



# MYCYFAPP NEWS

Nº 01 | March 2017 | [www.mycyfapp.eu/es/](http://www.mycyfapp.eu/es/) | [f Mycyfapp](#) | [t Mycyfapp](#) | [v Mycyfapp](#) | [c Mycyfapp](#)

## 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.



## MYCYFAPP 4TH PROGRESS MEETING

Members of the whole consortium met in Valencia at UPV last January. Multi-disciplinary sessions were created in order to discuss about the results achieved so far and to make agreements on the future activities. One of the most relevant achievements was the presentation of the results obtained from the WP 3 stage 1 study: "development of enzyme replacement predictive model".

The stage 2 of this pilot study will be conducted in February – March 2017. Furthermore, during a dedicated workshop, partners had the opportunity of testing the self-management app. The technical leader of these sessions presented the main features of the App.

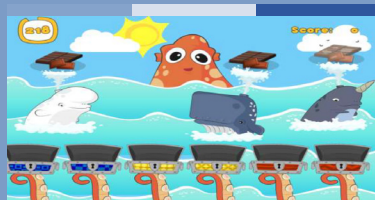
The mock-up of diary, food record and education workshops were tested and discussed by MyCyFAPP members.

Relevant details and other topics discussed during the 4th progress meeting are explained in the following articles.

Stay tuned: MyCyFAPP results are coming out!



## 2 IN VITRO DIGESTION STUDIES



## 3 OCTOPUS AND HIS WHALE FRIENDS COME TOGETHER IN THIS NEW GAME



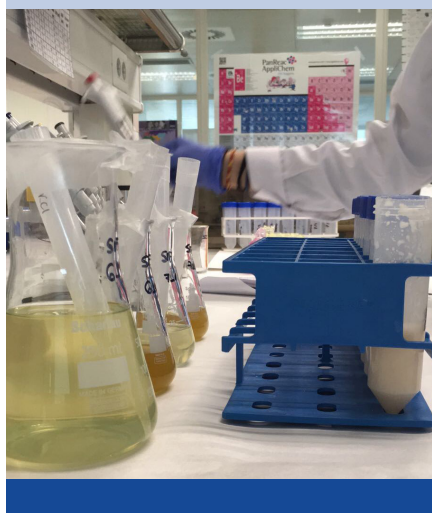
## 4 JOIN MYCYFAPPCOOKING CHALLENGE

## IN VITRO DIGESTION STUDIES

In vitro digestion studies are being carried out to estimate fats digestibility in real foods and meals under cystic fibrosis gastrointestinal conditions. These studies take place in the Institute of Food Engineering for Development (IIAD) of the Universitat Politècnica de Valencia (Spain). For this purpose, researchers from the IIAD mimic oral, gastric and duodenal stages simulating cystic fibrosis conditions to evaluate the influence of the inherent-to-food properties (such as fat origin (vegetal or animal), lipid profile or food structure) and intestinal conditions (pH and bile concentration and composition) on the effectiveness of the pancreatic enzymes supplement on lipolysis.

Biostatistical analysis of results and their modeling are key-oriented tools used for the calculation of fat digestion. The in vitro results together with the results from the in vivo studies, will be used to estimate the optimal dose of enzymes that the APP will recommend for the patient to be taken.

Up to now, more than 30 different food products have been analyzed, belonging to a total of 14 food groups selected for contributing significantly to the diet in terms of fat intake. Likewise, we have planned to digest the meals and the most popular dishes frequently consumed by the pediatric patients of cystic fibrosis enrolled in this study, in order to know the requirements of enzymes when eating complex combinations of individual foods.



## TWO FIRST SCIENTIFIC PUBLICATIONS OF MYCYFAPP AVAILABLE ONLINE:

The British Medicine Journal (BMJ) open has published the overall strategy of MyCyFAPP Project in a Protocol style paper. The article sets the reasons for the project and the objectives, describes the partners involved and the work packages, and provides an overview of the expected results and final scenario. The book will be published soon, but more importantly, all the contents are being adapted so the APP can support them and users can access them anywhere, anytime. Overall, they conform one of the main feature of the APP.

