



# CO-CREATION RESULTS

## *Report*

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### *D1.1 – CO-CREATION RESULTS*

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## Executive Summary

Currently, the rehabilitation of facial paralysis (FP) 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 FaceRehab 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 D1.1. 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 facial rehabilitation in patients with FP, on FaceRehab context. This process will cover the User-centred Design and Value Proposition. For User-centred 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.



# 1. Introduction

Currently, mirror biofeedback therapy, in the clinical context, has been associated with positive results in the treatment of FP. However, the therapeutic guidelines for continuing rehabilitation at home are mostly in paper format, with no visual biofeedback of the correct execution of the prescribed exercises. It does not allow monitoring by a health professional during home rehabilitation, neither in real time nor its subsequent analysis. This monitoring allows us to avoid complications, such as the presence of synkinesis, hyperlacrimation during mastication or the increase in inadequate muscle activity, due to the incorrect execution of the prescribed exercises, triggering negative outcomes in the user's rehabilitation.

FaceRehab 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 quantitative data like: quality of execution of the movements; time spent on exercises etc., 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 FaceRehab 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 FaceRehab, 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 FaceRehab

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: Analysing 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.

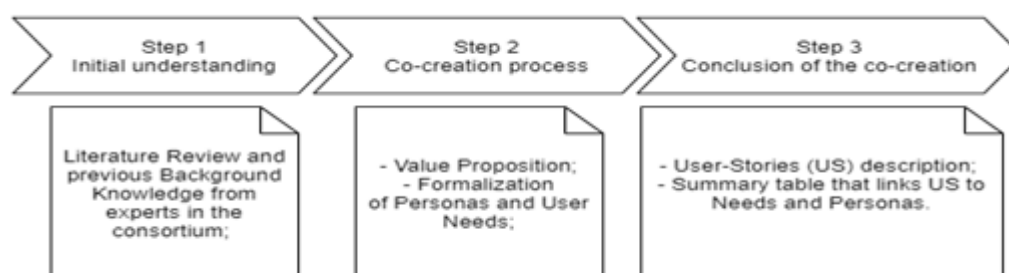


FIGURA 1: CO-CREATION PROCESS



## 2. Literature Review and Background Knowledge

Communication is a central aspect in life in society, people exchange information in different ways using not only words, but also their facial expression, essential for expressing emotions and socialization. The literature describes that people with FP experience psychological and social problems. These problems are caused not only by social stigmatization, but by their own self-stigmatization. There are factors that mediate the individual response, such as resilience, family and social support and the development of appropriate strategies to deal with the situation in the health area. 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. Currently, mirror biofeedback therapy, in the clinical context, has been associated with positive results in the treatment of idiopathic Facial Palsy. However, at this time the user's home rehabilitation is oriented in rehabilitation exercises in the paper format, not having any kind of visual biofeedback of the correct execution of the prescribed exercises in a clinical context. It does not allow the possibility of the health professional monitoring the execution of home rehabilitation, in real time or the subsequent analysis of it, thus avoiding complications, such as the presence of synkinesis or the increase of inadequate muscle activity, by incorrect execution of the prescribed exercises, triggering negative outcomes in the rehabilitation of the user. Currently in the market we are encountered with the existence of several applications for PF, but none of them allows the execution of exercises for recovery, feedback of the correct execution of exercises, evaluate the progress of the user, measure the degree of involvement of nerves at the same time, and none of them associates functionality such as chewing that is mostly compromised in these patients. In this sense, in perspective of FaceRehab we considered three personas and their stories are reviewed: Patient Therapist/Healthcare professional and Informal caregiver.

### 2.1 Personas

For a better identification and characterisation of users, a set of personas and respective scenarios are presented, and later on it is essential to translate these narratives into user stories in order to understand their main needs.

