racia

Co-Design Results

Report

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Executive Summary

Currently, the rehabilitation of Aphasia at home is carried out through the prescription of various exercises and indications in paper format without the guidance of the health professional. The transition from traditional but archaic methods will naturally be replaced by new processes that will be more accurate, reliable, and less random or discretionary. Thus, the assessment and intervention in physiotherapy and speech therapy, using a new software and technologic medical solution, as in ORACIA, will allow an innovative and more accurate assessment but also a treatment for users with this pathology.

The intention of this report is to describe the deliverables resulting from task 1.2. As can be analyzed below, the process of organizational co-creation is based on a systematic review of the assessment and exercises to be performed in aphasia rehabilitation, on ORACIA context. This process will cover the User-centered Design and Value Proposition. For User-centered Design, we will adopt the “Persona” method, which directly involves all participants (end-users, end-user support organizations and consortium companies) with an intermediate effort rate. In this method, archetypes of each user are specified. This technique helps to maintain a clear focus and shaping a consistent user-interface by making ‘the user’ present in the co-creation work. For Value Proposition it will be adopted the methods proposed by the Lean Start Up methodology to gather business requirements.

This report will also outline the methodological design of the co-creation from the ORACIA system, where these requirements are defined by stakeholders. Based on scientific literature and evidence-based practice, the features identified in the co-creation process will focus on three main areas: assessment, exercise plan and therapeutic guidance for aphasia. We will mainly use elements from three different understandings of co-creation: technology co-design and experienced-based co-design (EBD). The results will serve as an aid to understand and clarify the user's requirements and expectations of the system’s functionality and to provide a basis for the definition of the different system functional features. For the conceptualization of requirements, we organize a design-thinking session to determine what is more important for all involved stakeholders in the process, not only technical partners but also health care professionals that represent themselves, informal caregivers, and patients.
In the ORACIA project, different methods will be used to engage users, addressing different problem areas, from the technical to the social, because it is believed that the co-creation process in health will be able to favor both the techno-scientific evolution and to enhance the quality of the provision of health services. Through the involvement of patients, informal caregivers, professionals, researchers, and organizations in the processes of change, value in health will be created through the improvement and integration of the patient's social environment in the rehabilitation process.

1. Introduction

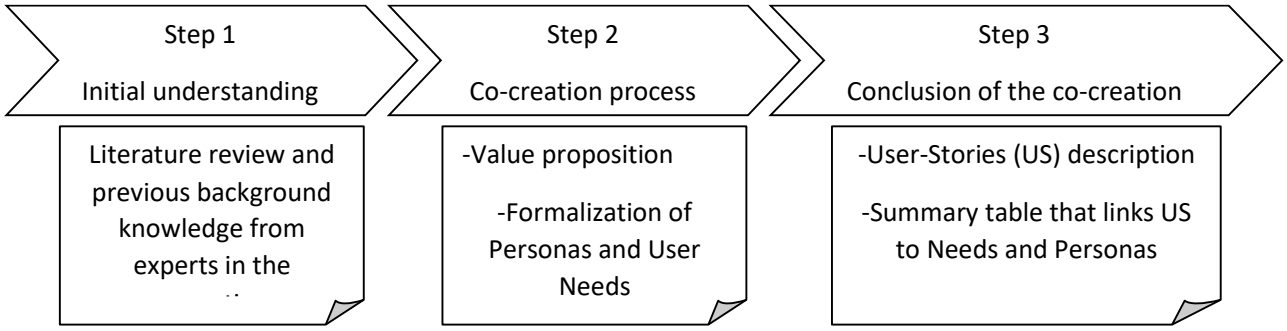
In-clinic speech and language therapy (SLT) are the gold standard for Aphasia treatment but its outcomes are dose-dependent; intensive, high-repetition, task-oriented and task-specific therapies are most effective. To achieve the greatest recovery possible, aphasic patients require ongoing, intensive therapy. However, for many reasons (i.e., unavailability of care resources - human and infrastructure), most patients are unable to attend SLT with the desired frequency. Also, there is a waiting list and limited number of outpatient therapy sessions are offered to each patient. Homework is an integral component of STL, with these assignments serving as a critical way to increase therapy intensity of the therapy and to encourage patients to practice using skills learnt in therapy into their ADLs. While patients appreciate the importance of home assignments, they find the lack of clear instructions, interaction, or real-time feedback discouraging, resulting in poor engagement rates. Home-based therapy and monitoring fit a crucial role towards increasing the availability and intensity of rehabilitation, enabling patients to enhance/prolong their therapy, and potentially improving outcomes. By performing therapy at home, patients can focus their energy on rehabilitation rather than the journey to the rehabilitation center, while creating fewer burdens for (in)formal caregivers. Despite studies were conducted to assess Aphasia rehabilitation targeted for informal settings (at-home), digital therapy is still fraught with limitations for these patients.

ORACIA will be a technological medical solution allowing the health care professional to configure patient-centered therapeutic plans with specific exercises regarding the patient's needs and will be adaptable to his/her progression over time. The patient will be able to complement the rehabilitation carried out in a clinical setting at home, and health professionals will have access to the quality record of the execution of exercises. Furthermore, it permits the professional to interact with the patient by distance and enable sending messages of correction, give positive reinforcement and encouragement to their users but also intervene when complications arise.
Finally, ORACIA will allow close monitoring of a patient´s progress and the efficacy of the proposed rehabilitation.

In addition, in this context, the co-creation methodology allows the involvement of relevant personas in all development processes, including the co-definition of problems, the co-development of alternatives and the co-implementation of solutions. This concept encompasses the engagement of personas in determining the technical and social objectives of ORACIA, analyzing the current situation and the problems in question, developing solution and implementation strategies, considering evaluation criteria, and reflecting collectively on the processes of change.

