent: uses shower chair; need assistance to towel and for transfer to and from wheelchair	uses shower chair; needs help for distal body parts and transfer to wheelchair	showers in standing position with handles; needs husband to towel	uses shower chair; needs help for transfer from wheelchair to shower chair
	Shaving/make-up		fully dependent: needs help with make-up	independent	independent	shaves with electrical razor
Dressing	Selection of appropriate clothes	semi independent; clothing choice by husband	clothing choice by assistant in agreement with patient	clothing choice made by wife	needs clothing choice; unable to take clothes out of the closet which is above shoulder level; insecure in standing with walker; hands needed to hold on to walker	independent
	Challenging clothes, e.g. shoes, buttoned shirts, socks...	fine motor deficits (i.e., fasten buttons)	fully dependent	dressing: t-shirt independent; assistance with other clothes, especially shoes (problems: sitting balance and complex body position transitions)	assistance from husband with bra, shoes, socks, blouse; fasten buttons; independent pullover and pants with elastic band independent when lying in bed or sitting on a chair with a back	dependent; needs help from caregiver
Activities (during hospitalisation: therapies)	Physical therapy		yes	yes	yes	yes
	Occupational therapy		yes	yes	yes	yes
	Swallowing therapy		yes; speech therapy	speech therapy	speech therapy	speech therapy
Health-conductive behaviour	Neuropsychological therapy	yes	no	no	yes	no
	Health(y) activities	workout for seniors 2 hours once a week; English language course 2 hours once a week	exercises for upper and lower body with therapist; training with help of a person appr. 30 min	outpatient therapies (OT, PT, speech)	walkes with walker (appr. 300 meters)	no activities
	Monitoring of health status	reduced health awareness caused by illness; blood pressure		home visit by the general practitioner twice a week; blood pressure	blood sugar; coagulation; blood pressure	only blood pressure control
Autonomy/ self-sufficiency	Indoor/at home	household chores: limited motivation and misjudgement of actual demand; Fiction/reality divergence	reads books; parlour games with auxiliary person several times a week	office work; wife is overprotective and assists more than necessary	assists with household chores	requires assistance with household chores (friends and professionals)
	Outdoor/local area	(grocery) shopping with help of daughter (with car); needs memo and structure by assistant; highly agitated during shopping, especially when other people are behind her at the counter; independent with bank transactions	needs assistance; walks 1 h a day; patient pushes wheelchair on her own and uses wheelchair if necessary; patient feels safe with wheelchair	fully dependent; no outdoor activities without assistance (pushing wheelchair)	walkes with walker (appr. 300m); maintains contact to neighbours	shopping with wheel chair partially possible; requires assistance for transport from caregiver
participation	Medication intake	selection by husband with memo for intake	independent; but memo from assistant	selection by wife with memo for intake	help from family and friends	independent (except from opening packaging)
	Self-practice (physical/occup. therapy)		outpatient speech therapy; gets help from daughter; needs help to get in and out of the car			independent (when sitting in wheelchair)
	Self-induced actions/interaction	not known	plans and discusses day/ week schedule with assistant	not known	no answer	not known
	Family/friends	main exclusive contact persons: family; friends abandon over time; contact to non-family persons only at grocery shopping	company by family and friends on a regular basis; parlour games with a friend once a week	socially well integrated; has often company of family and friends	good village community; family and friends	friends
	Communication	face-to-face or via telephone; needs help with dialing the number	uses phone; no internet	phone; email	needs adapted telephone; no autonomy in making contact (husband dials numbers)	phone; email
	Communities		meets friend from tennis 1-2 x per month; 1x 6 months; friends from school; meets friend at holidays	participates in a regulars' table; problem/limitation: not able to use bathroom in the basement		does not like to meet new contacts in person due to lowered self-esteem; is ashamed of hypersecretion

Figure 13: Analysis of patient profiles for 5 patients in neurological rehabilitation

3.2.5 Interviews

For this report no patient interviews were conducted by SK.

3.2.6 Defining personas

Josef represents patients with predominantly motor deficits and minor cognitive deficits.

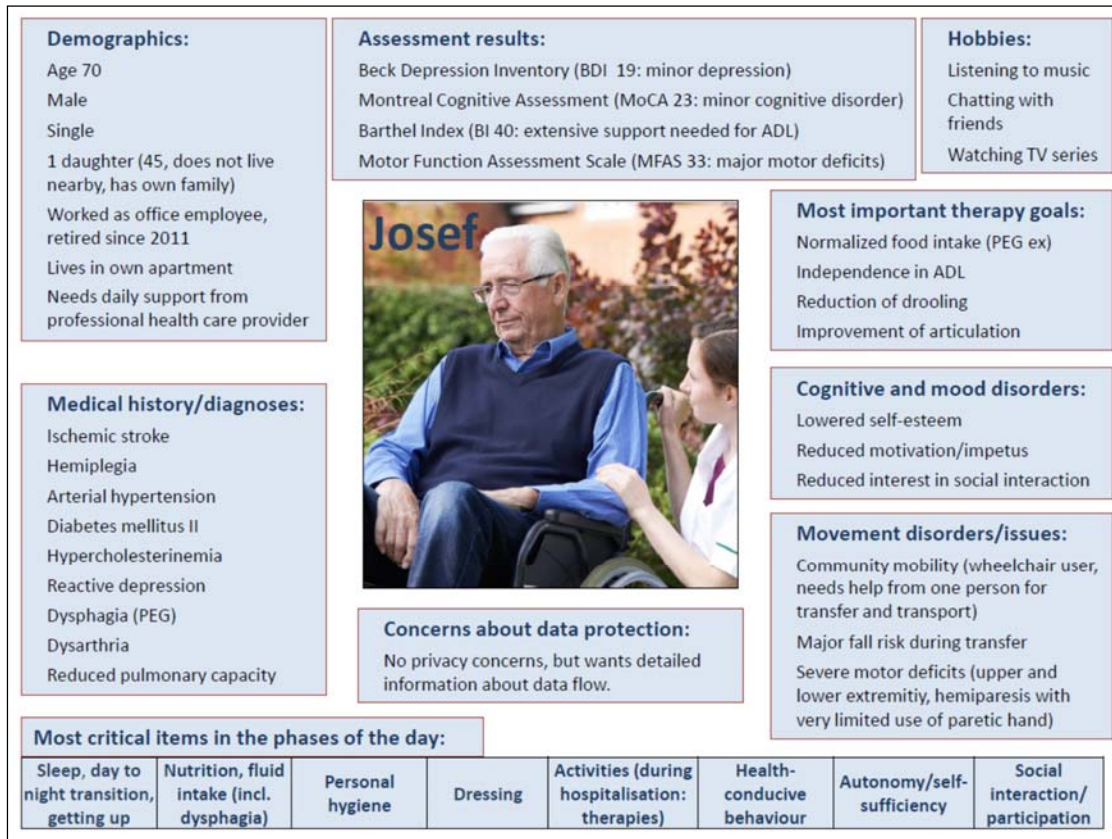


Figure 14: Persona Josef with motor deficits

Phases		Mood Issues	Cognition	Sensory Function	Motor Function	Disability	(Medical) equipment		intended behavior	expected solution
							Device used	Deficits of the equipment/Potentials		
Sleep, day to night transition, getting up	Sleep duration/quality									
	Changes in body position (active/passive)									
	Transfer out of bed				Hemiparesis	Transfer from bed to wheel chair is not possible without caregiver	Bed and wheel chair	No support of the parietic side during transfer		Bed which can be transformed into wheel chair, system to support the transfer from bed into the wheel chair
Nutrition, fluid intake (incl. dysphagia)	Preparation of meals									
	Support when eating				Dysphagia	No food intake per os	PEG			
Personal hygiene	Healthy food					Options reduced to highly processed food for enteral nutrition	PEG	Service and maintenance of PEG is complicated (needs caregiver)	Can handle PEG without support, has wide variety of enteral nutrition	More variations in enteral nutrition, natural food, simplified service and maintenance of PEG
	Toilet use (day/night time)				Hemiparesis	Unable to use the toilet without help from caregiver (transfer)	Wheel Chair	No assistance for transfer	Independent use of toilet	System to support the transfer from wheel chair to toilet
	Teeth brushing/combing				Hemiparesis	Cleaning of dental prosthesis not possible with one hand				Automated arm that assists in fixing dental prosthesis
	Showering				Hemiparesis	Not able to shower/bath without assistance (needs help to get from wheel chair to shower chair and back, needs help to use a towel)	Wheel chair/ shower chair	Transfer is only possible with the help of caregiver	Can shower independently (does not have to wait for caregiver)	Automated brush/ponge/towel arm(s) for cleaning and drying of hard-to-reach areas, wheel chair which can also be used as shower chair
	Shaving/make-up									
Dressing	Selection of appropriate clothes									
	Challenging clothes, e.g. shoes, buttoned shirts, socks			Tactile deficits	Hemiparesis (non-functioning hand)	Unable to dress with challenging clothes without caregiver (avoids small buttons, shoe laces)				
Activities (during hospitalisation: therapies)	Physical therapy					Unable to push wheel chair over longer distances (hemiparesis LE + UE), often rides wheel chair backwards by extending leg (mainly knee joint to gain higher torque production compared to heels)	Wheel chair without motor	Wheel chair does not provide support, cannot be driven with unilateral manual propulsion	Riding wheel chair forward and over longer distances	System for conversion of knee torque into forward movement, motor which provides adapted support on parietic side
	Occupational therapy				Hemiparesis (non-functioning hand)	Needs assistance in most ADL			Independent in ADL	Assistant tools/systems
	Swallowing/speech therapy					Drooling				
	Neuropsychological therapy	Minor depression (reactive)				Depression, reduced motivation, low self-esteem			More activities adapted to skills to experience success	Tools recommending activities and providing positive reinforcement
Health conducive behaviour	Health(y) activities									
	Monitoring of health status			Tactile deficits UE	Hemiparesis (non-functioning hand)	Needs support to use the following devices: BP (once a day), BG (several times a day)	BP: BP-meter BG: BG-meter	Wants to monitor BP and BG without support, wants GP to be informed about values automatically	Measures BP and BG accurately at given times	Easy to handle (with one hand, large buttons) BP- and PG-meter, supplemented with reminder function, warning indicator and direct data transfer to GP
Autonomy/self-sufficiency	Indoor/at home				Hemiparesis	Difficulties to reach upper shelves, difficulties to handle large/heavy objects (when both hands are needed)	Wheel chair	High risk of falling out of the wheel chair, object handling is possible only one-handed	Reach upper shelves in safe position, can handle objects	Robotic arm(s), e.g. attached to wheel chair
	Outdoor/local area				Hemiparesis	Only wheel chair use	Wheel chair	Wheel chair does not provide support, cannot be driven with unilateral manual propulsion	Mobility independent from distance and surface conditions	Motor which provides adapted support on parietic side
	Medication intake			Tactile deficits UE	Hemiparesis (non-functioning hand)	Unable to open packaging	Scissors	Cannot fix package and use scissors or open a bottle with one hand, cannot drop liquid medicines in a spoon	Independent intake of all kinds of medication	Robotic arm(s) with different extensions for multiple purposes, easy to change with one hand, attached to wheel chair and/or furniture
	Self-practice (physical/occup/other therapy)					Unclear pronunciation (blurred speech)			Practice pronunciation every day	Module which provides exercises with motivating feedback to improve pronunciation
Social interaction/participation	Self-induced actions/interactions/hobby			Tactile deficits UE	Hemiparesis (non-functioning hand)	Patient has difficulties to operate radio/audio system			Convenient handling of electronic devices	Easy to use electronic devices
	Family/friends	Lowered self-esteem				Lowered self-esteem leads to reduced contacts	Standard tablet/laptop		Participation in social media for stroke to induce higher self-esteem	Devices (mobile, tablet) adapted for patients with fine motor deficits and speech disorder
	Communication			Tactile deficits UE	Hemiparesis (non-functioning hand)	Patient has difficulties to dial phone numbers, he is hard to understand on the phone	Standard phone/mobile	Buttons and icons are too small, short messages (e.g. I'm ok, please call me back) should be carried out by sending symbols	Effortless communication by phone	Larger buttons/icons necessary, communication system which uses symbols or pre-recorded information
	Communities				Hemiparesis	Does not like to visit public institutions or community centers because he cannot use the toilet without help	Wheel chair	Transfer is only possible with the help of caregiver	Can use the toilet independently	Integrated and mobile device to support transfer from wheel chair to toilet

Figure 15: Persona Josef, 24 h schema

Antonia represents patients with predominantly cognitive deficits and minor motor deficits.

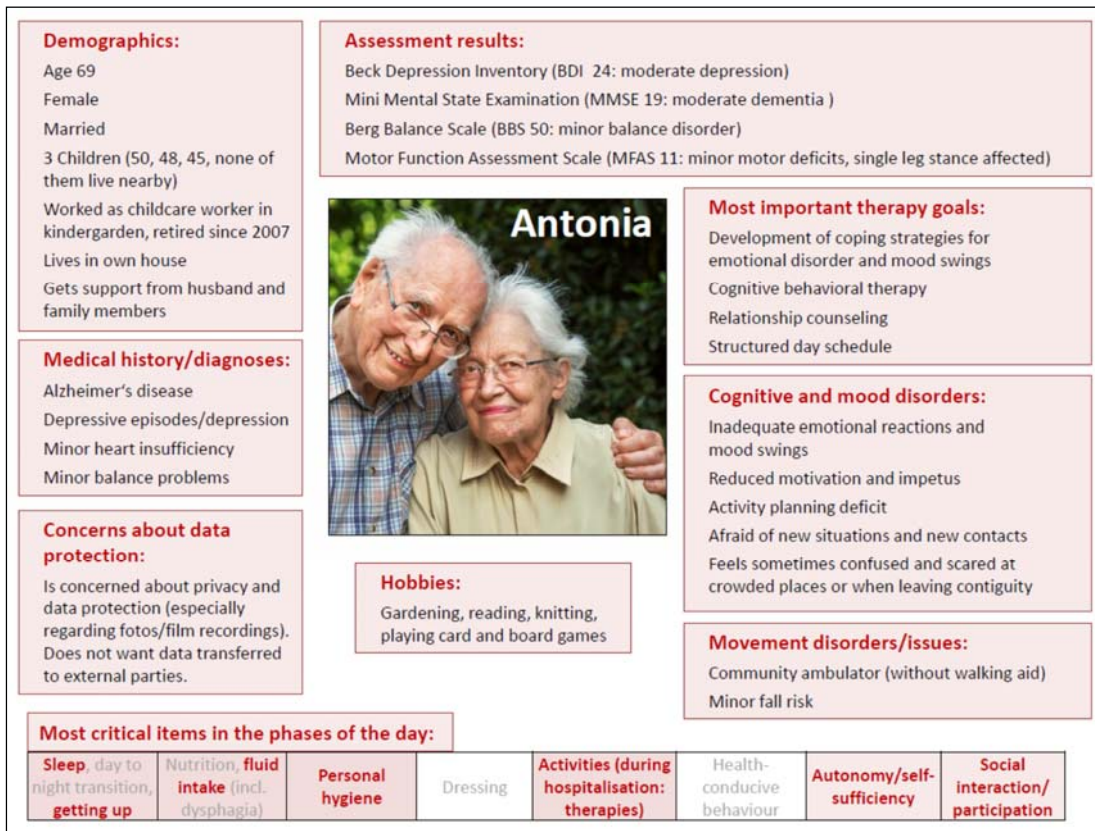


Figure 16: Persona Antonia with cognitive deficits

Phases		Mood Issues	Cognition	Sensory Function	Motor Function	Disability	(Medical) equipment	Intended behavior	expected solution	
Sleep, day to night transition, getting up	Sleep duration/quality	Sleep disorder/agitation				Wakes up at night, does not want to disturb others and finds it uncomfortable to sit in bed, therefore leaves bed. Feels alone and has to wait to get tired again to return to bed. Does not want to take sleep-inducing medication.	Standard bed	Has to get out of bed to sit comfortable and read or watch TV or knit. Would go back to sleep faster when staying in bed.	Staying in bed and feeling comfortable and spend time on quiet activities.	Bed with adjustment function, sleep-inducing light, attached units (e.g. for storage of knitting set, PC/TV with headphones...)
	Changes in body position (active/passive)									
	Transfer out of bed	Depression				Feels depressed and tired in the morning, no motivation to get up.			Get up latest at 9 am	Wants repeated reminder to get up and motivational information about the day-plan
Nutrition, fluid intake (incl. dysphagia)	Preparation of meals		Cognitive impairment			Forgets to turn off the stove, sometimes leaves the kitchen and forgets that a pot/pan is on the cooking plate.	Stove	Does not recognize whether cookware is on the cooking plate or not and if it is getting overheated.	Switches the oven off after cooking, does not leave the kitchen during cooking process.	Stove shuts down automatically, when cookware is removed, sensor recognizes when cooking plate is active and nobody is in the kitchen. For long-term cooking processes presetting is necessary.
	Support when eating									
	Healthy food	Reduced drive	Planning deficits, hypodipsia			Forgets to shop ingredients for cooking, and therefore cannot cook and eats food with high glycaemic index. Forgets to drink enough.			Wants to have one hot meal with vegetables per day, preferable in the evening, sufficient fluid intake.	Delivery service, online food selection and ordering, app, device which controls fluid intake and reminds her of drinking when insufficient.
Personal hygiene	Toilet use (day/night time)									
	Teeth brushing/comb		Planning deficits			Often forgets some tasks of personal hygiene, e.g. brushing teeth or taking a shower, does not like to be accompanied by others in the bathroom due to privacy reasons.			Being able to perform daily hygiene routines independently.	Monitor in the bathroom which guides her through the routine.
	Showering									
	Shaving/make-up									
Dressing	Selection of appropriate clothes		Planning deficits			Inability to assess situations which require to think ahead, sometimes does not select clothes adequate to weather/temperature and social situation.			Being able to choose adequate clothes.	System which provides hints depending on weather report, e.g. "today it is getting cold, long-sleeved pullover and jacket is needed when going out".
	Challenging clothes, e.g. shoes, buttoned shirts, socks									
Activities (during hospitalisation: therapies)	Physical therapy									
	Occupational therapy									
	Swallowing therapy									
	Neuropsychological therapy	Emotional instability, anxiety	Cognitive impairment			Gets aggressive and offended when being connected or excluded from decision-making, feels scared when surrounded by many people/being in new situations. Cannot plan several activities ahead, does not understand complex issues.			Reacts adequately to corrections/suggestions, feels comfortable and safe when being in company of many people/unfamiliar places.	Coping strategies
Health/active behaviour	Healthy activities	Depression				No motivation to initiate activities.			At least 1 outdoor activity per day.	Wants suggestions where to go to improve fitness.
	Monitoring of health status		Cognitive impairment			Forgets to measure and note BP.	BP-meter	Only last 5 values are saved automatically, long-term backup has to be initiated after every measurement.	Measuring BP once a day at the same time, reacting when values are out of range.	Wants to be reminded after breakfast. Values should be saved automatically and BP-meter should be equipped with reminder function and warning indicator which produces action proposals (e.g. "inform GP about values", "Repeat BP measurement in 15 min...").
Autonomy/self-sufficiency	Indoor/at home	Emotional instability, anxiety	Cognitive impairment			Feels scared when alone at home. Sometimes leaves the house to search for her husband.			Stays at home alone for at least short time.	Device connected with entrance door which provides information to the patient, where partner is and when he is intended to come home. Triggers alert when patient tries to leave the house.
	Outdoor/focal area	Sometimes feels not oriented when leaving contiguity and gets scared.	Sometimes does not remember the way home or to shop.			Cognitive impairment.	Paper with notes	Does not provide helpful information.	Finds way to target location.	Device which tracks patient (GPS) and guides her to target location or informs caregiver when patient needs help.
	Medication intake		Forgets to take medication.			Cognitive impairment.	Tablet dispenser	Does not remind patient to take medication.	Takes medication as directed by physician.	Device that triggers alert when medication is due.
	Self-practice (physical/occup therapy)	Has no motivation to start self-practice.				Depression.	Training devices	Does not provide examples for practical exercises, e.g. depending on mood, easy to perform.	Exercises following a regulary scheduled, but adapted to actual mood and motivation level.	Device which gives suggestions how to train with the devices, adjusted to health and motivation status.
	Self-induced actions/interactions/hobby									
	Social interaction/participation	Family/friends		Cognitive impairment			Partner has not enough patience to let her do ADL at her own pace, talks over nearly all activities. When making mistakes partner criticizes very often and carries out task by himself. Therefore the patient feels useless. Needs more time to remember the procedures step by step.			Performs ADL in target-oriented way in reasonable time.
Communication			Cognitive impairment			Sometimes forgets names of friends. Is ashamed when forgetting names.	Paper notebook	It is difficult to find the matching names without further details.	Addressing friends with correct names.	Device with foto of the person and matching name and additional helpful information.
Communities		Anxiety	Cognitive impairment			Is afraid to meet people which are not so familiar and don't understand her limitations. She feels inferior to smarter people.			Wants to exchange information with other people with the same problems.	Wants to be informed about activities in the day-care center.

Figure 17: Persona Antonia, 24 h schema

3.2.7 *Experience mapping*

In the following the time course of patient experiences during neurological rehabilitation until discharge from the hospital is described, focusing on problems that may occur:

Patients are transferred to SK with largely different clinical symptoms and therefore very differing experiences. Here we start with the most severe symptomatology and consider the problems the patient has to face during the slow recovery, keeping in mind that many patients start into the rehabilitation process at a later stage in case being way less affected.

Most severely affected patients may have lost consciousness during the initial neurological incident (trauma, stroke, encephalitis, brain edema) or may need sedation to allow respirator treatment. Personal experience in such a situation is hard to evaluate, because patients later do not remember any events at all or only short episodes from phases of less pronounced sedation. Usually consciousness does not recover suddenly but in a prolonged process during which phases of awareness gradually increase in duration. Recovering from unconsciousness also does not mean that the patient gets fully awake and cooperative in one step. Sometimes recovery starts with a minimal conscious state in which the patient may react to pain, may open his/her eyes, may fixate objects and follow moving objects with the eyes. When the patient recognizes a familiar face for the first time this is, of course, a very positive experience for the relative but not regularly remembered later by the patient.

After regaining basic functions of consciousness the mood may be unstable depending on the situation (e.g., with joy and affection during visits of relatives and during the presence of therapists and depression when left alone). Also after severe brain injury initiative may be lacking and cognition and memory may be impaired so that the patient remains in phases of apathy. In these situations psychopharmacological medication may be helpful to increase vigilance and drive. When the patient perceives that his/her abilities are increasing during rehabilitation, the mood also usually improves. Such phases may suddenly be interrupted when the patient gets aware of his/her deficits and the long way he/she has to go to full recovery or that full recovery cannot be expected.

Most frustrated of conscious patients are those with global aphasia which means that the patient cannot speak nor write nor can he understand and read because he has lost the ability to use language, usually as a consequence of a left sided brain lesion (in right-handers). This, of course, reduces human communication to a minimum. This can be only very partially compensated via gestures and facial expressions. Also motor deficits are a frequent obstacle during return to normal life. Hemiparesis is most frequent, usually gait improves better than hand and arm function, because leg movements are more controlled by the extrapyramidal and spinal motor system and need less brain function for deliberate planning than hand and arm movements. Sepsis may lead to very severe critical illness polyneuropathy resulting in almost complete tetraplegia and requiring support of breathing by ventilator treatment but has good prognosis once it is under control and feeding via the gastrointestinal tract is reestablished. Complete spinal injuries frequently do not improve, so that the spinal level of the lesion very much determines the deficits. Patients with a palsy of both legs

(and urine and fecal incontinence) usually adapt fairly well to a life in a wheel chair. The situation for patients with cervical injuries and therefore involvement of both arms (severity depending on the spinal level) is much worse as they can no longer live independently.

Urine and fecal incontinence are a severe burden for most affected patients as they may reduce their social contacts because they are ashamed of these deficits. Also swallowing disorders which may be compensated by tube feeding are limiting the zest for life as meals are positive elements structuring the day in the hospital and at home. But of course also neuropsychological and sensory deficits (most severe loss of vision) are very negative experiences. Usually mood is fairly positive as long as the patient perceives improvement and may turn negative when the patient is confronted with the fact that considerable deficits remain and certain personal targets cannot be reached by rehabilitation.

A critical phase is the preparation of hospital discharge and the first days in the new environment, i.e. home or in a nursing home. If recovery is not complete, discharge signals to the patient that recovery from there and on may be even slower, and that he/she may have to accept to continue life with deficits even if the prescription of customized aids may compensate partly for it. After returning home the patient often gets aware that his/her apartment is less suitable for a handicapped person, especially the toilet and the bathroom areas. Therefore an inspection by an occupational therapist that must be familiar with the handicap of the patient is advisable. Nevertheless the contrast between the rehabilitation hospital environment specifically adapted to handicapped persons and a conventional apartment or family home is a challenge for the patient frequently not fully anticipated. This contrast is usually smaller when the patient is discharged to a nursing home. In this case, however, the medical insurance sometimes refuses to pay for customized aids, a wheel chair made to measure for example and argues that a standardized wheel chair is sufficient and has to be provided by the nursing home.

An additional burden at discharge may be that the patient and his/her family are confronted with financial problems, getting aware of the fact that the difference between regular income and pension is larger than expected, or that the pension and the nursing insurance is not sufficient to pay for the nursing home and the family's financial support. Thus the family or the partner may decide to organize the nursing at home, even of very severely affected patients, or at least to try it. Within a few weeks this may lead to a state of exhaustion on the side of the nursing family member so that this person also needs medical or psychological support. The REACH project aims to significantly reducing the burden of nursing in the hospital and in the nursing home, and enable more patients to live independently or with less support at home. The experiences of a patient approaching the end of the rehabilitation process as an inpatient is represented in **Figure 16**.

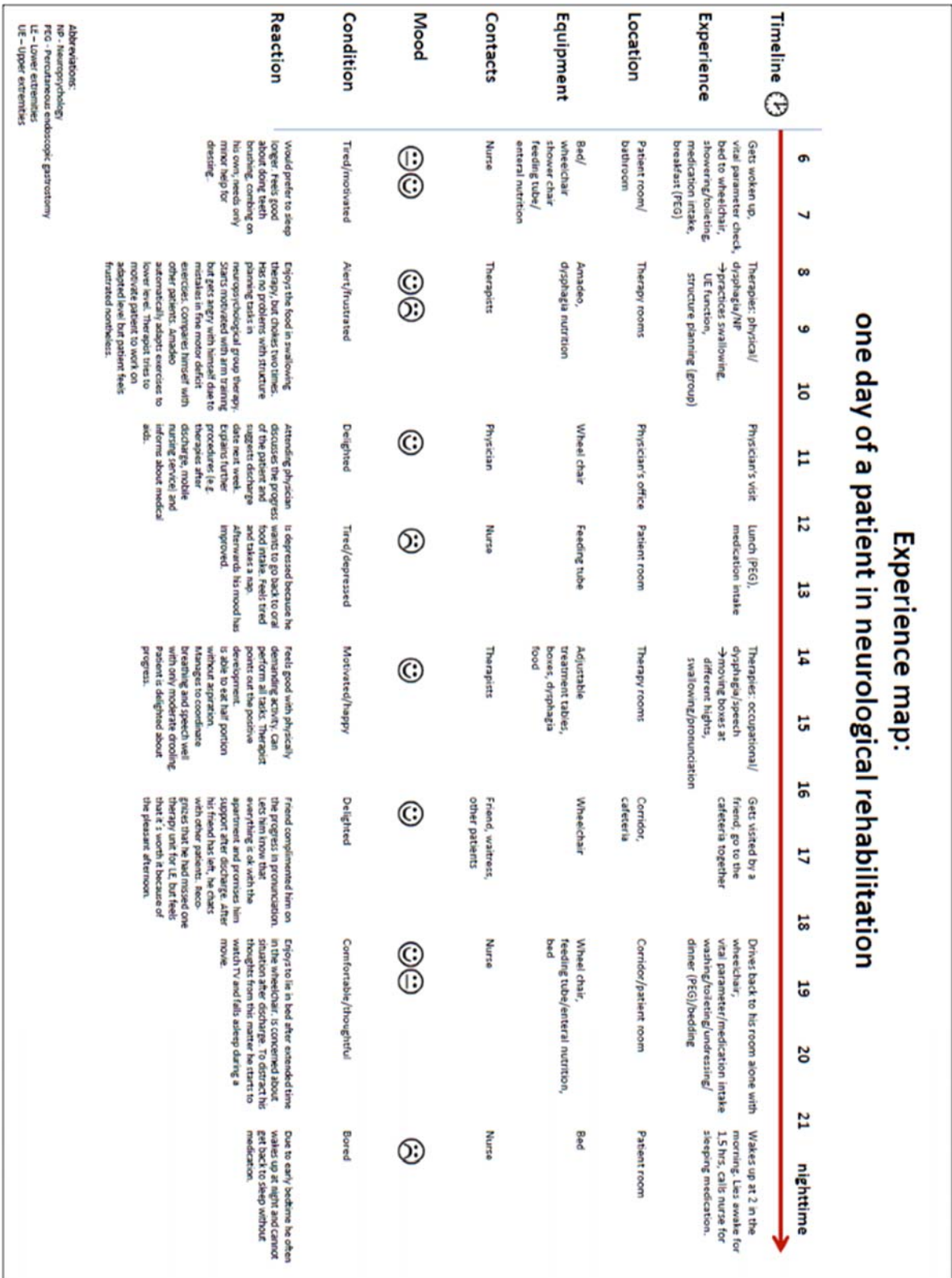


Figure 18: One day of a patient in neurological rehabilitation

3.3 Use case 3: ZuidZorg (ZZ)

ZZ will in the context of REACH focus on home care, represent in the REACH care continuum end-users with a relatively good baseline health (and that receive from ZZ some sort of care or household services) that need to be motivated for physical and cognitive activity (including ADL training) and rehabilitated at home from lighter disabilities in order to avoid nursing home or hospital/ acute care admission

3.3.1 *Description of use case, focus and target users/elderly*

ZuidZorg Extra is a business unit of ZuidZorg, a large home care organization in the southern part of the Netherlands. ZuidZorg Extra has about fifty thousand members who pay annual subscription to have access to our services and enjoy price reduction in our homecare shop and on special products and facilities such as collective health insurance. Members contact us if they need particular services from suppliers such as gardener or a hairdresser. In addition to this, the main focus is on the lonely elderly and to strengthen their social wellbeing.

To tackle loneliness amongst the elderly, ZuidZorg Extra visits them at home and organizes activities in a Meet and Greet centre where they receive support in creating their own social network. This platform stimulates and helps the elderly to live independently in their own homes for as long as possible, while remaining a healthy and social lifestyle.

The biggest meet and greet centre, located in Eindhoven, provides a wide variety of activities to bring elderly together. For instance, there is a cooking club, a knitting group, a social cafe, and a vitality program. There are two smaller activity centers where a selection of these activities are provided. Approximately 150 to 200 elderly visit the centers per week.

For the REACH concept, the target user consists of elderly that are 60 years or older that need help in their daily life, which varies from physical help such as help in the household, or on a social level because they feel lonely. All users are members of ZuidZorg Extra and visit one of the meet and greet centers.

To get a understanding of what these elderly experience and what opportunities there are within the REACH project, some main questions were stated:

1. What does a daily routine look like for our members?
2. How do they experience such day and what are the main struggles, both physically and mentally, they have?
3. Which stakeholders are involved and what role do they play in the life of our members?