#### 2.1.1 Elderly Patient

J. is a 70-year-old patient who lives with his wife in an interior region of his country. He was recently diagnosed with paralysis and has a diagnosis with central FP, hemiparesis, hemianopsia and paresis of the 12th cranial nerve to the left due to intravascular lymphoma. The patient has asymmetry in the right face, salivary and lacrimal secretions and tasting are altered, not able to close the eyelid, which may cause corneal damage. He was referred to the clinic for an interdisciplinary intervention. The evaluation was carried out by the team made up of the Physician, Physiotherapist and Speech Therapist and an intervention plan was prepared. Unfortunately, J. lives far from the clinic, doesn't drive and has difficulty in using public transport. Due to facial asymmetry and drooling, he says he feels very uncomfortable either eating or being in public. The wife says that sometimes she only eats at home, skipping meals and even lost weight. Usually, he is accompanied by his wife because he reveals difficulty in reading due to hemianopsia. Despite feeling comfortable with the clinical-therapeutic team, it reveals discomfort in travel daily, monetary difficulties and some fear of the hospital context. J. Also knows that, in addition to therapy, he must carry out the exercise plan frequently, however, at home, he mentions difficulty in remembering all the therapeutic guidelines and also, insecurity in performing some exercises, as he does not have real-time feedback. Both J. and his wife started to wonder if it was possible to have some of these therapies at home, in his own safe and familiar environment. The couple also inquired about the possibility to do these more often, and in accordance to their schedule. J. also mentioned that his son liked to be able to participate in his therapeutic plan in order to be able to promote his rehabilitation and allow his mother to rest, however, due to incompatibility of

schedules, he cannot accompany them to the treatments in a clinical context. They discussed this with their clinical team and the timing could not have been better. The hospital had just started to work with FaceRehab, a new medical solution, that will be able the therapeutic plans to be directed to each patient, allowing the therapist to select the exercises that are most appropriate to the clinical condition and evolution of the same. In this way, the patient will be able to complement the rehabilitation carried out in a clinical context at home, and health professionals will be able to have access to the record of the quality of execution of the movements, being able to monitor the home rehabilitation, sending messages of correction, positive reinforcement and encouragement to their users and avoiding complications that may arise during their recovery. Allowing in this way to evaluate the patient's progress, the training of the functionality and execution of the movement. Therefore, at the end of the session, FaceRehab facial rehabilitation software will be applied to the patient. The therapists select the most appropriate exercises for the individual and the necessary progression. In the comfort of his home, he could perform and correct the execution of exercises at the same time as FaceRehab assesses and records the progress of the session. The application subscription allows rehabilitation in a clinical context to be completed at home, also allowing that his wife and soon to have a more organic interaction with the treatment and the health professional who, in real time, can send orientations, messages of correction, positive reinforcement and encouragement to the patient, avoiding thus complications that may arise during your recovery. The health professional will have access to the record of the quality of movement execution, evaluating the J. progress by measuring the degree of the nerve involved, training the functionality and executing the movement in real time from session to session, thus avoiding future complications in the recovery. This intervention occurs on alternate days (Monday, Wednesday and Friday). The subscription of this app is monthly with an associated value but without limit of uses. As the frequency of intervention is directly proportional to the effectiveness and speed of the treatment, J. in some sessions began to feel improvements in the functionality and mobility of the affected muscles. J and his family found this solution improved J's well-being and disease monitoring, while allowing them to keep their independence and social life habits.

### 2.1.2 Therapist / Healthcare professional

C. is Speech Therapist and S. is physical therapist. The two are specialists in FP and are part of the medical-therapeutic team. The intervention with J. is performed daily at out-of-the-way times and the rehabilitation objective is the recovery of facial movement and oral functions, optimizing facial mimicry and chewing, swallowing and communication. In clinical intervention with J., mirror biofeedback therapy, has shown positive results, however, the therapeutic guidelines for continuing rehabilitation at home are mostly in paper format, with no visual biofeedback of the correct execution of the prescribed exercises at home, as well as, it does not allow S. and C. monitoring the home rehabilitation, neither in real time nor its subsequent analysis, avoiding possible complications, such synkinesis, hyperlacrimation during mastication or the increase in inadequate muscle activity, due to the incorrect execution of the prescribed exercises, triggering negative outcomes in the J's rehabilitation. The two therapists 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. In evaluation or reevaluation process, the use of motor scales to measure the degree of impairment of FP is a common routine in clinical practice that allows C. and S. perform an accurate diagnostic and individualized therapeutic planning however, knowing the importance of the continuity of the therapeutic plan at home is difficult to reevaluate without the monitorization of J. The therapists know that, before J.'s FP, 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 feel very tired about their daily trips to the hospital and that J. is not able to eat in public because of the escape of food and saliva, skipping meals, having already lost weight. As there were already patients in the hospital, with identical clinical characteristics and good results with FaceRehab, 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 FaceRehab, 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 FaceRehab, J. has shown a very positive evolution, he has already regained weight and there are no synkinesis associated with facial movement. Whether he wants his wife, they demonstrate a more positive and happier attitude, saying FaceRehab is a crucial help at home.