1.1 Co-Creation process in ORACIA

First step: Initial understanding was done in Proposal stage using Literature Review and previous Background Knowledge from experts in the consortium, these inputs help to formalize the initial description of Personas (at proposal stage).
Second step: Consortium exercise that takes the input from first step and further develops the understanding of the problem by designing a Value Proposition and a graphic design canvas to formalize the initial description of User Needs.
Third step: Analyzing the information from three previous steps and reformulating any required assumption in the project. Concluding the co-creation with the description of User-Stories (US) in the format of Gherkin Scenarios and a summary table that links US to Needs and Personas.


Step 1
Initial understanding
Literature review and previous background knowledge from experts in the
Step 2
Co-creation process
-Value proposition
-Formalization of Personas and User Needs
Step 3
Conclusion of the co-creation
-User-Stories (US) description
-Summary table that links US to Needs and Personas

2. Literature Review and Background Knowledge

Aphasia is an acquired disorder of language that affects an individual's comprehension and expression across the range of modes of communication (listening, reading, speaking, writing, gesture, and calculation). Aphasia is common in older adult patients in the context of vascular or neurodegenerative disorders. One of the most significant etiologies of Aphasia is a precondition of stroke (prevalent in older individuals), for which, about 30 - 40% of patients end up developing Aphasia. Around 60% of stroke survivors show consistent communication impairment one-year post-stroke. In 2017, there were 1.12 million incident strokes in the European Union and 9.53 million stroke survivors representing an incidence and prevalence of 392k and 3.3 million aphasic patients, respectively.

Adults with aphasia and their relatives report numerous negative impacts of aphasia: changes in communication situations, changes in interpersonal relationships, difficulty controlling emotions, physical dependency, loss of autonomy, restricted activities, loneliness, stigmatization, and negative feelings of irritation, stress, and anxiety. In situations of illness like this, the responsibility for caring often falls on the family, almost mostly on the spouse, who despite feeling overwhelmed and facing difficulties, feels fulfilled for being able to participate in the rehabilitation process and support their family member. In the range of responsibilities of the caregiver, three dimensions can be distinguished: responsibility (taking care of someone); satisfy (respond to someone's needs) and feel concern, interest, consideration, and affection for the person that they care for.

Effective rehabilitation for aphasia is vital to recovery. However, therapy outcomes are dose-dependent; intensive, high-repetition, task-oriented and task specific therapies are most effective. Home-based therapy fills an important role towards increasing the availability and intensity of rehabilitation. Given the complexity of the multiple needs displayed by patients and caregivers along the distinct phases of the rehabilitation process, the interest in multimodal and integrated care and interventions has increased.

At present, the market has some applications for Aphasia, but none allow the execution of exercises for recovery, feedback on their correct execution, assess the user's progress, in a combined and integrated way (e.g., as a stimulus sequence, built upon each other), and none links structured speech practice, cognitive, and motor functional activities, which are mostly compromised in these patients.

In this sense, in perspective of ORACIA, we considered three personas and their stories are reviewed: Patient, Therapist/Healthcare professional and Informal caregiver.

2.1 Therapeutic Guidelines

The biopsychosocial model of rehabilitation in aphasia imposes patient-centered care, expanding the sphere of health care beyond the patient, eliminating barriers to the social reintegration of the person with aphasia and focusing attention on the family caregiver(s). In this context, patient-family relationships are at the center of consistent and well-developed interprofessional interventions that encompass caregiver education, training and wellness (Off, Griffin, Murray & Milman, 2019, p.1).

In a clinical context, after assessment, the therapist explains the aphasia diagnosis to the patient and the caregiver, the type of aphasia, as well as the rehabilitation process. Normally, the main guidelines provided to caregivers are related to strategies to enhance and facilitate communication with the person with aphasia. From the experience of clinical caregivers, there is an overload of caregivers, which implies a difficulty in absorbing all the information given. In this sense, in the context of ORACIA, it is intended that the guidelines provided in a clinical context are available, in clear language, so that the caregiver can access them at any time.

Communication Facilitating Strategies for informal caregivers of people with aphasia

• Make sure the conversation takes place in a peaceful environment;
• Eliminate noise or distractions;
• Stay calm and positive;
• Speak slowly but naturally and without raising the tone of voice;
• Maintain proper language. Remember, you are talking to an adult;
• Repeat the message if necessary;
• Speak directly to the person with aphasia, maintaining eye contact;
• Use simple sentences more often, appropriate to the context or the message you want to convey;
• When the person with aphasia has difficulty expressing, ask simple questions for them to answer, by means of gestures, yes and no;
• Talk about one topic at a time;
• Write or emphasize keywords;
• Do not interrupt speech or finish sentences/words for the person with aphasia;
• Give the person with aphasia more time to understand the message or speak;
• If necessary, use gestures, images, or objects to support understanding;
• Encourage the person with Aphasia to communicate;
• Show interest in what the person with aphasia is saying, despite their difficulties in communicating;
• Always follow the medical and professionals' guidelines, present in the rehabilitation process;
• Try to offer pleasant activities and, as far as possible, go to places that were their favorite;
• Allow you to carry out activities that contribute to their self-esteem like getting your nails done, cutting your hair, shaving, among others.

Off, C. A., Griffin, J. R., Murray, K. W., & Milman, L. (2019). Interprofessional caregiver education, training, and wellness in the context of a cohort model for aphasia rehabilitation. *Topics in Language Disorders*,*39*(1), 5-28.

3. Personas

Contains Personas that define prototypical users of a system, or an example of the kind of person who would typically interact with the system.

