



MYCYFAPP NEWS

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THE CO-DEVELOPED APP MYCYFAPP IS AIMED AT A PERSONALISED SELF-MANAGEMENT OF PANCREATIC INSUFFICIENCY IN CYSTIC FIBROSIS

MyCyFAPP project aims at developing an APP for self-management of enzyme replacement therapy in children with Cystic Fibrosis (CF) through a personalised and interactive monitoring and learning process.



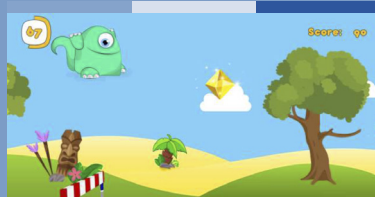
THE WAY AHEAD: NEW STRATEGIES FOR THE NEW STAGE OF THE PROJECT

The V Progress Meeting that took place last June in Trondheim (Norway) was, once again, a great opportunity for partners to keep themselves updated on the overall progress of MyCyFAPP. It was a very relevant meeting as the developmental phase of the project is almost completed and the evaluation of the product will start soon. Leaders of the different working groups presented last achievements and proposals to the whole Consortium and participants had the opportunity to test the Professional Web Tool, the self-management APP and the educational games. The meeting thus allowed all the partners to become aware of the last advances of the project to start preparing the next interim review in Brussels on September 2017. The protocol for the clinical trial that is about to start was discussed in details, taking into account the results recently obtained by the working group dedicated to development of the enzyme replacement predictive model. That study is almost completed and was based on in vitro digestion studies that have already analyzed the optimal enzymes dosage for 60 different food products. Two of the other MyCyFAPP working groups will increase their activities over the next few months: "Dissemination and Training" and "Exploitation". In order to redesign the website and to undertake new strategies, Ana Serra, a journalist, has joined the HULAFE team as Dissemination Manager.

In Trondheim agreements on the training program were also made: some webinars will be done to explain to professionals how to use the valuable features included in the application developed. Very productive work was also done on Exploitation, and during the meeting partners agreed on several exploitable products.



2 NEW CRITERIA FOR ENZYME DOSE ADJUSTMENT



3 NEW GAME ABOUT SPORT



4 JOIN MYCYFAPP COOKING CHALLENGE. LAST DAY: 30 SEPTEMBER



NEW CRITERIA FOR ENZYME DOSE ADJUSTMENT

Based on the results obtained in the in vitro digestion study on different kind of foods, the Consortium designed a pilot study in CF patients: a 24-hour diet containing those foods was designed and patients were enrolled from the five University Hospitals involved in the Project: La Fe (leader of this working group), Ramón y Cajal, Milan, Leuven, Rotterdam.

Forty-two CF patients agreed to take part in the study between June and October 2016. However, in the first round, the results led to inconclusive results, probably due to a low adherence level to the recommended meals.

The Consortium therefore decided to re-evaluate the protocol. A new menu was designed and the modality of the stool collection was also reviewed to make it easier for patients. These changes led to a more reliable analysis of fat absorption.

Indeed, the analyses in the second round were very satisfying as 100% of patients followed the diet. In addition, in our patients the average coefficient of fat absorption was over 90%, suggesting that the new proposed methodology derived from in vitro studies is reliable and can be used for clinical purposes.

This work means a step forward in the research as the new data permits developing a new approach for a more accurate adjustment of enzyme dosage based on scientific evidence. The following step will be a clinical trial enrolling higher number of patients.



BEHIND “MYCYFAPP PROJECT” PRESENTED BY ANA ANDRÉS AT ECFS IN SEVILLE

The talk was focused on the events occurring during digestion of complex food systems and their implications on lipids digestion.

Foods are highly complex systems that often contain a wide variety of different components, including sugars, salts, proteins, polysaccharides, lipids, vitamins, etc. Many of these components are capable of interacting with each other and forming complexes that could potentially alter the rate and extent of lipid digestion. For this reason, food matrix characteristics have a big impact in food digestion. A lot of fat we eat is already emulsified (ice cream, yogurt or cheese) while a significant amount of fat is also obtained in a relatively un-emulsified form (cooking fat or oil, the visceral fat from meat or fish and structural fat from seeds or nuts for example). All these structures can change during digestion due



to changes of pH, ionic strength of digestive fluids, the presence of surf-active substances, the action of enzymes, and also because of the forces and flow profiles along the GI tract. Other factors such triglyceride type and chain length, degree of saturation, extent of solid fat content as well as crystal type and structure, can also have consequences on lipid digestibility. Additionally, during digestion commonly take place what we call binding interactions making even more complex the

task of predicting the lipolysis extent. The influence of some of these factors was illustrated with results from in vitro digestion studies in MyCyFAPP project as well as the preliminary model to estimate the optimal dose of enzyme for a certain group of foods.