### 2.1.3 Informal caregiver

G. Is a 68-year-old woman, healthy and active. She and J. have been married for 40 years and have always had many hobbies together mainly, growing a vegetable garden they have at home and going to the park with their grandchildren. Before J. was diagnosed with FP, she did daily walks with her friends and 3x water aerobics per week. They live in a village in the interior of their country, where everyone knows each other and go out on the street to talk. G. points out that J. used to play cards with his neighbours often and that every day while she was walking, they went to the café in the area. As J. feels very complex with his image, are more tired of travel and trips to treatments, G. besides feeling more tired does not want her husband to feel alone then, since he started his treatments, she has put aside all his hobbies. In addition to feeling more tired and overwhelmed, she is concerned about her husband's recovery and some disagreements have arisen at home when she corrects or feedback on performing the exercises. She is concerned because he often forgets the exercises in the plan but says he is very motivated. On the one hand<ins>,</ins> she would like to be able to help him more, on the other, she wishes to give him more independence during the realization. Usually, before this health problem, the grandchildren went almost every day to their home, but lately, besides feeling tired, they haven't a compatible schedule with the school to be with them, G. says that this causes them a lot of sadness. After talking in family and then exposing their needs to the rehabilitation team, they started using FaceRehab. G. says his quality of life has improved immensely. They stopped going to the hospital every day and were able to continue the therapeutic plan in the comfort of their home. G. feels that J. is happier, motivated, can do the exercises more easily with the strategies and visual support given and in addition, she can in those moments, go for a walk, take care of his vegetable garden or simply talk to friends. G. also points out that his son's support in his father's rehabilitation has been crucial, he manages to go almost every day to his home and while he can support J. she manages to be with her grandchildren or have time for herself.

## 2.2 Patient Journey on FaceRehab context

- 1- The patient gets in touch with the clinic after consulting with a family doctor or private doctor where he was diagnosed with FP.
- 2- After making an appointment at the clinic, the patient is called for an appointment with a physician at the hospital/clinic.
- 3- After evaluation and diagnosis, the physician prescribes adequate treatment, and the patient is referred for physical therapy and speech therapy.
- 4- First session to with a therapist, assigned to the patient and treatment begins with a functional, Static and Dynamic Evaluation and yet the orientation and clarification of the patient's doubts.
- 5- Patient starts treatment with passive techniques: Facial heat against lateral, Ice motor points and Relaxation massage.
- 6- After the steps described above, patient starts the active methodology: Exercises aimed at rehabilitation of FP in the context of FaceRehab.
- 7- 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 favourable progression.
- 8- 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.
- 9- The health professional will have access to data regarding of the quality of the executed movements. They will be able to evaluate the user's progress over time and train the functionality and executing the movement in real time from session to session, thus avoiding future complications in user recovery.
- 10- This intervention occurs on alternate days (for example Monday, Wednesday and Friday). The subscription of this app is monthly with an associated value but without limit of uses.