By interviewing and discussing their day with elderly in the meet and greet centers, a better view on their daily routines is generated which helps to answer question 1. The second question goes hand in hand with the first question, as the interviews and discussions on how they feel and what they think during each step of their daily routine. By developing persona's based on the gathered insights during the interviews and discussions, an experience map can be developed which then helps to detect what stakeholders are involved and what their role is.

The interviews consisted of 14 participants varying between the age of 60 and 95. The interviews were held in the meet and greet center which the elderly visit, and were held face to face.

3.3.2 *Stakeholder identification*

The target group is placed in the center, all involved stakeholders can be placed around them and can be connected to each other if suitable. ZuidZorg Extra is a company which can be divided into different chunks and persons as stakeholders. (In)formal caregivers are provided to help the elderly with mainly physical disabilities such as showering in the morning, or cleaning the house. They can also have a social talk with the elderly, which then contributes to the social wellbeing to some extent. Next to these caregivers, there is a meal service where elderly can order meals. Both caregivers and the meal service focus mainly on the physical help and wellbeing of the elderly. On the other hand there is the meet & greet center, which emphasizes the social wellbeing of elderly. In these meet and greet centers there are social connections to the hostess and volunteers that help organize the activities and act as the contact persons for questions or comments. The visitors and participants are the main social contacts, as they are the main persons who are socially engaged with each other during activities. For transport, the taxibus and other taxi services play an important role, as they are the ones who bring the elderly back and forth between their home environment and the meet and greet center. Family and friends play a big role on both aspects. They can help with the household or other physical activities, but they can also act as a social contact.

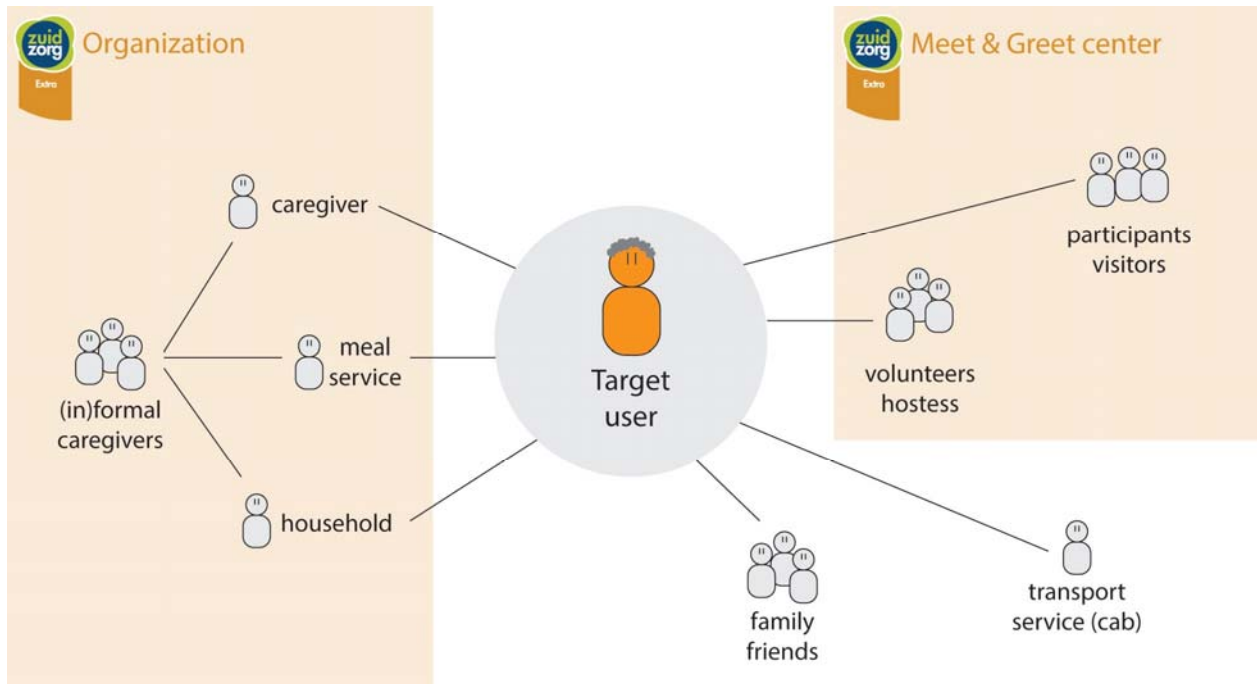


Figure 19: One day of a patient in neurological rehabilitation

For each persona ZZ made a stakeholder identification to show who is involved in the persona’s daily live. It shows the stakeholders and what their function is in general.

Stakeholder identification for Jan: Jan is the only persona, which has a lot of social contact with friends. The patient’s friends help in the household and come by for social talk and coffee. The caregiver supervises when Jan takes a shower and makes sure he takes his medicines in the morning. The hostess and volunteers at the meet and greet center supervise during activities, lunch, and his medicines. The visitors and participants of the meet and greet center can be seen as social contacts

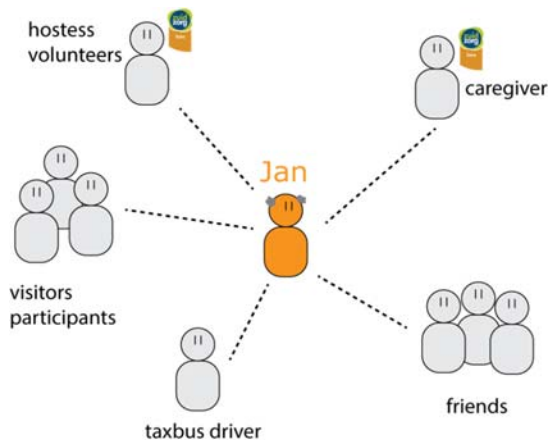


Figure 20: Stakeholder map for persona Jan

Stakeholder identification for Chris: Chris has a house help in the afternoon to clean the house. Chris helps her while she cleans and afterwards they drink coffee and chat. Like Jan, the taxi bus driver assists him from door to door when he travels. The hostess and volunteers help during the activities and prepare the lunch. Chris has a lot of social interaction with the visitors and participants. One of the participants has contact with Chris over the phone.



Figure 21: Stakeholder map for persona Chris

Stakeholder identification for Ellie; Ellie participates during activities and is also a volunteer at the meet and greet center. She discusses what needs to be done during the day with the hostess and volunteers. She helps the visitors and participants during activities and chats with them. She also has social contact at the supermarket in the coffee corner. Her daughter calls or uses Skype in the evening to check how she is doing.

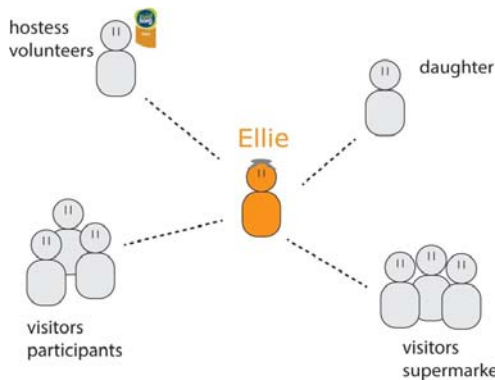


Figure 22: Stakeholder map for persona Ellie

Stakeholder identification for Henk: Henk can't be on his own without any supervision. His wife Anita is supervising him most of the day and is also his main social contact. A caregiver comes by to wash him and help in the morning. The hostess and volunteers at the meet and greet center keep an eye on him during activities so Anita has some time for herself. The visitors and participants are his social contacts, although he does not really chat with them.

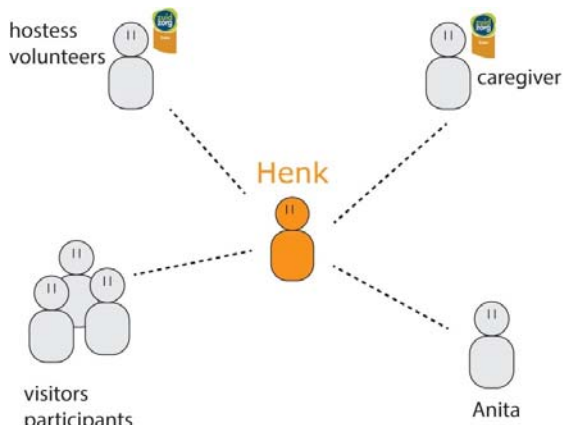


Figure 23: Stakeholder map for persona Henk

3.3.3 Assessment method

ZuidZorg Extra uses TFI to measure the frailty and vulnerability of elderly people in participating in social and physical activities. Details can be found in **Section 2.2.11**.

3.3.4 Analysis of real-world end-user profiles

At the meet and greet center, 80 elderly were asked to fill in the TFI. Out of these 80 elderly, 60 elderly scored a 5 or higher which means that they can be seen as vulnerable. To get a better understanding of how these 60 elderly experience their daily life and why they gave specific answers, 14 elderly were selected randomly. The age diversion and cohabitation is as follows:

N= 14	women	men
60-65	1	0
65-75	5	2
75-80	1	2
80-85	1	1
90-95	1	0

Cohabitation

Not married	1	1
Married	2	2
Divorced	1	0
Widow(er)	5	2

With these 14 elderly a face to face discussion was held about their personal TFI questionnaire. For instance, when they indicated that they miss people around them, they were asked to explain why they feel that way and how that is noticeable in their daily life. For example, a few questions and answers amongst person A and B were:

1. Do you feel physically healthy?

Person A: I see myself as quite healthy. I do have some complains but they do not influence my lifestyle on a daily basis. I have to take daily medication and once a week a meal is delivered at my home. I try to eat healthy and I try to stay physically active throughout the day, although this is difficult sometimes.

Person B: Physically I feel healthy. I do notice that I tend to forget things which makes it hard for me to take part in activities. I think I can use some support in that area, but that is more mental than physical.

2. Are you satisfied with your living environment?

Person A: I live comfortable. I have my own house and I am lucky that people visit me quite often. Otherwise I would feel lonely because it is a rather big house.

Person B: I am quite happy with my living situation. I rent a small house but I notice that the neighborhood is starting to impoverish which decreases my feeling of safety.

3. Do you experience problems with walking on a daily basis?

Person A: I notice that my ability to walk is decreasing. I use a walking stick and when I have to walk a longer distance I use my stroller. It makes me feel less mobile.

Person B: I am quite ok with walking. I still feel that I can be active and I am able to walk and cycle. I did experience once that I forgot the road.

All interviewed elderly live by themselves, 4 of them in their own house and 10 of the elderly rent their 'house/apartment'. For the amount of visits the interviewees made to the meet and greet center each week, a total average was found for the 14 elderly of 3,2 total visits per week.

Based on the insights from this quantitative user research that was done in the past, and the results of 14 semi-structured interviews that were held face to face in the meet and greet centre, a reliable and realistic representations was generated. To combine all insights, 4 personas were made as realistic representations for the target group. With these personas, the main questions 1) "What does a daily routine look like for our members?" and 2) "How do they experience such day and what are the main struggles, both physically and mentally, they have?" can be answered.

The representations focus on four main themes which pinpoint recurrent issues for the target group:

A. Transportation: elderly have difficulties with traveling between their home and the meet and greet center, which makes the threshold to become socially engaged outside their home environment higher.

B. Dementia/Forgetfulness: elderly often suffer from forgetfulness or in some cases dementia, which makes it more difficult for them to live independent in their own home environment.

C. Social Isolation: a lot of elderly experience loneliness, especially in the situation where a husband or wife has passed away.

D. Physical limitations: these are most of the time connected to aging problems, such as getting stiff joints, becoming hearing or seeing impaired, and a reduction in the equilibrium organ.

3.3.5 Interviews

To get a general idea of how the elderly think and feel about the REACH project. In particular we asked about their opinion on the usefulness of sensors (wearables). They would like to be part of the project and use some sensors and wearables as a kind of reciprocity. They don't see/understand what it has to offer them personally. They think it could be working for other elderly, but not for them. Some of them said; "I'm too old for that", "I don't know anything about technology". "What is the use of it and I don't need that".

On the other hand they think it can stimulate and encourage them in the future to be more active, but at the moment they don't understand how. It can certainly be positive for children, family and care givers so they can be more relaxed if they know what's going on with them.

** More in depth interviews can be generated later, when there are more insights in the type of product/service that will be developed for the REACH project.*

Table 13: Age distribution of the interviewees

N= 14	Men	Women
60-65	0	1
65-75	2	5
75-80	2	1
80-85	1	1
90-95	0	1

Table 14: Cohabitation status of the interviewees

N= 14	Men	Women
Not married	1	1
Married	2	2
Divorced	1	0
Widow(er)	5	2

1. **Home situation:** All live by themselves, 4 of them in their own house and 10 of the elderly rent their 'house/apartment'.
2. **Visits per day/week average:** For this one we took the amount of visits each week, included the visits to the meet and greet center. Total average for the 14 elderly = 3.2 total visits per week included 1.7 visits to the meet and greet.
3. **Use the internet:** 12 of 14 use the internet. 2 of 12 uses a PC, 7 of 12 use a tablet and 3 of 12 use a Smartphone
4. **Format:** All the interviews were face to face, semi-structured in the Meet and Greet center. There were 11 individual interviews, 2 face to face interviews with elderly and professional caregiver and 1 interview with a married couple

5. Questions

- a) Main Reason for visiting the Meet and Greet Center: leisure experience, what is your motive to visit the Meet and Greet Center.
- b) Mobility: possibility to travel by themselves, feeling (in)dependent on other people
- c) Social Network: children and moments of contact per week, contact with neighborhood, friends, outdoors activities
- d) Health: physical, mental, daily activities, Long term care, restrictions in daily life, morbidity
- e) The summary of all interview results is listed in **Table 15**.

Table 15: Interview results at ZuidZorg

Questions	Do you feel physically healthy?	Are you satisfied with your living situation?	Do you experience problems in everyday life with walking?	Can you handle your problems well?	Do you ever miss people around you?
Elderly 1 Man 75-80 Not married	I see myself as a quite healthy person. I do have some complains but they do not influence my lifestyle on a daily basis. I have to take daily medication and once a week a meal is delivered at my home. I try to eat healthy and I try to stay physically active throughout the day, although this is difficult sometimes.	I live comfortably. I have my own house and I am lucky that people visit me quite often. Otherwise I would feel lonely because it is a rather big house.	I notice that my ability to walk is decreasing. I use a walking stick and when I have to walk a longer distance I use my stroller. It makes me feel less mobile.	Whenever I experience a setback and don't feel too great, I have enough people around me who give me enough attention.	People visit me quite often, but still I feel lonely from time to time. I do visit the activity centers in the neighborhood.
Elderly 2 Man 65-75 widower	Physically I feel healthy. I do notice that I tend to forget things, which makes it hard for me to take part in activities. I think I can use some support in that area, but that is more mental than physical.	I am quite happy with my situation. I rent a small house but I notice that the neighborhood is starting to impoverish which decreases my feeling of safety.	I am quite ok with walking. I still feel that I can be active and I am able to walk and cycle. I did experience once that I forgot the road.	No, it is becoming more difficult for me because my memory is suffering. I don't know where to go with my problems or to whom.	Yes, because I feel that people don't understand what I am going through and they rather stay away because of that.

<p>Elderly 3 Woman 75-80 widow</p>	<p>I feel rather healthy. I do suffer from osteoarthritis of the hip. I got a new pelvis 10 years ago but due to that it is difficult for me to bend over.</p>	<p>I live comfortable and my daughter lives nearby. I live in a bungalow for age 55+ in an apartment complex.</p>	<p>No, I can still walk but I am very dependent on the taxi/bus to travel. I attend a program to help me be vital to stay active.</p>	<p>Last year I felt better than before. My husband died 7 years ago and I don't like to share my feelings with others. It took me a long time to face the world again.</p>	<p>It is becoming less, but I still live alone. I don't want to put a burden on my daughter, but we do meet once a week.</p>
<p>Elderly 4 Woman 65-75 widow</p>	<p>I am quite healthy I don't feel like I should complain. I didn't need a doctor for years. I had eye surgery and pills to help me pee due to kidney problems.</p>	<p>My apartment is on the ground floor. Me and my husband lived there, who passed away 10 years ago, but I still enjoy living there.</p>	<p>In the morning I have difficulties with moving around, but after that I feel ok. I can walk for small distances, but for longer distances I need to make reservations for the Taxi/bus.</p>	<p>I have 2 children and I live in an apartment complex, so I feel very rich in social contacts. If anything is wrong I can contact my children. I have always been a volunteer and I am a good listener.</p>	<p>Because everybody has things to do it is quiet during the week. I know some people whom I visit and I often chat with one of my neighbors.</p>
<p>Elderly 5 Man 75-80 widower</p>	<p>I don't feel healthy, I had multiple complaints about my hip, stomach, shoulders, knee and ankle. They all seem to get worse, especially after my wife died.</p>	<p>Actually, the house is too big for me, but I lived here since I married 50 years ago and always lived here with my wife. I don't want to leave this place.</p>	<p>I have a stick to help me walk but I cannot walk very far. I can still drive my car and I have a special card to park in the disabled spot.</p>	<p>It is difficult for me, especially because I can't talk to my wife anymore. My children have their own lives. I try to do as much as possible to be distracted.</p>	<p>Yes, I don't like the silence in house so I try to avoid it as much as possible. Then I try to gather people around me, but every time I come back in an empty house. I try to eat healthy by myself every day.</p>
<p>Elderly 6 Woman 65-75 married</p>	<p>I am healthy, but taking care of my husband, my knees and hip hurt, and it also costs me a lot of energy. I want to do as much by myself as I can.</p>	<p>We live very nice. The neighborhood is getting older, but I still know a lot of them from back in the days. Not that we share a lot of time though. It is taking me a lot of time and effort to do the household by myself, especially upstairs now that we only live downstairs.</p>	<p>I can move around quite easily, but if I go together with my husband I push the wheelchair which takes me a lot of effort and tires me. I am curious how much longer I can keep doing that.</p>	<p>We still have each other, but my husband sees how much energy it takes from me as he can't take care of himself. We talk about it, also with our children. Other than that, we are happy.</p>	<p>As long as we are together we are ok. We chat to each other and share a lot of time together. We don't have a lot of friends, which makes it nice for us to visit the activity center twice a week.</p>

<p>Elderly 7 Woman 65-75 Widow</p>	<p>I feel very tired all the time, during the last few months. I think that this has to do with the fact that, after 1,5 year, I start to feel the pain and tears from my husband who died.</p>	<p>I am happy with my home, which is almost completely free from mortgage. The garage still has stuff from my husband. I am very close with my neighbors.</p>	<p>Walking is going ok. I feel tired but I like to cycle. I never liked to walk, and I want to keep on cycling to stay in contact with others and be active.</p>	<p>I used to take care of my husband for a few years. It all worked and I was able to talk about it with my children and the doctor. Now I notice that it is getting more difficult for me.</p>	<p>I didn't know I could feel this alone. Of course the children visit me and I go to activities, but it is very quite in my home.</p>
<p>Elderly 8 Man 65-75 Married</p>	<p>I am rather healthy but I have back problems and rheumatism. It can also be due to the stress because my wife moved to the geriatric ward.</p>	<p>We live in a very large house near to a courtyard. I am afraid my wife will not come back here, but I still want to live here. It feels familiar and comfortable.</p>	<p>I can walk very well, but sometimes it is difficult for me due to inflammations. My knees or joints hurt then. I do everything by bike which works out for me.</p>	<p>Having a partner with dementia is very hard which gives me problems. I am happy I can talk to caregivers who know what I feel and go through when I say I am happy she is taken care of now.</p>	<p>I notice that is easy for me to talk with people in similar situations. People who saw their partner suffer from this, know what it is like. I can feel alone and sad when I think about it.</p>
<p>Elderly 9 Woman 60-65 Not married</p>	<p>I take some medicine to help me from stressing out to much, but further I am in good health.</p>	<p>I live in a small apartment in a deprived area for 10 years. I ended up there due to debt restructuring. I feel ok, but I feel that there is a lot of drugs going on. I often see the police driving by.</p>	<p>I am still rather young and I have no physical disabilities. I do the groceries while I walk. I often walk because I don't have a bicycle and not a lot of money for other transport.</p>	<p>Luckily someone helps me once a week with the post and who helps me. I can talk with that person. There are no other social contacts in my life.</p>	<p>It is starting to get better. In the winter it is so dark and then I feel more alone compared to the summer. During winter I am inside a lot. I like taking part in activities.</p>
<p>Elderly 10 Woman 90-95 widower</p>	<p>I experience a lot of problems such as diabetes and osteoarthritis, which make my hands too fat, and I need medication for my heart.</p>	<p>20 years ago after my husband died, I ended up in a sheltered house and I like it there. If it is needed, people can help me, but I don't really need it so far.</p>	<p>Walking is ok, but I can only do short distances. I don't want to get a stroller but I am afraid I will need one soon. My daughter wants me to buy a stroller because she is afraid I will fall.</p>	<p>I experienced a lot throughout my life, but I try to keep on going and not let it defeat me. It is starting to get more and more difficult to live up to that.</p>	<p>There are moments where I feel alone, especially when I see what is going on in the world with wars and people fighting, it makes me sad. I like to eat with others to keep me distracted.</p>
<p>Elderly 11 Man 80-85 Married with elderly 12</p>	<p>I am in a wheelchair and can't do a lot by myself. I need help with everything. My wife can barely read or write, so I read the recipes and she cooks for instance. She cannot take care</p>	<p>We live in a bungalow which is altered to my needs. It is not large, but large enough for the two of us.</p>	<p>I can't get out of my wheelchair so I need help with everything. A caregiver comes twice a day to get me out of bed and bring me to bed.</p>	<p>We can handle these problems well together. My wife and I know each other so well and know what we need, so it works for us.</p>	<p>We don't have children so we do everything together, just the two of us. We are happy with that.</p>

	of me by herself.				
Elderly 12 Woman 80-85 Married with elderly 11	My husband is in a wheelchair and I don't really know how to take care of him. I am healthy myself.		I can still walk and sometimes I push the wheelchair so we can do groceries together or something like that.	We have a caregiver that comes by twice a day, but other than that we try to manage everyday with the two of us.	We still have contact with one nephew of my husband. He visits us quite often. We try to eat fresh every day.
Elderly 13 Woman 65-75 divorced	I feel rather healthy, but divorcing my husband took a lot of energy from me. It was a marriage with a lot of troubles which gave me a lot of stress. He was an alcoholic.	I wanted to go away from my living environment in Utrecht so I moved to Eindhoven. I have a comfy apartment for myself and I feel good about it. It is small, but big enough for me.	I am still quite young and don't have any physical problems. I live above a mall and walk around every day.	I am doing better now, especially after the divorce. I live here because my two children live nearby. I can handle my problems quite well, and they aren't nearly as bad as before my divorce.	Sometimes I miss people around me. I haven't really met people here and it is difficult to make new contacts. I knew this would be the case, but it is harder than I thought.
Elderly 14 Woman 65-75 Widow	I have diabetes and Apnea for which I have a special device when I sleep at night.	I live in an apartment. I moved there after my husband died 4 years ago.	I can only walk when I have my stroller with me. I feel insecure and with the stroller I feel better. Without the stroller I would not leave the house anymore.	I try to make the best out of every day. I am very close with my two children. If anything is up I can always call them.	I like to be socially involved and I can chat quite easily with others. It makes me feel like I am less alone, but coming home still feels lonely. I try to go out once a week so that I am not alone every day.

3.3.6 Defining personas

ZZ developed 4 personas to represent the visitors of the centers.

Persona 1: Jan de Groot



Figure 24: Persona Jan de Groot

Age: 83 years, Gender: Man
Widower, no children

1. Looking for: Social contact, tell his story to others, support for health to live independent
His motto: *"You have to make the most out of life, but that is easier said than done"*
2. Loves: Playing cards, conviviality, chat, watching sport, cooking.
3. Demography: Jan was business manager and had to retire in 1992 due to a sudden visual disability. His wife passed away last year after a short illness. Jan tries to make the most out of life and therefore he looks for social contact. He also chooses to live independent. To achieve this, Jan visits the vitality zone twice a week. Since 2012 Jan started to have problems with his heart. This is also a reason for him to participate in the vitality zone. Jan has support from ZuidZorg to stimulate the Activities of Daily Living
4. Mobility: Jan is completely dependent on transport by others. Walks with blind stick. For transportation he uses of particular public transport for the elderly.

TIME	WHAT	HOW	WHY
08.30	Getting out of bed	Alarm clock wakes him up, he is alone	His wife passed away he lives alone
08.35	Caregiver comes (3x a week). He showers and gets dressed	Caregiver supervises and helps when needed, supervised medicine box. Does as much by himself as possible, such as electric shaving	He can't see very good in the mirror, electrical shaving is safer for him, he wants to be independent as much as possible
9.00	Breakfast	Bread, coffee, alone, drinks orange juice and it is very quiet	He starts his day the same everyday, orange juice is for his vitamins
09.30	Listen to spoken newspaper	On the iPad while sitting in his chair	Routine, to feel part of society and knowing what is going on in the world. He used to be on top of this during his career, he can't read due to bad sight so he listens
10.00	a friend is visiting	he passes by according to a schedule, jan knows who is coming what day. they drink coffee and chat	social company and to help with visual disabilities. they check the house if everything is normal and in place
11.00	Go to meet and greet center	he is picked up at home by taxibus around that time	no specific time can be given. public transport is too far away and difficult with blind stick, he feels insecure, taxibus can not guarantee being on time
11.40	Arrives at meet and greet	taxibus driver helps him to get out and brings him inside, volunteer takes over	jan needs support because he can't see well, he uses a small travel blindstick
11.45	Livingroom activity already started, Jan is late	drink coffee, social contact between 16 visitors and 4 volunteers, lunch, cardgames.	social aspect and to fill up his day with one activity center each day. volunteers help with cardgame, some special games with big numbers
15.00	Goes home by taxibus	reservation made the day before, they pick him up inside but Jan needs to be ready	Reservation because transport picks up multiple people and needs to plan . Jan doesn't know who drives with him. Taxibus can arrive 15min early/late, jan needs to be ready
16.00	Listen to music and read	Read on special monitor (blue background, yellow letters) in livingroom	color combination is easiest to read, sometimes he reads books with large letters

TIME	WHAT	HOW	WHY
17.00	Dinner with a friend and take medicines	Friend visits, they have dinner together delivered by ZZZ	Friend helps preparing and microwave, social aspect, jan can't prepare food himself and doesn't want to obligate friends to cook. in weekends he goes to restaurants guided by a friend
18.00	Do dishes and clean up	together with friend, friend takes care of laundry and places clothes for next day on chair in sleeping room	jan knows his kitchen well enough to help with dishes, he knows where his clean clothes are everyday
20.00	Listen to news and sports on tv	putting on tv and special screen to enlarge it, he has sport provider	to kill the time, to stay on top of news, he really likes sports
23.00	Goes to bed	by himself, no help	to sleep and rest for the next day

Figure 25: One day of persona Jan

Persona 2: Chris van Straeten



Figure 26: Persona Chris van Straeten

Age: 81 years, Gender: Man, Widower, 2 children, 3 grandchildren, feels lonely

1. Looking for: Social contact, something to fill his day, security, stimulation to travel
2. His motto: *"I am insecure but I would like to keep meeting new people. Live without my wife feels empty"*
3. Loves: Reading, physical exercises, sports and listen to music.
4. Demography: Chris became widower last year. His wife passed away all of a sudden. They were married for 58 years and being alone is hard for him. Until he retired when he was 63 years, he used to be manager of a production department. He has two children. His son lives in Veldhoven and his daughter in Nuenen. They have contact with Chris weekly and pick him up or visit him with the grandchildren. Chris gave his car to one of his grandchildren to travel to his school in Den Bosch.

5. Mobility: He used to travel with his own car, together with his wife. He does not want to drive his car anymore due to physical limitations and his age. He does not want to use public transport because the bus stop is too far away and he is not familiar with the public transport chip card. The taxi bus works ok for him, but he has to wait very long and it gives insecurity. The 'witte raaf' is a possibility, but it takes him too long. When he uses a special scooter he feels incapable of traveling.
6. Golden experience circle: Persona **CHRIS**
7. TFI rate: **5**

Table 16: One day of persona Chris

TIME	WHAT	HOW	WHY
07.30	Wakes up	Alarm goes off	Be on time ready for transport to M&G
07,45	Takes a shower	By himself	Chris is able to does his own personal care
08.15	Breakfast	Taking stair to go downstairs en make some bread and coffee	Chris is sleeping on first floor. He wants to do daily activities much as possible
	Reading newspaper	During his breakfast	Chris likes to read and also want to know what's going on in the word.
09.00	Toilet	On the ground floor, but he has also a second toilet on the first floor	Yesterday, Chris reserved the taxi bus (public transport) for today 09,30, but they have a margin of 15 minutes before or after reserved time. Chris wants to be ready (with his coat on) at 09,15. And he really doesn't know how long the ride (5km) will take. He is afraid to go to the toilet when he sits in the buss.*
09.15	Waiting in the hall	Sitting on a chair with mobile phone in his hand and his coat on	Chris is insecure and afraid to miss the call of the taxi office. After the call he has to be ready within 5 minutes*
09.30	Call from taxi office	In the hall, he hears a computer remote voice; 'your cab will arrive within 5 minutes'	They warn Chris to be ready
09.40	Chris sees the taxi	Through the window beside his front door.	The driver will ring the bell, but most of the time, he will not help Chris with his coat, keys etc. There are other travelers sitting in the taxi bus. And it's also a possibility the driver has to pick up some more elderly.
10.10	Arrives at M&G, Chris pays € 2,- for the ride to the driver	Taxi bus is dropping him off	It was a ride of 5 km, but the driver picked up 2 others elderly travelers and after that he first drove to another address to bring one of the travelers home.*
10.12	Greets all the visitors of the Meet and Greet	Rises his hands and talks to them	It feels familiar and good for Chris. It supports his well-being.
10.15	Drinks coffee	With the participants of the vitality (FIEF) zone. Fief is an acronym ; Fit, Interactive, Energetic, Fun	The start of the activity, social contact, chat with the sport coach about the daily activities of the last week*
10,45	Start FIEF	Different interactive	To keep and stay in shape, be

		movements. Some with colleague sportsmen	active, physically health*
11.45	End of the program	Cooling down	Take care for the health of the elderly sportsmen. Make a specific end of the physical activities.
12.00	Healthy Lunch	At the central table in the meet and greet center with other participants	Social contact, encourage Chris and the other visitors eat together.*
12.45	Call from the taxi bus (computer voice)	While Chris is sitting at the table	Chris booked the taxi for 1 o'clock pm.
12.45	Chris goes to the wardrobe	Walks to the wardrobe closet	He wants to be ready
12.50	Taxi bus arrives and Chris leaves	Says goodbye and walks to the taxi	Chris has to back home at al least 2 o'clock pm because the domestic/household help from ZuidZorg will arrive
13.05	At home	By taxi	The taxi was almost empty, so Chris has some rest time.
13.10	Looks at the picture of his wife	With sadness	Each time it's difficult for Chris to enter his home alone*
13.15	Powernap	Sitting in the seat in the sitting room	He is tired of the morning program and a little bit sad
14.00	Wakes up Helps household help Drinking cup of tee	By the door bell Chris takes dust Together	The household help from ZuidZorg comes to clean up his house. He wants to be independently as much as possible. Also social contact Chat with each other, social contact and he can tell his 'story' to an independent person, without guilt
16.30	Chris says goodbye to the ZuidZorg employee	Opening the front door and waves her goodbye	She helps him a lot and listens to his stories. Reminds him of the moments he was cleaning the house together with his wife.
16.30	Relax	Listen to classical music	A moment of rest and listen to classical music (classic fm.nl) feels good and satisfies him.
17.30	Preparing dinner	In the kitchen, preparing his meal. Chris eats every day a different meal. Depends on his mood, but most of the time he cooks fresh food. Max. twice a week he is heating up a prepared diner (Albert Heijn) in the micro wave	Chris is afraid to become more and more dependent and he wants to train himself to living independently with the help of his Children, grand children and social activities. He trains himself in ADL (daily activities) and make a lot of social contact
18.15	Dinner	To a set kitchen table with dishes	He tries to make his life good and not a gloomy widower*
18.45	Cleaning up the dishes		
19.00	Contact with a woman who is also a participant of the 'lunch-concerts' activity.	By phone call	Chris contacts her, because they both will visit the classical lunch concert tomorrow (which is every 2 weeks). He asks her to pick him up. She drives Chris to the concert, so they can join each other. Social talk
19.30	Watches local television and drinking coffee	TV program broadcast; Broadcast Brabant	Chris sees and hears the local news. Daily routine
20.00	NOS News	TV program national broadcast NOS	Watches the news of the world
20.30	Watches sport		Daily routine and filling up his lonely evening.