START OF THE CLINICAL TRIAL

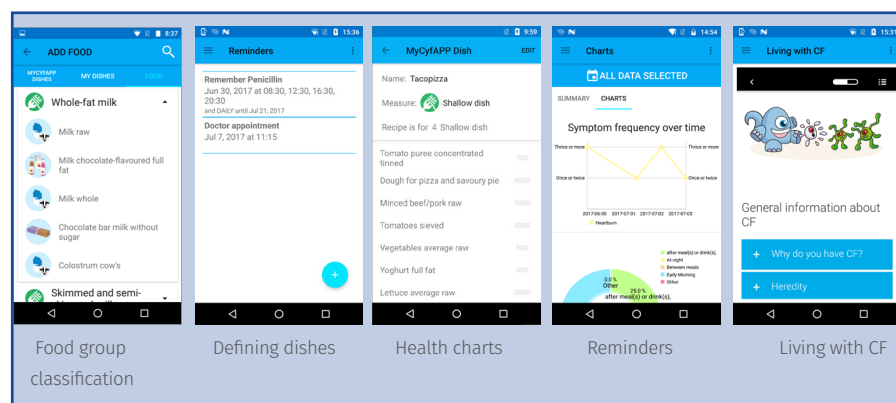
The MyCyFAPP is nearly ready for use, and so we are preparing to test and evaluate it in the clinical trial.

In the first part of the trial we wanted to gain insight into gastro-intestinal (GI) symptoms and health related quality of life of patients with CF. That is why we asked about 250 patients and their parents to answer questions related to GI problems through different questionnaires: the PedsQL GI questionnaire consists of 74 questions, related to gastro-intestinal issues (stomach, bowel, food). As this questionnaire was not used in patients with CF yet, we wanted to explore its use in this disease and compare the results with the CFQ-r, a more general quality of life questionnaire for patients with CF.

The first results indicate that, compared to healthy controls, patients with CF have abnormal scores for some subgroups of symptoms or complaints: constipation, heartburn and reflux, gas and bloating, diarrhea and worries about stomach aches. These first results indicate that the PedsQL may be useful for evaluation of gastro-intestinal related quality of life in patients with CF, both in clinical practice as in a research setting.

The second part of the trial will start in a few months. In this part we will ask patients to use the APP and the games (in children younger than 12 years) using the different features over a period of 6 months. We will examine whether the result of the selected questions from the PedsQL change over time with the use of the APP. The final aim of this trial is to find out whether the number of Creon capsules, food intake, GI symptoms and health related quality of life change over time whilst patients and parents use the APP.

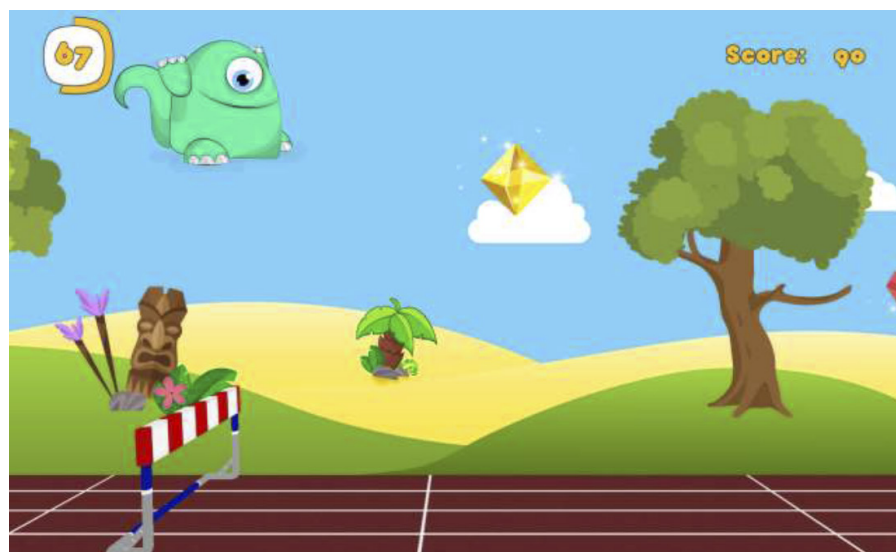
THE SELF-MANAGEMENT APP: THE FINAL TOUCH



In a few weeks, the clinical trial will start using a well-functioning self-management app available in 5 different languages. The developers had busy days in June. The last features, such as food diary and setting of goals, were completed, the synchronization with the back-end allowing exchange of data with health professionals was put in place, support for managing user accounts has been implemented, and many other issues were solved. The self-management app will be used during six months by around 200 persons. The project is delivering a mature and robust app thanks to a skilful and dedicated developed team at SINTEF Digital in Norway and ITACA in Spain, and thanks to the health professionals at CF Centres who provided medical content and advice.