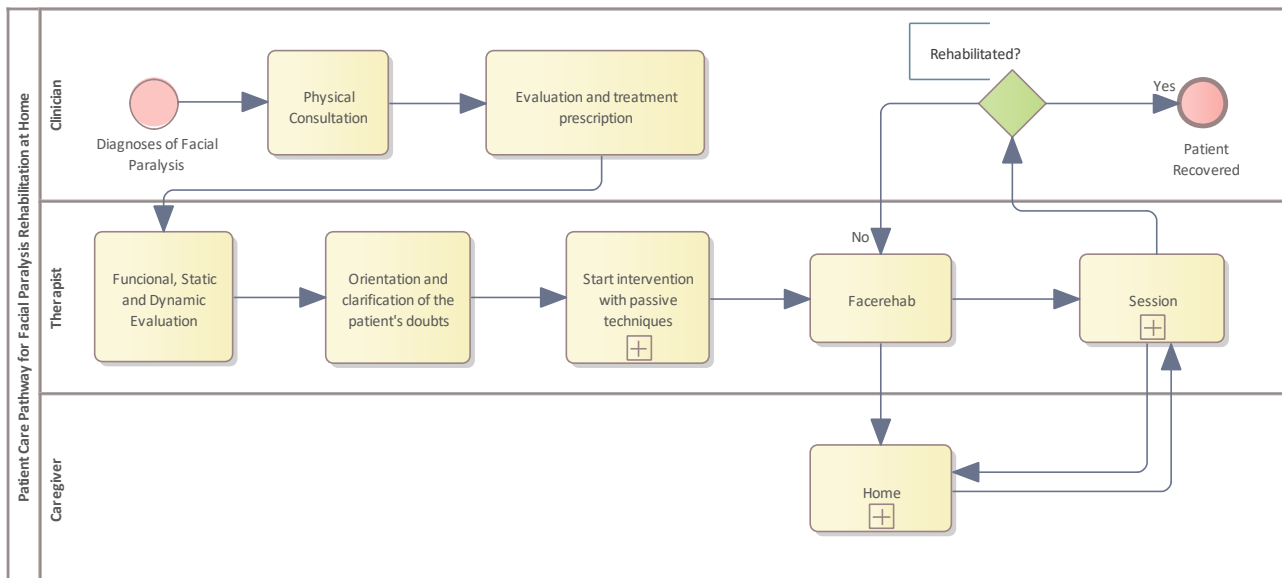


FIGURA 2: USER/PATIENT JOURNEY

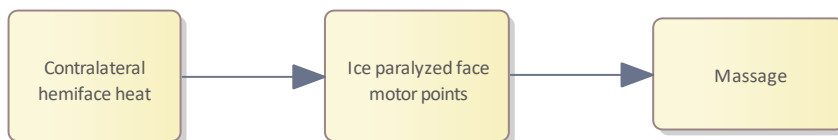


FIGURA 3: START INTERVENTION WITH PASSIVE TECHNIQUES



FIGURA 4: SESSION

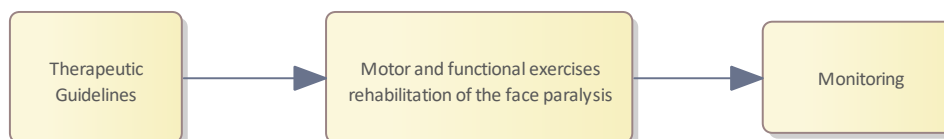


FIGURA 5: HOME

### 3. Value Proposition

The Value Proposition exercise allows the consortium to understand the major concerns for each stakeholder and clarify the problems that will appear during the implementation. Some questions came to the discussion, they will be very helpful to keep the concentration on the most important points for everyone involved in building the solution.

This exercise helps to position FaceRehab in the market and its role in people's lives. During this session the participants follow the diagram represented in figure below to identify value that this project could represent to its customers.