3.1 Elderly Patient

Mr. P. is a 76-year-old man who suffered a stroke with an injury to the middle cerebral artery and Broca area. P. was diagnosed with Aphasia and presents difficulties in speech, language, attention, memory, executive functions, visuoconstructive skills and changes in neuromotor behavior of the contralesionally upper limb. These deficits directly affect his participation in activities of daily living (ADLs) and his quality of life (QoL). He was referred to the clinic for interdisciplinary evaluation by the Physiatrist, Speech and Language Therapist, Psychologist and Physiotherapist. A therapeutic plan was delineated with clinical sessions and the use of the ORACIA application for the home context. The therapist will select in ORACIA's professional interface the most appropriate strategy for progression, directed to the individual, through naming exercises, cognitive and functional movements training. ORACIA is delivered to Mr. P. as an interactive artificial companion. ORACIA will give guidance as well as real-time and appropriate feedback to Mr. P. allowing him to repeat and correct his performance while helping him to stay engaged with the therapy. It allows his rehabilitation in a clinical context to be completed at home and allows the caregiver to have a more organic interaction with the treatment and the health professional in real time. Each session starts with language training by asking Mr. P. to name a presented image (e.g., a book), and if necessary, he can choose semantic or/and phonemic cues. ORACIA will evaluate the answer using speech recognition and give feedback indicating whether he named it correctly or needs to repeat it using new cues. After this exercise, the session continues to Cognitive Training (dual-task training approach), and Mr. P. is asked to perform a static pose of the trunk and right upper limb to answer an "Equal or Different'' exercise that is showing two equal or different images (e.g., same book twice vs two distinct books). The session will conclude with Motor Functional Training, which will integrate the function and selectivity of functional movement into a specific task, by asking Mr. P to fetch the object from the images previously shown (i.e., fetch a book). This will allow movements such as reaching, rotating, transferring, and standing during the action, obtaining live visual and auditory feedback to provide synchronous correction of the exercise. This intervention runs daily to obtain the desired results faster. ORACIA will adopt a B2B2C model, thus a monthly subscription fee is paid by the care organization or insurance company that provided ORACIA to Mr. P. as a service. ORACIA will not impose a limitation on usage time per month, as the frequency of the intervention is proportional to the efficacy and speed of treatment. After starting to use ORACIA, Mr. P., began to feel improvements in language, cognition, and functional movements.

3.2 Therapist / Healthcare professional

C. is Speech Therapist, S. is physical therapist and B. is a Psychologist. The three are specialists in neurology and are part of the medical-therapeutic team for aphasia rehabilitation. The intervention with J. is carried out daily with the aim of rehabilitating cognitive and language skills as well as recovering mobility and strength, enhancing an improvement in the quality of life.

In clinical intervention with J., cognitive, language and physical therapy, has shown positive results, however, the therapeutic plan for continuing rehabilitation at home are mostly in paper format, with no feedback of the correct execution of the prescribed exercises at home. It is important to point out that the exercises prescribed for home, as they are mostly in paper format, J. often forget them at home when he returns to the clinic, lose them or they degrade easily, not allowing, S., C. and B. monitoring the home rehabilitation, neither in real time nor its subsequent analysis, allowing to adapt the intervention plan and enhance J´s rehabilitation. The medical-therapeutic team are concerned because they can perceive those exercises may not be performed properly at home and that the patient shows difficulty in memorizing and following some of the strategies/orientations at home. On the other hand, Aphasia presupposes the adequacy of a biopsychosocial rehabilitation model integrated in the community, allowing the caregiver's participation, and

eliminating barriers to the reintegration of J. in society, which is difficult, with the current home rehabilitation methodology.
In one of the last consultations, G, showed a free app that they tried to use at home to train naming however, the vocabulary used was completely out of context for J. and was in Brazilian, which undermines rehabilitation and can even leave language sequelae. The therapists know that, before J.'s aphasia, he and his wife G. were a happy, sociable couple with lots of hobbies. Knowing that these changes can often lead to depression or social isolation, they want to be able to promote rehabilitation as quickly as possible and integrate the clinical and home contexts. J. and his wife G. also said that they want their children and grandchildren to be able to participate in rehabilitation by helping J do his prescribed exercise plan.
As there were already patients in the hospital, with identical clinical characteristics and good results with ORACIA, after an interdisciplinary clinical meeting, all agreed that it would be a good methodology for the case of J. So, in session, the therapists explained the concept and suggested the use of ORACA, which was very well received, with motivation and enthusiasm. After the direct intervention in session, the therapists are able to exemplify and define the exercise plan, strategies and guidelines to be performed at home. In addition, they can register, monitor, and re-evaluate J.'s case more effectively. With the use of ORACIA, J. has shown a very positive evolution, he has already I improved the naming ability, decreasing the number of semantic paraphasias as well as improved range movement Whether he wants his wife, they demonstrate a more positive and happier attitude, saying ORACIA is a crucial help at home.

3.3 Informal caregiver

G. Is a 70-year-old woman, healthy and active. She and J. have been married for 45 years and they live in Portugal, in a small village where they know most of the neighbors. They even had a community garden. Before J. was diagnosed with Aphasia, their main hobby was joining the senior dance club. They have been dancing since they were young. They had dance classes twice a week and at weekends, they liked to have lunch with family and friends. As J. has difficulty communicating with others, he has been more depressed and isolated, refusing to go out. For G., communicating with J. after the Aphasia has not always been easy either, their relationship has also been more conflicted because J. gets nervous when he changes words or cannot name what he needs. She notices that he is unmotivated and is also anxious about the situation. Most of the time, he always ends up giving up on the exercises at home and she tries to help him but feels that she cannot do it in the best way. She does not always correctly understand what J. says or manage to give him the cues he needs for naming. G. knows that continuing the treatment at home is very important and that the more often he performs the exercises, the better his chances of rehabilitation will be however, she feels that J., in addition to being unmotivated, is unable to have diversified material at home, having to repeat the exercises already performed or on his own initiative, go to google and use material that is not always in Portuguese. The speech therapist has already explained that exercises in another language can harm J.'s evolution due to differences in vocabulary and phonetics.
J. has always been very attached to his children and grandchildren. G. notes that J. wishes they could be more involved in his rehabilitation. He tries several times to explain the exercises to them, but as he has communication difficulties, he ends up not being able to or giving up, it would be fantastic if they understood how to help him.
After talking to the family and then exposing their needs to the rehabilitation team, they started using ORACIA.
G. says his quality of life has improved immensely. They were able to continue the therapeutic plan in the comfort of their home, with more variety of exercises and no repetition limits. Even more importantly, J. can perform exercises with vocabulary and cues customized to his needs, and in Portuguese.
G. feels that J. is happier, motivated, can do the exercises more easily and in addition, children and grandchildren can support J. in the exercises, better understanding his evolution, G. says she no longer feels so anxious and responsible for her husband, having started to have some time for herself again.