21.15	Drink a glass of wine	Cheers to his wife	It is a ritual from his marriage with his wife.
22.30	Chris goes upstairs	Takes the stair	Prepares for the night and tomorrow
22.40	Searches for his clothes for tomorrow	He lays them on the chair in the bedroom	Every other day he swaps his clothes. Because he would look good.
23.00	Goes to sleep		

Persona 3: Ellie Lemmers



Figure 27: Persona Ellie Lemmers

Age: 79 years,
 Gender: Woman
 Divorced, 2 daughters, feels lonely

1. Looking for: Social contact, participation in activities and work as a volunteer
2. Her motto: “My daughters say I should go visit other people”
3. Loves: Reading, making puzzles and hiking.
4. Demography: Ellie is divorced 7 years ago because her husband was an alcoholic. Last year she moved to Eindhoven to be closer to her daughters. She lives in social isolation. Her children advise and help her to look for activities in her living environment. Ellie is physically healthy and has her own apartment. Children visit her once a week. Lives of a low income.
5. Mobility: Ellie lives independently and has a car. She comes with her stroller to the meet and greet center.
6. Golden experience circle: Persona **ELLIE**
7. TFI rate: **7**

Table 17: One day of persona Ellie

TIME	WHAT	HOW	WHY
8.00	Wakes up	Alarm goes off	Daily pattern
8.15	Takes a shower	Walking to the bathroom without walker	Morning ritual and hygiene
08.40	Breakfast	Ellie prepares her own breakfast. She makes fresh orange juices, 1 bread with cheese and 1 cracker with jam	Daily activity and to get vitamin C for better health.
09.05	Cleaning up the breakfast,	Doing dishes	She doesn't have a dishwasher and want to do things by her own as a kind of activity*
09.25	Leaves the house	With walker*	She is a volunteer at the meet and greet center. Walks from her apartment about 750 m to the center. Twice a week she's also a participant of different activities*
09.40	Arrives at M&G	Walking with her walker for 15 minutes	To be on time for the activity she'll be helping
09.45	Consultation with other volunteer	Chat	Preparing the activity and make a schedule/tasks for the participants
10.00	Start Old time favorites	Drinking coffee with the	Social contact and divide tasks

		participants at the central table	
	Baking cookies and apple pie	Helping and supporting the participants of the activity in the kitchen	The participants can't do it by themselves and Ellie is a part of the activity and group. She feels useful*
11.15	Pause	Drinking coffee	Rest moment, while the cookies and apple pie are in the oven. It's before cleaning up
11.30	Cleaning up	Doing dishes and place all the equipment in the cabinets and drawers	Part of the activity and get everything clean for a new group/activity
12.00	Reads newspaper at meet and greet center	Sitting in relax fauteuil with the newspaper form the center.	She wants to lunch with participants of another project which ends at 12.30. She doesn't have a newspaper by herself
12.30	Lunch	With other visitors of the center	Social contact, tackling loneliness and build up some friends*
13.30	Leaving center and shopping in the grocery. In the grocery store she drinks a free cup of thee in the 'special corner'	With walker	On her way home she passes a grocery store. Ellie makes her own meals. Three times a week she cooks for 2 days. On Sunday she is taking bread with (like she use to say) a simple soup. During the three-stop she meets other people. These are mostly the same elderly*
15.15	Back home and put away the groceries	Drawers, and fridge	Normal activity and Ellie likes to live in a clean house.
15.30	Playing solitaire on or any other game	Using her tablet	She has received a tablet, so Ellie could Skype to her daughters when she lived not in Eindhoven. Nowadays her daughters are visiting Ellie once a week in a regular schedule (Mon- and Thursday). Ellie likes playing tablet games. She forgets her loneliness*
16.45	Preparing Dinner	In the kitchen with the food she has bought this afternoon	It's a 'daily' routine and fills up her day. Eating fresh, self prepared food is better for your health, she says.
17.30	Taking Dinner	At the kitchen table alone	There isn't anyone else who eat with her.
18.00	Cleaning up dinner	Doing dishes	She doesn't have a dishwasher and want to do things by her own as a kind of activity*
18.45	Reading a book	In her chair by the window	Ellie likes to read novels. That started when she had problems with her husband. It gave her a distraction and also now she still goes up in the stories without thoughts of her loneliness.
19.50	Small talk with one of her daughters	By telephone or sometimes by Skype	Control/supervise from the daughters to get informed about her daily program and loneliness feeling*.
20.00	Watching news at the television and a film or series	Sitting at her couch	Watching the news and be aware what's happening in the world.
21.00	Get a drink	Taking a glass of lemonade	Ellie takes care of her food and drinks for the day*
23.00	Bed time		

Persona 4: Henk Bosman



Figure 28: Persona Henk Bosman

Age: 70 years,

Gender: Man

Married, Forgetful/Dementia, 3 children

1. Looking for: Company and being together with other men, low threshold activities
2. His motto: "I like to be busy"
3. Loves: Technique, crafts and 'working' with his hands
4. Demography: Henk is married to Anita. They have 3 children. Only 1 child, a daughter, lives in the neighborhood. Their son lives about 100 km from Eindhoven and the other daughter lives in England. Since 3 years Henk suffers from forgetfulness/dementia. Anita has physical limitations. They receive care from ZuidZorg. Both have AOW and a small pension. They both are fragile.
5. Mobility: Henk likes biking but does not recognize the road any more. His driver's license has been revoked. He cannot travel outside by himself. Comes once a week with Anita and once a week with special public transport. The public transport makes him nervous.

TIME	WHAT	HOW	WHY
7.00	wake up	alarm goes off	personal care giver arrives between 8 and 8.30
7.05	henk waits in bed while anita takes a shower	anita showers while henk is doing nothing	henk waits for personal caregiver to shower
7.30	anita helps henk out of bed	anita helps with his bathrobe, henk stays in his pyjama	henk cannot get out of bed by himself and go downstairs alone
7.35	have breakfast and take medicines	together at table, henk dresses the table and they make their own bread. henk is quickly distracted. henk takes medicines	ritual in daily activity to so that henk recognizes this. anita supervises the medicine box and fills it once a week.
8.15	caregivers arrives to wash henk	henk undresses himself and shaves himself, caregivers helps where needed	3x a week because anita cannot do this by herself. he shaves himself etc. to have a feeling of independence
9.15	henk and anita leave to m&g center, henk asks for keys	henk looks in his jacket and gets nervous because he cannot find the keys, anita says she has them	henk gets aware of dementia which makes him upset and nervous, he tries to do his ritual of taking the keys but can't.
9.20	they cycle to m&g	with their own, normal cycles	henk likes to bike and it helps him to stay fit, anita brings him because he can't remember the way to the center
9.40	henk and anita drink coffee with participants/ guests/informal caregivers/host	at the center table, host provides coffee and tea with a cookie.	social contact and to get more at ease in this new environment before the activity. also waiting for all participants to start
10.00	henk participates in men of metal	they sit at a table in separate room, volunteer has prepared it. they work individual, volunteer leads social atmosphere	most participants are introvert and have difficulties with social contact, this activity helps bringing them together. low threshold - > nothing can be damaged, no insecurity and no work-pressure.
12.00	lunch at m&g and take medicine	at center table, host provides bread lunch and they eat with hostes, participants and guests. host supervises medicines	social aspect, interaction between different type of guests

TIME	WHAT	HOW	WHY
13.00	anita arrives to pick up henk	comes inside to pick him up, cycles are outside	they cycle back together because henk cannot travel alone
14.00	henk takes a nap	on the couch	he is tired due to a lot of triggers (cycling, lunching, activity). he does not sleep in bed because he gets desoriented
15.00	henk reads newspaper, makes puzzles, listens to music etc.	in living room in his lazy chair	part of his routine, moment of rest, trigger to be active and to train his emotion/brain
17.30	have dinner and take medicines	eat together at the table, he prepares the table while anita cooks. anita supervises medicines	to stay active and be part of this routine, have contact with his wife
18.15	washing dishes	together cleaning the dishes	routine and being together
18.45	going out for a walk with anita	together through the neighborhood	to keep in shape and to stay physically active
19.30	watch tv, read, play cardgames with anita	in livingroom together	to kill the time before they can go to bed
22.30	go to bed and take medicines	henk undresses himself and anita helps with pyjama and supervises medicines	to sleep and rest for the next day

Figure 29: One day of persona Henk

3.3.7 Experience mapping

To deepen the insights on the problems ZZ pinpointed for the personas, ZZ organized a workshop and made experience maps. As an example in figure 1 a simplified timeline of Jan’s experience map is shown. The complete visualization from Jan and the others experience maps can be found in appendix 9, figures 34 - 37. The visualization shows the timeline for Jan (orange). It starts when he wakes up (left) and ends when he goes to sleep (right). Underneath Jan’s timeline the stakeholders and their role can be found. When the timeline of Jan and a stakeholder are close together, it indicates social interaction. In the appendixes you can find the complete experience flows. For each location the main motivations and feelings are written beneath it. In addition, the activities are described in more detail.

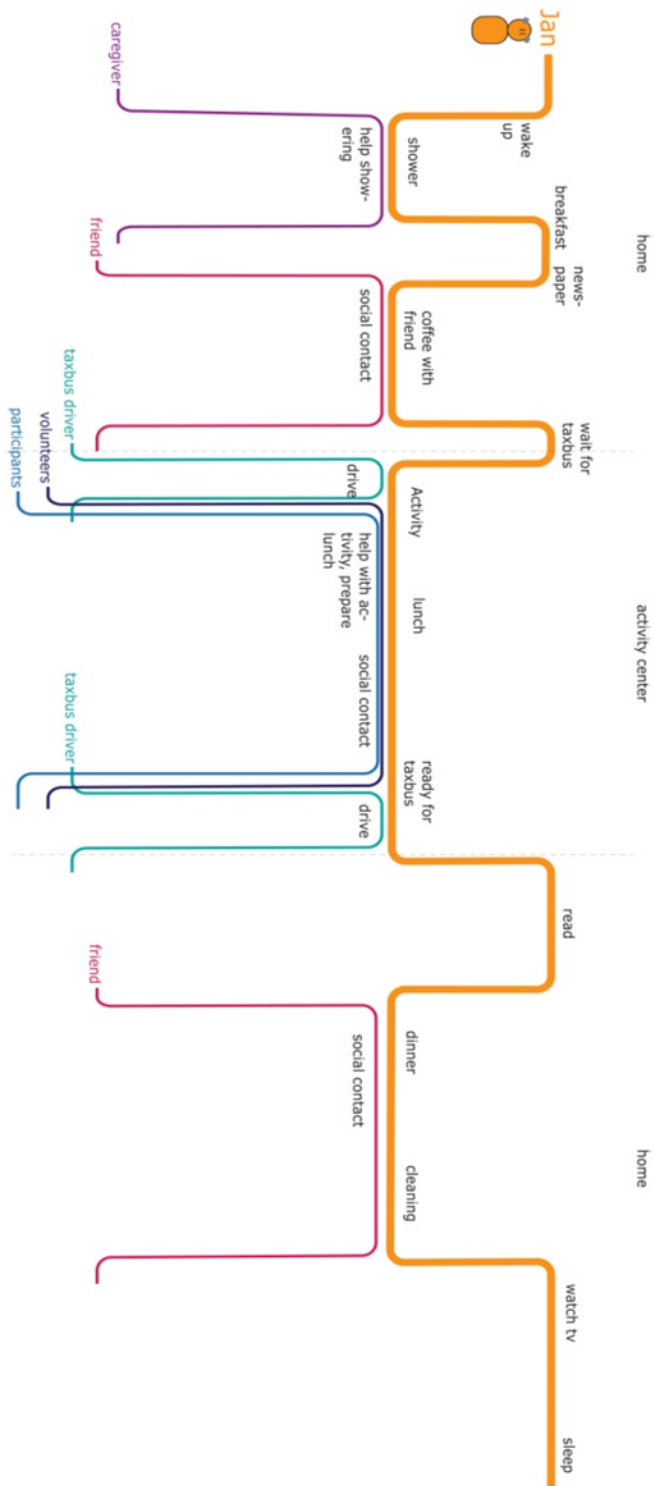


Figure 30: Experience mapping of persona Jan

3.4 Use case 4: Lyngby-Taarbæk Municipality (Lyngby)

Lyngby will in the context of REACH focus on home care and elderly living in smart homes, represent in the REACH care continuum end-users with a relatively good baseline health that need to be motivated for physical and cognitive activity (including ADL training) and rehabilitated at home from lighter disabilities in order to avoid nursing home or hospital/ acute care admission.

3.4.1 Description of use case, focus and target users/elderly

Lyngby-Taarbæk Municipality is a city with 54.778 citizens and a part of the capital region. The municipality delivers home care and health care for 1.953 elderly citizens above 65 years and distributed as shown in **Tables 18** and **19**.

Table 18: FIM scoring criteria

Age 65+	
Male	530
Female	1423
Total	1953
Share of 65+ year olds receiving home care/health care	18%
Age 75+	
Male	411
Female	1253
Total	1664
Share of 75+ year olds receiving home care/health care	33%

Table 19: FIM scoring criteria

Male	671
Female	1589
Total	2260
Proportion of citizens receiving home care/health care	4%

At the moment there are 749 citizens receiving home care assistance for cleaning and/or laundry. The activity day center has in average 350 visits per week. The municipality service delivers to new users on average 25 new emergency call devices per month.

3.4.2 Stakeholder identification

For each persona the respective stakeholder were identified to illustrate which persons or organizations are involved in the daily life of the elderly citizens concerning health care & home care. Details about personas e.g. friends and social activity will be described in **Section 3.3.4**. General stakeholders and their relations are identified in **Figure 31**.



Figure 31: Stakeholder identification in Lyngby

3.4.3 Assessment method

In the context with Lyngby the SF 36 Health Survey (Danish version, Health Assessment Lab, and Hillerød Hospital 1993, QUOLA SF-36 Danish Special Version 1.1 “Den Danske SF-36 manual”) was used and filled in by the interviewer at the participant’s home. As described in **Section 2.2.6**, the SF-36 it gives us an insight in the following self-rated health parameters:

1. Vitality
2. Physical functioning
3. Bodily pain
4. General health perceptions
5. Physical role functioning
6. Emotional role functioning
7. Social role functioning
8. Mental health

To measure performance in Activities of Daily Living (ADL) the Barthel 20 index scale (**Collin et al., 2009; Lauritsen J / Maribo T, 2007**) was used. ADLs measured by the Barthel 20 index scale is the same as in Barthel Index, described in **Section 2.2.1**, but scoring system is different, since the items are rated between 0, 1, 2 and 3, while the original Barthel scores in steps of 5 for the same items: Bowels, Bladder, Grooming, Toilet use, Feeding, Transfer, Mobility, Dressing, Stairs, Bathing. Total scores range from 0 – 20, and lower scores indicate increased disability. Best overall score is 20 points.

3.4.4 Analysis of real-world end-user profiles

Lyngby developed its personas based on the insights gained from semi-structured qualitative face to face interview with 6 participants. Each interview lasted 30-45 minutes, was a combination of a survey where Barthel 20 and SF-36 was filled out; the interview was recorded by phone. In cooperation with professional nurse assistants from Lyngby-Taarbæk Municipality two personas were developed that are representative for the in the context of REACH targeted home care/health care scenarios for Lyngby:

1. Persona 1: Motivated for activity and changes in daily life
2. Persona 2: Less motivated for activity and changes in daily life

In the future a group of participants of the project will be included if they are going to receive an emergency device, as a new user. We assume this group to be more motivated and open-minded for new kind of devices.

3.4.5 Interviews

Six citizens were interviewed, and invited by the Municipality to participate. Inclusion criteria were: 65+, receiving some amount of care either personal or nursing, light “care load”, i.e. the best functioning group of elderly citizens (about 5-8 % of all 65+ year olds who have some assistance from the care and social service). Care load group 1-2 (range 1 to 4). Care load grouping from 1-4 differs between how much help the citizen gets. Care load group 1-2 only need some light assistance from the Care and social service. Care load group 3-4 are more depended of personal assistance from the Care and social service. In general, it was very hard for the participants to imagine different kind of sensors, the usefulness of sensors and what it has to offer them personally. Despite a lot of examples under the interview, they could not get the picture. None of the participant was regular internet users and none of them owns a smartphone or tablet.

3.4.6 Defining personas

For Lyngby two personas were developed that are representative for the in the context of REACH targeted home care/health care scenarios. For each persona the (1) general situation (age, household situation, etc.), (2) social situation, (3) health, care and practical assistance situation, (4) daily living situation, and (5) IT use habits were described.

1. Persona 1 – Elsa Jensen

- a) Elsa Jensen is an 83-year-old widow, living by herself in a 3-room rented flat (70 m²), first floor in a 3 story block of flats, with a wide balcony. She retired from her work as a hair-dresser 19 years ago when she had her own small saloon. The municipal health and social service has classified Elsa in Care Load group 1 - the best functioning group of elderly citizens (about 5 - 8 % of

all 65+ year olds who have some assistance from the care and social service).

- b) Social: Elsa's husband, who was a machinist, died 8 years ago. Their two daughters, Inger (married, 2 children); Bitten (divorced, 2 children) live nearby, Inger half an hour away by bus or car, Bitten about 1 hour away by car. Elsa has most daily contact with Inger or Inger's husband –often just a short phone call. Inger, who is an assistant nurse, is a bit worried about her mother and visits her at least once a week, her grandchildren more rarely. Bitten, originally qualified as sales assistant in the food sector, has had periods of unemployment and sees her mother less frequently, she uses public transport and will often stay over during holidays including Christmas and Easter. Elsa has a fairly large network of friends, she usually visits the municipal bingo center on Wednesday evenings and on two afternoons she helps at the local church bazaar where they sell second-hand items (Kirkens Korshær). She goes to church about once or twice a month and on most church holidays. Elsa's older sister is frail and Elsa visits her at least once a week. Elsa has frequent contact with her husband's family and she joins family gatherings with large groups of nephews and nieces and their children. Else is a lively and optimistic.
- c) Health, care and practical assistance: Elsa has no severe health problems but she is affected by chronic urinary incontinence (minor leakage; she uses diaper that she handles herself). Her sleep is interrupted once or twice every night, urge to relieve bladder. She is also bothered by hearing problems and for the last 6 years she has been using a hearing aid. She has been using compression stocking for 10 years, she is able to put them on and take them off herself with her compression stocking aid. Her BMI is 29, and she is able to walk at a pace that is age appropriate and that allows her to pursue a comparatively busy social schedule. She gets out of breath if she climbs stairs too quickly or lifts heavy items. After a fall 4 years ago getting out of her bath and when she broke an arm, she receives bath assistance once a week from the municipal service. She was given a robot vacuum cleaner by her family, and receives every second week half an hour's assistance for "light cleaning" and clothes washing. Her block of flats has washing machines and dryers in a basement section. Her flat is well kept, clean and inviting.
- d) Daily living: Elsa does most of her daily shopping herself, her family helps her with heavier items. She does her own cooking and, in addition to family visits, she has a friend or acquaintance for lunch or dinner or just coffee and tea at least once a week – and equally, is invited out herself. She rarely eats at a restaurant, but often at the church bazaar or with a friend in connection with her weekly bingo evening.
Her economic situation is somewhat tight, since she has only her state pension and a small pension after her husband. She receives a subsidy for her moderate rent of her flat. It bothers her that she is not able to buy larger

gifts for grand-children or great-grand-children. She takes pride and great pleasure in keeping lush hanging flower beds on her balcony.

- e) IT use: She began to use a tablet 3 years ago to communicate with her grand-children studying far away. She is able to Skype with family members and can read and respond to e-mails. She has not gotten accustomed to browsing but can click on links sent to her.

2. Persona 2 – Kurt Hansen

- a) Kurt Hansen is a 78-year-old widower, living by himself in a self in a small 4-room old fashioned terraced house, built in the 50's and not modernized, with a small back garden. He worked as a book keeper in a large public company for almost all of his working life, and retired 10 years ago. The municipal health and social service has classified Kurt in Care Load group 1 - the best functioning group of elderly citizens (about 5-8 % of all 65+ year olds who have some assistance from the care and social service).
- b) Social: Kurt's wife (also an office worker), died suddenly 4 years ago. Kurt has two sons, Ole (married, 2 children); Erling (divorced, remarried, 2 stepchildren) who each lives in another part of the country – 3 and 4 hours away by car or public transport. Kurt has infrequent contact with his son Erling (a dairy engineer) and mainly by phone when Erling calls his father around Christmas and at holidays. Erling and his new wife visit Kurt once a year, usually in connection with their summer vacation when they go on a charter flight. They usually leave their car at Kurt's house to save parking fee at the airport during their 2-week vacation. Kurt's other son Ole is worried that his father has become rather inactive after the death of Kurt's wife. Ole calls his father about once a week, and Ole or his wife visit Kurt a few times a year, usually when they have work related meetings that justify the travel expenses. Kurt accepted their invitation to stay over Christmas the first couple of years after his wife's death, but Kurt finds it too cumbersome to travel during the holidays so he now prefers to stay at home. His granddaughter visits him a few times during the year and tries to cheer him up – persuaded him to accept an artificial Christmas tree and usually mounts a Christmas decoration on his front door. Ole does maintain his old hobby of interest in WW2 history and especially in the resistance movement in Norway and Denmark, and he is a member of a club that gathers socially about once monthly to review and discuss WW2 memorabilia. Similarly, Kurt follows with interest war history documentaries on TV. In general, Kurt spends most of his day watching television. After his wife's death, Kurt has gradually slipped into infrequent contact with their, already then, rather narrow circle of friends, and Kurt is now a bit of a recluse who may not speak with anyone for days on end. He is on brief greeting terms with his neighbors and staff at his local news stand where he plays on lotto twice a week – in fact, his greatest physical activity is

walking 2* 600 meter distance back and forth to the news stand to get select the lotto coupons.

- c) Health, care and practical assistance: Kurt has no severe, but several moderate health problems. He suffers from type 2 diabetes and hypertension and visits his GP every 3rd month to be controlled for these parameters. He is obese (BMI 36) and his weight has increased after the death of his wife. He and his wife used to enjoy cake which is rich in calorie (evening or afternoon coffee and tea) and often desserts. Kurt likes sweets and engages in very little physical activity. He receives daily visits in the morning from the municipal service to help him put on compression stockings but he is able to take them off himself when going to bed using a compression stocking aid he has been given by the service. He receives a hot meal every day from the home service, has food and daily purchases brought to him once a week. Receives support for light house work and laundry every two weeks.
- d) Daily living: Kurt's daily life is monotonous, and on some days he does not get out his house. Due to his weight he moves slowly and gets out of breath if he has to climb stairs. His back garden is not well kept and he is considering buying a robot garden lawn mower – though his lawn is very small – instead of pushing the very light electric lawn mower he already owns. His grandson helped him for a few years with the lawn but has told his grandfather he cannot find time any longer for this. Kurt spends most of his day in front of his large TV set and is mostly preoccupied with watching documentaries, especially WW2 pieces, on Discovery, History and similar channels. His home is somewhat messy and not well kept, and although the floor carpets are reasonably clean due to his robot vacuum cleaner, there is dust on the surfaces.
- e) Kurt has a relatively ample pension, his rent is very low and he feels he has no financial worries. On several occasions, he has been urged by the municipal health services as well as his GP to attend the municipal activity center, and they have offered to fetch and bring him by mini bus. He did attend once immediately after his wife's death, but he said he did not like all the old ladies' talk and told them not to fetch him again. He frequently complains that the municipal services do not really help him – that he is paying taxes and has done so all his life, and therefore they owe him now some proper assistance with house cleaning. He is also very unsatisfied with the quality of the hot meal he receives every day.
- f) IT use: Kurt has a PC which he uses for banking and occasional mails. He also follows some news portals and especially sports and football results.

3.4.7 Experience mapping

Patient Profiles based on interviews	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5	Participant 6
Demographics	Age 69 Male Divorced Single for 23 years 2 children Lives in own apartment Needs daily support from professional health care provider.	Age 83 Female Husband died 36 years ago. Had a friend that died 8 years ago. 3 children, 7 grandchildren, 1 great grandchild. Lives in a rented apartment.	Age 88 Male Widower for 22 years. 2 daughters & 1 son Lives in a rented apartment.	Age 91 Female Widow for many years. Alone since. Lives in a rented apartment. 2 sons	Age 78 Male Widower for 7 years. Married for 47 years. Lives in a rented apartment. 3 sons, 1 daughter, 5 grandchildren.	Age 101 Female Widow for 22 years. Alone since. Lives in a rented apartment. No children.
Medical History	Dialysis since 1980 Type 2 diabetes Overweight Dizziness for 10 years	Iron deficiency anaemia Weight loss Urinary incontinent Balance problems	Atherosclerosis. Chronic atrial fibrillation. Stroke 4 years ago. After rehabilitation: Epilepsy and reduced strength in right side of the body. Weight loss from 96 kg to 60 kg.	No medical history	Stroke one year ago Hypertension Hypercholesterolemia After rehabilitation: Impaired vision	Very weak eyesight due to glaucoma Bad back
Home Care/Health Care Needs from professional health care provider	1 x daily for preparation of dialysis bags. Help with cleaning and laundry. Catering 3 x weekly.	1 x daily looks after how she is today. Medication dosage. Phone call at 8 o'clock checking medication intake Protein drink. Check weighing once a week. Help with cleaning. Her son buys readymade meals at the local butcher shop that she can warm up, and grocery once a week. She cooks her own potatoes.	1 x daily prepares open sandwich. Readymade meals from the municipality delivery. Emergency device to wear around neck. Help with cleaning. Earlier got laundry but now testing doing it by himself as a part of rehabilitation. Takes delivery of all kind of grocery.	1 x daily receiving help for medication dosage and handing out daily dose. Medicine is locked in - citizen does not know why. Emergency device to wear around neck. Hot meals from the municipality delivery. Takes delivery of all kinds of grocery.	Every second week help with cleaning. Medication dosage from the pharmacy.	2 x daily: Eye dripping. Medication dosage. Compression. Stockings on and off. Preparing breakfast and lunch. Readymade meal for dinner she can warm up. Cleaning every 14th day. Emergency device to wear around neck.
Barthel 20 index Activities of Daily Living: Bowels, Bladder, Grooming, Toilet use, Feeding, Transfer, Mobility, Dressing, Stairs, Bathing. Total scores range from 0 – 20, lower scores increased disability	20 points Going with Walker	19 points Urinary incontinent diaper on Going with Walker	18 points Can't go up/down stairs	19 points Needs guidance or personal support for going up/down stairs	20 points	19 points Needs guidance or personal support for going up/down stairs
Health Survey SF-36	Poor health - worse	Less good health but better within the latest	Less good health. Better now than 1	Good health, roughly the same in the latest	Good health. Better than during the latest	Good health considering the age.

Figure 32: Experience mapping I

Activity Daycentre	Not motivated	Very motivated 2 x a week. Gymnastics Social activities	Not motivated	Very motivated 2 x a week. Gymnastics and hand work. Eat in Activity Daycentre these days	Very motivated 2 x a week. Bingo and Men's Club	Very motivated 2 x a week. Gymnastics and classical music
Hobbies	No hobbies	No hobbies	No hobbies	Handwork	Dub videos to DVD Writes texts	No hobbies
Attitude to sensors in the home	A good idea. All that can help making everyday life easier.	Won't have any sensors at all. Cannot see possibilities in it. Even if she became more independent of Health Care professionals	A good idea. All that can help making everyday life easier. Find it hard to imagine the examples	Hard to imagine how it could be. Is positive if it is something that can help in everyday life.	The idea is good if he can stay in his own home for a longer time and being independent	If it is necessary, it is a good idea. Find it hard to imagine.
Concerns about data protection	No concerns. Doesn't matter if others see data	Don't want any of it – don't like it at all, no matter what. Feels like a prisoner	No concerns. Registration for home care – can't imagine it	No concerns	No concerns	No concerns
IT and web facilities: Smartphone Tablet Computer www.	Regular user of the internet but only for YouTube at the TV Uses PC	None	Is a regular user of the Internet "not for nonsense – only to the Bank" Uses PC	None Her son helps her with everything	None Use the PC to write texts. Should have been on an IT course, but got his stroke. Wants to learn it.	None Sister in law helps in relation to money and accounts.
Obstacles in everyday life	Cannot go on the street without walker because of dizziness and is afraid of falling	Think that it follows the fact of being old. Would like to walk a lot more	Cannot go on the street without Walker	None	Misses the reading room at the library.	Difficulty with walking – can't go alone due to the vision and general debility
Activity during the day	Linking of the dialyse machine in the morning. Gets dressed. TV, radio listening, little bit computer food intake	Calling her sister and girlfriends. Watching TV and listening to the radio. Tidies up. Goes to the gym Mondays and Thursdays.	Taking a shower, gets dressed, makes breakfast, reads the newspaper. Contact to the daughter. Watching TV.	Cleaning, watching TV. Someone comes with the hot meal. Tuesday and Thursday activity centre. Less activity in the weekend	Gets up, have a shower, makes breakfast. Watches TV. Dishwashing, vacuuming, laundry. Hobby: Video tape to DVD. Old 8 mm films. Calling the children. Cook, make lunch. Get visits, cooking for guests.	Dishwashing. Contact with sister-in- law. Listening to radio (Cannot read or watch TV) Gets something good for dinner
Social interaction	Prefers to stay in the apartment. Lonely in daily life, but does not want to see others – has tried activity centre. Owns a car –drives out for light shopping occasionally. Sparse contact with the family – sees them only for birthdays and Christmas. Only few acquaintances.	Family lives nearby. Enjoys togetherness with others. Has several female friends. Previously been very active in gymnastics and golf. Is not troubled about being alone	Talking with his daughter by phone every morning. Social activity in the property once a month e.g. lunch. Visit by the Family regularly. Goes to the library	Close contact with her son. Particularly pleased with her visits at The Activity Daycentre. Thinks she belongs to the Centre and if it gets necessary she wants to live there at the Nursing Home.	Joy of family. Very social. Often going out with his children for shopping or dinning. Loves cooking and dinner parties.	Has only her sister in law left. Has no children, and all friends are dead. Has a friend that walks with her once a week (cannot go alone)
Concerns	Main concern is if The Home Care Unit sends a new helper	Home Care – never know when they are coming: between 8-12	Fond of life and have survived. No concerns	No concerns	Worried about whether a new stroke will hit him.	At the weekend there are random helpers – and it is often late

Figure 33: Experience mapping II

4 Comparison of use cases: communalities and differences

As discussed earlier in the report, the four use cases cover the different stages of the health and care process that an elderly citizen may experience in his/her daily life.