### BMJ Open Innovative approach for self-management and social welfare of children with cystic fibrosis in Europe: development, validation and implementation of an mHealth tool (MyCyFAPP)

Joaquim Calvo-Lerma,<sup>1,2</sup> Celia P Martínez-Jimenez,<sup>3,4</sup> Juan-Pablo Lázaro-Ramos,<sup>5</sup> Ana Andrés,<sup>6</sup> Paula Crespo-Escobar,<sup>1</sup> Erlend Stav,<sup>6</sup> Cornelia Schaubert,<sup>7</sup> Lucia Pannese,<sup>8</sup> Jessie M Hulst,<sup>9</sup> Lucrecia Suárez,<sup>10</sup> Carla Colombo,<sup>11</sup> Celeste Barreto,<sup>12</sup> Kris de Boeck,<sup>13</sup> Carmen Ribes-Koninckx,<sup>1</sup> on behalf of MyCyFAPP

<http://bmjopen.bmj.com/content/bmjopen/7/3/e014931.full.pdf>

The outcome of one of the first tasks of the project, was the comparison of the nutritional status, nutrient intake and use of enzyme supplements in the study population of MyCyFAPP as referred to the current guidelines. These results have been published in the Journal of Cystic Fibrosis, and soon a version for lay readers will be ready.



ELSEVIER

Journal of Cystic Fibrosis xx (2017) xxx–xxx



www.elsevier.com/locate/jcf

Original Article

### Nutritional status, nutrient intake and use of enzyme supplements in paediatric patients with Cystic Fibrosis; a European multicentre study with reference to current guidelines

Joaquim Calvo-Lerma<sup>a</sup>, Jessie M. Hulst<sup>b</sup>, Inês Asseiceira<sup>c</sup>, Ine Claes<sup>d</sup>, Maria Garriga<sup>e</sup>, Carla Colombo<sup>f</sup>, Victoria Fornés<sup>a</sup>, Sandra Woodcock<sup>b</sup>, Tiago Martins<sup>c</sup>, Mieke Boon<sup>d</sup>, Mar Ruperto<sup>e</sup>, Sylvia Walet<sup>b</sup>, Chiara Speziali<sup>f</sup>, Peter Witters<sup>d</sup>, Etna Masip<sup>a</sup>, Celeste Barreto<sup>c</sup>, Kris de Boeck<sup>d</sup>, Carmen Ribes-Koninckx<sup>a,\*</sup> on behalf of MyCyFAPP Project

<http://www.sciencedirect.com/science/article/pii/S1569199317300887>

## TRAINING WORKSHOP

Before the start of the trial the MyCyFAPP team will develop a training tutorial about the app, the game and the professional web-tool. At this moment CFE together with KU Leuven and Youssef are working at the preparation of these tutorials. They will be offered in the different languages for the patients and made available to all participants in the trial, both patients & their parents and health care professionals, in order to inform them as well as possible about the use of this innovative tool for self-management. The initial idea to organize training session has been adapted because of practical considerations. It will be much more efficient and effective for people to go through the tutorial when they choose and with whom they choose. Obviously a section with FAQ and a contact possibility for extra questions will be offered at the end of the tutorial. The aim is to make a tool that will be useful also after the end of the trial end the project, a tool that can be exploited, together with the App.

## LOOK! THIS IS REALLY GREAT!

This is what a young teenager involved in the mid-term evaluation, told her father when back home after the test of the self-management App at the hospital.

The mid-term evaluation of the self-management App was recently conducted in the Netherlands and in Spain. The App prototype included support for recording of symptoms ("diary"), recording food and retrieving educational content. 10 teenagers from 9 to 18 years old, and the parents of 4 young children participated. The evaluation consisted of two steps: a usability test while the participants discovered the app for the first time, and an acceptance test over one week where participants were able to explore the app in more details.

In addition to the user evaluation, the app was also tested by a group of health professionals involved in MyCyFAPP with the aim to check the correctness of the information shown to the App users, e.g. the parameters related to symptoms in the diary.

Inline with our initial interview-based investigation, the evaluation shows a diversity of needs. There is no preferred feature. The different participants wish to use the App in different ways depending on their situation and health conditions:

- Several participants are looking forward to support for calculating enzyme.

As this is a core research issue in MyCyFAPP, it is encouraging to ascertain that there is a demand for that feature among persons with CF.

- The diary was found useful in the case where a problem happens. Some participants pointed out that diary reports would be useful during consultations.

- Support for educational content received a mixed feedback. Some participants already know much about CF or search on Internet when needed, and do not see a need for education in the App. On the other hand, some participants liked to be able to easily retrieve trusted content provided by health professionals. They also appreciated the wide and detailed coverage of the educational content.

- The sharing of the recorded information is an important concern: some participants wish to keep control of what information is shared. Also, the participants have different expectations from the health professionals: some expect the professionals to look at information as soon it is shared.

- Among the missing support, a feature for managing medication is definitely required. This means reminding about intake and tracking intake. Several participants also expect "smart" support, such as simple advices to tackle a symptom, or easy retrieval of the appropriate educational content.

Following the evaluation, we have revised priorities on the development tasks. A usability test will be conducted one month before the delivery of the final app version. The goal is to fix all main usability issues before the clinical trial starts.