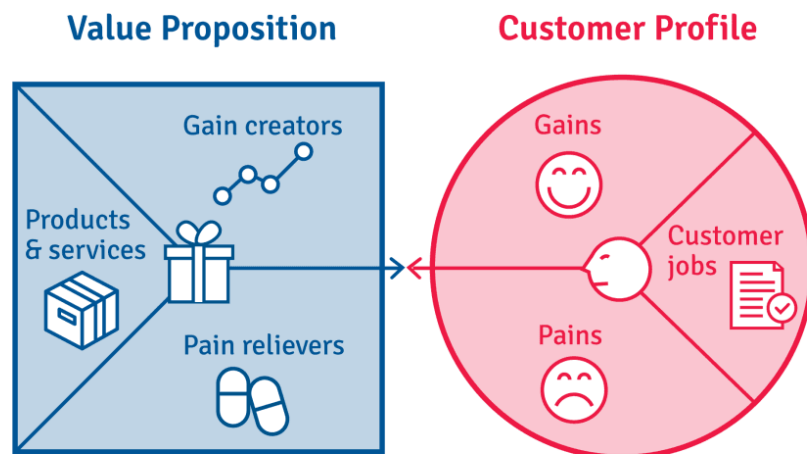
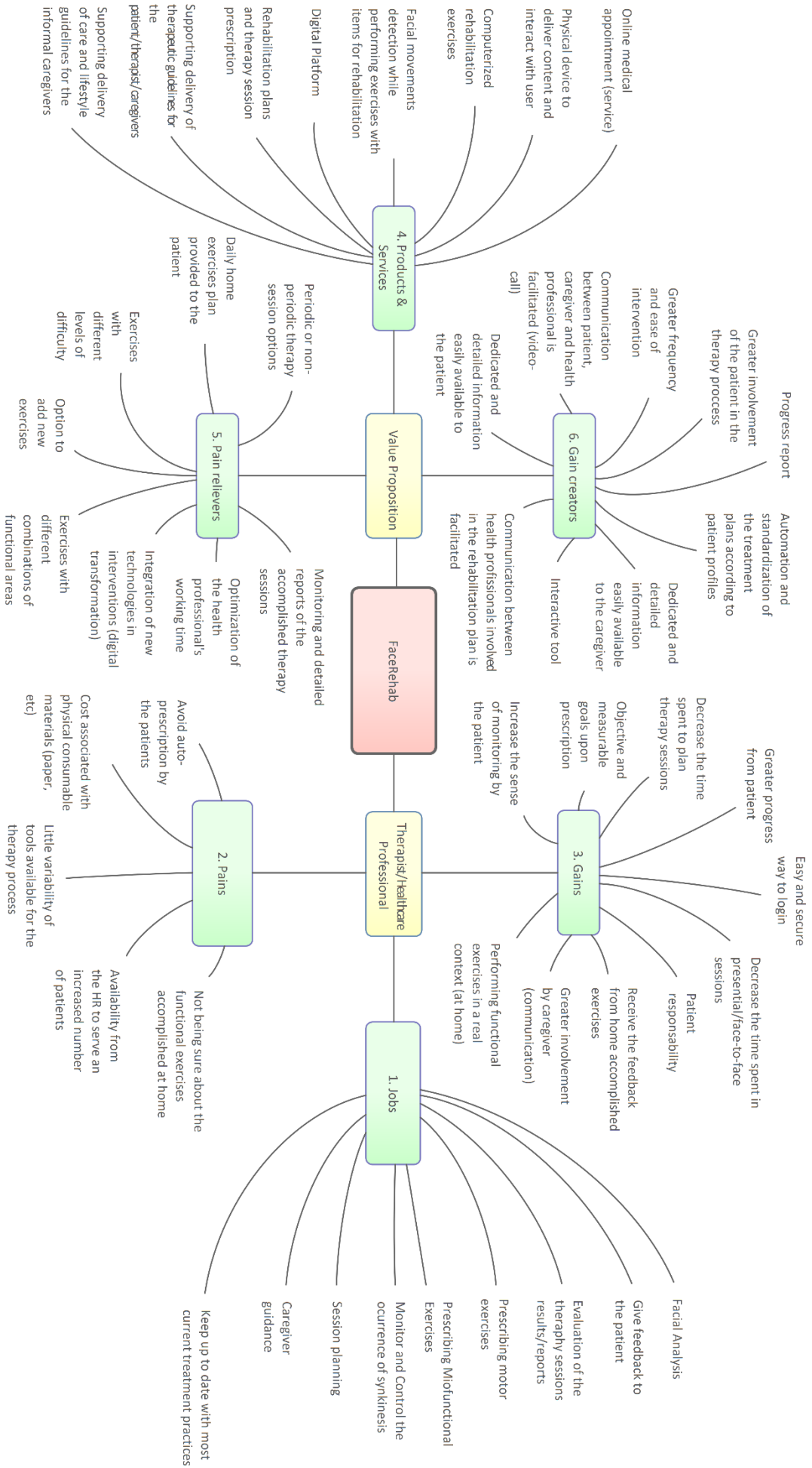