4. Patient Journey

1. The patient is hospitalized due to a stroke.
2. A diagnose is formalized by a Neurologist or Physiatrist after clinical discharge and the specialist makes a recommendation for General Practitioner (GP) follow-up.
3. After assessment, the patient is referred for physical therapy, speech therapy and psychology.
4. In the first session with speech therapist, the patient is evaluated at the level of language and diagnosed with Aphasia. Orientations are given to the patient and caregivers, as well as the rehabilitation methodologies are explained and some doubts are clarified.
5. The patient is also followed by a physical therapist and psychologist.
6. An intervention strategy is defined and the patient starts language therapy, functional and motor therapy and cognitive training.
7. After the steps described above, patient starts rehabilitation of aphasia in the context of ORACIA.
8. Therapist selects exercises that are most appropriate to the patient's needs (e.g. level, frequency and type of exercises) to ensure a steady and favorable progression.
9. Subscribing to the application allows rehabilitation in a clinical context to be performed at home, also allowing the caregiver to have a more organic interaction with the treatment and the health professional who, in real time, can send messages of correction, positive reinforcement and encouraging the patient, thus avoiding complications that may arise during recovery.
10. The health professional will have access to data regarding the quality of the executed exercises. They will be able to evaluate the user's progress over time.
11. This intervention occurs every day. The subscription of this app is monthly with an associated value but without limit of uses.