After a critical immediate incident (e. g. stroke) or as a consequence of a serious illness an elderly citizen can be admitted to an acute hospital (e.g. HUG) if outpatient treatment is not sufficient. The main aims are to stabilize the vital functions of the elderly citizen, to diagnose then to treat according to medical standards with the objective of curing and preventing or minimizing permanent impairment. To this end a hospital has specialized departments and wards. It is equipped with special units for intensive treatment and surveillance (intensive care unit, intermediate care unit, stroke unit). Frequently the elderly citizen recovers and can be discharged after a few days or weeks to his/her former social setting, usually his/her home.

But hospital treatment is not sufficient in all cases. If the elderly citizen does not recover quickly and permanent impairment and handicap are imminent, rehabilitation is indicated. Rehabilitation ought to start as early as possible as outcome has shown to be better. Nowadays elements of rehabilitation may be introduced into the treatment at any stage of disease, even on the intensive care unit and thus also in the acute hospital. Acute hospitals may have specialized rehabilitation departments (as HUG).

On the other hand the elderly citizen may be transferred to a specialized rehabilitation hospital (for example a neurology clinic such as SK) which may be equipped with an intensive care unit and an intermediate care unit, to be prepared to accept even very severely affected elderly citizens for rehabilitation, and to be able to continue to provide acute hospital treatment during the rehabilitation process. Rehabilitation starts with diagnosing the impairments of the elderly citizens and planning mental and physical exercises to activate the elderly citizen and counteract the impairment by mental and physical (re)learning and training. To this end a neurological rehabilitation hospital usually employs specialized therapists in the fields of neuropsychology, physiotherapy, occupational therapy, physical therapy, speech and swallowing therapy as well as professionals specialized in counseling in matters of health services, insurance, entitlement to a pension, procuring medical aids, orthoses and prosthesis.

If rehabilitation is entirely successful the elderly citizen is discharged to his/her former social and professional setting. If not, the question arises whether the elderly citizen should continue rehabilitation as an outpatient and whether he/she may be discharged to his/her home (possibly with home care as a professional support and after adaptation of his home to his handicaps) or whether he/she needs to be discharged to a nursing home.

After a stay in an acute or rehabilitation hospital the elderly citizen and his/her family usually desire the discharge to his/her home. Whether this can be realized depends on the medical condition and the handicaps of the elderly citizen and the abilities of family members to compensate for the deficits of the elderly citizen and, if that is not possible,

to organize appropriate home care by a professional service. Frequently this means that a professional nursing service helps with getting up in the morning and bedding in the evening, taking the prescribed medication. Occasionally support at lunchtime may be necessary in addition. To employ a nursing staff for full time care at home is beyond the financial means of the vast majority of elderly citizens. If the elderly citizen is immobile or has to use a wheel chair it is frequently necessary to rebuild or adapt the building, mainly the toilet and the bathroom, to the new requirements.

The continuation of rehabilitation treatment very much depends on the mobility of the elderly citizen. If he/she can make the way to the therapist by him/herself or with the help of a family member continuation of rehabilitation treatment may be feasible. When the therapist has to come to the home of the elderly citizen, rehabilitation is of course much more costly and often not covered by the health insurance system. Therefore techniques for tele-rehabilitation are under development.

If the elderly citizen cannot be supported sufficiently at home, he/she has to be discharged from the acute or rehabilitation hospital to a nursing home. The choice of the nursing home should be done considering the medical and social demands of the elderly citizens. A short distance to the home of the family makes social contacts with the family and friends easier and the elderly citizen happier. The amount and quality of rehabilitation treatment offered by nursing homes varies and may be a criterion for selection. Rarely elderly citizens need highly specialized continuing medical treatment (i.e. permanent or intermittent respirator assistance for breathing) which may limit the choice of nursing homes.

As soon as the elderly citizens recover sufficiently and can be discharged from hospital/rehabilitation center/nursing home the focus shifted to preventing their readmission to these institutions again. Healthcare services at home (e.g., home visiting nurses, ZuidZorg and Lyngby) and formal and informal social services (children/friends and meet and greet center at ZuidZorg Extra) are of great values to these citizens to remain reasonably healthy and active in their daily lives. These services can help to prevent these elderly citizens to be readmitted to the formal health and care institutions again. What kinds of services are more desired and should be offered and how to motivate this type of elderly citizens to actively use the provided services and take the necessary benefits remain challenging for the related home care/smart home organizations.

It should be noted that not every elderly citizen goes through the entire process. Elderly citizens who recover quickly can be directly discharged to their home. Only if impairments at the end of the hospital stay are hindering the elderly citizen from independent life rehabilitation is indicated. Home care is needed when the elderly citizen and his/her family cannot support him/her sufficiently. This normal development may be altered by complications and other adverse events.

All these insights call for a close cooperation of the types of partners in this project (hospital, rehabilitation hospital, nursing and social service for home care and nursing

homes). The REACH system aims to be established under the collaboration of a network of partners with experience in smart sensing, monitoring and intervention technologies, and industrial partners. As a result, not only advanced and complex technology platforms will be created for more structured environments such as clinic and hospitals (e. g, HUG) or rehabilitation centers (e.g., SK) but also an adapted and simplified form is needed to support the home care (ZZ) and smart home (Lyngby) contexts.

5 Identification of technological potentials and opportunities

As part of several task-level in-person meetings and teleconferences in the first project month (M1) several key aspects and requirements of REACH were discussed and detailed:

1. The core idea of REACH is not to (passively) assist elderly people but to *activate and rehabilitate* their bodily and cognitive resources (physical activity, cognitive activity, nutrition, mobility, etc.) and through that allow for better health, less frailty, better accomplishment of tasks/ADLs, etc. and thus ultimately for more health-adjusted life years.
2. The main target group: ageing persons that have a risk of long-term care (LTC) admission due to diseases such as Alzheimer, diabetes etc., or develop frailty possibly due to dehydration, reduced activity and social contacts
3. Points of contact: with the system/scenarios:
 - a) *Scenario 1*: The system might be acquired by elderly (or their relatives) showing e.g. light signs of frailty and installed in their home with the aim of preventing a deterioration of their health status.
 - b) *Scenario 2*: Point of contact might also be an institution like a clinic or a care home. Aim of the system would then be to bring the elderly citizen (or patient) through activation (rehabilitation) back into “normal life” and reduce risks of re-admission to LTC.
4. Advanced health state prediction: In all possible scenarios sensors placed in the environment or at the body of the person should allow detection of living patterns (emotions, calories burned, physical activity, cognitive functions, etc.), predict possible future health states and allow thus targeted, customized interventions that “activate” the person.
5. Parameters to be obtained by sensors that can be useful in the context of REACH’s sensing and prediction system: physical activity, accomplishment of tasks and ADLs, structure and organization of a day, energy expenditure, energy intake/nutrition, body composition, gait, motivation/emotions.
6. Parameters to be obtained by sensors that can be useful to indicate physical inactivity:
 - a) Accomplishment of tasks
 - b) Structure/ organization of the day
 - c) Motivation/ emotions (how could motivation be measured consistently?)
 - d) Social interaction (face to face or by phone/Skype with others)
 - e) Possibilities for muscle function analysis (as the basis for frailty detection):
 - Bioelectrical Impedance Analysis
 - Autonomic regulation
 - Body Composition Analysis
 - Electromyography (EMG)
 - Real-time ultrasound imaging
 - Dynamometry
 - f) Energy expenditure
 - Directly: Continuous direct measurement possible?

- Indirectly:
 - Over CO² “emission”
 - Over ECG > SmartCardia
 - Over activities and body composition
- 7. Modularity of the system: The system should be highly modular in order to allow an adaptation to various use cases/scenarios and to be able to adapt/evolve over time with the user.
- 8. Platform approach: A digital platform and interior equipment modules should serve as digital/physical platforms that tie together a variety of products and services developed within REACH.
- 9. Portability of the system: the system should be able to follow the elderly person through different life phases (e.g., from light frailty to more severe frailty), institutions (e.g. from clinic to care home to home; or vice versa), and environments/settings.
- 10. “Evolutionary” approach: the system should be able to “assemble” and “disassemble” itself (e.g., from light frailty to more severe frailty and optimally back to light or no frailty).
- 11. Aggregated sensor data – either in real time for potential emergency situations (e.g. falls) or summary over time – to professional care givers.
- 12. Privacy, ethics, data security - usability: Importance of motivational strategies and concepts of privacy, data security and ethics for acceptance and usability of the REACH system.

In order to serve these aspects and requirements following technological resources of REACH partners will be utilized:

1. AlrehMedical: mobilization and physical activation technology
2. ArjoHuntleigh: equipment, beds, monitoring systems, etc.
3. Philips: HealthSuite Digital Platform
4. DTU: Playware’s gamification technology
5. TUM: building interior/furniture, sensors embedded in the environment, contactless sensing
6. SmartCardia: medical wearable sensors, detection of emotions
7. EPFL: sensors and prediction (based on time series analysis)
8. Fraunhofer: BigData analytics (e.g. from patient histories and statistical data)
9. Biozoon: personalized nutrition

In that context, the state of the art overview provided in the DoA is taken further with a particular focus on technological potentials for REACH’s sensing-prediction-physical/cognitive activation loop.

5.1 Sensing furniture

In the context of REACH sensing furniture can be developed to include a range of (medical) onboard sensors that can be used to obtain a range of parameters (e.g., task accomplishment, day structure, muscle function, energy expenditure, energy intake,

etc.) relevant for early detection of risks in a seamless and unobtrusive manner in the targeted homecare, care home, and rehabilitation environments. Eight categories of sensing furniture can be identified (**Table 20**).

Table 20: Sensing furniture

	Category	Description	Examples	References
1	Sensor Chairs	Sensors (with body contact or contactless) placed in chairs, seats, sofas, etc.	GEWOS, SensSeat	(Erdt et al., 2012; Future Shape, 2016)
2	Sensor Floors/Surfaces	Sensors systems turning a floor or other large surfaces of a room into a large sensor surface	SensFloor®	(Future Shape, 2016)
3	Sensor Beds	Sensors placed in beds to analyses body positions, movement, heart rate, etc. at beds in a contactless manner.	SleepNumber®	(Sleep Number, 2016)
4	Sensor Tables	Sensors integrated into tables and work desks e.g. to recognize/analyze food or activities	IKEA concept kitchen, Bauknecht Interactive Cooktop	(IKEA, 2015; Bauknecht, 2015)
5	Sensor Mirrors	Sensor systems (e.g. for vital signs detection) made part of a bath mirror	MIT Media Lab Medical Mirror	(MIT, Media Lab, 2016)
6	Sensor Walls	Sensors that are part of functional wall elements, cabinets of storages	LISA	(Linner et al., 2015)
7	Sensor Toilets	Sensors (e.g. for urine analysis) integrated in a toilet	Daiwa House/Toto	(Toto, 2016)
8	Sensor Plates/Cups	Sensors integrated in plates and cups to analyses nutrition habits and energy intake	Vessyl	(Vessyl, 2015)

5.2 Playfulness and fitness furniture

Used as furniture as well as fitness device. Without going to the gym the user can benefit from using the fitness furniture in a home or rehabilitation environment. The system is easy to operate and reconfigure by the user due to its design. The system offers multi-functional exercise activity and various exercise gestures can be performed (e.g. muscular strength and endurance, cardio respiratory endurance, flexibility, and balance, etc.). Six categories of fitness furniture can be identified (**Table 21**).

Table 21: Fitness furniture

	Category	Description	Examples	References
1	Fitness Chairs	It can be used as conventional chair also once reconfigured it can be used as exercise device (a chair, recumbent cycle, and elastic resistance tubing all in one exercise device, etc.)	Chairmaster, GEWOS, GymGymLLC	(ChairMaster™, 2015; Erdt et al., 2012)
2	Fitness work desk	The fitness work desk provide light exercise opportunities while working, studying or simply watching TV or playing games at home. A set of accessories and parts can be added onto the desk depending on the user's preference	FitDesk®	(TheFitDesk, 2016)

3	Fitness cabinets/closets	A multi-functional set of fitness device (body stretching and muscle building, etc.) that incorporates with interior of your home or office.	Process® Tumidei XFit Gym	(<i>Process, 2016;</i> <i>Coolthings, 2016</i>)
4	Fitness Walls	Fitness wall is a wall like furniture specially designed for training at home. It helps user to rediscover the basic skills such as resistance, balance, strength and flexibility.	Kinesis® IQflow	(<i>Technogym, 2016;</i> <i>World Architecture News, 2016</i>)
5	Fitness Table	A side table design offers a function as a table as well as a work out platform for some basic exercises at home	Ram&Row®	(<i>Ram & Row, 2016;</i> <i>Coolthings, 2016</i>)
6	Fitness Couches	The design enables user to perform basic gym activity at home. It is foldable, reconfigurable and has compartment to store weights and other accessories	gprero	(<i>Gabriel Prero Design, 2008</i>)

5.3 Mobilization and rehabilitation devices

In the context of REACH mobilization and rehabilitation devices are designed to assist the user to recover physical strength independently. It should also monitor the users' vital signs while engaging in exercises and document the progress. It can be used as a training device in rehabilitation, as a therapeutic product in nursing homes, hospitals and at home. The system is adjustable, reconfigurable based on the user's body type. Four categories of mobilization and rehabilitation devices can be identified (**Table 22**).

Table 22: Mobilization and rehabilitation devices

	Category	Description	Examples	References
1	Muscle Function Analysis Furniture	Seats or devices that allow to analyze muscle function and strength by methods such as electromyogram, ultrasonic or dynamometry.	Full Body Dynamometers, EMG	(<i>Allet et al., 2012</i>)
2	Therapeutic ADL Exercise	The Endorphin STS is designed to assist the user in sitting and standing and perform basic exercise independently	Endorphin ®	(<i>Endorphin, 2010</i>)
3	Mobility/Mobilization Devices	The product is a mobility and transfer device to help the user to perform seated transfer, sit-to-stand transfer and other training	rifton®	(<i>Rifton, 2016</i>)
4	Rehabilitation Exercise Devices	The product will assist the user to perform cycling activities with either arms or legs in both seated or lie down position	RT300Arm Cycle, MOTomed	(<i>Restorative-Therapies, 2016;</i> <i>MOTomed, 2015</i>)

5.4 Rehabilitation beds and transfer devices

In the context of REACH a rehabilitation and transfer bed (actually the “center of life” in clinics, rehabilitation settings and home care) shall become part of the solution. It allows the mobilization of the user, adjusting their body gestures either upright or seated. This enables the user to independently engage in daily activity in a desired position. It can be

used for rehabilitation purposes in hospitals, nursing homes or at home. Five categories of Rehabilitation beds and transfer devices can be identified (**Table 23**).

Table 23: Rehabilitation beds and transfer devices

	Category	Description	Examples	References
1	Therapy stand-up bed	The design ensure the user is in a upright position while perform essential exercise or therapy	LogicMove®	(<i>TeamSacon, 2016</i>)
2	Tilting rehabilitation bed	The bed specially designed for rehabilitation and mobilization. It offers safety, comfort and reduced care from the nursing staff	OLDSway –T2000	(<i>Olds Engineering, 2016</i>)
3	Rotary rehabilitation bed	The bed enables the user to get up and out of the bed independently.	Hi-Lo Rotation bed	(<i>PatientCareProducts, 2016</i>)
4	Care Assistance Bed	The electric assistance bed equipped an integrated wheelchair and hair washing robot. The bed provides safety and comfortable living for the users while reducing the burden of caregivers	Care Assistance Bed Panasonic	(<i>Panasonic, 2016</i>)
5	Modular rehabilitation bed	The modular bed allows the patient to stay in the same bed through admittance to discharge. It can be equipped with modules for transport, rehabilitation, critical care, etc.	Modular hospital bed and method of patient handling Patent US5513406A	(<i>Hill-Rom, 2016</i>)

5.5 Contactless vital signs sensing and measurement

Nowadays the technological diagnostic possibilities are advancing continuously. Technologies such as computer tomography, magnetic resonance imaging, 2-D and 3-D ultrasound allow patients and physicians an insight into the human body and its anatomy, physiology as well as patho-physiology (**Hutton et al., 2006**). However, this technology is space consuming, needs trained/skilled staff, energy and time. Therefore, appointments with physicians are rare and often expensive and the new trend towards wearables is quite successfully. To measure vital signs such as activity, blood pressure, heart rate, cerebral activity, obesity treatment, blood glucose levels, oxygen saturation, and food/calorie intake using wearable devices, the presence of a physician or expert is not necessarily required. However, end-user tend to lose interest and to neglect accessories (which include also wearables) after some time of use.

TUM will focus in the unobtrusive implementation of sensors into the surrounding environment, in order to enable optimally “real-time” pre-diagnostics, even if the end user forgets/neglects to wear the sensor accessories. This approach relieves patients and physicians of redundant detailed measurements such as 24-hour blood pressure measurements. As the user’s health condition can thus be analyzed in a continuous manner 24 hours per day, these embedded sensors can foster decisions regarding which wearable sensor, physician investigation, or activity to select, in order to improve

the health condition. Of course a contactless measurement of vital signals is limited and devices used to perform computed tomography (**Frush et al., 2003**), or magnetic resonance imaging (**Dill, 2008**), as well as ultrasound devices are impossible to be introduced or installed into the home environment in an unobtrusive manner, because of factors such as safety, size, and power consumption.

Previous research suggests, that by embedding sensors into interior environments, the accuracy of the measurement is lowered, since the user is not always compliant with special postures (such as needed, for example, for a blood pressure meter measurement (**Netea et al., 1998**)) required for properly obtaining certain measurements. Additionally, the clothes, movements, surrounding temperature and light conditions, comprise parameter that can hinder a successful and reliable measurement. The integration of the different sensors into the environment must be done in a modular way, in order to dynamically adapt with regard to the individual characteristics of each user and setting (e.g. as listed in **Table 20**). Therefore, the TUM analyzed which sensors can be integrated in such a manner into the home environment, and what types of limitations are thereto concerned, due to unstructured nature of some care settings (e.g. home care settings). The outcome of the analysis for different measurement categories is outlined in the following sub-sections.

5.5.1 *Gesture analysis using infrared*

By using the Leap Motion Controller or the Microsoft Kinect (**Fern'ndez-Baena et al., 2012**), it is possible to detect and further analyze the movement activity of a user. Both devices are using infrared light. The detection range here starts from simple activities up to precise measurement of tremor and bradykinesia (**Galna et al., 2014; Gttler et al., 2015**).

5.5.2 *Electrophysiology*

The (Electrocardiogram) ECG measures the electrical conduction of the human heart, and allows analyzing the health condition of the most important muscle in the human body. Normally 4 electrodes are necessary in order to receive a 6 channel lead. The main problem is, that electrodes with special gel are need, as well as direct skin contact. However, through the use of capacitive electrodes, it is possible to measure without gel or even through clothes (i.e. contactless) the ECG (**Leonhardt and Aleksandrowicz, 2008**). Furthermore devices has been developed (e.g. Brain Computer Interface, BIC), which use the electrodes also for EEG (**Chi et al., 2012**) signals. However, of course also EMG and EOG can be measured using capacitive electrodes (**Matthews et al., 2007**).

The main problem of this technology is artefacts in the environment, which may disturb heavily the signal quality.

5.5.3 *Pulse oximetry*

The pulse oximetry indicates the oxygen saturation of the blood, as well as the pulse. Nowadays the end-user can utilize this technology already by wearing add-ons and wearables like watches (**Parak and Korhonen, 2014**), where the sensors are

embedded into. This technology is not new, however useful to increase the reliability of other measurements, like the ECG.

5.5.4 Hypertension

Blood pressure recording is one of the most important measurements that can be obtained, considering the so called “deathly quartet” (**Kaplan, 1989**) nowadays. High blood pressure (hypertension) is mostly symptom free, but leads sooner or later to diseases such as heart attacks, strokes, and peripheral vascular diseases. Up to today, to safely diagnose a hypertension, a long-term-blood pressure monitoring using an inflatable cuff is necessary, which requires frequently measuring on the upper arm of the affected person. However, technologically it is possible to measure cuff free (the systolic value), by comparing the time difference of the ECG (R-Peak) with the incoming blood wave detected by the pulse oximetry (**Fung et al.**). This allows a implementation into furniture, or into the bath environment, as proposed by (**Kim et al., 2006**).

5.5.5 Breathing

To measure the breath rate special stretchable material e.g. embedded into belts (**Li et al., 2014**), or thermal resistors (also thermistors called) (**BaHammam, 2004**) are used. However, using thermal imaging, enables to measure the breath according to the temperature change on the nose (comparable with the thermistor). This allows e.g. an unobtrusive implementation into i.e. a bed in order to be able to detect sleeping apnea.

5.5.6 Body temperature

The body temperature is an indicator for the overall health condition. E.g. if the user is infected, he/she usually gets fever. Using thermal imaging this symptom can be detected. Several studies and first implementations do exist, regarding and unobtrusive integration of this technology into the environment implementation (**Ring et al., 2008**; **Güttler et al., 2016**).

5.5.7 Fall detection

A fall means that suddenly a person is lying on the floor and in the worst case is unable to stand up without the support of a third person, because of a broken hip or other fracture, caused by the fall. Therefore, several developments and studies in the past have tried to sense this event also without using wearables. Pressure mats, infrared (**Ariani et al., 2010**), and capacitive sensor grids have been developed for this purpose. At the moment the capacitive sensor floor “SensFloor” (**Future Shape, 2016**) is already on the market, used in retirement homes. However, such types of sensor floors are expensive and cannot perform efficiently in areas such as the bathroom, because of the presence of humidity in these environments, which could lead to false detected fall events. In such cases an alternative system which used laser-based sensors could enhance the robustness and provide more security to the end user of the REACH system.

5.5.8 Cameras and imaging

Even normal web-cameras can be used to detect physical conditions, such as the pulse of a person. The proposed source code provided by **Wei et al. (2013)** allows to

measure the pulse on the forehead. However, only when the lighting conditions are proper, the measurement can be done efficiently. Of course also by using a web-camera the user activities can be tracked, and analyzed, similar as can be done by using the Microsoft Kinect, with the difference that the depth information is missing. However, most end users do not appreciate much monitoring by cameras.

5.6 Wearables, sensing and prediction

For a reliable analysis concerning needs and opportunities with respect to sensing and prediction, EPFL surveyed longitudinal studies for behavioral changes, and identified their experiment setup and interventions. EPFL used this information to understand the trends and opportunities in longitudinal study designs for behavior change. EPFL analyzed 15 longitudinal studies from the fields of human-computer interaction, preventive healthcare, and behavior science. 2 of them were eliminated since they did not contain interventions. The remaining 13 studies were summarized based on the following features: Year of study, number of participants, length of the study, sensor-based/automatically collected data types, manually collected data types (either expert reports or self-reported), experiment setup (baseline groups and/or randomized controlled trials (RCTs), intervention dates and types of intervention.

The rest of this section is organized as follows: (1) analysis summary, (2) the table for comparison, and (3) competitive analysis map figures, and (4) identified opportunities and needs with respect to sensing and prediction - a design for our REACH's own longitudinal study.

5.6.1 Analysis of 15 longitudinal studies

Summarization of analysis outcomes:

1. Sensing/wearables, prediction and longitudinal studies: Both the number of longitudinal studies regarding wearable sensor-based, and the user acceptance for wearing sensors are increasing. The sensor technology now makes it feasible to collect temporal information about physical activity, water intake, weight, emotions, and blood glucose levels in a seamless manner. All these information are important for a sensor-based wellness management system.
2. The lengths of such studies are very variable - 2 weeks to 3 months, with an average of 50 days. Earlier studies in 2006 (**Lin et al., 2006**) and 2009 (**Chiu et al., 2009, September**) were particularly longer; the average drops to 46 days when they are excluded. Average number of participants in a longitudinal study is $N=36$.
3. Interventions come in the form of:
 - a) increased means of self-reflection
 - b) social influence
 - c) gamification/rewards
 - d) persuasive messages (or reminders) to change behaviors
 - e) mandatory setting of goals.
4. The majority of the sensor-based studies include "baseline periods" to justify the effects of their interventions. These approaches either allocate a period of sensor-

- based data logging before the intervention, or provide a detailed documentation of participants' behavioral habits before the intervention.
5. Only one study - “Fish’n’Steps” (Lin *et al.*, 2006) - considered tracking post-intervention phase. This is an important design aspect, as it allows us to observe whether the intervention had lasting effect.
 6. Many sensor-based longitudinal studies miss the RCT methodology, which is considered to be the golden standard for clinical trials. Such longitudinal studies involve a group of users that do not get exposed to the technology intervention.

5.6.2 Table of comparison of study designs

Table 24: The studies included in our analysis

Study	Year	N	Length	Sensor Data?	Non-sensor data?	Baseline/RCT?	In-study Interventions?	Type of Intervention
[1] Bentley et al. (Health Mashups)	2013	60	90 days	Location, weather, calendar, step, sleep, weight	Food, mood, pain	Baseline	Mobile app introduced after 3 weeks	Self reflection, reminders
[2] Cafazzo et al. (mHealth App)	2012	20	12 weeks	blood glucometer	14-item self care inventory	Baseline	Mobile app introduced	Social influence, rewards
[3] Chen & Pu (HealthyTogether)	2014	36	2 weeks	steps, floors, calories	food, mood	Baseline	mobile app introduced after 1 week	Social influence
[4] Chiu et al. (Playful Bottle)	2009	16	7 weeks	water intake	N/A	Randomized Controlled Trial	mobile app introduced after 3 weeks	Social influence
[5] Epstein et al. (Lifelogs)	2014	13	1 month	Steps	N/A	Baseline	Mobile app introduced	Self reflection
[6] Isaacs et al. (Technology mediated reflection for well-being)	2013	38	4 weeks	N/A	Memory and mood	Randomized Controlled Trial	Visualization software introduced	Self reflection
[7] Jones et al. (The FIT game)	2014	251	3 months	Weight scale	N/A	Baseline	After 2 weeks	social gamification
[8] Kaptein et al. (Adaptive Persuasive systems)	2012	73	2 weeks	N/A	Snacking frequency	Baseline	After 1 week	persuasive messages
[9] Lin et al. (Fish'n'Steps)	2006	19	14 weeks	steps	N/A	Baseline	4 week pre-intervention, 6 weeks intervention, 4 weeks post-intervention	goal setting
[10] Mueller et al. (Jogging study)	2012	32	22 runs	heart rate	N/A	Baseline	Mobile app introduced	social gamification
[11] Riva et al.	2014	51	8 weeks	N/A	Diary	Randomized Controlled Trial	interface introduced after 4 weeks	goal setting, gamification, reminders
[12] Thorsteinsen et al.	2014	21	3 months	N/A	self reported physical activity	Randomized Controlled Trial	mobile app introduced after 4 weeks	goal setting, gamification, self reflection
[13] Zuckerman and Gal-Oz (StepByStep)	2014	40	2 weeks	steps	N/A	Baseline	Mobile app introduced	Rewards and social influence

5.6.3 Competitive analysis maps

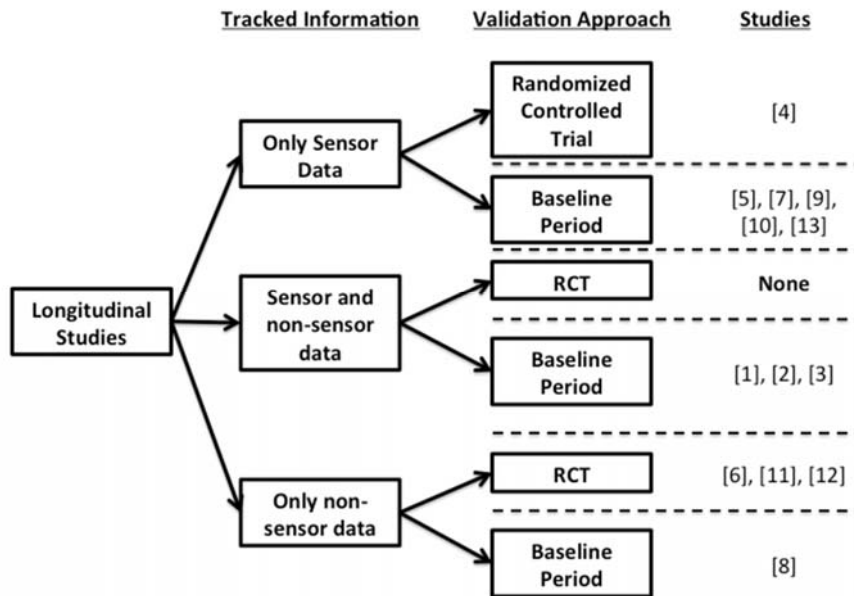


Figure 34: Segmentation of studies based on tracked information and validation approaches

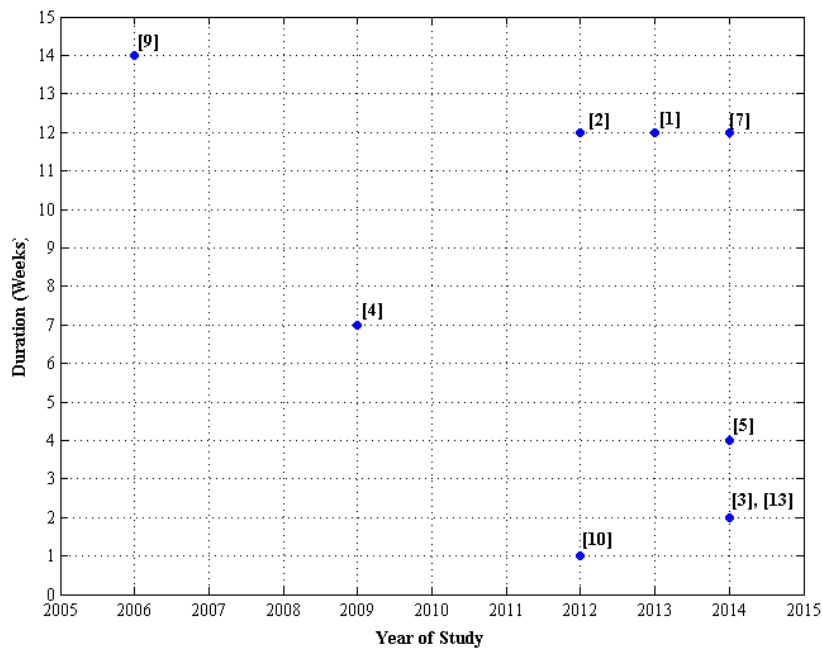


Figure 35: Segmentation of sensor-based longitudinal studies based on their duration and the date of conduct.

- | | |
|--|--|
| [1] (Bentley <i>et al.</i> , 2013) | [2] (Cafazzo <i>et al.</i> , 2012) |
| [3] (Chen and Pu, 2014) | [4] (Chiu <i>et al.</i> , 2009, September) |
| [5] (Epstein <i>et al.</i> , 2014, June) | [6] (Isaacs <i>et al.</i> , 2013, April) |
| [7] (Jones <i>et al.</i> , 2014) | [8] (Kaptein <i>et al.</i> , 2012) |
| [9] (Lin <i>et al.</i> , 2006) | [10] (Mueller <i>et al.</i> , 2013, April) |
| [11] (Riva <i>et al.</i> , 2014) | [12] (Thorsteinsen <i>et al.</i> , 2014) |
| [13] (Zuckerman and Gal-Oz, 2014) | |

5.6.4 Identified opportunities and needs

Opportunities: In the context of REACH, a sensor-based prediction application can predict the outcomes of interventions and other attempts for behavioral change. The sensor-based longitudinal studies analyzed in **Table 24** and in **Figures 34** and **35** clearly indicate the viability of such an application: the sensor technology now makes it feasible to collect temporal information about physical activity, water intake, weight, emotions, and blood glucose levels in a seamless manner. Such data is known to be more reliable than self-reported information, and can be collected with high levels of granularity.