FIGURA 6: VALUE PROPOSITION CANVAS





## 4. User Needs

- N-001 - Extend the clinical process of rehabilitation of FP to the home
- N-002 - Myofunctional training more often
- N-003 - Promote faster and more effective rehabilitation
- N-004 - Home monitoring
- N-005 - More efficient follow up by the professional
- N-006 - Have visual feedback at home, in order to correctly perform the exercises prescribed by the therapists
- N-007 - Avoid complications, such as synkinesis, triggering negative outcomes in rehabilitation
- N-008 - Reduce the costs associated with travels
- N-009 - Remote supervision by a professional (avoid auto-prescription)
- N-010 - Provide guidance/strategies and support material more easily
- N-011 - Allow greater independence autonomy and accountability in the rehabilitation process
- N-012 - Support the role of the informal caregiver
- N-013 - Create less burden for caregivers
- N-014 - Integrate the FP rehabilitation process in the biopsychosocial model
- N-015 - Informed follow-up on his relative by checking the exercises performed through the system
- N-016 - Improve digital transformation of the health and care for people affected with FP
- N-017 - Provide a new service model that can reduce the costs associated with health care for people with FP but maintaining or increase the performance of caregivers and therapists
- N-018 - Improve the number and types of services related with FP rehabilitation
- N-019 - Analyse the impact of the system in patients with FP
- N-020 - More personalized intervention protocol for each recovery phase (e.g. session planning, prescription to home and decrease time spending in the session planning)
- N-021 - Check whether the exercises trigger correct responses in home
- N-022 - Integrate in oral rehabilitation plans functions such as speaking, chewing, swallowing, sucking and breathing
- N-023 - Integrate more functional exercises such as chewing in the rehabilitation plan in the patient's environment
- N-024 - Supporting development of evidence-based practice in FP (e.g. keep up to date with most currently treatment practice)
- N-025 - Clinical evaluation and reassessment (objective and measurable results from rehabilitation plan)

## N-026 - Easy and secure way to logged in the system



FIGURA 7: USER NEEDS

Target Source	Personas::Elderly Patient	Personas::Informal caregiver	Personas::Therapist / Healthcare professional
Needs::N-001	↑	↑	↑
Needs::N-002	↑		↑
Needs::N-003	↑		↑
Needs::N-004	↑		↑
Needs::N-005			↑
Needs::N-006	↑		↑
Needs::N-007	↑		↑
Needs::N-008	↑		
Needs::N-009			↑
Needs::N-010	↑	↑	↑
Needs::N-011	↑	↑	
Needs::N-012		↑	
Needs::N-013		↑	
Needs::N-014	↑	↑	↑
Needs::N-015		↑	
Needs::N-016			↑
Needs::N-017		↑	↑
Needs::N-018			↑
Needs::N-019			↑
Needs::N-020			↑
Needs::N-021			↑
Needs::N-022			↑
Needs::N-023			↑
Needs::N-024			↑
Needs::N-025			↑
Needs::N-026			↑

FIGURA 8: MAPPING USER NEEDS TO PERSONAS

## 5. User Stories

In order to collect all the work developed with the personas, all the information was consolidated in user stories, so as to allow a better understanding of their needs and to establish the bridge to the later development phases (e.g. requirements analysis and technical specifications). The main set of user stories is then described following the generic format.

### US\_001 - Authentication

**As a:** User

**I want to be able to:** Access to FaceRehab System

**So that:** I can complement the rehabilitation carried out in a clinical context.

**Given:** The system has authentication screen

**When:** The User login

**Then:** Access to his personal area.

### US\_002 - Therapeutic Evaluation

**As a:** Therapist

**I want to be able to:** get a facial analysis

**So that:** I can perform a static and dynamic evaluation to the patient in the first use, revaluation and final evaluation.

**Given:** The Therapist logged in the system.

**When:** The system makes the metric or photographic record of the static and dynamic face of the user.

**Then:** The system register facial symmetry at rest, symmetry of ocular, nasal and mouth muscles in movement.

### US\_003 - Therapeutic Guidelines

**As a:** Patient

**I want to be able to:** Have access to FaceRehab guidelines

**So that:** I can learn how to properly execute the various recommended exercises and have access to specific care tips and recommendations related to my clinical situation

**Given:** The patient logged in the system.

**When:** Access to his personal area.

**Then:** A "reminder" type guidelines and triggering an avatar to exemplify the self-massage and a performance of cleaning nasal and eye hygiene prescribed by the therapist.

**Given:** The patient logged in the system.

**When:** The patient performs the massage and nasal eyes hygiene before the exercise protocol and/or whenever you feel the need;

**Then:** The therapists could check the patient performance.

### US\_004 - Caregiver Guidance

**As a:** Caregiver

**I want to be able to:** Have access to detailed information and dedicated guidelines

**So that:** I can help the patient in the rehabilitation carried out at home

**Given:** The system FaceRehab provides detailed information dedicated to the Caregiver

**When:** The caregiver logged in the system.

**Then:** Access to the dedicated guidelines.

**And:** Helps the patient to perform the rehabilitation exercises at home.

## US\_005 - Prescription

**As a:** Therapist

**I want to be able to:** Prescribe exercises according to the therapeutic evaluation

**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:** As an option to validate the treatment plan

## US\_006 - Clinical Rehabilitation Program

**As a:** Patient

**I want to be able to:** Have access to specific exercises suitable for my needs

**So that:** I can improve my clinical condition over time

**Given:** The patient already has prescribed exercises

**When:** The patient logged in the system.

**Then:** A list of prescribed exercises is available

**And:** The patient perform the chosen exercise

## US\_007 - Adjustment of Treatment

**As a:** Therapist

**I want to be able to:** Adjust exercises according to the patient clinical condition and progress

**So that:** I can improve the efficiency of the proposed rehabilitation plan, consequently, a faster recovery from patient