The work of the technical research team is not over yet. In the next weeks, we will work with training materials for the health professionals who are about to introduce the app to the users. We will also set in place a support service allowing users to report bugs and ask questions. Further, the app includes feedback questionnaires allowing us to better understand the benefits and drawbacks of the provided ICT features for self-management.

A HEALTHY MIND IN A HEALTHY BODY: THE NEW GAME ABOUT SPORT



Walking around the island, the protagonist monster finds an athletics track, but it is no ordinary running track, it is the setting for the new game that aims to raise children's awareness of the link that exists between nutrition, hydration and physical activities. The monster has to run along the course collecting food and water gems: the more it collects, the better it feels, and the more obstacles it can avoid in order to cross the finish line.

This new game will be added to the whole saga of MyCyFAPP games and by playing this, children affected by Cystic Fibrosis can increase their awareness of the importance of nutrition, hydration and sport in order to adopt healthier behaviours in real life.

THE THREE MYCYFAPP APPLICATIONS FROM THEN TO NOW

The development of MyCyFAPP applications is coming to an end and it is now time to recap the work we did together with patients, families and experts, to be able to develop solutions which perfectly match the needs of their users: 71 interviews with children and teenagers with CF, parents and health professionals from 7 different countries in Europe, combined with field trips and desk research helped us to understand the users' requirements. Several co-creation workshops with the different target groups all over Europe were organized to develop first mock-ups of the applications together with the users. Finally the prototypes developed on the base of these mock-ups were assessed in repeated testing iterations to improve them further and further. The three final prototypes can now be checked on their impact in the clinical trial starting this autumn.



THE CURRENT VERSION OF HEALTH PROFESSIONAL'S WEB

The current version of Health Professional's Web Tool (PWT) is ready for testing. In the context of the mid-term evaluation of the tool, it was decided to use a set of refined paper prototype screens. The actual implemented version of the tool was based on the design resulting from this mid-term evaluation. PWT main features are aimed at health professionals to manage and follow patients' progress. After login into the system, professionals access to the main panel with the list of the patients, that provides a quick overview of their status. The professional can thus decide quickly who should be checked first. Then they can open the patient's profile (as shown in the Figure) where nutritional goals and motivational messages can be set. These will arrive to the patients through the self-management app. Patients' progress will be shown in the Patient Record section by means of graphs and charts of the health diary (symptoms, mood and other), nutritional intake (nutrients), food record (food intake), and in the case of children, growth pattern.

The screenshot displays the 'MyCyFAPP' interface for a health professional. The top navigation bar includes 'Patient Profile', 'Patient Records', 'Patient List', 'doctor1', and 'Log out'. The main section is titled 'User profile' and shows a patient's details: Code, Gender (Male), Birthdate (11/26/2014), Age (2 years), Height (86.0 cm), Weight (12.3 Kg), BMI (16.6), Absolute Z-Score (-1.5), Percentile (4.7%), Lipids (%), Proteins (%), Carbohydrates (%), Calories (KCAL), and Correction factor (1.5). Below this, the 'Health profile' section includes 'Allergies', 'Individual correction factor' (1.1), 'Observations', and 'Mutations (father)'. At the bottom, a 'Goals' table lists various goals with columns for 'From', 'Status', 'Goal', and 'Set by'.

#MYCOOKINGFAST INSTRUCTIONS

01

TAKE A VIDEO / PHOTO

PICTURE of the recipe that you have prepared with a short description of the ingredients and the process for preparing it OR RECORD a 2 minutes video while you are cooking

02

RECIPE

Listing the ingredients and the recipe in the body of the post

03

IDENTIFY

Include your country and the name of your recipe, including the hashtag #MyCookingFast, and tag @MyCyFAPP

04

NOMINATE

Add our slogan: HERE IS "MY COOKING FAST", SHARE YOURS! and nominate 2 friends that you want to involve in the challenge

My Cooking Fast will finish at the end of September 2017 and the recipe with more "like" will be announced on social networks so JOIN US! Follow the instructions on the left and remember to set the post as "public". We are waiting for your tasty recipe!

SOCIAL NETWORKS:



TO STAY UP TO DATE FOLLOW US ON OUR SOCIAL NETWORK PAGES: "MYCYFAPP".

COMING SOON

MYCYFAPP 6TH PROGRESS MEETING, DECEMBER 2017 IN LEUVEN (BELGIUM)



THE MYCYFAPP CONSORTIUM

We are a multidisciplinary research team, integrated by nutritionists/dieticians, paediatric gastroenterologists and pulmonologists, food technologists and engineers. IT experts, game developers, software developers, psychologists, biologists and patients' representatives who will bring their expertise to ensure the successful development of the project through a holistic and integrative approach of the different and complementary areas of knowledge and experts included.