Needs: Such an application requires a dataset that is (1) large and (2) well-annotated.

1. **Satisfying the largeness requirement:** Our analysis shows that REACH can satisfy this requirement in two aspects: Firstly, the data should be collected over a long period of time. The analysis suggests that 6 to 8 weeks of data collection will start to yield acceptable. Secondly, the collection should include as many streams of information as possible (for instance: physical activity, water intake, weight, emotions, and blood glucose levels). These streams should be supplied from especially the wearable sensors.
2. **Satisfying the annotation requirement:** Manual annotation of every segment of sensor data is prohibitively expensive. Fortunately, given a rigorous annotation of interventions (date and type; well-being values before and after the intervention), it is still possible to assess the significance of these interventions, which would lead to tailoring better recommendations and interventions – thus, allowing us to address the opportunities.

According to the different use case descriptions from HUG, SK, ZZ and Lyngby, the type of data that will need to be sensed include:

1. Movement (position in space, mechanical force, acceleration, steps, duration...)
2. Calories expenditure
3. Blood pressure
4. Heart rate
5. Weight
6. Cerebral activity (Electroencephalogram)
7. Treatment observance (number and nature of pills taken, for instance through the use of connected pill-boxes)
8. Blood glucose levels
9. Oxygen saturation
10. Measure of food/calorie intake
11. Smoke detection
12. Of course, all of these correlated to time

These data should ideally be collected through longitudinal studies using a RCT methodology that also includes a baseline period and a post-intervention phase with a sufficient data volume and annotation. This will allow the development of algorithms able to identify patterns of data associated with successful or temporary behavior

change, as well as with the evolution of a given patient's health; all of which could be addressed with specific interventions. These specific interventions or recommendations may include:

1. Promotion of physical activity
2. Target oriented exercise and training
3. Mobilization and rehabilitation
4. Cognitive and neurological activation
5. Prevention of falls
6. Continuation and adaptation of physical therapy
7. Suggestion of treatment adaptation based on sensed parameters
8. Alarm in case of fall or important change in sensed parameters (blood pressure, oxygen saturation etc.)
9. Brain exercise
10. Meal reminder and planning
11. All of these eventually shared with formal and informal care-givers
12. Social support: grouping people with each other to achieve daily goals for nutrition and physical activities

5.6.5 *Longitudinal study design*

Figure 36 summarizes a study design for data collection. The sensors in this design are intentionally unspecified: depending on the course of the project, they could be a combination of the hardware developed during the REACH project, and off-the-shelf sensors such as FitBit.

Longitudinal User Study Design For Wearable Sensor-Based Health Monitoring With Technology-Mediated Interventions

Brief

A longitudinal study involves users in an experiment over an extended period of time. We investigate how technology-mediated interventions can improve the self-efficacy of users, and help them achieve active lifestyles. We propose a **randomized controlled trial**, where we monitor two groups of patients. One group starts using a wearable sensor 3 weeks after the start. The diagram below shows how Agata, a typical participant, would undergo this user study.

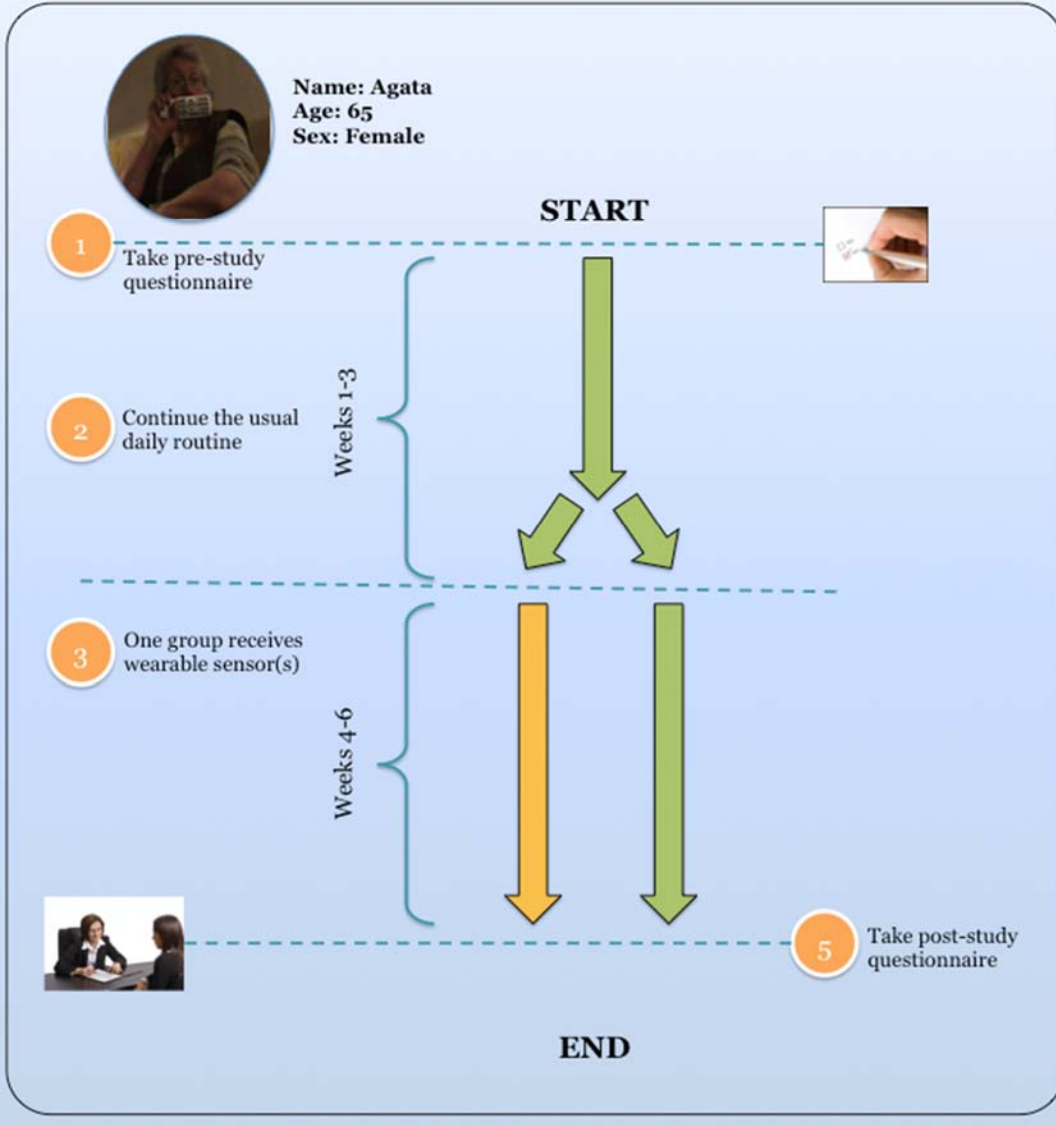


Figure 36: Longitudinal study design based on the analysis of the opportunities and needs with respect to sensing and prediction

6 Conclusion: potential of the utilization of REACH and initial, concrete use scenarios

This deliverable report presented the outcomes of the analysis (including on-site analyses, stakeholder identification, identification of used assessment practices, patient profiles, personas, interviews with patients and stakeholders, etc.) of the as-is situation and practices at the use case partner's settings and the formulation of first, initial use scenarios (including concrete application opportunities/experience maps for each setting, opportunities arising from transfer through institutions/settings, technological potentials and opportunities, etc.). To accomplish this task first, an analysis framework (**Section 2**) was developed (Month 1), then the analysis was carried out (Month 2), and finally conclusions were drawn (experience maps, scenarios, opportunities, etc.; Month 3). Key feature of the analysis was an in-depth analysis of more than 50 real-world end-user profiles. In this section based on the analyses of the four use cases (**Section 3**), their comparison (**Section 4**), and the identification of technological potentials (**Section 5**), it is concluded how the use cases can be brought into logical arrangements (scenarios) that represent the care continuum at the transition between use cases, how potential scenarios for the use of REACH with in each use case look like, how technology can be used in that context, and how requirements formalization will be accomplished in upcoming work tasks.

6.1 Utilization of REACH cross use cases along the care continuum

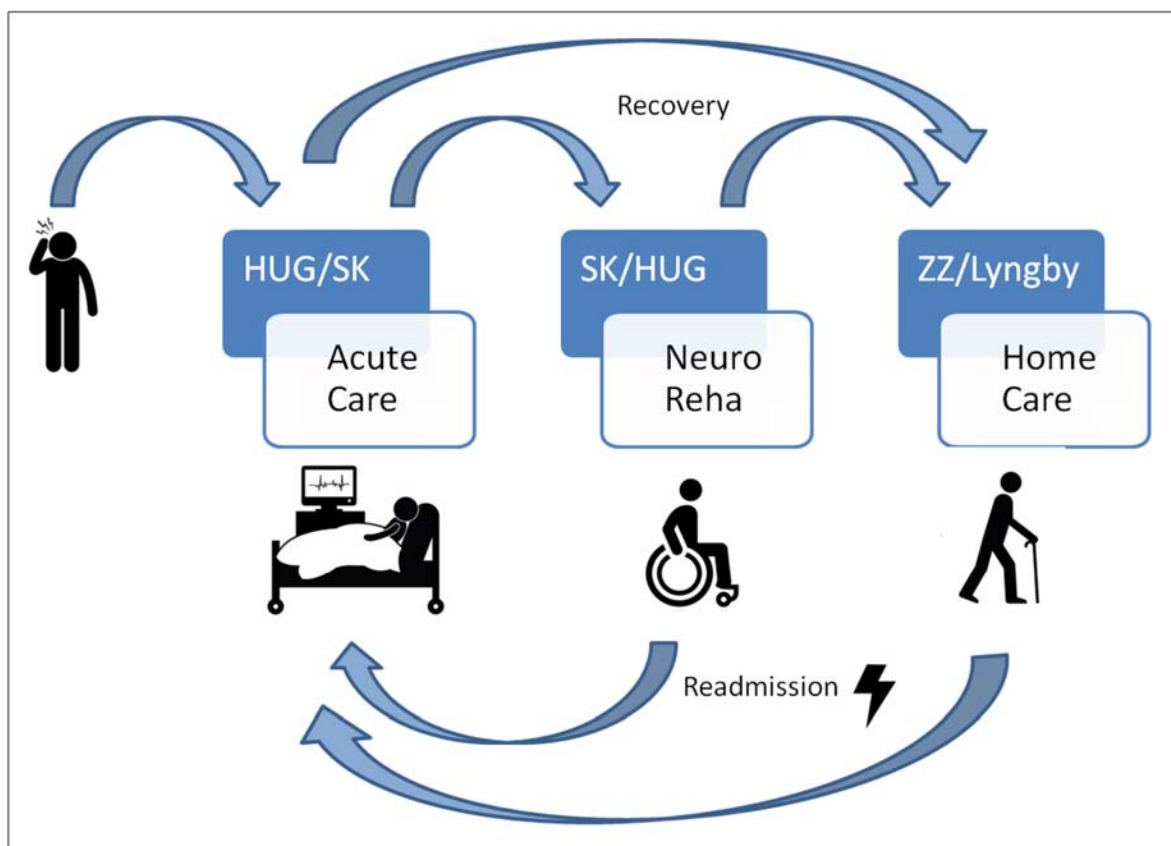


Figure 37: Patient transition between use cases

The analysis showed that the four use cases cover the different stages of the health and care process that an elderly citizen may experience in his daily life. They can thus be considered not only as separate instances in which REACH functionality can be integrated, but they can be brought into a logical arrangement (scenario) that represents the care continuum and the transition between use cases or health states (**Figure 37**).

The use case partners thus represent usual and also in the context of the MAFEIP addressed “health state dimension” addressing the most relevant ways or transfer possibilities of elderly citizens through various health states and institutions (e.g. from hospital to rehabilitation to home in case of a health state improvement; alternatively, from home to hospital/rehabilitation in case of a health state deterioration). REACH can be adopted in each of the represented health states/use cases, should –if necessary– be able to move with the elderly through the various health states/institutions and optimally activate and rehabilitate elderly citizens to and active and healthy life at home.

The use case partners thus represent the REACH “system development strategy” and development activities will in the beginning phases of the project target the more structured environments (clinic/HUG; rehabilitation/SK) for efficient requirements

engineering and system implementation and verification. Furthermore, the technically more complex solutions that are demanded for these use cases can then in later project phases be stepwise (in an adapted and simplified form) transferred into the home care (ZZ) and smart home (Lyngby) contexts and open new markets in this filed for the REACH industry partners.

6.2 Potential of the utilization of REACH in each use case

REACH will develop a sensing-monitoring-intervention system that can be placed in an unobtrusive and customized manner in various settings (in this report called use cases) and the living environment of elderly citizens. The system will be able (1) to use a set of sensors to detect selected vital signs, behavioral/care patterns, and health states, (2) predict – as early as possible - future health states, risks or events (loss of function, frailty, stroke, etc.) and (3) provide and coordinate proactively a set of customized services and products. Early intervention by REACH should allow that the time spent in a desirable health state (baseline health), and Healthy Life Years (HLYs) are increased and that the time spent in Long-Term Care (LTC) facilities is reduced. For the use cases HUG and SK this means that REACH intervention will make the rehabilitation process faster and more efficient with the goal to bring the elderly citizens optimally back to their home environments. For the use cases ZZ and Lyngby REACH will develop interventions that proactively activate and train elderly cognitively and physically in order to reduce their risk to develop from baseline health towards a deteriorated health state.

As part of the analysis (particularly through the experience maps produced) a focus was put amongst others on daily routines to identify the potential of the utilization of REACH in each use case which is summarized for each use case in the following sections (**Sections 6.2.1–6.2.4**)

6.2.1 Geneva Hospital (HUG)

For HUG in accordance with the REACH concept and our focus, the target population consists of patients in the age 65+ with functional and/or cognitive impairment. They are hospitalized in the geriatric hospital of Geneva (Hôpital des Trois-Chêne) with a planned discharge to home care provided by the public Institution genevoise de Maintien A Domicile (IMAD). The IMAD supports more than 19.000 persons per year. Specific scales described in the assessment methods and analyzed with the methods patient profiles and personas, were used to specify the degree of physical and cognitive impairment of the REACH target users at HUG.

The HUG hospital to (rehabilitation to) home transition comprises a critical period in patient care and this particular aspect was emphasized in the overall aim of this use case: to facilitate the hospital to home transition and the home care, in order to limit hospital readmissions and long-term care. In accordance with this aim and the geographical location of HUG, the two main organizations in direct contact with the REACH target population will be the Institution IMAD for home care and the Geriatric Division at HUG for hospital care. Regarding the development of REACH, the eHealth

and Telemedicine Division at HUG will act as a field partner and the Human Computer Interaction Group at EPFL and SmartCardia will be involved in the technical development.

Based on the analyses conducted HUG formulated following key needs that should be addressed by REACH:

1. Advanced sensing and prediction: Focusing on important problems linked to hospital readmission (falls, heart failure, dangerous situations induced by cognitive impairment).
2. Collaborative tools: Include a collaborative tool that facilitates interactions between patients and their formal and informal care givers, empowering social or medical support. REACH must not dehumanize the care for elderly.
3. Privacy and autonomy: Respect patients' privacy and autonomy: REACH monitoring and recommendation activities have to be easy to turn off when a patient decides to do so. Moreover, sharing of REACH records with care givers or family member must be both easy to turn on and easy to cancel.

6.2.2 *Schön Klinik (SK)*

SK is a neurological rehabilitation hospital where rehabilitation aims at reducing the impairment and handicap of patients and thus improving their independence from nursing. Rehabilitation is organized according to medical specializations (neurology, orthopedics, cardiology, psychosomatics, etc.) or age (pediatric or geriatric rehabilitation). The treatment is based on relearning and exercising of prior abilities or compensation strategies.

Based on the analyses conducted SK formulated the following key needs that should be addressed by REACH:

1. Improving mobility: The problem of a patient with a severe paresis of one or both legs or a disorder of equilibrium is that he/she cannot get up, cannot walk and may even not be able to manage the transfer from bed to wheel chair, from wheel chair to toilet and back. For such a patient it may be impossible to live at home if a nursing person is not present permanently. Even if he/she was transferred in the morning by a nursing person from the bed into the wheel chair he/she cannot be left alone for several hours because sitting permanently, hardly being able to change the sitting position, leads to pain in the lower back and bottom and may lead to pressure sores. Therefore it is desirable that the patient can change his/her position and recline into a lying position. As urination is necessary at irregular time intervals the patient should also be able to position himself over the toilet. So a wheel chair which allows toileting and may change the position of the patient actively up to a recumbent position reduces nursing demand and allows to leave the patient alone for several hours during the day.

2. Improving the manipulation of objects: As a consequence of strokes in the territory of the medial cerebral artery (the most common form of stroke) a palsy of one arm frequently remains. The patient can use his/her healthy arm for some tasks, but he/she cannot handle a situation where he/she needs both arms, one to manipulate an object, the other to keep hold of the object so that it stays in place in spite of the manipulation, i.e. the forces exerted by the other hand. Situations like that are frequent in everyday life (cleaning any mobile objects, slicing bread, preparing a sandwich etc.). To compensate for the function of the affected hand an arm with a gripping device which can be deliberately positioned by the healthy hand in 3D-space would be of great help and thus increase independence of the patient.
3. Improving cognition by reminding the patient: Memory deficits, a main symptom of dementia, are a very common and increasing problem in the elderly. As shown in our persona these patients may forget to measure their blood pressure or take their medication. Such problems may be relatively easily solved by a computer system asking the patient after predetermined intervals whether he/she has executed the demanded action. More demanding is the wish of the persona to be reminded of the names of persons he/she meets. This requires a system able to recognize faces and name the person correctly via an in-ear device. Much more difficult is the surveillance of patients with further progressed dementia which tend to be restless and leave their home not able to find the way back because of the memory deficit. Here a complex analysis of the behavior of the patient is necessary which requires permanent optical surveillance, the acceptance of which will be questionable. Also in such patients reminding may be insufficient as they might be physically hampered and bring themselves into dangerous situations. So a device reminding the patient is only applicable in patients with mild memory deficits and not in patients with severe dementia.

6.2.3 ZuidZorg (ZZ)

ZuidZorg Extra is a business unit of ZuidZorg, a large home care organization in the southern part of the Netherlands. ZuidZorg Extra has about 50.000 members who pay annual subscription to have access to our services and enjoy price reduction in our homecare shop and on special products and facilities such as collective health insurance. Members contact us if they need particular services from suppliers such as gardeners or a hairdressers.

Based on the analyses conducted ZZ formulated the following key needs that should be addressed by REACH:

1. ZuidZorg Extra aims to achieve independent living for the elderly, especially for those who are frail to some extent. This can be achieved by increasing and strengthening the social network around the elderly and through empowerment and motivation to enhance self-sufficiency.

2. These are the two main design opportunities for ZuidZorg Extra:
 - a. Increasing the social comfort by strengthening the social network.
 - b. Empowering the elderly to take care of themselves and motivate them to achieve this.

Some questions can be derived from the gained user insights and the customer journey maps, with focus on the previous design opportunities:

- a. How could the threshold be lowered for elderly to travel between their house, the activity center, and other public spaces? This threshold is detected as one of the barriers that have to be overcome to enable the elderly to leave the house more often and get socially involved.
 - b. How could self-reliance be increased to enable frail elderly to feel more in control of their life? The interviews showed that many frail elderly struggle with the feeling of being dependent on others. When the feeling of self-reliance becomes stronger, their feeling of empowerment and motivation could increase.
3. The overall outcome for the elderly should emphasize their social and physical wellbeing.

6.2.4 Lyngby-Taarbæk Municipality (Lyngby):

Lyngby-Taarbæk Municipality delivers Home Care and Health Care for more than 2.200 citizens. For 75+ years old citizens, one out of three (33%) receives Home Care and Health Care. Home Care and Health Care are provided primarily by public employees. For the municipality the main opportunities in the context of REACH are to provide the background for a reduction of the number of citizens in Home Care and Health Care in the future.

Based on the analyses conducted Lyngby formulated the following key needs that should be addressed by REACH:

1. The citizens can be and feel safe without the care
2. The citizens will be motivated and empowered to live an active life both socially and physically.
3. REACH will provide necessary user information to conclude the following:
 - a) How can different kind of home integrated REACH products and services motivate citizens into activity, in order to prevent lack of physically functionalities?
 - b) Can REACH products replace persons and still provide safety?
 - c) What kind of reaction is received from users, their families and friends and what is the reaction from the employees?

4. The outcome of REACH for the citizens must be better service and security and at the same time reduction of costs for the municipality.

6.3 Technological potentials and scenarios

The core idea of REACH is not to (passively) assist elderly people but to use technology to efficiently *activate and rehabilitate* their bodily and cognitive resources (physical activity, cognitive activity, nutrition, mobility, etc.) and through that allow for better health, less frailty, better accomplishment of tasks/ADLs, etc. and thus ultimately for health-adjusted life years. Throughout the four use cases sensors placed in the environment or at the body of the person, the detection of everyday living patterns (emotions, calories burned, physical activity, cognitive functions, etc.) can be realized, as well as the prediction of possible future health state, to allow thus targeted, customized interventions that “activate” the persons.

Analyses and initial discussions amongst the partners indicate that particular importance, regarding the parameters that need to be obtained by sensors, must be given to: (1) accomplishment of tasks (2) structure/ organization of the day (3) motivation/emotions, (4) muscle function analysis (as the basis for frailty detection), (5) energy expenditure (real time and/or time series approach). An optimal combination of ambient integrated/embedded (contactless) sensors and wearable sensors need to be used, acquiring some measurements in real-time and some at specific instances in time with enhanced accuracy and reliability. In order to counteract physical and cognitive inactivity detected by sensors, approaches from the field of medical rehabilitation and mobilization devices as well as from the field of fitness and ADL training will be utilized and brought along with additional digital or personal services into a modular and customizable kit system. Both sensors and intervention devices shall be embedded in an unobtrusive manner in furniture (in case of ZZ and Lyngby) or rehabilitation/hospital equipment and beds.

REACH should be highly modular in order to allow an adaptation to various use cases/scenarios and to be able to adapt/evolve over time with the user. A digital platform and interior equipment modules should serve as digital/physical platforms that tie together a variety of products and services developed within REACH. The system should be able to follow the elderly person through different life phases, use cases and health states (e.g., from light frailty to more severe frailty), institutions (e.g. from clinic to care home to home; or vice versa), and environments/settings. REACH should adopt an “evolutionary” approach and allow that the system should be able to “assemble” and “dis-assemble” itself (e.g., from light frailty to more severe frailty and optimally back to light or no-frailty). Privacy, data security and ethics are considered as key regarding the acceptance and usability of the REACH system.

6.4 Next step: requirements engineering

As part of T1.1 (outlined in this deliverable report) the as-is situation of the four use cases was analyzed and relevant problems, stakeholders, were identified and initial,

use scenarios were formulated. In the following T1.2 the system vision will be detailed, an in-depth stakeholder analysis (with stakeholder workshops at each use case partner's site) will be conducted, and as part of a "requirements engineering" process, requirements will be elicited and formalized. Then, in T1.3 these requirements will be prioritized and selected, and an initial value proposition and product-service-system concept will be developed together with the stakeholders. Finally, in T1.4 the product-service-system architecture (modularity, standards, software architecture, etc.) will be detailed.

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8 Enclosures

HUG application to the Geneva state ethical committee

(see page 120 and following pages)

9 Appendix

9.1 Appendix ZuidZorg use cases

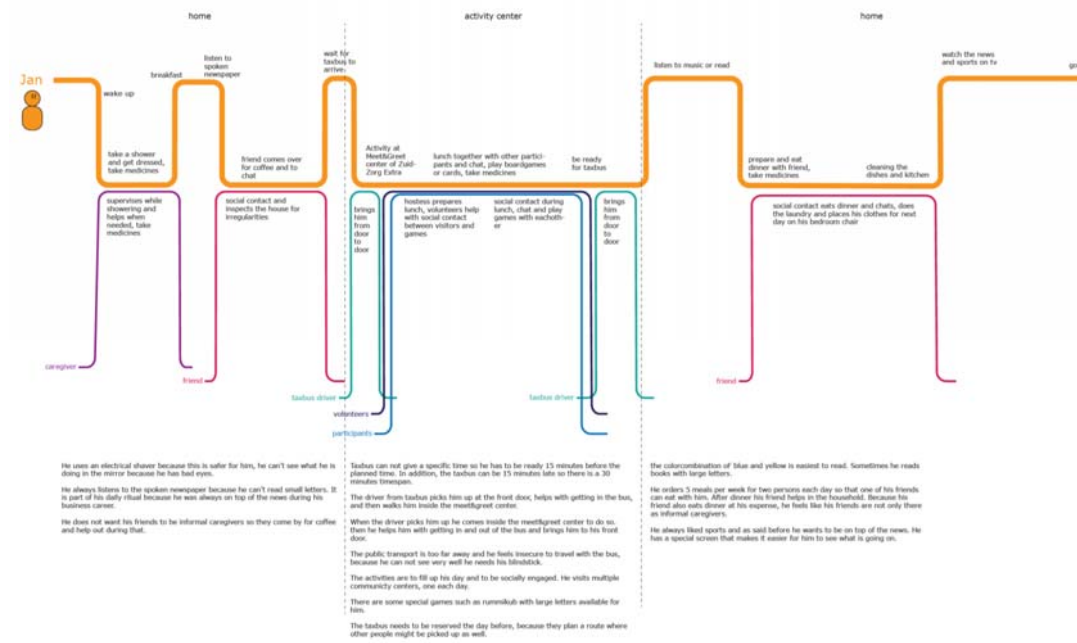


Figure 38: Experience mapping of persona Jan

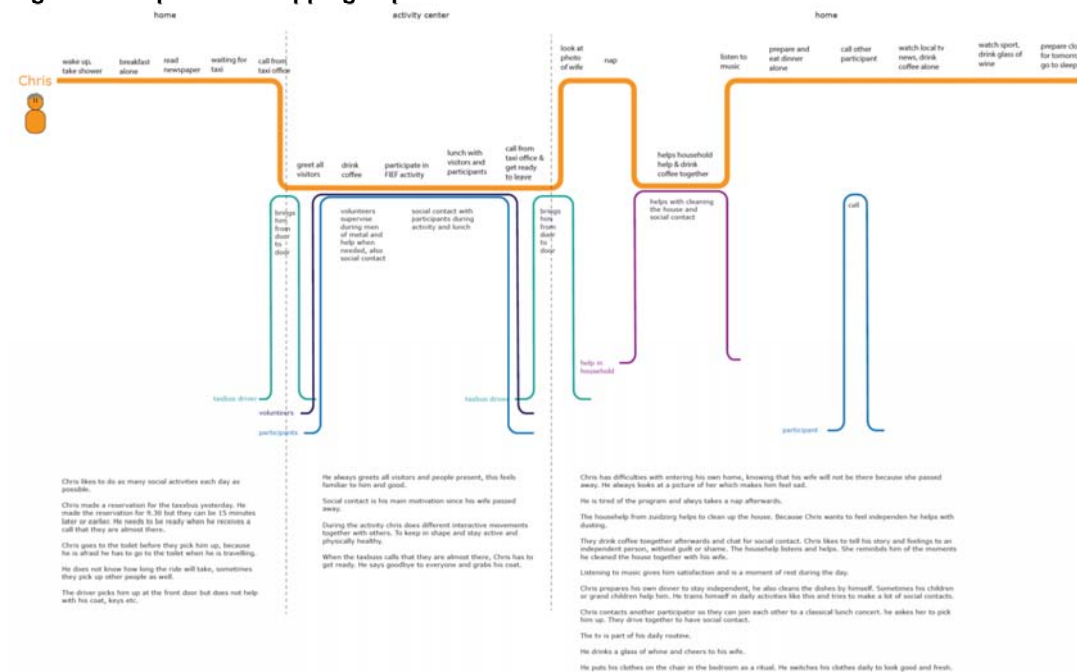


Figure 39: Experience mapping of persona Chris

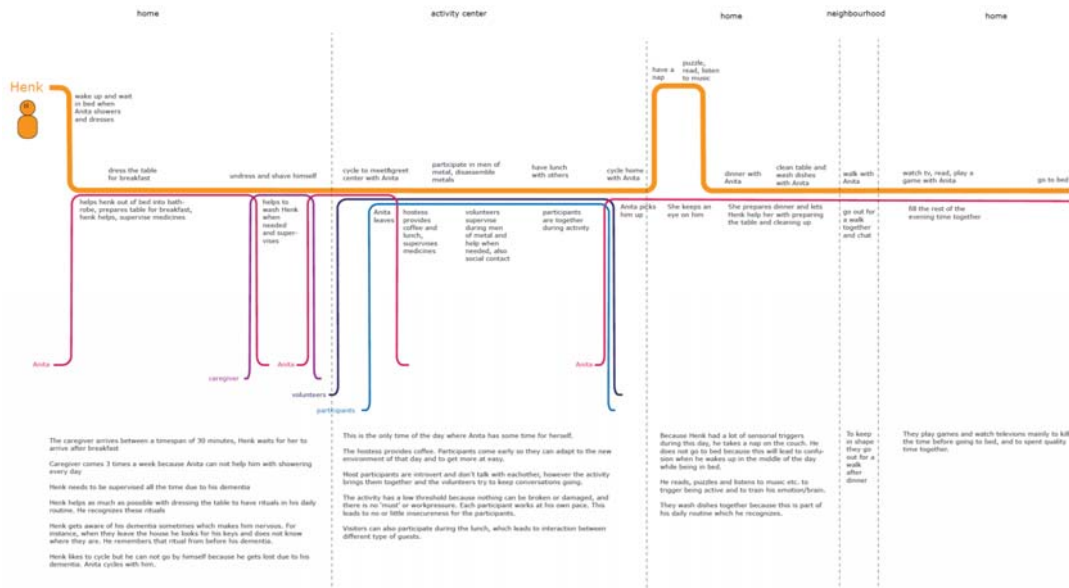


Figure 40: Experience mapping of persona Henk

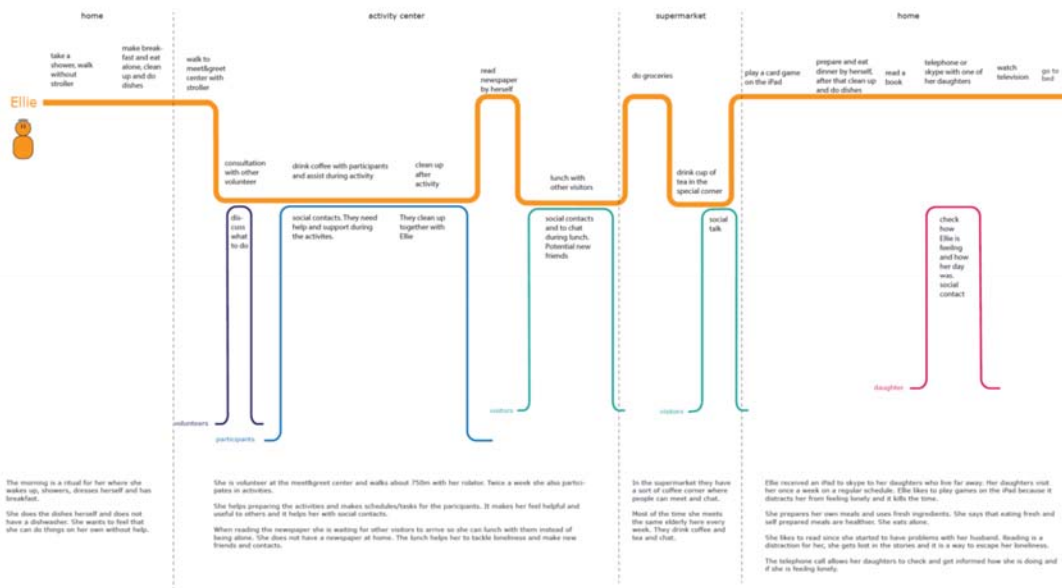


Figure 41: Experience mapping of persona Ellie

Commission cantonale d'éthique de la
recherche (CCER)
8 Rue Adrien-Lachenal
1207 Genève

Genève, le 7 avril 2016

Département
d'Imagerie et des
Sciences de
l'Information
Médicale

Service de
cybersanté et
télé médecine

N/réf : AG
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Concerne : soumission de l'étude intitulée « Etude de la population-cible du projet de recherche européen REACH ».