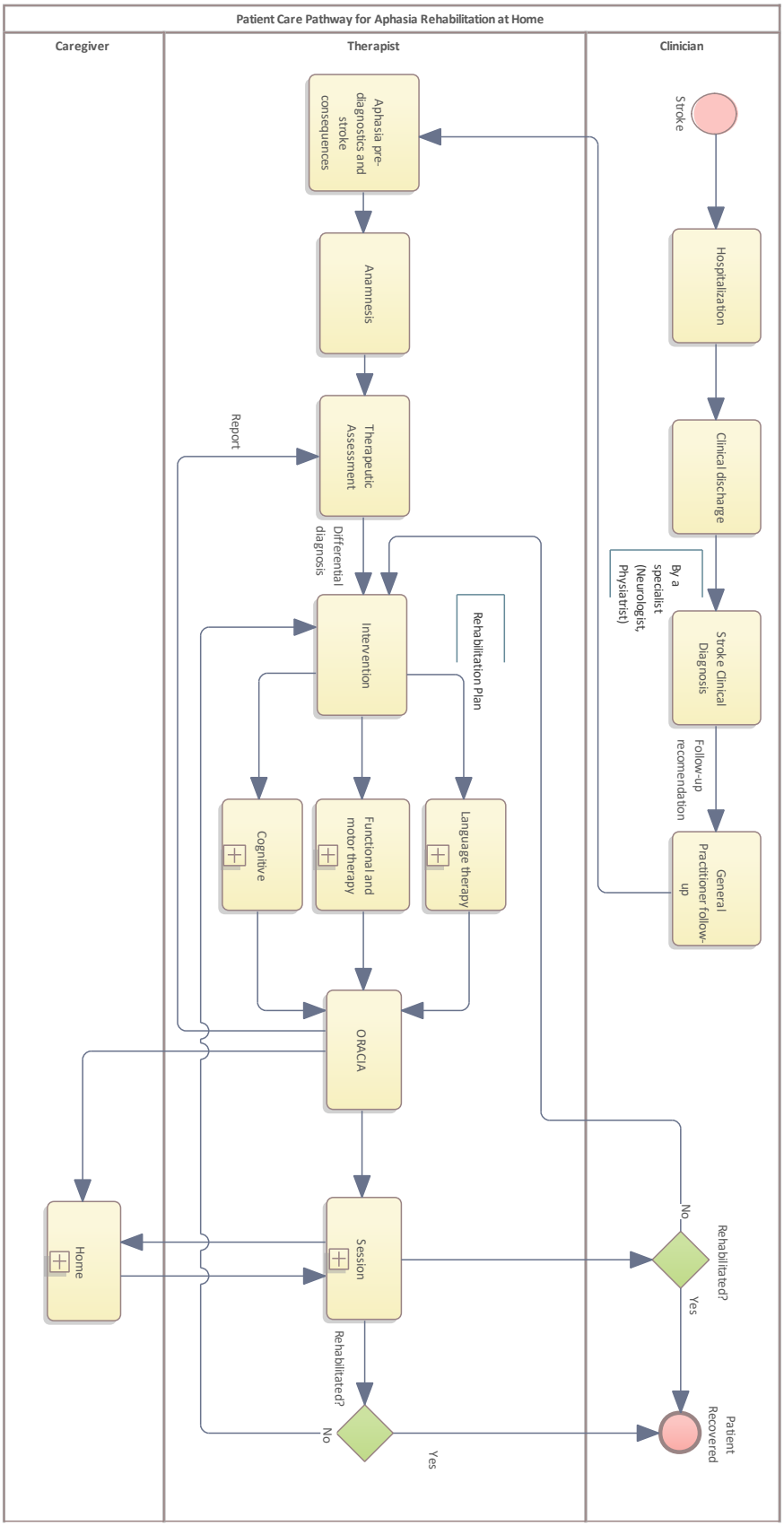


Figure 1: Patient journey for Aphasia Rehabilitation

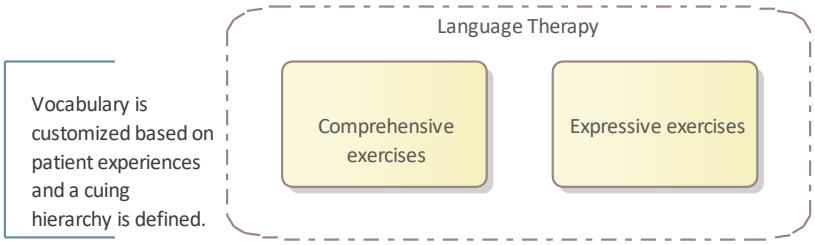


Figure 2: Language Therapy

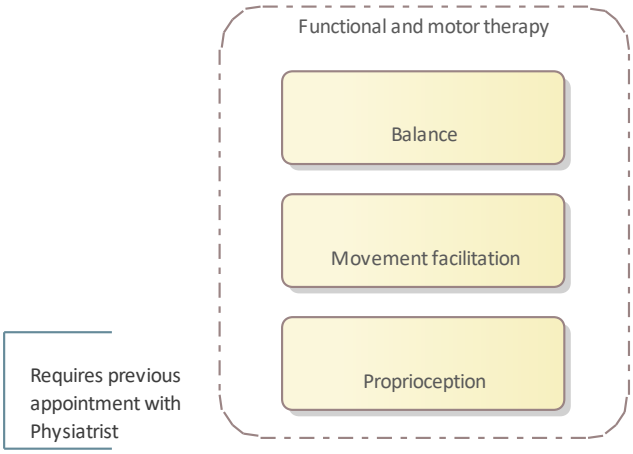


Figure 3: Functional and motor therapy

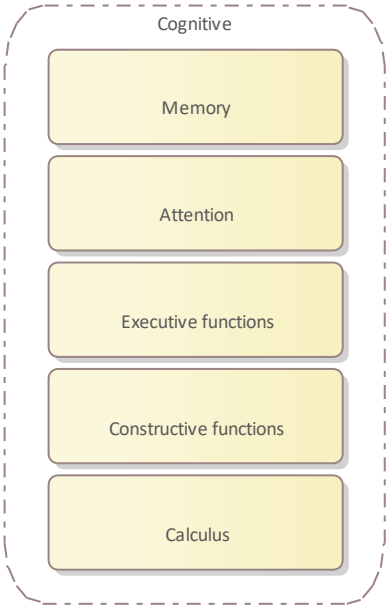


Figure 4: Cognitive

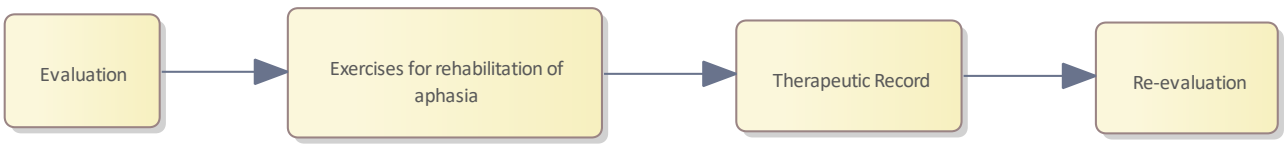


Figure 5: Session

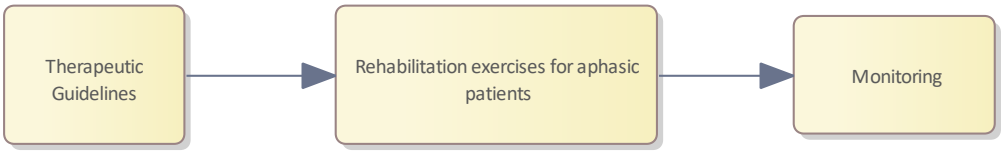


Figure 6: Home

5. Needs

Needs express the necessities of the defined Personas for the project. The project should aim to fulfil those needs.