## OCTOPUS AND HIS WHALE FRIENDS COME TOGETHER IN THIS NEW GAME.

A big and friendly octopus is the protagonist of the new game about food macronutrients.

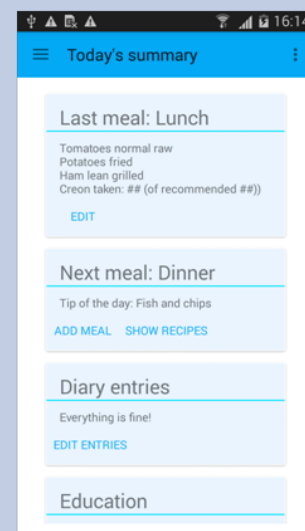
He pops up, out of the water smiling and balancing a number of chests on his tentacles.

In the surrounding waves, some whales are swimming around him suspending in their water spouts all the different food types: meat, fruits, vegetables, sweets, etc.

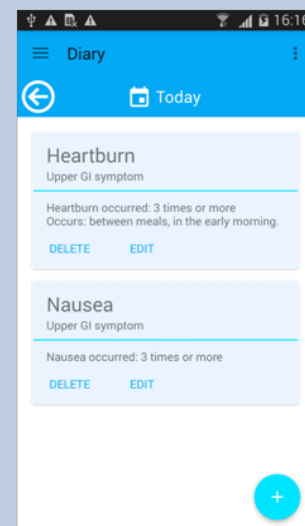
The octopus must collect all the foods into its chests correctly separating and sorting them by their macronutrients types: complex carbohydrates, animal protein, etc.

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 and hydration in order to adopt healthier behaviours in real life.

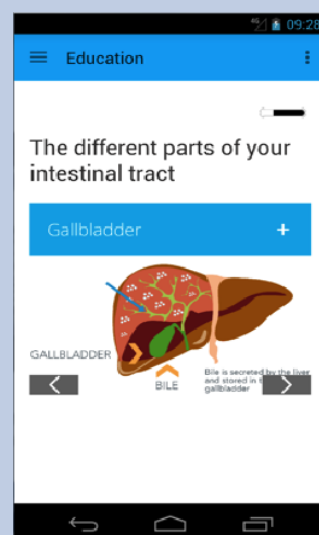
## TODAY'S SUMMARY



## DIARY (SYMPTOMS)



## EDUCATIONAL CONTENT



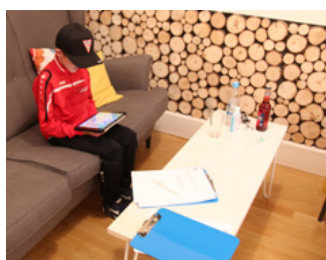


## THE MID-TERM EVALUATION OF MYCYFAPP PROFESSIONAL WEB TOOL!

The mid-term evaluation of the MyCyFAPP Professional Web Tool took place last January during the 4th Progress Meeting in Valencia and in Rotterdam. It was conducted in form of mock-ups with a total of 8 professionals. The methodology followed was based on three main steps. Firstly we organized individual interviews with internal and external users, where it was mainly focused on evaluating functionality through methods such as commenting aloud and qualitative interview for getting feedback and ideas for improvement. Then, as second iteration, we continued with meetings in groups where a qualitative interview based on the feedback obtained in the first iteration. The main objective was to discuss between participants in order to agree on decisions. Last phase was composed by different workshops with HPs for prioritisation new tasks and fit it in the current implementation plan.

Nowadays we are refining the last details, and starting to setup development environment for starting implementing. Accordingly to the current plan the PWT will be ready at the beginning of June.

## MIDTERM EVALUATION OF THE MYCYFAPP GAME: CHILDREN AND TEENAGERS PUT THE PROTOTYPE OF THE MYCYFAPP GAME TO THE ACID TEST



In September and October 2016, 18 children and teenagers with CF tested the prototype of the MyCyFAPP game.

The patients from Belgium, Germany and Italy were each asked in a usability testing session to try out the prototype of the game app and to give honest feedback. At the same time all their interactions with the game were observed, to back up the self reported data with objective observations.

The overall results of the evaluation are very pleasing: the participants in Italy gave the game a very positive rating, while the ratings of the participants in the northern countries were distributed more evenly over the whole spectrum. For a prototype still missing important

features, this is a very positive outcome. The midterm evaluation although allowed gathering important insights about the usability, fun and comprehensibility of the game. Those insights now can be used to further improve the application.

### #MYCOOKINGFAST

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

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

### SOCIAL NETWORKS:



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

### COMING SOON

MYCYFAPP 5<sup>TH</sup> PROGRESS MEETING  
12<sup>TH</sup> - 13<sup>TH</sup> JUNE 2017 IN TRONDHEIM (NORWAY)



## 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.