Mesdames et Messieurs les membres de la commission cantonale d'éthique de la recherche,

Merci de trouver ci-joint notre dossier de soumission pour l'étude intitulée « Etude de la population-cible du projet de recherche européen REACH ».

Cette étude aurait lieu dans le cadre du projet de recherche européen REACH qui vise à développer un outil technologique capable de promouvoir l'autonomie, la littératie et la condition physique des personnes d'âge gériatrique avec une limitation de l'autonomie, afin de favoriser le maintien à domicile, faciliter la transition hôpital domicile et éviter les ré-hospitalisations.

Dans le but de guider le développement technique futur de REACH, nous souhaiterions étudier notre population-cible. Pour ce faire, nous prévoyons de réaliser :

- Une extraction de données du dossier médical des patients ciblés par REACH après obtention de leur consentement, afin d'obtenir leurs caractéristiques médicales et démographiques globales.
- Des interviews semi-structurées auprès de patients, proches-aidants et soignants après obtention de leur consentement, pour recueillir leurs attentes et inquiétudes vis-à-vis du développement de REACH.

Nous espérons que notre dossier saura satisfaire aux exigences de votre commission. Les instructions les plus récentes disponibles sur votre site internet et celui de swiss ethics ont notamment été suivies.

Dans l'attente de vos nouvelles, je vous adresse mes plus sincères salutations,



Prof. Antoine Geissbuhler
Médecin-chef de service

Plan de recherche

Titre principal : étude de la population cible du projet européen REACH.

Titre utilisé sur le formulaire de consentement : étude de la population cible du projet européen REACH.

Numéro de projet	690425 (numéro de demande de financement horizon 2020)
Type de projet de recherche	Cette étude, observationnelle et transversale comprend <ul style="list-style-type: none">- Etude de données existantes issues du dossier médical, qui seront anonymisées.- Bilan d'ergothérapie au cours desquels de nouvelles données seront collectées puis anonymisées.- Des interviews semi-structurées et des groupes de discussion auprès de patients, proches-aidants et soignants dans lesquels de nouvelles données seront collectées et anonymisées.
Catégorie de risque	A pour les interviews semi-structurées, groupes de discussion et bilan d'ergothérapie. Non applicable pour l'extraction de données du dossier médical.
Chef de projet	Prof. Antoine Geissbühler, chef du service de cybersanté et télémédecine, Hôpitaux Universitaires de Genève, Rue Gabrielle-Perret-Gentil 4, 1205 Genève, +41 (0)22 372 62 01
Problème de santé étudié	Limitation de l'autonomie des personnes âgées. Phénomène de ré-hospitalisation. Application de nouvelles technologies pour lutter contre ces problèmes.
Durée du projet	6 mois.
Version et date du document	Version 1.0, 04.04.2016.

Confidentialité

Les informations présentées dans le document sont confidentielles et la propriété du consortium de recherche REACH. Ces informations ne peuvent donc pas être transmises à d'autres personnes que celles impliquées dans la commission cantonale d'éthique de la recherche de Genève, sauf après autorisation du consortium REACH.

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SYNOPSIS

Chef de projet	Prof. Antoine Geissbühler, chef du service de cybersanté et télémédecine, Hôpitaux Universitaires de Genève, Rue Gabrielle-Perret-Gentil 4, 1205 Genève, +41 (0)22 372 62 01
Titre du projet	Etude de la population cible du projet européen REACH
Numéro de financement européen Horizon 2020	690425
Version et date	Version 1.0, 04.04.2016
Catégorie de risque	A pour les interviews semi-structurées, groupes de discussion et bilan d'ergothérapie, non applicable pour l'extraction de données issues du dossier médical.
Type de recherche et design	<p>Cette étude, observationnelle et transversale comprend</p> <ul style="list-style-type: none"> - Etude de données existantes issues du dossier médical, qui seront anonymisées. - Bilans d'ergothérapie au cours desquels de nouvelles données seront collectées puis anonymisées. - Interviews semi-structurées et groupes de discussion auprès de patients, proches-aidants et soignants dans lesquels de nouvelles données seront collectées et anonymisées.
Etat des connaissances et problématique	<p>La direction générale des affaires économiques et financières de l'Union Européenne (UE) prévoit une augmentation des coûts de la santé de 350% d'ici à 2050. Les hospitalisations de longue durée, de plus en plus fréquentes dans le contexte du vieillissement de la population, sont responsables d'une part importante de cette inflation.</p> <p>Le projet REACH (Responsive Engagement of the elderly promoting Activity and Customized Healthcare), financé par le programme Horizon 2020 de l'UE, tente de répondre à cette problématique. Il vise à combiner les expertises de 18 partenaires afin de développer un produit technologique capable d'agir positivement sur l'état de santé général, la condition physique, l'autonomie et la littératie de la population gériatrique pour limiter les admissions en soins de longue durée.</p> <p>Techniquement, tout reste à faire mais un concept est imposé : utiliser des signaux issus de capteurs insérés dans des meubles ou portés afin de fournir des recommandations de santé en temps réel aux patients et éventuellement de les accomplir. Les données pourraient être de toute sorte (mouvement, tension artérielle, quantité de nourriture, etc.) mais seraient collectées de manière non-invasive.</p> <p>Afin de guider la phase de développement technique, nous souhaitons dans un premier temps étudier notre population cible, notre service se focalisant particulièrement sur la transition hôpital-domicile et la limitation du phénomène des ré-hospitalisations.</p>
Objectifs	<ul style="list-style-type: none"> - Déterminer les caractéristiques démographiques et médicales de notre population-cible. - Recueillir les attentes et inquiétudes des patients, proches-aidants et soignants vis-à-vis de REACH. - Déterminer d'éventuels liens entre attentes, inquiétudes et données démographiques et médicales dans le but de créer des profils-types d'utilisateurs permettant un développement ciblé de REACH.

Critère d'inclusion, d'exclusion	<ul style="list-style-type: none"> - Inclusion des patients : patients âgés de 65 ans et plus ET hospitalisés à l'hôpital des Trois-Chênes avec un retour à domicile prévu avec l'aide de l'IMAD ET une limitation de l'autonomie en raisons de facteurs somatiques ou cognitifs (défini par $21 \leq \text{MMSE} \leq 27$ OU $64 \leq \text{MIF} \leq 120$). - Inclusion des proches-aidants : proches-aidants des patients recrutés, fournissant une aide au minimum 1x/semaine pour les activités de la vie quotidienne, les activités instrumentales de la vie quotidienne ou les loisirs. - Inclusion des soignants : soignants de l'hôpital des Trois-Chênes ou de l'IMAD en contact régulier (minimum 2 jours par semaine) avec des patients correspondant aux critères d'inclusion. - Exclusion des patients: $\text{MMSE} \leq 20$, $\text{MIF} \leq 63$, incapacité d'interagir avec une interface homme-machine, incapacité de discernement.
Read-outs	<p>A partir d'une collecte de données issues du dossier médical des patients, éventuellement complétée d'un bilan ergothérapeutique, nous définirons les caractéristiques médicales et démographiques globales de notre population.</p> <p>A partir des interviews semi-structurées et groupes de discussion, nous recueillerons les attentes et inquiétudes des patients, proches-aidants et soignants vis-à-vis de REACH.</p> <p>Enfin, par analyse statistique, nous tenterons de déterminer d'éventuels liens entre attentes, inquiétudes et données démographiques et médicales dans le but de créer des profils-types d'utilisateurs permettant un développement ciblé de REACH.</p>
Nombre de participants	<p>Minimum 20 participants de chaque catégorie. La catégorie des proches-aidants apparaissant comme la catégorie limitante probable, le recrutement des patients sera poursuivi jusqu'à atteindre 20 proches-aidants.</p>
Durée du projet	<p>6 mois. Le projet débiterait le plus tôt possible après accord de la CCER.</p>
Centres	<p>Hôpital des Trois-Chênes</p>
Considérations statistiques	<p>Etant donné qu'il n'existe pas, à notre connaissance, d'étude similaire dans la littérature nous permettant d'estimer la taille d'échantillon nécessaire à l'obtention d'une image exacte de notre population cible, nous proposons d'inclure au minimum 20 patients, soignants et famille sur la durée de l'étude.</p> <p>Nous pensons que cette taille d'échantillon devrait nous permettre de répondre au but de cette étude qui est d'obtenir une première idée sur les caractéristiques, attentes et inquiétudes de la population-cible de REACH.</p>

Risque-bénéfice	<p>Lors de cette étude, les patients donneront, ou non, leur consentement éclairé pour la collecte de données issues de leur dossier médical et la réalisation d'un bilan ergothérapeutique et d'une interview (à noter que lors de cette dernière, les données collectées seront majoritairement non liées à la santé). Les données seront anonymisées et stockées sur un ordinateur dédié dans un lieu sécurisé (Campus Biotech, Genève). La clef d'identification sera stockée sur un autre ordinateur, toujours dans ce même lieu sécurisé. Le risque d'identification après anonymisation apparaît donc faible. Les bilans d'ergothérapie, effectués seulement s'ils n'ont pas déjà été faits lors de l'hospitalisation en cours, sont constitués par un bilan des activités de la vie quotidienne et une mesure de la MIF. Ces tests sont non invasifs, durent environ 1h pour le bilan des AVQ et 15 minutes pour la MIF. Il ne nécessite de la part du patient que des réponses à des questions et une participation à des épreuves pratiques de la vie quotidienne. Une fois réalisé, ces bilans seront disponibles pour les médecins en charge et pourront aider à adapter l'aide à domicile notamment. Au final, le principal dommage pour le patient dans cette étude provient donc de la consultation du dossier médical par l'équipe de recherche. Ce dommage est clairement expliqué dans le formulaire de consentement. En contrepartie, les données recueillies seront extrêmement utiles afin de créer un produit correspondant aux besoins des patients.</p> <p>Concernant les proches-aidants et les soignants, les données recueillies lors des interviews seront non liées à la santé personnelle. Elles concerneront des points de vue généraux à propos d'un système technologique. Toutefois, les données seront anonymisées et traitées de la même manière que celle décrite pour les patients dans le paragraphe précédent. De ce fait, le risque pour les proches-aidants et soignants apparaît quasi-nul. En revanche, les bénéfices attendus pour le développement de REACH sont importants.</p>
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ABBREVIATIONS

AVQ : Activités de la Vie Quotidienne

CCER : Commission Cantonale d’Ethique de la Recherche

HRO : Human Research Ordinance

HUG : Hôpitaux Universitaires de Genève

IMAD : Institution genevoise de Maintien à Domicile

MIF : Mesure d’Indépendance Fonctionnelle

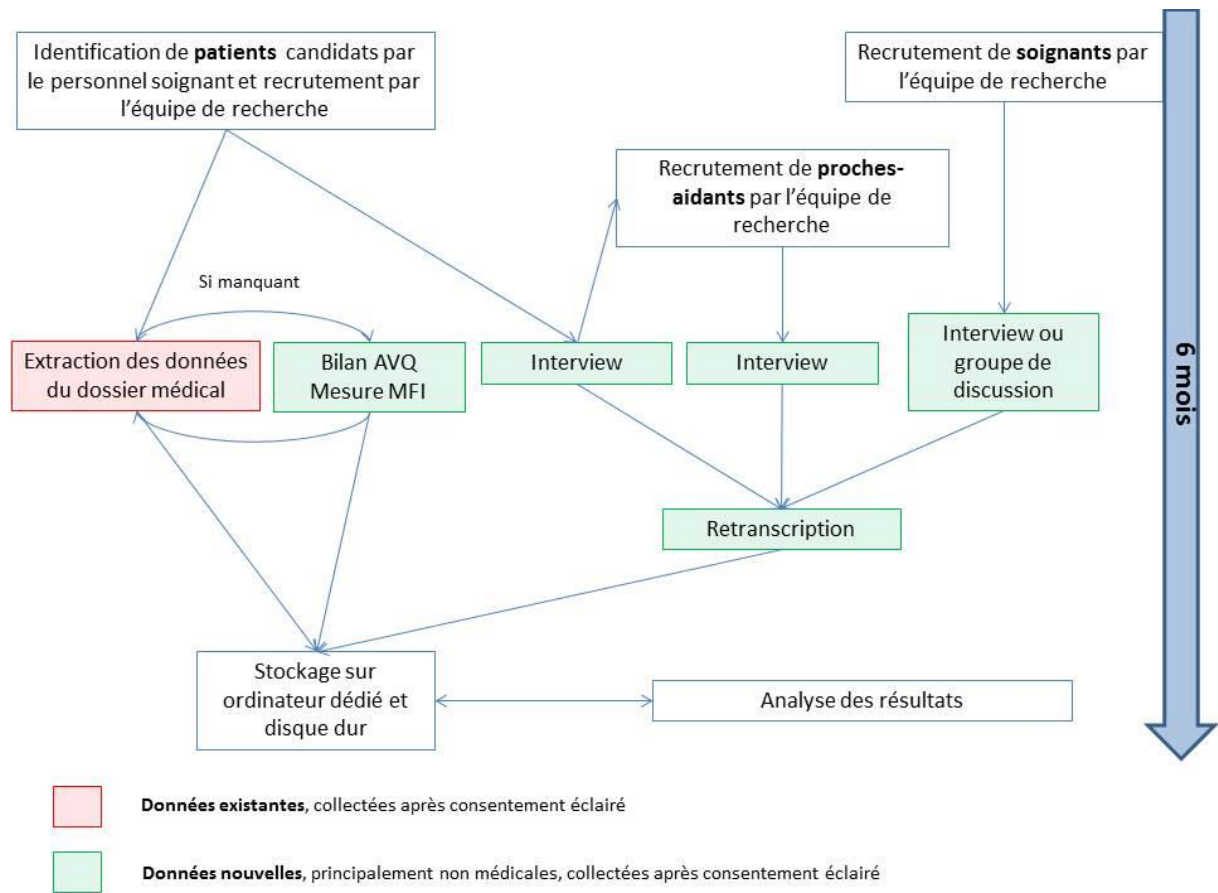
MMSE : Mini Mental State Examination

REACH : Responsive Engagement of the elderly promoting physical Activity and Customized
Healthcare

STROBE : Strengthening the Reporting of Observational studies in Epidemiology

UE : Union Européenne

SCHEMA DU DEROULEMENT DE L'ETUDE



1. STRUCTURE ADMINISTRATIVE

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Chef de projet pour les HUG en charge de l'étude présentée dans cette demande	Prof. Antoine Geissbühler, chef du service de cybersanté et télémédecine, Hôpitaux Universitaires de Genève, Rue Gabrielle-Perret-Gentil 4, 1205 Genève, Suisse. Email: antoine.geissbuhler@hcuge.ch Tel : +41 (0)22 372 62 01
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2. ASPECTS ETHIQUES ET LEGAUX

2.1 Conduite éthique de l'étude

(HRA Art. 45-49; HRO, Art. 14, 17-23, Annexe 2)

Ce projet de recherche débutera uniquement après acceptation par la CCER et sera conduit en accord avec la version actuelle de la déclaration d'Helsinki et la loi suisse. La CCER sera informée du début et de l'arrêt du projet.

2.2 Catégorie de risque

(HRO Art. 7, 33)

Cette étude, observationnelle et transversale comprend

- Etude de **données existantes** issues du dossier médical, qui seront anonymisées.
- Réalisation de bilans d'ergothérapie au cours desquels de **nouvelles données** seront collectées puis anonymisées.
- Interviews semi-structurées et groupes de discussion auprès de patients, proches-aidants et soignants dans lesquels de **nouvelles données** seront collectées et anonymisées.

Le risque est « A » pour les interviews semi-structurées, groupes de discussion et bilan d'ergothérapie et non applicable pour l'extraction de données issues du dossier médical.

2.3 Commission Cantonale d'Ethique de la Recherche

(HRO Art. 14-23, 34, 37, 41, 45)

Le présent projet sera débuté seulement après acceptation par la CCER. La récolte et l'analyse des données se feront sur une période de six mois au maximum. La CCER sera informée du début et de la fin du projet (dans les 90 jours au maximum après l'arrêt effectif).

2.4 Informations aux participants et formulaires de consentement

(HRO Art. 8, Annexe 2/1.3-1.5)

Avant la récolte de données, chaque participant recevra une information adaptée, par oral et par écrit, expliquant les motivations de l'étude et les éventuels risques encourus. Cette information sera compréhensible, formulée en termes simples, et permettra au patient de donner ou non son consentement éclairé pour la participation à l'étude. L'acceptation sera documentée au moyen d'un formulaire de consentement dédié.

A noter que nous avons décidé d'exclure les patients incapables de discernement.

2.5 Vie privée et sécurité des participants

(HRA Art. 1, Annexe 2/1.7)

La présente étude sera conduite en respect du droit à la dignité, la vie privée et la santé et respectera la législation en vigueur s'y rapportant.

Lors de la phase de collecte de données, l'équipe de recherche (Prof. Antoine Geissbühler, Dr. Damien Dietrich, Mirana Randriambelonoro et Caroline Perrin) sera confronté à des données médicales non anonymes, notamment lors de l'extraction de données du dossier médical. **Ceci constitue le principal dommage pour le patient lors de cette étude.**

Les données seront anonymisées immédiatement après la collecte et resteront anonymes durant toutes les phases ultérieures du projet, c'est-à-dire, l'analyse par l'équipe de recherche et le partage lors de meetings (scientifiques ou du consortium REACH) ou de publications (scientifiques ou internes au consortium). De plus, les données seront conservées sur un ordinateur et un disque dur dédiés, eux-mêmes gardés dans les locaux sécurisés du Campus Biotech. La clef d'anonymisation sera conservée sur un autre ordinateur, lui-même gardé également dans les locaux sécurisés du Campus Biotech. De ce fait, le risque d'identification des patients a posteriori apparaît faible.

Hormis l'accès aux données médicales par l'équipe de recherche, notre étude ne présente pas de risque notable pour le patient. En effet, les autres procédures dans lesquels ceux-ci sont impliqués consistent en des interviews et des bilans ergothérapeutiques (détaillés au paragraphe 3.3).

Dans le but de vérifier le bon déroulement de l'étude, le comité d'éthique de REACH, la CCER ou toute autorité accréditée, pourront accéder aux données collectées.

Ces informations sont clairement stipulées dans le formulaire de consentement.

2.6 Arrêt prématuré du projet

(HRO Art. 22)

Dans le cas de notre étude observationnelle, n'impliquant pas d'intervention thérapeutique ou invasive, nous n'anticipons pas de situations dans lesquelles le projet devrait être stoppé en urgence.

Toutefois, si cela devrait se produire, la CCER en serait informé dans un délai maximal de 90 jours.

2.7 Amendements, changements du plan de recherche

(HRO Art. 18, 22, Annexe 2)

Dans le cas où des modifications du plan de recherche seraient souhaitées, les démarches suivantes seraient entreprises :

- Rédaction d'un amendement, expliquant de manière détaillée les changements envisagés pour chaque partie de l'étude (objectifs, critères d'inclusion, mesures, analyse, modification du risque-bénéfice du point de vue éthique, notamment) et les raisons de ces changements.
- Rédaction ou modifications des autres documents tels que mentionnés dans l'HRO Art. 18, 22, Annexe 2.
- Transmission des documents pour approbation à la CCER et éventuellement au consortium REACH selon l'adéquation ou non des modifications envisagées avec le plan d'étude cadre REACH.
- Les modifications seront appliquées uniquement après acceptation par la CCER.

3. INTRODUCTION

(STROBE 2; HRO Annex 2/1.2)

3.1 Contexte

La direction générale des affaires économiques et financières de l'Union Européenne (UE) prévoit une augmentation des coûts de la santé de 350% d'ici à 2050. Les hospitalisations de longue durée, de plus en plus fréquentes dans le contexte du vieillissement de la population, sont responsables d'une part importante de cette inflation.

Le projet REACH (Responsive Engagement of the elderly promoting Activity and Customized Healthcare), financé par le programme Horizon 2020 de l'UE, tente de répondre à cette problématique. Il vise à combiner les expertises de 18 partenaires afin de développer un produit technologique capable d'agir positivement sur l'état de santé général, la condition physique, l'autonomie et la littératie de la population gériatrique pour limiter les admissions en soins de longue durée.

Techniquement, tout reste à faire mais un concept est imposé : utiliser des signaux issus de capteurs insérés dans des meubles ou portés afin de fournir des recommandations de santé en temps réel aux patients et éventuellement de les accomplir. Les données pourraient être de toute sorte (mouvement, tension artérielle, quantité de nourriture, etc.) mais seraient collectées de manière non-invasive.

3.2 Justification du projet de recherche

Afin de guider la phase de développement technique, nous souhaitons dans un premier temps étudier notre population cible, notre service se focalisant particulièrement sur la transition hôpital-domicile et la limitation du phénomène des ré-hospitalisations.

Ainsi, notre étude comprendra :

- Collecte de données issues du dossier médical des patients, éventuellement complétée d'un bilan ergothérapeutique, afin de définir les **caractéristiques médicales et démographiques globales de notre population**.
- Interviews semi-structurées et groupes de discussion, afin de recueillir les attentes et inquiétudes des patients, proches-aidants et soignants vis-à-vis de REACH.
- Analyse statistique, afin de tenter de déterminer **d'éventuels liens entre attentes, inquiétudes et données démographiques et médicales** dans le but de créer des profils-types d'utilisateurs permettant un développement ciblé de REACH.

Ces différents items nous permettront de caractériser notre population cible et d'ainsi développer un produit répondant à ses besoins.

3.3 Risque-bénéfice

(HRA Art. 12; HRO Art. 15)

Lors de cette étude, les patients donneront, ou non, leur consentement éclairé pour la collecte de données issues de leur dossier médical et la réalisation d'un bilan d'ergothérapie et d'une interview (à noter que lors de cette dernière, les données collectées seront majoritairement non liées à la santé). Les données seront anonymisées et stockées sur un ordinateur dédié, gardé dans un lieu sécurisé (Campus Biotech, Genève). La clef d'identification sera stockée sur un ordinateur séparé, également gardé dans ce même lieu sécurisé. Le risque d'identification après anonymisation apparaît donc faible. Les bilans d'ergothérapie, effectués seulement s'ils n'ont pas été faits lors de l'hospitalisation en cours, sont constitués par un bilan des activités de la vie quotidienne et une mesure de la MIF. Ces tests sont non invasifs, durent environ 60 minutes pour le bilan des AVQ et 15 minutes pour la mesure de la MIF. Ils ne nécessitent de la part du patient que des réponses à des questions et une participation à des épreuves pratiques de la vie quotidienne (par exemple, transfert d'une chaise au lit, s'habiller, etc.). Une fois réalisé, les bilans seront disponibles pour les médecins en charge et pourront aider à adapter l'aide à domicile notamment.

Au final, le principal dommage pour le patient provient donc de la consultation du dossier médical par l'équipe de recherche. Ce dommage est clairement expliqué dans le formulaire de consentement. En contrepartie, les données recueillies seront extrêmement utiles afin de créer un produit correspondant aux besoins des patients.

Concernant les proches-aidants et les soignants, les données recueillies lors des interviews ne seront pas liées à la santé personnelle. Elles concerneront des points de vue généraux à propos d'un système technologique. Toutefois, les données seront anonymisées et traitées de la même manière que celle décrite pour les patients dans le paragraphe précédent. De ce fait, le risque pour les proches-aidants et soignants apparaît quasi-nul. En revanche, les bénéfices attendus pour le développement de REACH sont importants.

4. OBJECTIFS, CRITÈRES PRINCIPAUX, SECONDAIRES ET AUTRES VARIABLES DE L'ETUDE

4.1 Objectifs

(STROBE 3)

- Déterminer les caractéristiques démographiques et médicales de notre population-cible.
- Recueillir les attentes et inquiétudes des patients, proches-aidants et soignants vis-à-vis de REACH.
- Déterminer d'éventuels liens entre attentes, inquiétudes et données démographiques et médicales dans le but de créer des profils-types d'utilisateurs permettant un développement ciblé de REACH.

4.2 Critères principaux et secondaires

(STROBE #7)

La définition de critères d'évaluation principaux et secondaires (primary and secondary endpoints) au sens strict du terme correspond peu au design de l'étude. Toutefois, voici les critères qui seront évalués.

A partir d'une collecte de données issues du dossier médical des patients, éventuellement complétée d'un bilan ergothérapeutique, nous définirons les **caractéristiques médicales et démographiques globales de notre population**. Pour ce faire, les items suivants seront évalués :

- Âge
- Sexe
- Etat civil
- Type de logement
- Nombre de personnes dans le logement
- Profession
- Présence d'enfants,
- Diagnostics médicaux
- Traitements
- Paramètres cliniques et paracliniques dont MMSE et MIF
- Durée de la dernière hospitalisation
- Nature des professionnels de santé impliqués dans la prise en charge à l'hôpital
- Rapports des physiothérapeutes, ergothérapeutes, infirmières, infirmières de liaison
- Bilan des AVQ
- Nature et fréquence de l'aide à domicile instaurée.
- Rapports de l'IMAD.

A partir des interviews semi-structurées et groupes de discussion, nous recueillerons les **attentes et inquiétudes des patients, proches-aidants et soignants vis-à-vis de REACH**. De manière plus précise, les items suivant seront évalués :

- Attentes et inquiétudes des patients quant à la récolte de données par des capteurs.
- Attentes et inquiétudes des patients quant à l'encouragement à l'activité physique ou à d'autres actions visant à promouvoir la santé par REACH.
- Attentes et inquiétudes des patients quant aux fonctions que REACH devrait posséder pour faciliter la transition hôpital-domicile et le maintien à domicile.
- Besoins spécifiques des patients auxquels REACH pourrait répondre en fonction des différentes périodes d'une journée.
- Caractéristiques démographiques de la personne interviewée (cf. 7.2)

Enfin, par analyse statistique, nous tenterons de déterminer **d'éventuels liens entre attentes, inquiétudes et données démographiques et médicales** dans le but de créer des profils-types d'utilisateurs permettant un développement ciblé de REACH.

4.3 Autres variables

(STROBE #7)

Non applicable.

5. DESIGN DU PROJET

(STROBE 4,5, 9; HRO Annex 2/1.2)

5.1 Type de projet et design général

(STROBE 4)

Ce projet visant à mieux connaître la population-cible du projet européen REACH est une étude **observationnelle transversale** comprenant :

- Etude de **données existantes** issues du dossier médical, qui seront anonymisées.
- Réalisation de bilans d'ergothérapie au cours desquels de **nouvelles données seront collectées puis anonymisées.**
- Interviews semi-structurées et groupes de discussion auprès de patients, proches-aidants et soignants dans lesquels de **nouvelles données seront collectées et anonymisées.**

Pratiquement, le personnel soignant de l'hôpital des Trois-Chênes identifiera les patients correspondant à nos critères d'inclusion et un membre de l'équipe de recherche (Antoine Geissbühler, Damien Dietrich, Mirana Randriambelonoro, Caroline Perrin) inclura les patients au moyen du formulaire de consentement. Les données du dossier médical des patients ayant acceptés l'étude seront alors collectées, et un bilan des activités de la vie quotidienne et une mesure de la MIF seront effectués par les ergothérapeutes si cela n'a pas déjà été fait lors de l'hospitalisation en cours. De plus, les patients participeront à une interview avec un membre de l'équipe de recherche.

Les proches-aidants de ces mêmes patients seront ensuite recrutés par un membre de l'équipe de recherche pour une interview au moyen du formulaire de consentement. Enfin, et en parallèle, les soignants de l'hôpital des Trois-Chênes et de l'IMAD seront recrutés par l'équipe de recherche pour des interviews ou groupes de discussion, toujours au moyen du formulaire de consentement.

Toutes ces informations sont schématisées dans la figure expliquant le déroulement de l'étude en page 8.

5.2 Procédures

(STROBE 5; swissethics 3a)

1. Les patients correspondant à nos critères d'inclusion (cf. 6.), seront identifiés par les soignants de l'hôpital des Trois-Chênes.
2. Un des membres de l'équipe de recherche (Antoine Geissbühler, Damien Dietrich, Caroline Perrin, Mirana Randriambelonoro), informera le patient sur l'étude par oral et par écrit au moyen du formulaire de consentement.
3. Le patient donnera ou non son consentement éclairé qui sera récolté au moyen du formulaire de consentement.
4. En cas d'accord, l'équipe de recherche pourra consulter le dossier médical du patient et extraire de manière anonyme les informations détaillées au point 4.2. qui seront stockées et analysées sur un ordinateur du laboratoire de recherche et sur un disque dur (tous deux gardés sous clef dans les locaux sécurisés du campus biotech). Le code d'identification des patients sera stocké sur un ordinateur séparé, également gardé sous clef dans les locaux sécurisés du campus biotech.
5. Si l'information n'est pas déjà disponible dans le dossier médical, le patient effectuera un bilan d'indépendance pour les activités de la vie quotidienne et une mesure de la MFI avec les ergothérapeutes des HUG selon leur protocole usuel. Les informations obtenues feront partie intégrantes du dossier médical et seront disponibles pour les médecins en charge. Du point de vue de la recherche, ces informations seront traitées comme les autres données extraites du dossier médical.
6. Le patient sera également interviewé selon la trame d'interview « patient » ci-jointe. Les interviews seront enregistrées à l'aide d'un dictaphone et retranscrites de manière anonyme sur un logiciel de traitement de texte afin d'en extraire les éléments importants. Concernant le codage et le stockage, les données seront traitées comme les données extraites du dossier médical. A noter que l'interview du patient se déroulera de manière randomisée, soit à l'hôpital, soit au domicile.
7. Suite au recrutement des patients, l'équipe de recherche pourra proposer aux proches-aidants de ces patients de participer eux-aussi à une interview au moyen du formulaire de consentement.

8. En cas d'acceptation, l'interview sera conduite à l'aide de la trame d'interview « proche-aidant » et les données seront traitées de la même manière que pour les patients. Notre code d'anonymisation nous permettra de faire un lien anonyme entre le proche-aidant et le patient correspondant. Par exemple, le proche-aidant du patient A1 sera appelé « PA-A1 ».
9. Enfin, l'équipe de recherche recrutera, toujours à l'aide du formulaire de consentement, des soignants de l'IMAD ou de l'Hôpital des Trois-Chênes impliqués dans la prise en charge régulière (minimum 2x/semaine) de notre population-cible de patient afin de réaliser des interviews. Ces dernières seront conduites à l'aide de la trame d'interview « soignant ». Les données seront traitées de la même manière que pour les interviews de patients et de proches-aidants. Des groupes de discussion pourront éventuellement remplacer les interviews afin de faciliter la logistique. Les items des groupes de discussion seront les mêmes que ceux des interviews et les données traitées de manière identique.
10. Suite à la phase de collecte, et éventuellement en parallèle, les données seront analysées, à l'aide de l'ordinateur et du disque dur dédié.