**Given:** The patient finishes the set of exercises.

**When:** The therapist access to the patient profile

**Then:** The therapist can check how the session occurs

**And:** Adjusts the prescription according to the evaluation on the patient performance

## US\_008 - Home Rehabilitation Program

**As a:** Patient

**I want to be able to:** Have access to specific exercises suitable for my needs

**So that:** I can improve my clinical condition over time at home

**Given:** The system FaceRehab allows his therapists to prescribe exercises

**When:** The patient logged in the system.

**Then:** Access to the prescribed exercises.

**And:** Perform the exercises

**And:** The system makes the record of the exercises, for therapist give feedback on the correct execution, evaluating the patient's progress and avoiding associated complications, such as the presence of synkinesis, hyperlacrimation during mastication or increased inappropriate muscle activity, due to incorrect performance of prescribed exercises, triggering negative outcomes in the user's rehabilitation.

## US\_009 - Professional Guidelines

**As a:** Therapist

**I want to be able to:** Have access to FP rehabilitation newest best practices and guidelines

**So that:** I can stay updated with state of the art clinical practice and prescribe better treatment

**Given:** The therapist is authenticated and accessed therapist's dashboard

**When:** The therapist clicks the news tab

**Then:** The therapist can browse a catalog of curated articles and scientific and clinical materials and visualize their contents.