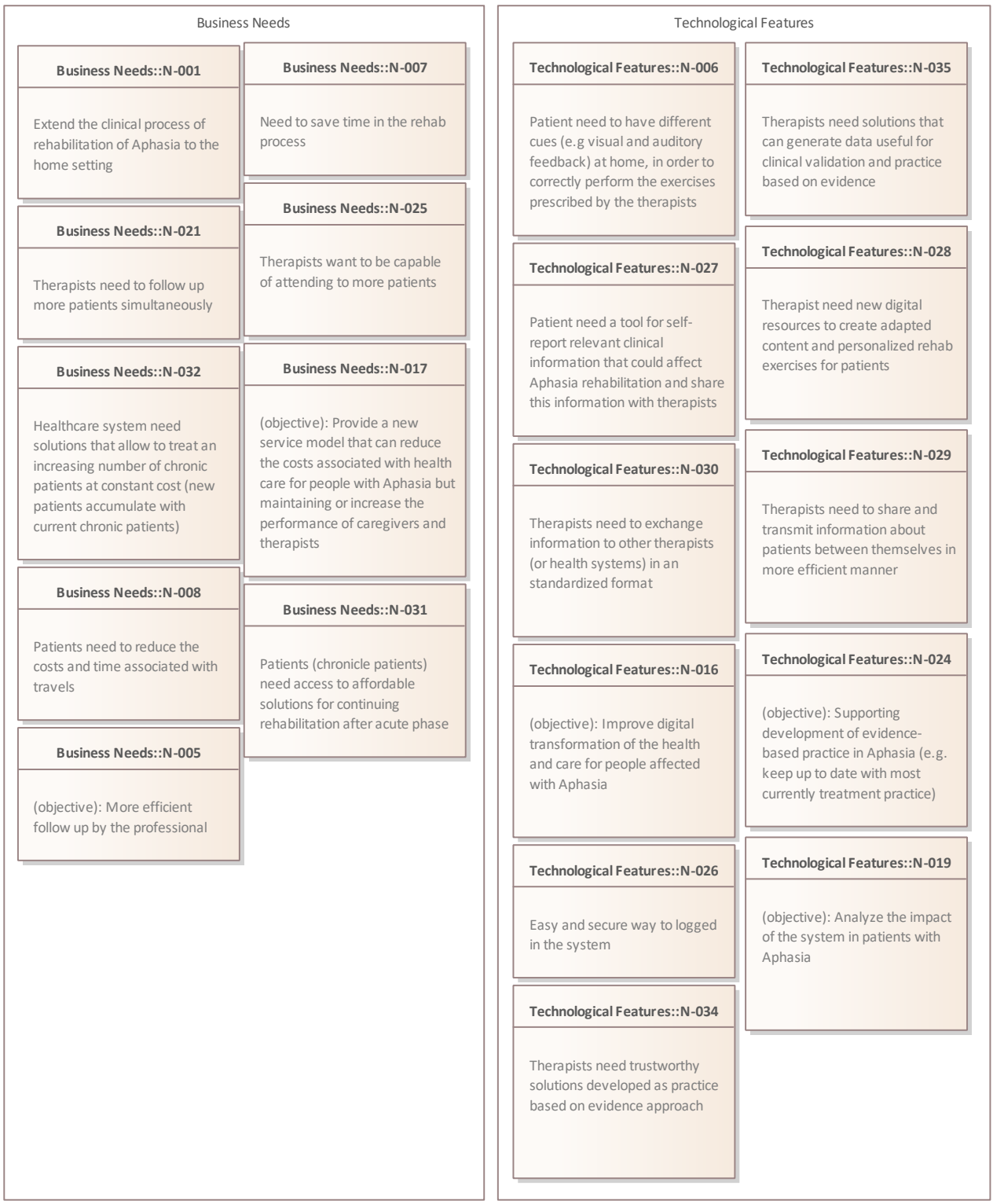


Figure 7: Business and Tech Features

6. User Stories

A user story represents a small, concise statement of functionality or quality needed to deliver value to a specific stakeholder. It identifies possible functionalities of the system, describing a usage scenario, so it must be associated with a set of personas which in turn have a set of needs. It's described in the format:
As a [type of user]
I want to be able to [perform some task]
so that I can [achieve some goal or benefit];
It should be supported by Acceptance Criteria, where a more detailed description is made of what is intended to be obtained from the system taking into account the action that the user intends to perform:
Given [Input]
When [Action]
Then [Output]

6.1 US_001 - Authentication

As a: User
I want to be able to: Access to ORACIA System
So that: I can access the functionalities addressed to my type of user.

Given: The system has authentication screen
When: The User login
Then: Access to his personal area.

6.2 US_002 - Therapeutic Assessment Registration and Monitoring

As a: Therapist
I want to be able to: Register an aphasia assessment
So that: I can monitor patient progression

Given: The Therapist logged in the system.
When: The Therapist accesses Therapeutic Assessment Registration interface in ORACIA back office.
Then: The Therapist registers the patient's Aphasia Assessment.

6.3 US_003 - Therapeutic Guidelines

As a: Patient
I want to be able to: Have access to ORACIA guidelines
So that: I can have access to specific tips and recommendations related to my clinical situation

Given: The patient logged in the system.
When: Access to his personal area.
Then: Mindfulness/psychology cue is presented to heal dealing with depression, anxiety and frustration

Given: The patient logged in the system.
When: The patient performs the exercise protocol.
Then: The therapists could check the patient performance and provide guidelines for improvement.

Given: The patient logged in the system.
When: Access to his personal area.
Then: A “reminder” type guideline provide literacy content about the need of therapist follow-up

6.4 US_004 - Prescription

As a: Therapist
I want to be able to: Prescribe exercises according to the therapeutic assessment
So that: The treatment plan is available in a given patient profile

Given: The therapist logged in the system.
When: The therapist needs to prescribe a treatment plan to a given patient
Then: The therapist has access to a specific exercise list from which to choose
And: Has an option to validate the treatment plan

Given: The therapist logged in the system.
When: The therapist needs to prescribe a treatment plan to a given patient with personalized exercises
Then: The therapist has the possibility to add personal information, such as pictures of family members associated with their names

7. Use Cases

A Use Case models who or what (Actors) will use the system and what they will be able to do with it (Functionalities). It describes the functionality that a system should provide to achieve user goals, identifying interfaces between the systems and its users (Actors), and models the system from a user's point of view. Requirements can then be defined based on the proposed Use Cases.