5.3 Recrutement et screening

(swissethics 3b)

Comme détaillé dans la section 5.2. :

- Les patients correspondant aux critères d'inclusion seront identifiés par les soignants de l'Hôpital des Trois-Chênes lors de leurs activités quotidiennes. L'équipe de recherche inclura les patients à l'aide du formulaire de consentement dédié.
- Les proches-aidants des patients inclus seront recrutés par l'équipe de recherche à l'aide du formulaire de consentement dédié.
- Les soignants seront recrutés par l'équipe de recherche au sein du personnel de l'Hôpital des Trois-Chênes ou de l'IMAD à l'aide du formulaire de consentement dédié.
- Les critères d'inclusion de ces différentes populations sont décrits au point 6.1.

5.4 Méthodes utilisées pour minimiser les biais

(STROBE 9; swissethics 2)

L'information sur le recrutement des patients sera donnée à l'ensemble des unités du service de médecine interne, réhabilitation et gériatrie de l'Hôpital des Trois-Chênes afin de limiter un éventuel biais de sélection.

Les interviews de patients seront aléatoirement conduites à l'hôpital ou au domicile des patients afin de recueillir les attentes et inquiétudes vis-à-vis du développement de REACH dans un contexte ambulatoire et hospitalier.

6. POPULATION-CIBLE DU PROJET

(STROBE 6; HRO Annexe 2/1.2)

Le projet REACH se concentre sur des patients de 65 ans et plus avec une limitation de l'autonomie due à des troubles somatiques ou cognitifs, en situation de réhabilitation ou ambulatoire.

C'est donc en accord avec cette description et en prenant en compte notre localisation géographique et notre domaine d'intérêt particulier (**transition hôpital-domicile**), que nous avons défini nos critères d'inclusion.

6.1 Critères d'inclusion et d'exclusion

- **Inclusion des patients** : patients âgés de 65 ans et plus ET hospitalisés à l'hôpital des trois-chênes avec un retour à domicile prévu avec l'aide de l'IMAD ET une limitation de l'autonomie en raisons de facteurs somatiques ou cognitifs (défini par $21 \leq \text{MMSE} \leq 27$ OU $64 \leq \text{MIF} \leq 120$).
- **Exclusion des patients** : $\text{MMS} \leq 20$, $\text{MIF} \leq 63$, incapacité d'interagir avec une interface homme-machine, incapacité de discernement.
- **Inclusion des proches-aidants** : proches-aidants des patients recrutés, fournissant une aide au moins 1x/semaine pour les activités de la vie quotidienne, les activités instrumentales de la vie quotidienne ou les loisirs.
- **Inclusion des soignants** : soignants de l'hôpital des trois-chênes ou de l'IMAD en contact régulier (minimum 2x/semaine) avec des patients correspondant aux critères d'inclusion.

6.2 Exclusion de participants en cours d'étude

Dans le cas où un patient, un proche-aidant ou un soignant exerce le souhait de retirer sa participation à l'étude, les données seront effacées sur sa demande et le retrait sera pris en compte dans l'analyse des résultats.

7. DETAILS SUR LES MESURES DU PROJET

(STROBE 7; HRO Annex 2/1.2)

7.1 Planning du projet

Nous nous référons au schéma de déroulement de l'étude page 7 et aux parties 5.1 et 5.2 détaillant le design général et les procédures. Afin d'éviter une redondance, nous donnons ici le planning par type de participant.

- Concernant les **patients** : une fois identifiés par les soignants et recrutés par l'équipe de recherche, un système de randomisation décidera si l'interview aura lieu en ambulatoire ou à domicile. Une date sera ensuite convenue entre les deux parties. L'extraction des données médicales se fera à n'importe quel moment compris dans la durée de l'étude. Si le dossier médical n'en contient pas, un bilan d'indépendance et une mesure de la MFI sera effectué par les ergothérapeutes des HUG à une date dépendante de la planification de leur service mais incluse dans la période de l'étude et de l'hospitalisation du patient. La participation active du patient se fera donc uniquement lors de l'interview et éventuellement lors du bilan d'ergothérapie.
- Concernant les **proches-aidants** : le recrutement sera fait par l'équipe de recherche et l'interview sera réalisée à une date convenue entre les deux parties. La participation active des proches-aidants se limite à l'interview.
- Concernant les **soignants** : ils seront recrutés par l'équipe de recherche pour une interview ou un groupe de discussion à une date convenue entre les différentes parties. La participation active se limite à l'interview ou au groupe de discussion.
- La phase d'**analyse** débutera dès les premières récolte de données et se poursuivra jusqu'à la fin du projet. Elle comprendra l'ensemble du travail sur les données collectées (transformation, calculs, statistiques, rédaction de rapport).

7.2 Méthodes de mesure des critères d'évaluation

Le design de l'étude ne permettant pas de définir des critères primaires et secondaires, nous traiterons ici de l'ensemble des critères.

Pour l'**extraction des données du dossier médical des patients**, l'équipe de recherche se connectera au dossier du patient et les données relatives aux items listés en 4.2 seront collectées dans un fichier Excel à partir des informations issues de la lettre de sortie de l'hospitalisation la plus récente. Les données médicales manquantes dans la lettre de sortie seront recherchées dans le dossier patient informatisé ou le dossier de l'IMAD. Les données démographiques manquantes seront demandées lors de l'interview.

Pour les **interviews semi-structurées et groupes de discussion** de patients, proches-aidants et soignants, les différents items listés en 4.2 seront investigués au moyen de questions ouvertes et en suivant la trame d'interview correspondante (cf. fichiers trame d'interview patient, proche-aidant et soignant ci-jointe). En plus des items listés en 4.2, les données démographiques seront collectées afin de compléter les données issues du dossier médical. Ces données seront :

- **Pour les patients** : âge, sexe, état civil, type d'habitation, nombre de personne dans le logement, aide à domicile, utilisation d'internet.
- **Pour les proches-aidants** : âge, sexe, situation familiale, et profession du proche-aidant, lien avec le patient, fréquence et le type d'aide apportée, distance entre les domiciles du patient et du proche-aidant, utilisation d'internet.
- **Pour les soignants** : âge, profession, lieu d'exercice, utilisation d'internet.

Pratiquement, un code sera attribué au patient, au proche-aidant ou au soignant en début d'interview et son nom ne sera ensuite plus utilisé dans l'enregistrement. L'interview sera enregistrée au moyen d'un dictaphone puis retranscrite dans un fichier Word.

Concernant l'**analyse statistique** pour tenter de déterminer d'éventuels liens entre attentes, inquiétudes et données démographiques et médicales, nous nous référons à la partie 8.3.

7.3 Méthodes de mesure des critères d'évaluation secondaires

Non applicable.

7.4 Méthodes de mesure des autres variables

Non applicable.

7.5 Mesure de surveillance et rapport d'évènements indésirables

(HRO Art. 20. 21)

Etant donné la nature de notre étude, nous ne prévoyons pas d'évènements indésirables. Toutefois, dans le cas où un patient, un proche-aidant ou un soignant exerce le souhait de retirer sa participation à l'étude, les données seront effacées sur sa demande et le retrait sera pris en compte dans l'analyse des résultats.

8. CONSIDERATIONS STATISTIQUES

8.1 Taille d'échantillons

(STROBE 10)

Etant donné qu'il n'existe pas, à notre connaissance, d'étude similaire dans la littérature nous permettant d'estimer la taille d'échantillon nécessaire à l'obtention d'une image exacte de notre population cible, nous proposons d'inclure au minimum 20 patients, soignants et famille sur la durée de l'étude.

Nous pensons que cette taille d'échantillon devrait nous permettre d'arriver au but de cette étude qui est d'avoir une première idée sur les caractéristiques, attentes et inquiétudes des patients ciblés par REACH et de leurs proches-aidants et soignants.

8.2 Traitement des données

Avant analyse, les interviews seront retranscrites manuellement dans un fichier Word. Les autres données ne seront pas modifiées.

8.3 Analyse

(STROBE 12a-d)

L'analyse consistera en premier lieu en des statistiques descriptives des différents items investigués pour lesquels un intervalle de confiance à 95% sera calculé si possible.

Par exemple, nous souhaitons, à partir des données issues du dossier médical, estimer la fréquence des différents diagnostics principaux, des différentes co-morbidités, déterminer l'âge moyen, etc.

De même, nous identifierons la nature et la fréquence des diverses attentes et inquiétudes des patients, proches-aidants et soignants relevées lors des interviews et groupe de discussion.

Sur cette base, nous tenterons d'établir des liens entre les caractéristiques intrinsèques du patient, de son environnement, et les attentes et inquiétudes quant à REACH. Dans cette démarche comparative, nous utiliserons éventuellement un test de t pour séries non appariées.

8.3.1 Types de données analysées

Les types de données analysées sont décrits en 8.3.

8.3.2 Procédures en cas de données manquantes

Notre protocole devrait nous permettre de limiter les données manquantes.

Les données démographiques pourront être obtenues via le dossier médical et les interviews, rendant improbable le fait qu'elles viennent à manquer.

En ce qui concerne les données médicales, celles-ci sont en grande majorité systématiquement rentrées dans le dossier patient informatisé.

Les éléments particulièrement importants pour notre étude sont le MMSE, la MFI, et le bilan d'indépendance pour les activités de la vie quotidienne. Afin d'empêcher l'absence préjudiciable de ces mesures, deux d'entre elles font partie des critères d'inclusion. De plus, la MFI et le bilan d'indépendance pour les activités de la vie quotidienne seront effectués par les ergothérapeutes des HUG dans le cas où l'information manquerait. Enfin, le MMSE fait partie intégrante du bilan de routine lors de l'admission à l'hôpital des Trois-Chênes et il est improbable qu'il manque au dossier médical.

Si malgré ces précautions, un des éléments venait à manquer, l'analyse serait tout de même effectuée et l'absence d'un ou plusieurs patients signalés.

8.3.3 Analyse auxiliaire

Nous nous référons au dernier paragraphe de l'introduction de la partie 8.3.

8.3.4 Changement par rapport au plan statistique initial

En cas d'analyse supplémentaire nécessaire, la CCER sera informée et si besoin, un amendement sera déposé. L'analyse supplémentaire ne sera effectuée qu'après aval de la CCER.

9. GESTION DES DONNÉES ET DE LA QUALITE

(HRO Art. 5, 25-27, Annexe 2/1.7)

9.1 Stockage et archivage des données

(HRO Art. 5, 26, 27, Annexe 2/1.7)

Comme décrit dans la partie 5.2., les données récoltées seront anonymisées et stockées sur un ordinateur et un disque dur dédiés du laboratoire, tous deux gardés sous clefs dans les locaux sécurisés du campus biotech. L'ordinateur servira aussi à l'analyse des données. Le code sera conservé sur un ordinateur séparé, également gardé sous clef dans les locaux du campus biotech.

Seule l'équipe de recherche, soumise au secret professionnel, aura accès à l'ensemble des données (données anonymisées et code).

9.2 Confidentialité, protection des données

(HRO Art. 5)

La génération, la transmission, le stockage des données décrits dans cette partie du plan de recherche sont en accord avec la loi Suisse et particulièrement l'ordonnance HRO Art. 5.

Le stockage, le codage et l'archivage sont décrits dans les paragraphes 9.1, 9.3 et 9.4.

Les données anonymisées pourront faire l'objet de publications et présentation à visée scientifiques et de transmission interne (REACH, Université de Genève, Hôpitaux Universitaires de Genève).

Les données complètes seront en tout temps accessibles aux organismes de régulation accréditées à surveiller le bon déroulement du projet. Ceux-ci incluent la CCER et le comité d'éthique de REACH.

En dehors de ce cadre précis, les données de santé collectées durant ce projet sont strictement confidentielles et ne seront pas transmises à des tierce-parties.

9.3 Codage

(HRO Art. 25-27)

Comme mentionné dans la partie procédure (5.2), les données collectées seront anonymisées. Lors de la collecte, chaque participant se verra attribuer une lettre +/- un chiffre (ex : A jusqu'à Z, puis A1 jusqu'à Z1, puis A2, ...) qui sera utilisé en lieu et place du nom et prénom. Un fichier Excel permettant de lier les données anonymes des patients à leur identité réelle sera conservé sur un ordinateur séparé, gardé sous clefs dans les locaux du campus biotech.

Les données récoltées à partir des interviews des proches-aidants seront codées de manière à ce qu'un lien anonyme avec un patient précis puisse être visible. Par exemple, le proche-aidant du patient A1 sera codé PA-A1. Si un autre proche aidant du même patient est inclus dans l'étude, il sera codé PA2-A1, etc.

9.4 Archivage et destruction des données

Les données seront conservées durant toute la durée du projet REACH, soit jusqu'au 1^{er} mars 2020. Cette période permettra d'une part un temps suffisant pour d'éventuelles publications et présentations scientifiques, mais également l'utilisation de ces données dans d'autres phases du projet. Cette éventualité serait bien sûr soumise à un amendement ou à une nouvelle demande auprès de la CCER. Passée le 1^{er} mars 2020, les données seront supprimées de l'ordinateur et du disque dur dédié.

10. POLITIQUE DE PUBLICATION ET DE PARTAGE DES DONNEES

(HRO Art. 15j; STROBE 22; HRO Annexe 2/1.10)

10.1 Publication des résultats

Les résultats (anonymes) feront l'objet de rapports et présentations internes (REACH, Université de Genève, Hôpitaux Universitaires de Genève), voire de publications scientifiques dans des journaux utilisant la revue par des pairs et de présentations scientifiques lors de meetings spécialisés.

10.2 Partage des données

Nous ne prévoyons pas de partager nos données à d'autres personnes physiques ou morales que celles décrites en 9.2 et 10.1.

11. FINANCEMENT ET SUPPORT

(HRO Art. 15j; STROBE 22; HRO Annexe 2/1.10)

Ce projet est financé par le programme européen Horizon 2020.

Les signataires du présent document ne déclarent aucun conflit d'intérêt.

12. ASSURANCE

(HRO Annex 1; HRO Annexe 2/1.6)

En accord avec le risque de catégorie A, ce projet ne bénéficie d'aucune assurance.

13. REFERENCES

- Declaration of Helsinki, Version October 2013, (<http://www.wma.net/en/30publications/10policies/b3/index.html>)
- Essentials of Good Epidemiological Practice (EGEP; http://www.public-health.ch/logicio/client/publichealth/file/EGEP_en.pdf)
- Humanforschungsgesetz, HFG Bundesgesetz über die Forschung am Menschen (Bundesgesetz über die Forschung am Menschen, HFG) vom 30. September 2011/ Loi fédérale relative à la recherche sur l'être humain (loi relative à la recherche sur l'être humain, LRH) du 30 septembre 2011. (<http://www.bag.admin.ch/themen/medizin/00701/00702/07558/index.html?lang=de>)
- Verordnung über die Humanforschung mit Ausnahme der klinischen Versuche (Humanforschungsverordnung, HFV) / Ordonnance relative à la recherche sur l'être humain à l'exception des essais cliniques (Ordonnance relative à la recherche sur l'être humain, ORH) / Ordinance on Human Research with the Exception of Clinical Trials (Human Research Ordinance, HRO) (<http://www.admin.ch/opc/en/classified-compilation/20121177/index.html>)
- von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, et al. (2007) The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: Guidelines for Reporting Observational Studies. PLoS Med 4(10): e296. doi:10.1371/journal.pmed.0040296
- Vandembroucke JP, von Elm E, Altman DG, Gøtzsche PC, Mulrow CD, et al. (2007) Strengthening the Reporting of Observational Studies in Epidemiology (STROBE): Explanation and Elaboration. PLoS Med 4(10): e297. doi:10.1371/journal.pmed.0040297

14. APPENDICES

- Lettre de couverture.
- CV du directeur de recherche (Prof. Antoine Geissbühler).
- Résumé du CV du directeur de recherche (Prof. Antoine Geissbühler).
- Formulaire de consentement.
- Trame d'interview « patient ».
- Trame d'interview « proche-aidant ».
- Trame d'interview « soignant ».
- Description détaillée du projet REACH soumise au programme Horizon 2020
- Page de signature scannée

PAGES DE SIGNATURES

(swissethics 0, 1a)

Numéro de projet 690425 (numéro de demande de financement horizon 2020)

Titre du projet Etude de la population cible du projet européen REACH.

Le chef de projet et ses collaborateurs acceptent la version actuelle du plan de recherche (version 1.0, 04.04.2016). En cas d'accord de la commission d'éthique, ils s'engagent à effectuer cette recherche selon ce plan, et en accord avec la déclaration d'Helsinki ainsi que les règles fédérales, cantonales et institutionnelles en vigueur.

Chef de projet : Prof. Antoine Geissbühler

Genève, le 8.4.2016

Signature

Collaborateur : Dr. Damien Dietrich

Genève, le 8.4.2016

Signature

Collaboratrice : Mirana Randriambelonoro

Genève, le 11.04.2016

Signature

Collaboratrice : Caroline Perrin

Genève, le 11.04.16

Signature

ETUDE DE LA POPULATION CIBLE DU PROJET EUROPEEN REACH

Ce projet est organisé par : le service de cybersanté et télémédecine des Hôpitaux Universitaire de Genève (HUG) dans le cadre du projet de recherche européen REACH (Responsive Engagement of the elderly promoting physical Activity and Customized Healthcare).

Madame, Monsieur,

Nous vous proposons de participer à notre projet de recherche. Cette feuille d'information décrit le projet de recherche.

1. Objectifs du projet de recherche

Notre étude se déroule dans le cadre du projet de recherche européen REACH et vise à **guider le développement d'un produit technologique** permettant d'améliorer la condition physique, l'autonomie et l'éducation thérapeutique des patients d'âge gériatrique, afin de **faciliter la transition entre l'hôpital et le domicile, d'éviter les réadmissions à l'hôpital et de favoriser le maintien à domicile**. Pour ce faire, cette étude a pour but :

- D'étudier les caractéristiques médicales (par exemple, diagnostics, traitements) et démographiques (par exemple, âge, sexe, statut familial) de la population ciblée par REACH.
- D'étudier les attentes et inquiétudes des patients, de leurs proches-aidants et de leurs soignants quant aux fonctionnalités futures de REACH.

2. Sélection des personnes pouvant participer au projet

La participation est ouverte à toutes les personnes de 65 ans et plus, ayant une limitation légère à modérée de leur autonomie en raison d'une problématique physique ou cognitive (des scores cliniques utilisés de routine à l'hôpital permettent de caractériser cette perte d'autonomie). Ces personnes doivent de plus être hospitalisées à l'hôpital des Trois-Chênes avec un retour à domicile prévu avec l'aide de l'institution genevoise de maintien à domicile (IMAD).

L'étude est également ouverte aux proches-aidants de ces patients. Nous définissons comme proches-aidants les personnes aidant au minimum 1x/semaine les patients décrits ci-dessous. L'aide apportée peut-être de toute sorte.

Enfin, l'étude est aussi ouverte aux soignants de ces patients. Les soignants doivent avoir un contact régulier (minimum 2x/semaine) avec des patients correspondant à la description ci-dessus.

3. Informations générales sur le projet

Dans les années à venir, les systèmes de santé suisse et européen s'attendent à une augmentation très importante des coûts de la santé dans le contexte du vieillissement de la population. L'augmentation des hospitalisations de longue durée est une cause majeure de cette inflation en plus d'être une source importante de souffrance pour les patients concernés.

C'est afin de lutter contre ce phénomène que le projet REACH (Responsive Engagement of the elderly promoting Activity and Customized Healthcare), financé par le programme Horizon 2020 de l'UE, a été créé. Il vise à combiner les expertises de 18 partenaires afin de développer un produit technologique qui permettrait d'améliorer la condition physique, l'autonomie et l'éducation thérapeutique des patients d'âge gériatrique, afin de faciliter la transition entre l'hôpital et le domicile, d'éviter les réadmissions à l'hôpital et de favoriser le maintien à domicile.

Techniquement, tout reste à faire, seul un concept est imposé : utiliser des signaux issus de capteurs insérés dans des meubles ou portés afin de fournir des recommandations de santé en temps réel aux patients et éventuellement de les accomplir. Les données pourraient être de toute sorte (mouvement, tension artérielle, quantité de nourriture, etc.) et seraient collectées de manière non-invasive.

Afin de développer un produit utile, nous souhaitons dans un premier temps étudier la population cible de REACH à travers une étude descriptive comprenant :

- Une analyse de données issues du dossier médical, qui sera complétée, dans le cas où l'information serait manquante, par un bilan réalisé avec les ergothérapeutes.
- Des interviews et groupes de discussion avec des patients, des proches-aidants et des soignants afin d'identifier leurs attentes et inquiétudes vis-à-vis d'un système tel que REACH.

Pratiquement, nous souhaitons recruter au minimum 20 patients, 20 proches-aidants et 20 soignants de différentes catégories professionnelles.

Nous effectuons ce projet dans le respect des prescriptions de la législation suisse. La commission cantonale d'éthique compétente a contrôlé et autorisé le projet.

4. Déroulement pour les participants

Si vous acceptez de participer à notre étude en tant que **patient**, voici les événements dans lesquels vous serez impliqués directement ou indirectement :

- Participation à une **interview** durant entre 30 et 45 minutes qui aura lieu de manière aléatoire, soit à l'hôpital, soit à votre domicile. Hormis ce facteur imposé, la date sera convenue avec vous. Le but est d'étudier vos points de vue, attentes et inquiétudes quant au développement de REACH. Vos données démographiques de base (âge, sexe, profession, logement, etc.) seront également collectées. Toutes les informations collectées le seront de manière **anonyme**.
- L'équipe de recherche extraira de manière **anonyme** les données suivantes de votre **dossier médical** : âge, état civil, type de logement dans lequel vous habitez, nombre de personnes dans le logement, profession, présence d'enfants, de petits-enfants, diagnostics médicaux, traitements, paramètres cliniques et paracliniques, durée de la dernière hospitalisation, nature des professionnels de santé impliqués dans la prise en charge à l'hôpital, rapports des physiothérapeutes, ergothérapeutes, infirmières, infirmières de liaison, bilan des activités de la vie quotidienne, nature et fréquence de l'aide à domicile instaurée, rapports de l'IMAD.
- Dans le cas où cette information ne figurerait pas déjà dans le dossier médical, les ergothérapeutes des HUG effectuerait avec vous un bilan des Activités de la Vie Quotidienne (AVQ) et une mesure de la Mesure d'Indépendance Fonctionnelle (MIF). Ces tests non invasifs durent environ 60 minutes pour le bilan des AVQ et 15 minutes pour la mesure de la MIF. Ils sont constitués de questions et de périodes d'observations lors d'épreuves pratiques (par exemple se lever d'une chaise).
- Votre participation active se limitera donc à une interview de 30 à 45 minutes et éventuellement à un ou deux tests non invasifs avec les ergothérapeutes d'une durée maximale d'1h15.

En tant que **proche-aidant ou soignant**, votre participation se limiterait uniquement à une interview de 30-45 minutes telle que décrite ci-dessus. Pour les soignants, l'équipe de recherche se réserve le droit de remplacer les interviews par un groupe de discussion de même durée regroupant plusieurs soignants.

La durée totale du projet sera elle de 6 mois, correspondant au temps nécessaire pour récolter les données et effectuer les analyses.

5. Bénéfices pour les participants

Concernant les **patients**, votre participation au projet ne vous apportera aucun bénéfice direct hormis la réalisation éventuelle d'un bilan des AVQ et d'une mesure de la MIF qui pourraient servir à mieux adapter votre aide à domicile. En revanche, le développement de REACH sera grandement aidé par votre participation et nous espérons que vous ou vos proches pourront en bénéficier dans un futur proche.

Concernant les **proches-aidants et soignants**, la participation au projet ne vous apportera aucun bénéfice direct mais nous permettra de développer un produit au plus près de vos attentes.

6. Droits des participants

Vous ne devez prendre part à ce projet que selon votre propre volonté. Si vous choisissez de ne pas participer ou si vous choisissez de participer et revenez sur votre décision pendant le déroulement du projet, vous n'aurez pas à vous justifier. La participation ou non au projet ne changera rien à votre prise en charge médicale habituelle. Vous pouvez à tout moment poser toutes les questions nécessaires au sujet de l'étude. Veuillez-vous adresser pour ce faire à la personne indiquée à la fin de la présente feuille d'information.

7. Obligations des participants

En tant que **patient** participant au projet, vous serez tenu :

- De participer à l'interview précédemment décrite.
- D'effectuer le bilan des AVQ et la mesure de la MIF avec les ergothérapeutes, si nécessaire.

En tant que **proche-aidant ou soignant**, vous serez tenu de participer à l'interview ou au groupe de discussion.

8. Risques et confidentialité

En tant que **patient** participant au projet, le principal dommage auquel vous êtes soumis consiste en la consultation de votre dossier médical par l'équipe de recherche lors de la phase de collecte.

Par la suite, vos données seront anonymisées par un code et stockées sur un ordinateur et un disque dur gardé dans des locaux sécurisés. Le code sera stocké sur un autre ordinateur dans des locaux sécurisés. Ainsi, les seules personnes ayant accès à vos données médicales non anonymisées sont les membres de l'équipe de recherche qui les utiliseront uniquement afin de pouvoir accomplir le projet de recherche et qui sont tenues au secret professionnel. De plus, l'accès aux données non anonymisées par l'équipe de recherche sera nécessaire uniquement lors de la collecte. Lors de la phase d'analyse, le travail s'effectuera sur les données anonymisées. Ceci permet de respecter le plus possible votre confidentialité. Vous avez de plus à tout moment le droit de consulter vos données.

A noter que le codage signifie que toutes les données permettant de vous identifier (p. ex. le nom, la date de naissance, etc.) sont remplacées par un code, de sorte que les personnes ne connaissant pas ce code ne peuvent pas lier ces données à votre personne.

Durant son déroulement, le projet peut faire l'objet d'inspections. Celles-ci peuvent être effectuées par la commission d'éthique qui s'est chargée de son contrôle initial et l'a autorisé, mais aussi être mandatées par l'organisme qui l'a initié. Il se peut que la direction du projet doive communiquer vos données personnelles et médicales pour les besoins de ces inspections.

Enfin, les résultats de l'étude utilisant les données codées (donc anonymes), peuvent faire l'objet de publications et présentations à visée scientifiques ou internes (HUG, université de Genève, consortium REACH).

En tant que **proche-aidant ou soignant** participant à l'étude, votre dossier médical ne sera pas consulté et seules les données issues des interviews seront collectées. Toutefois, celles-ci seront traitées de la même façon que pour les patients, garantissant par là-même un risque minimum pour votre confidentialité et celle des patients que vous aidez.

9. Retrait du projet

Vous pouvez à tout moment vous retirer du projet si vous le souhaitez. Les données recueillies seront alors supprimées.

12 Rémunération des participants

Aucune rémunération n'est prévue pour cette étude.

13 Réparation des dommages subis

Les dommages de santé que vous pourriez subir du fait de cette étude relèvent de la responsabilité de l'organisme qui l'a initiée et est en charge de sa réalisation. Toutefois, au vu de la nature de l'étude, nous ne prévoyons aucun dommage.

14 Financement du projet

L'étude est financée par le programme Horizon 2020 de l'Union Européenne.

15 Interlocuteur(s)

En cas de doute, de craintes ou d'urgences pendant ou après l'étude, vous pouvez vous adresser à :

Chercheur coordinateur

Dr. Damien Dietrich, service de cybersanté
et télémédecine, Hôpitaux Universitaires de
Genève,
Campus Biotech, chemin des Mines 9, 1202
Genève.
Email: damien.dietrich@hcuge.ch
Tel : +33 (0)7 87 19 99 01

DECLARATION DE CONSENTEMENT ECRITE POUR LA PARTICIPATION A UN PROJET DE RECHERCHE

- Veuillez lire attentivement ce formulaire.
- N'hésitez pas à poser des questions lorsque vous ne comprenez pas quelque chose ou que vous souhaitez avoir des précisions.

Numéro BASEC du projet : (après soumission à la commission d'éthique compétente) :	
Titre de l'étude : (titre scientifique et titre usuel)	Etude de la population cible du projet européen REACH
Institution responsable : (adresse complète) :	Service de cybersanté et télémédecine, Hôpitaux Universitaires de Genève, Rue Gabrielle-Perret-Gentil 4, 1205 Genève
Lieu de réalisation du projet :	Hôpital des Trois-Chênes
Directeur / directrice du projet sur le site : (nom et prénom en caractères d'imprimerie) :	Dr. Damien Dietrich
Participant / participante : (nom et prénom en caractères d'imprimerie) : Date de naissance :	<input type="checkbox"/> femme <input type="checkbox"/> homme

- Je déclare avoir été informé, par le médecin responsable du projet soussigné, oralement et par écrit, des objectifs et du déroulement du projet ainsi que des effets présumés, des avantages, des inconvénients possibles et des risques éventuels.
- Je prends part à cette étude de façon volontaire et j'accepte le contenu de la feuille d'information qui m'a été remise sur le projet précité. J'ai eu suffisamment de temps pour prendre ma décision.
- J'ai reçu des réponses satisfaisantes aux questions que j'ai posées en relation avec ma participation au projet. Je conserve la feuille d'information et reçois une copie de ma déclaration de consentement écrite.
- J'accepte que les spécialistes compétents de l'institution, du mandataire du projet, de la Commission d'éthique compétente pour cette étude, puissent consulter mes données brutes afin de procéder à des contrôles, à condition toutefois que la confidentialité de ces données soit strictement assurée.
- Je sais que mes données personnelles peuvent être transmises à des fins de recherche **dans le cadre de ce projet uniquement** et sous une forme codée.
- Je peux, à tout moment et sans avoir à me justifier, révoquer mon consentement à participer à l'étude, sans que cela n'ait de répercussion défavorable sur la suite de ma prise en charge médicale usuelle.
- Je suis informé que la responsabilité civile de la direction du projet couvre les improbables dommages imputables au projet que je pourrais subir.
- Je suis conscient que les obligations mentionnées dans la feuille d'information destinée aux participants doivent être respectées pendant toute la durée de l'étude. La direction de l'étude peut m'en exclure à tout moment dans l'intérêt de ma santé.

Lieu, date	Signature du participant / de la participante
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Attestation du médecin-investigateur : Par la présente, j'atteste avoir expliqué au participant / à la participante la nature, l'importance et la portée du projet. Je déclare satisfaire à toutes les obligations en relation avec ce projet conformément au droit en vigueur. Si je devais prendre connaissance, à quelque moment que ce soit durant la réalisation du projet, d'éléments susceptibles d'influer sur le consentement du participant / de la participante à prendre part au projet, je m'engage en l'en informer immédiatement.

Lieu, date	Dr. DIETRICH DAMIEN Signature du médecin-investigateur
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TRAME D'INTERVIEW SEMI-STRUCTURÉE VERSION PATIENT

1. OBJECTIF

Recueillir les attentes et inquiétudes des patients quant à un système technologique nommé REACH visant à favoriser le maintien à domicile et limiter les ré-hospitalisations.

2. INTRODUCTION DESTINE AU PATIENT

Cette interview se déroule dans le cadre d'un projet de recherche européen nommé REACH (Responsive Engagement of the elderly promoting physical Activity and Customized Healthcare). Ce projet implique divers centres européens dont les HUG font partie. **Le but est de développer un produit technologique qui permettrait de promouvoir l'autonomie, l'éducation thérapeutique et la condition physique des patients d'âge gériatrique afin de favoriser le maintien à domicile et d'éviter les ré-hospitalisations.**

Techniquement, tout reste à faire, seul un concept est imposé : utiliser des signaux issus de capteurs insérés dans des meubles ou portés afin de fournir des recommandations de santé en temps réel aux patients et éventuellement de les accomplir (Cf. illustrations). Les données pourraient être de toute sorte (mouvement, tension artérielle, quantité de nourriture, etc.) et seraient collectées de manière non-invasive.