## Rehabilitation Program

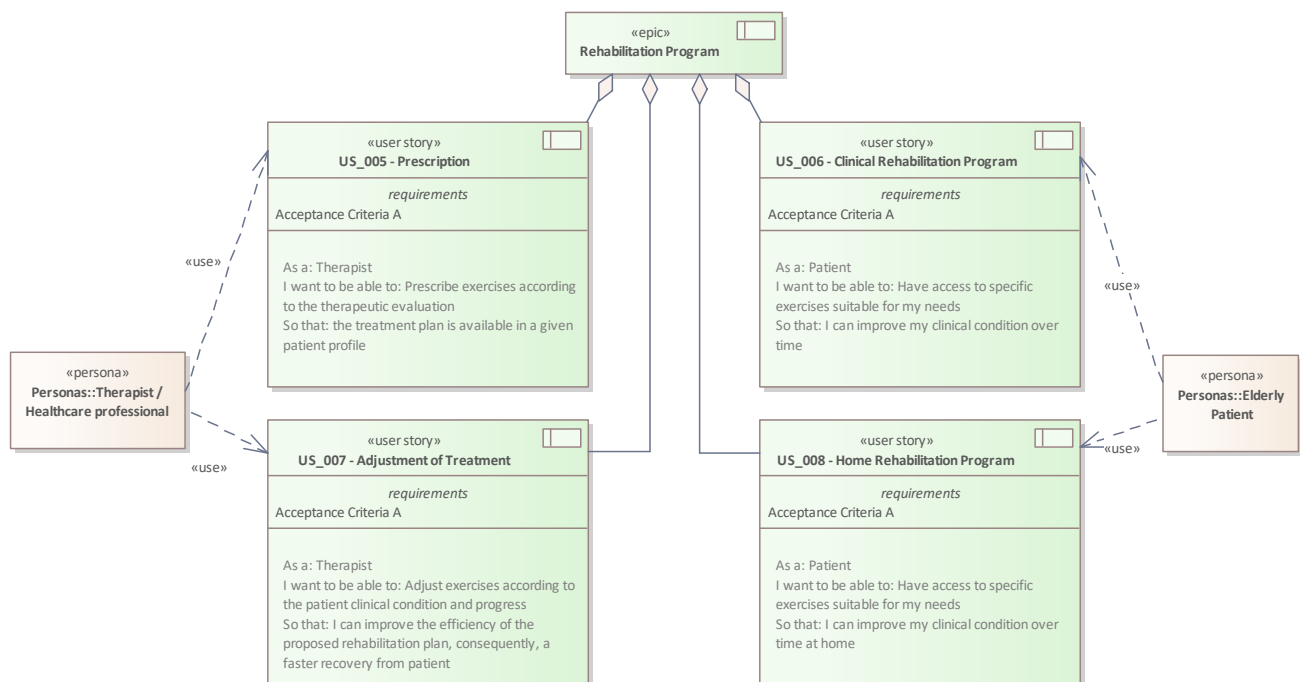


FIGURA 9: CLINICAL REHABILITATION PROGRAM

## Guidelines

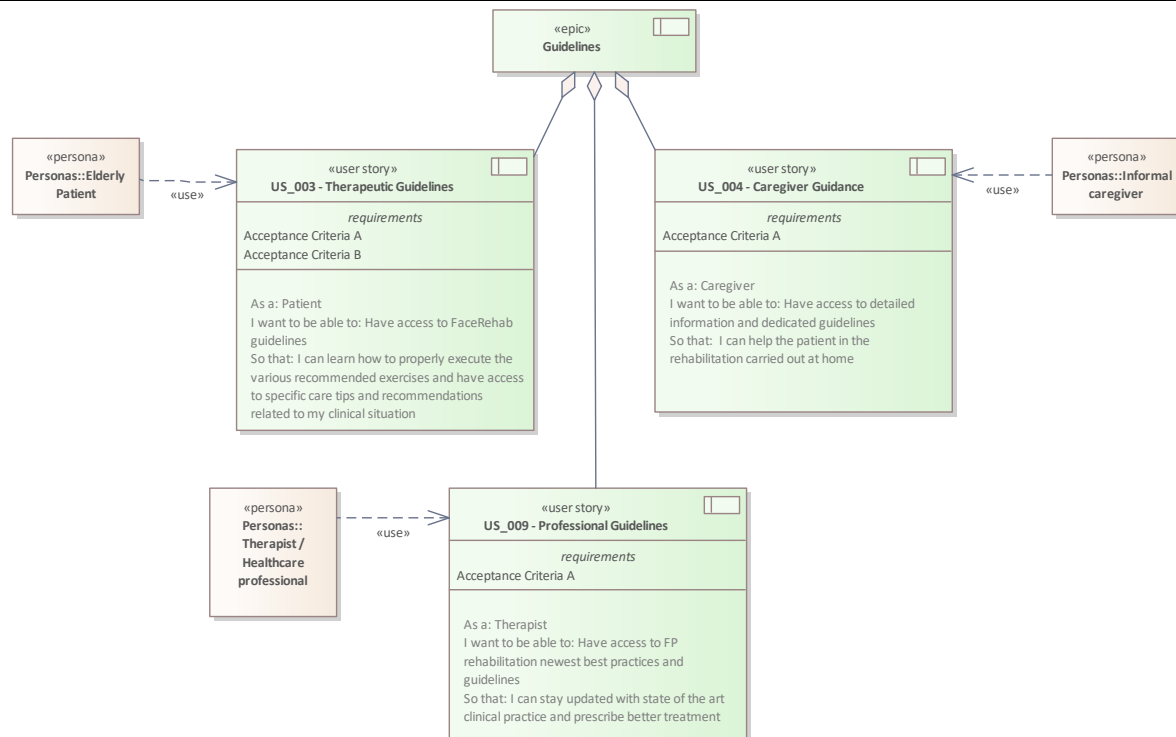


FIGURA 10: GUIDELINES



## 6. Mapping User Stories to User Needs

Target \ Source	User Stories::US_001 - Authentication	User Stories::US_002 - Therapeutic Evaluation	User Stories::US_003 - Therapeutic Guidelines	User Stories::US_004 - Caregiver Guidance	User Stories::US_005 - Prescription	User Stories::US_006 - Clinical Rehabilitation Program	User Stories::US_007 - Adjustment of Treatment	User Stories::US_008 - Home Rehabilitation Program	User Stories::US_009 - Professional Guidelines
Needs::N-001								↑	
Needs::N-002								↑	
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Needs::N-023								↑	
Needs::N-024		↑							
Needs::N-025		↑							
Needs::N-026	↑								

FIGURA 11: MAPPING USER STORIES TO USER NEEDS

## 7. Conclusion

During this document, it is possible to analyse how the co-creation process adopted in FaceRehab 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 FP. 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. 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.