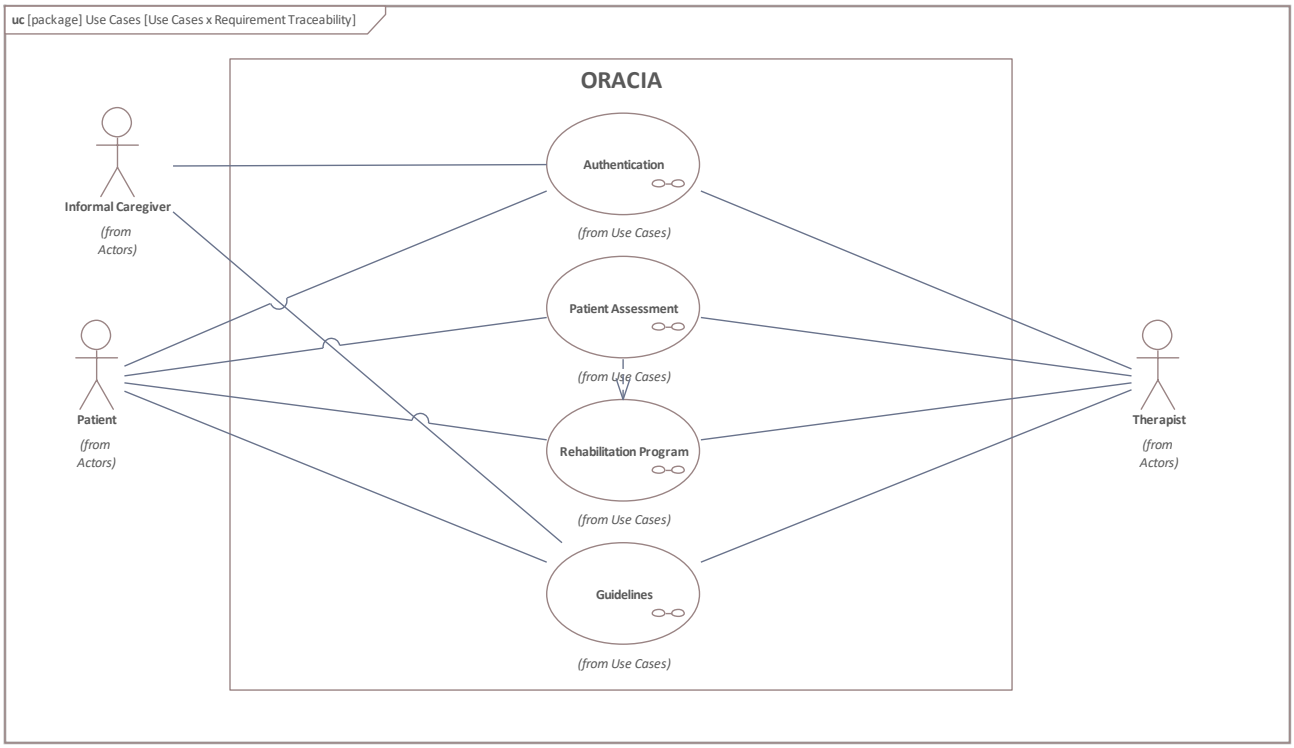


Figure 8: Use Cases x Requirement Traceability

7.1 Actors

The users of the system are depicted as Actors. Each Actor performs a specific role in the system, which is called a use-case. An actor can be a person or a computer, representing, for example, a database. In ORACIA we consider the Patient, Therapist, Caregiver and Database.

8. Requirements

The Requirement Analysis shall be performed using information gathered after:
- Stakeholders are identified
- Needs are identified
- User Stories are described

Requirements shall be described using information from:
- Requirements repositories
- Literature references
- User Stories collected from stakeholders referring to their needs
- Regulation and standards documents
- Similar systems

8.1 Functional

Functional requirements specify functions that the system must perform.

8.1.1 General functionalities

The following diagram shows the general functionalities of ORACIA.

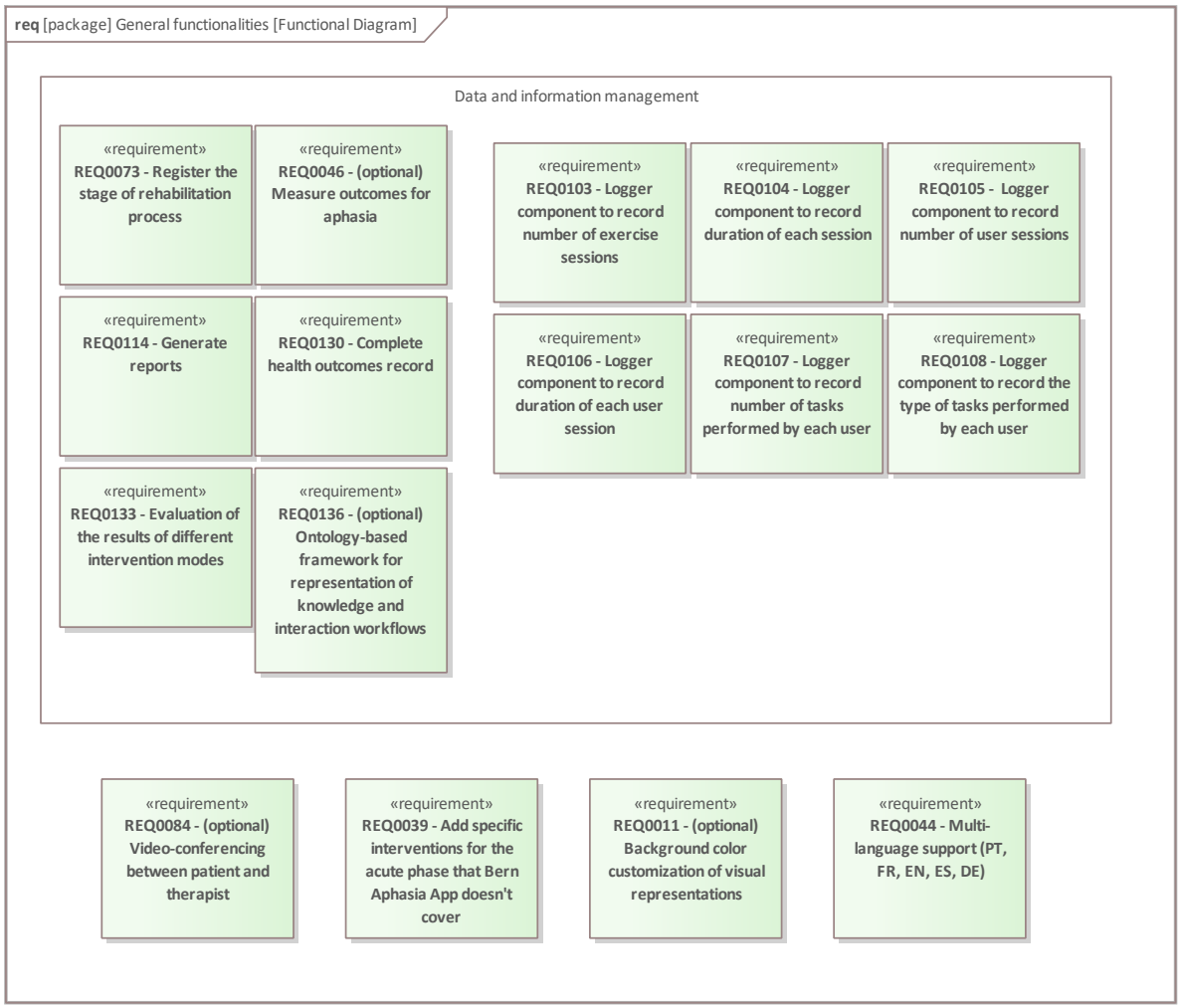


Figure 9: Functional Diagram

8.2 Performance

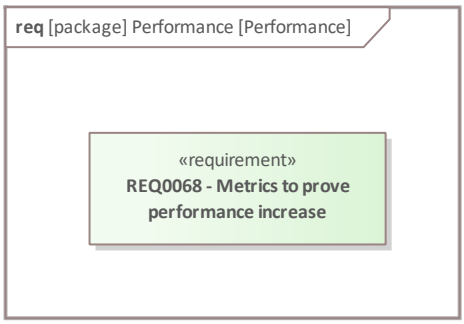


Figure 10: Performance

REQ0068 - Metrics to prove performance increase

The system shall include metrics to prove performance increase (remove myths that therapist is not needed after patients are more independent).