Afin de guider la phase de développement technique, nous devons définir les fonctions souhaitées de notre produit. C'est dans ce contexte que cette interview est réalisée. Elle vise à recueillir points de vue, attentes et inquiétudes quant au développement de REACH.

3. DÉROULEMENT

- Se présenter.
- Expliquer le but de l'interview en s'aidant du paragraphe de l'introduction. Montrer des illustrations si nécessaire (cf. Partie 5).
- Attribuer un numéro de code au patient et le noter sur le fichier Excel dédié (fichier comprenant la clef de l'anonymisation).
- Démarrer l'enregistrement par le dictaphone. Pour le reste de l'interview, ne pas utiliser le nom du patient dans les dialogues enregistrés
- Réaliser le questionnaire en suivant la trame d'entretien tout en étant ouvert à d'autres questionnements intéressants amenés par la discussion.
- A la fin de l'entretien, copier le fichier du dictaphone sur l'ordinateur de recherche et effectuer la retranscription.

4. QUESTIONNAIRE

4.1. Données démographiques

<i>Age</i>	<i>Enfants / Petits-enfants ?</i>
<i>Sexe</i>	<i>Ancienne profession</i>
<i>Etat civil</i>	<i>Aide à domicile (nature et fréquence)</i>
<i>Type d'habitation et escalier OUI-NON</i>	<i>Utilisation d'internet régulière OUI-NON</i>
<i>Nombre de personnes dans le logement</i>	

4.2. Collecte de données par des capteurs fixes ou portés pour mesurer l'état de santé

Donner l'exemple de types de données pouvant être captées : mouvement, pression artérielle, poids, etc. Donner un exemple d'utilisation de ces données, par exemple, une absence de mouvement pourrait déclencher une alerte pour une chute. Eventuellement s'aider des illustrations (partie 5.). Puis demander :

- Pensez-vous que les données collectées par ces capteurs puissent être utiles pour vous ? Expliquez pourquoi.
- Comment ce système devrait-il se présenter idéalement ?
- A l'inverse, quelles fonctions d'un tel système jugeriez vous inutiles voire dérangeantes ?
- Pensez-vous que le fait de partager sur une base volontaire des données issues de ce système avec les membres de la famille ou les soignants soit utile, et si oui, en quoi ?
- Trouvez-vous un tel système acceptable du point de vue de votre vie privée ?

4.3. Motivation à la promotion de l'activité physique ou d'autres activités de santé

Donner l'exemple au patient que le système détecte qu'il n'effectue pas assez d'activité physique et qu'il le motive à travers une recommandation auditive ou visuelle (par exemple « je vous propose d'effectuer une demi-heure d'activité physique cette après-midi ») à en faire. Cette activité pourrait s'effectuer à travers du mobilier connecté (type vélo d'appartement ou autre) permettant de mesurer l'effort. Des stratégies innovantes en termes de motivation pourrait être utilisée comme par exemple la réalité virtuelle ou les jeux sérieux. Enfin, d'autres exemples de motivation à des comportements sains peuvent être donnés (adaptation de l'hygiène alimentaire par exemple). Suite à cet exemple, demander :

- Actuellement, souhaitez-vous augmenter votre activité physique (donner des exemples : danse, bowling, marche, nage, vélo, Tai-chi,...) ? Si non, pourquoi ? Si oui, comment ?
- Pensez-vous qu'il soit utile de recevoir des encouragements par des moyens technologiques tel que REACH et un feedback sur votre activité ?
- Trouvez-vous acceptable, du point de vue de votre vie privée, de partager les données se rapportant à ces activités avec votre famille et/ou vos soignants ? Trouveriez-vous cela utile ?
- Afin de respecter votre autonomie, qu'est-ce que le système devrait faire ou ne pas faire ?

4.4. Transition hôpital-domicile et éviction des ré-hospitalisations

Quelles fonctions REACH devrait posséder pour faciliter votre transfert entre l'hôpital et le domicile ?

Imaginez-vous des fonctions de REACH permettant d'éviter un retour à l'hôpital ?

En regard de ces aspects, qu'est-ce que REACH ne devrait pas faire ?

4.5. REACH et les phases de la journée

Quelles seraient vos besoins spécifiques auxquels REACH pourrait éventuellement répondre :

- Le matin ?
- A midi ?
- L'après-midi ?
- Le soir ?
- La nuit ?

4.6. Autres remarques éventuelles

Avez-vous d'autres commentaires concernant REACH à formuler ?

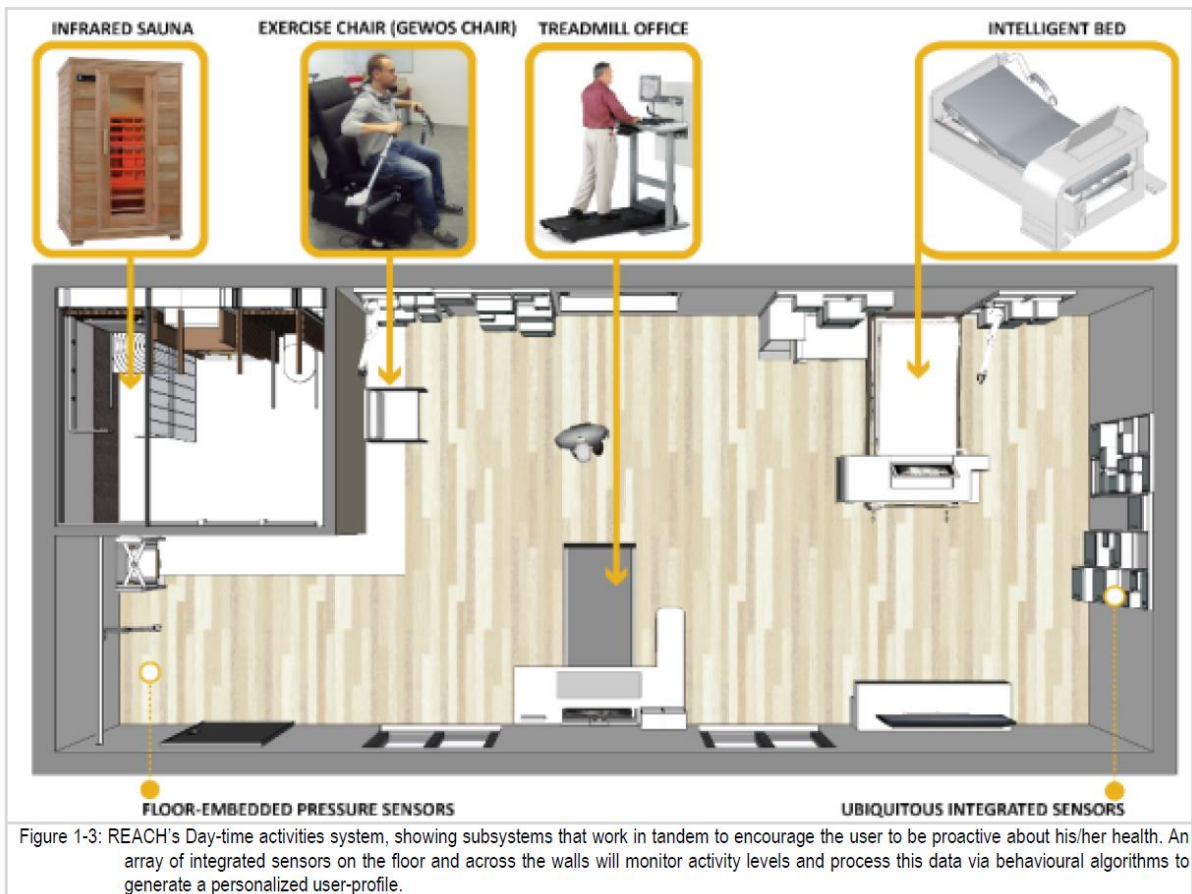
5. ILLUSTRATIONS



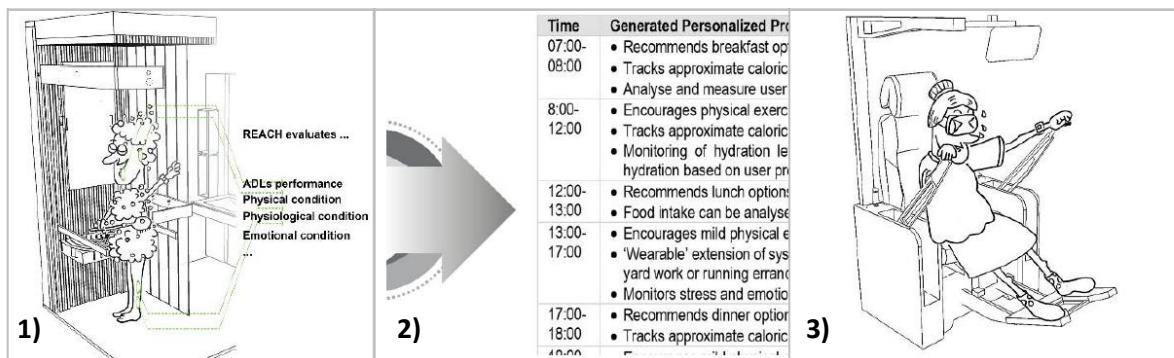
Capteurs de mouvement



Capteur porté type « Fitbit »



Exemple imaginaire de mobilier connecté constituant REACH. En fonctionnant ensemble, ces modules seraient capables de mesurer des données de santé, de les analyser et de formuler sur cette base des recommandations de santé que l'utilisateur pourrait effectuer.



REACH serait capable de mesurer les données de santé (1), les analyser et fournir sur cette base des recommandations (2) et éventuellement de les appliquer (3).



TRAME D'INTERVIEW SEMI-STRUCTURÉE VERSION PROCHE-AIDANT

1. OBJECTIF

Recueillir les attentes et inquiétudes des proches-aidants quant à un système technologique nommé REACH visant à favoriser le maintien à domicile et limiter les ré-hospitalisations des patients gériatriques.

2. INTRODUCTION DESTINE AU PARTICIPANT

Cette interview se déroule dans le cadre d'un projet de recherche européen nommé REACH (Responsive Engagement of the elderly promoting physical Activity and Customized Healthcare). Ce projet implique divers centres européens dont les HUG font partie. **Le but est de développer un produit technologique qui permettrait de promouvoir l'autonomie, l'éducation thérapeutique et la condition physique des patients d'âge gériatrique afin de favoriser le maintien à domicile et d'éviter les ré-hospitalisations.**

Techniquement, tout reste à faire, seul un concept est imposé : utiliser des signaux issus de capteurs insérés dans des meubles ou portés afin de fournir des recommandations de santé en temps réel aux patients et éventuellement de les accomplir (Cf. illustrations). Les données pourraient être de toute sorte (mouvement, tension artérielle, quantité de nourriture, etc.) et seraient collectées de manière non-invasive.

Afin de guider la phase de développement technique, nous devons définir les fonctions souhaitées de notre produit. C'est dans ce contexte que cette interview est réalisée. Elle vise à recueillir points de vue, attentes et inquiétudes quant au développement de REACH.

3. DÉROULEMENT

- Se présenter.
- Expliquer le but de l'interview en s'aidant du paragraphe de l'introduction. Montrer des illustrations si nécessaire (cf. Partie 5).
- Attribuer un numéro de code au proche-aidant et le noter sur le fichier Excel dédié (fichier comprenant la clef de l'anonymisation).
- Démarrer l'enregistrement par le dictaphone. Pour le reste de l'interview, ne pas utiliser le nom du proche-aidant dans les dialogues enregistrés
- Réaliser le questionnaire en suivant la trame d'entretien tout en étant ouvert à d'autres questionnements intéressants amenés par la discussion.
- A la fin de l'entretien, copier le fichier du dictaphone sur l'ordinateur de recherche et effectuer la retranscription.

4. QUESTIONNAIRE

4.1. Données démographiques du proche-aidant

<i>Age</i>	<i>Nature du lien avec le patient</i>
<i>Sexe</i>	<i>Aide apportée (nature et fréquence)</i>
<i>Situation familiale</i>	<i>Distance entre domicile patient et aidant</i>
<i>Profession</i>	<i>Utilisation d'internet régulière OUI-NON</i>

4.2. Collecte de données par des capteurs fixes ou portés pour mesurer l'état de santé

Donner l'exemple de types de données pouvant être captées : mouvement, pression artérielle, poids, etc. Donner un exemple d'utilisation de ces données, par exemple, une absence de mouvement pourrait déclencher une alerte pour une chute. Eventuellement s'aider des illustrations (partie 5.). Puis demander :

- Pensez-vous que les données collectées par ces capteurs puissent être utiles ? Expliquez pourquoi.
- Comment ce système devrait-il se présenter idéalement ?
- A l'inverse, quelles fonctions d'un tel système jugeriez vous inutiles voire dérangeantes ?
- Pensez-vous que le fait de partager sur une base volontaire des données issues de ce système avec les membres de la famille ou les soignants soit utile, et si oui, en quoi ?
- Trouvez-vous un tel système acceptable du point de vue de la vie privée de la personne aidée ?

4.3. Motivation à la promotion de l'activité physique ou d'autres activités de santé

Donner l'exemple que le système détecte que le patient n'effectue pas assez d'activité physique et qu'il le motive à travers une recommandation auditive ou visuelle (par exemple « je vous propose d'effectuer une demi-heure d'activité physique cette après-midi ») à en faire. Cette activité pourrait s'effectuer à travers du mobilier connecté (type vélo d'appartement ou autre) permettant de mesurer l'effort. Des stratégies innovantes en termes de motivation pourrait être utilisée comme par exemple la réalité virtuelle ou les jeux sérieux. Enfin, d'autres exemples de motivation à des comportements sains peuvent être donnés (adaptation de l'hygiène alimentaire par exemple). Suite à cet exemple, demander :

- Pensez-vous qu'il soit utile pour la personne aidée de recevoir des encouragements par des moyens technologiques tel que REACH et un feedback sur son activité ?
- Trouvez-vous acceptable, du point de vue de la vie privée de la personne aidée, de partager les données se rapportant à ces activités avec la famille et/ou les soignants ? Trouveriez-vous cela utile ?
- Afin de respecter l'autonomie de la personne aidée, qu'est-ce que le système devrait faire ou ne pas faire ?

4.4. Transition hôpital-domicile et éviction des ré-hospitalisations

Quelles fonctions REACH devrait posséder pour faciliter le transfert entre l'hôpital et le domicile de la personne que vous aidez ?

Imaginez-vous des fonctions de REACH permettant d'éviter un retour à l'hôpital de la personne que vous aidez ?

En regard de ces aspects, qu'est-ce que REACH ne devrait pas faire ?

4.5. REACH et les phases de la journée

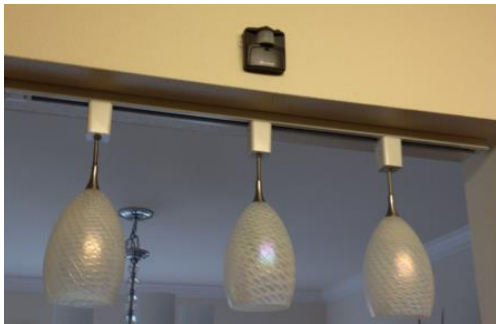
Quelles seraient les besoins spécifiques de la personne que vous aidez auxquels REACH pourrait éventuellement répondre :

- Le matin ?
- A midi ?
- L'après-midi ?
- Le soir ?
- La nuit ?

4.6. Autres remarques éventuelles

Avez-vous d'autres commentaires concernant REACH à formuler ?

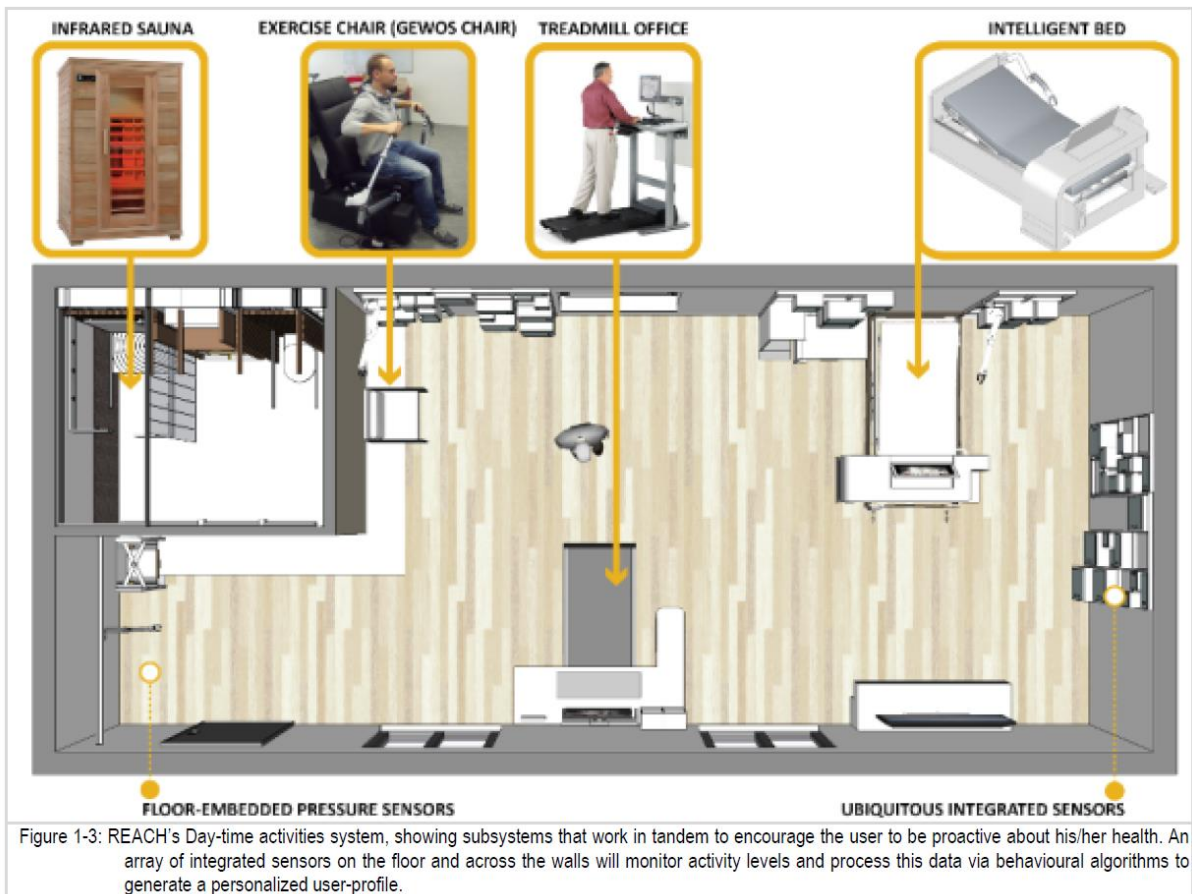
5. ILLUSTRATIONS



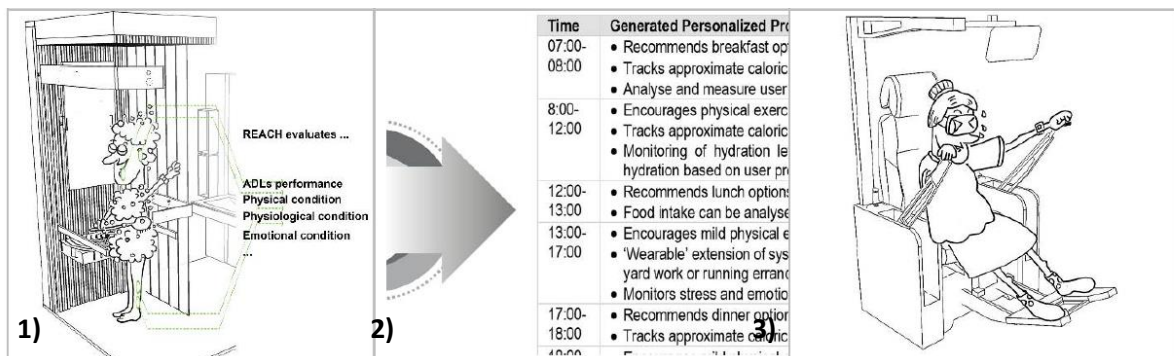
Capteurs de mouvement



Capteur porté type « Fitbit »



Exemple imaginaire de mobilier connecté constituant REACH. En fonctionnant ensemble, ces modules seraient capables de mesurer des données de santé, de les analyser et de formuler sur cette base des recommandations de santé que l'utilisateur pourrait effectuer.



REACH serait capable de mesurer les données de santé (1), les analyser et fournir sur cette base des recommandations (2) et éventuellement de les appliquer (3).



TRAME D'INTERVIEW SEMI-STRUCTURÉE VERSION SOIGNANT

1. OBJECTIF

Recueillir les attentes et inquiétudes des soignants quant à un système technologique nommé REACH visant à favoriser le maintien à domicile et limiter les ré-hospitalisations des patients gériatriques.

2. INTRODUCTION DESTINE AU PARTICIPANT

Cette interview se déroule dans le cadre d'un projet de recherche européen nommé REACH (Responsive Engagement of the elderly promoting physical Activity and Customized Healthcare). Ce projet implique divers centres européens dont les HUG font partie. **Le but est de développer un produit technologique qui permettrait de promouvoir l'autonomie, l'éducation thérapeutique et la condition physique des patients d'âge gériatrique afin de favoriser le maintien à domicile et d'éviter les ré-hospitalisations.**

Techniquement, tout reste à faire, seul un concept est imposé : utiliser des signaux issus de capteurs insérés dans des meubles ou portés afin de fournir des recommandations de santé en temps réel aux patients et éventuellement de les accomplir (Cf. illustrations). Les données pourraient être de toute sorte (mouvement, tension artérielle, quantité de nourriture, etc.) et seraient collectées de manière non-invasive.

Afin de guider la phase de développement technique, nous devons définir les fonctions souhaitées de notre produit. C'est dans ce contexte que cette interview est réalisée. Elle vise à recueillir points de vue, attentes et inquiétudes quant au développement de REACH.

3. DÉROULEMENT

- Se présenter.
- Expliquer le but de l'interview en s'aidant du paragraphe de l'introduction. Montrer des illustrations si nécessaire (cf. Partie 5).
- Attribuer un numéro de code au soignant et le noter sur le fichier Excel dédié (fichier comprenant la clef de l'anonymisation).
- Démarrer l'enregistrement par le dictaphone. Pour le reste de l'interview, ne pas utiliser le nom du soignant dans les dialogues enregistrés
- Réaliser le questionnaire en suivant la trame d'entretien tout en étant ouvert à d'autres questionnements intéressants amenés par la discussion.
- A la fin de l'entretien, copier le fichier du dictaphone sur l'ordinateur de recherche et effectuer la retranscription.

4. QUESTIONNAIRE

4.1. Données démographiques du soignant

Age

Profession et lieu d'exercice

Sexe

Utilisation d'internet régulière OUI-NON

4.2. Collecte de données par des capteurs fixes ou portés pour mesurer l'état de santé

Donner l'exemple de types de données pouvant être captées : mouvement, pression artérielle, poids, etc. Donner un exemple d'utilisation de ces données, par exemple, une absence de mouvement pourrait déclencher une alerte pour une chute. Eventuellement s'aider des illustrations (partie 5.). Puis demander :

- Pensez-vous que les données collectées par ces capteurs puissent être utiles ? Expliquez pourquoi.
- Comment ce système devrait-il se présenter idéalement ?
- A l'inverse, quelles fonctions d'un tel système jugeriez vous inutiles voire dérangeantes ?
- Pensez-vous que le fait de partager, sur une base volontaire, des données issues de ce système avec les membres de la famille ou les soignants soit utile, et si oui, en quoi ?
- Trouvez-vous un tel système acceptable du point de vue de la vie privée de la personne aidée ?

4.3. Motivation à la promotion de l'activité physique ou d'autres activités de santé

Donner l'exemple que le système détecte que le patient n'effectue pas assez d'activité physique et qu'il le motive à travers une recommandation auditive ou visuelle (par exemple « je vous propose d'effectuer une demi-heure d'activité physique cette après-midi ») à en faire. Cette activité pourrait s'effectuer à travers du mobilier connecté (type vélo d'appartement ou autre) permettant de mesurer l'effort. Des stratégies innovantes en termes de motivation pourrait être utilisée comme par exemple la réalité virtuelle ou les jeux sérieux. Enfin, d'autres exemples de motivation à des comportements sains peuvent être donnés (adaptation de l'hygiène alimentaire par exemple). Suite à cet exemple, demander :

- Pensez-vous qu'il soit utile pour les patients de recevoir des encouragements par des moyens technologiques tel que REACH et un feedback sur leur activité ?
- Trouvez-vous acceptable, du point de vue de la vie privée de votre patient, de partager les données se rapportant à ces activités avec la famille et/ou les soignants ? Trouveriez-vous cela utile ?
- Afin de respecter l'autonomie de votre patient, qu'est-ce que le système devrait faire ou ne pas faire ?

4.4. Transition hôpital-domicile et éviction des ré-hospitalisations

Quelles fonctions REACH devrait posséder pour faciliter le transfert entre l'hôpital et le domicile de vos patients ?

Imaginez-vous des fonctions de REACH permettant d'éviter un retour à l'hôpital de vos patients ?

En regard de ces aspects, qu'est-ce que REACH ne devrait pas faire ?

4.5. REACH et les phases de la journée

Quelles seraient les besoins spécifiques des patients-types que vous aidez auxquels un système technologique tel que REACH pourrait éventuellement répondre :

- Le matin ?
- A midi ?
- L'après-midi ?
- Le soir ?
- La nuit ?

4.6. Autres remarques éventuelles

Avez-vous d'autres commentaires concernant REACH à formuler ?

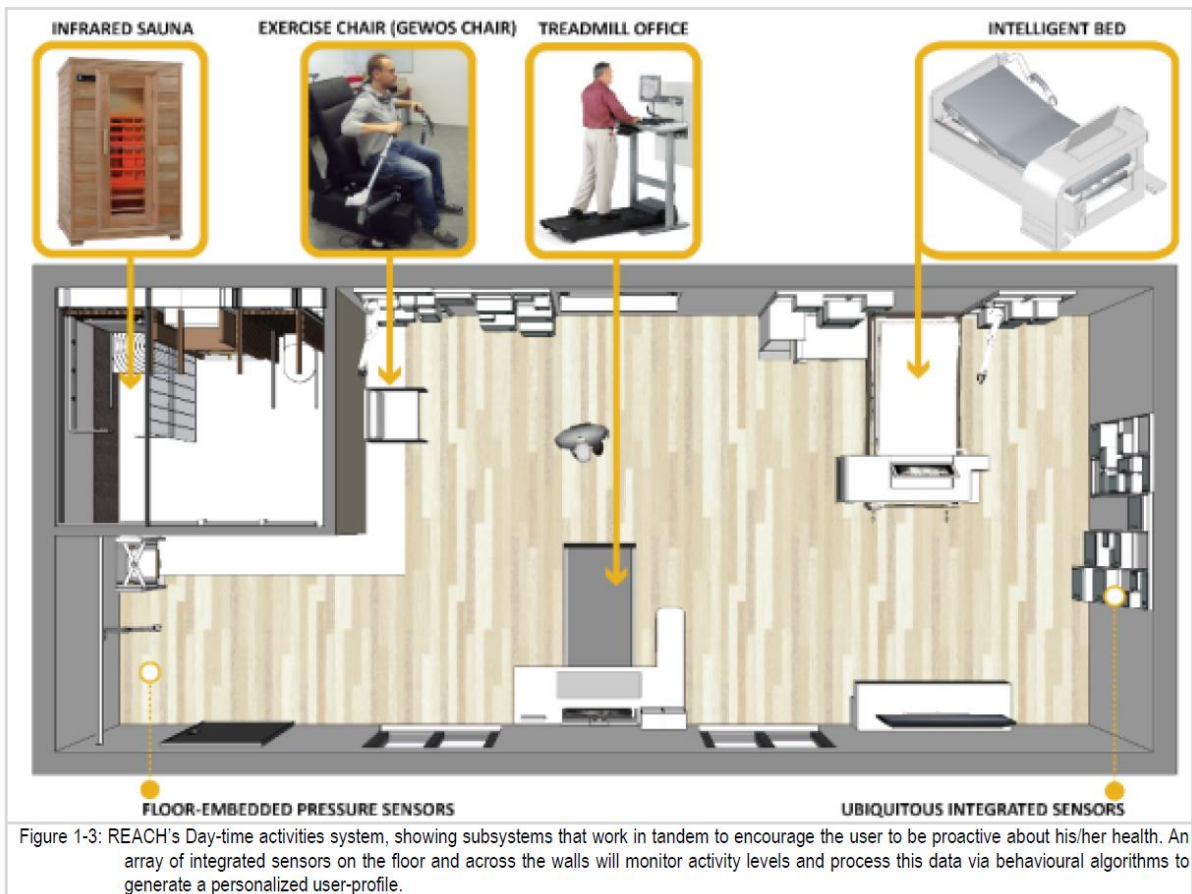
5. ILLUSTRATIONS



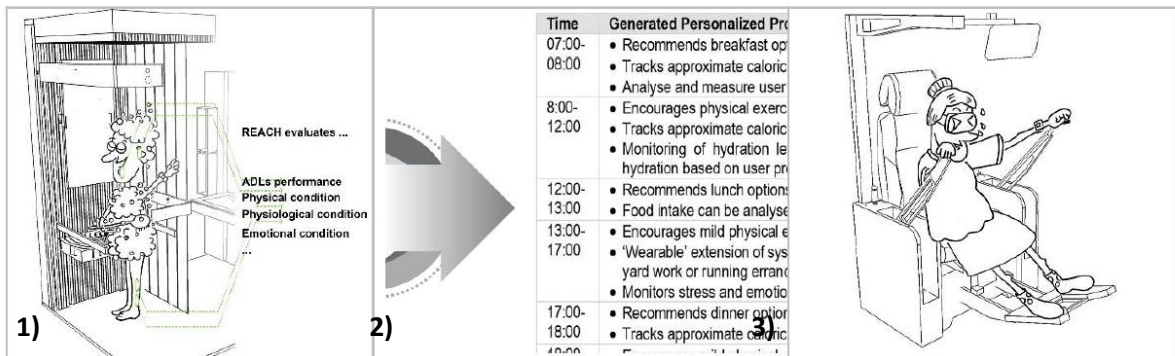
Capteurs de mouvement



Capteur porté type « Fitbit »



Exemple imaginaire de mobilier connecté constituant REACH. En fonctionnant ensemble, ces modules seraient capables de mesurer des données de santé, de les analyser et de formuler sur cette base des recommandations de santé que l'utilisateur pourrait effectuer.



REACH serait capable de mesurer les données de santé (1), les analyser et fournir sur cette base des recommandations (2) et éventuellement de les appliquer (3).

PAGES DE SIGNATURES

(swissethics 0, 1a)

Numéro de projet 690425 (numéro de demande de financement horizon 2020)

Titre du projet Etude de la population cible du projet européen REACH.

Le chef de projet et ses collaborateurs acceptent la version actuelle du plan de recherche (version 1.0, 04.04.2016). En cas d'accord de la commission d'éthique, ils s'engagent à effectuer cette recherche selon ce plan, et en accord avec la déclaration d'Helsinki ainsi que les règles fédérales, cantonales et institutionnelles en vigueur.

Chef de projet : Prof. Antoine Geissbühler

Genève, le 8.4.2016

Signature

Collaborateur : Dr. Damien Dietrich

Genève, le 8.4.2016

Signature

Collaboratrice : Mirana Randriambelonoro

Genève, le 11.04.2016

Signature

Collaboratrice : Caroline Perrin

Genève, le 11.04.16

Signature