Priority: Medium, Status: Proposed

8.3 Usability

Other very important category is usability. ORACIA needs to be prepared for users with aphasia.

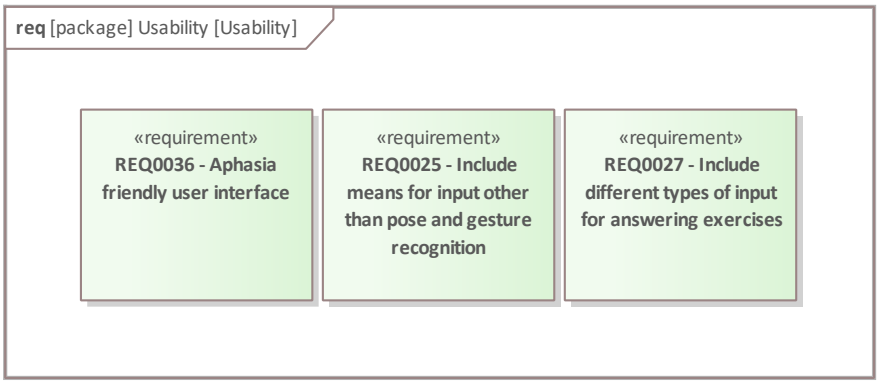


Figure 11: Usability

8.4 Security

Since ORACIA deals with sensitive health information, there are several security requirements that need to be fulfilled.

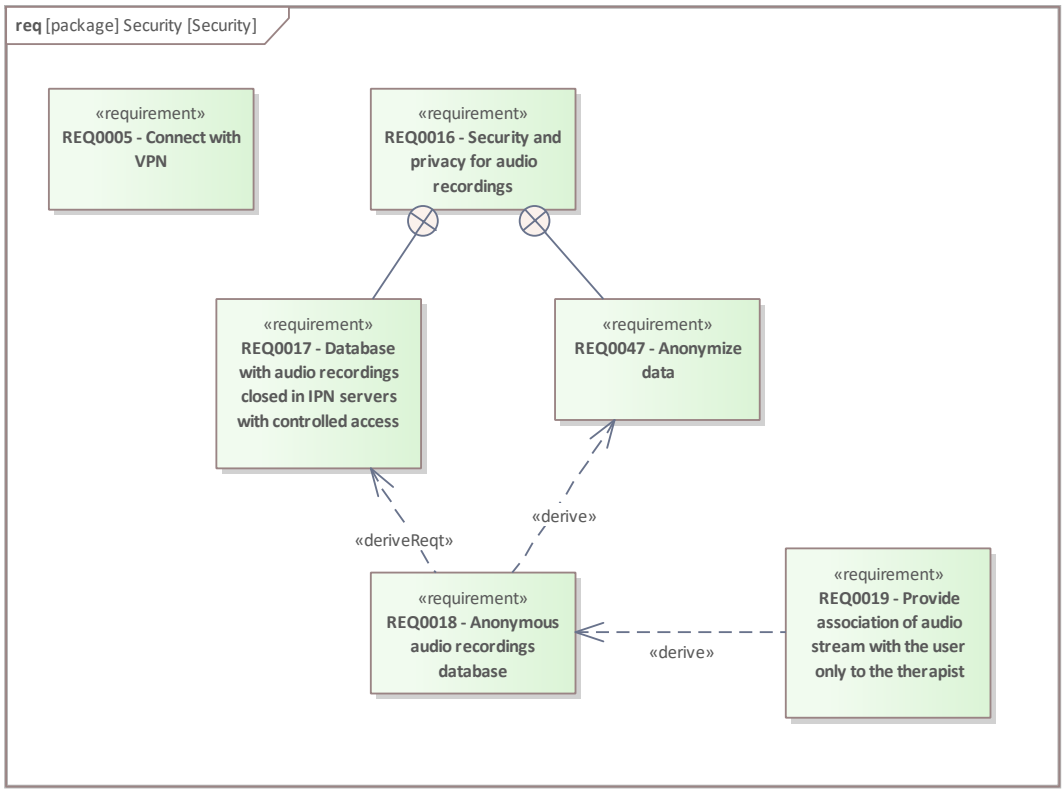


Figure 12: Security

9. Conclusion

During this document, it is possible to analyze how the co-creation process adopted in ORACIA allowed to integrate all the perspectives, needs and expectations of the various stakeholders.
By including multidisciplinary teams in this process of innovation in health, is intended to create scientific, economic but above all social value, seeking a full integration between rehabilitation in a clinical, social and home context of the person with aphasia.
The rigorous analysis of the user needs of each persona, especially of the patient and informal caregivers, allows a process of co-creation of services that integrate a participatory model of patient engagement or patient involvement, so valued by the World Health Organization. The Co-design process allows to identify precisely what is more important for all different users. It helps to achieve the defined objectives more efficiently and precisely. Cooperating with the users in developing a system also helps the system to be accepted and more user-friendly.
From a clinical-scientific point of view, the collection and sharing of clinical information about the user will allow to have health outcomes, allowing to act in a model of practice based on evidence and economic sustainability.