



Funded by the  
European Union  
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# A platform for the self-management of Cystic Fibrosis

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Game app



**MyCyFAPP**  
My APP for CF self-management



Handbook

# H2020 Project



Exact doses of pancreatic enzymes

abdominal pain, constipation, diarrhoea



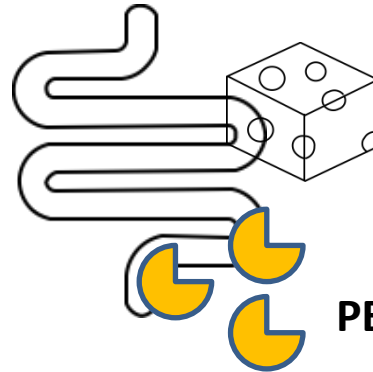
to estimate

# Hypothesis

PERT action and efficacy depends on the combination of 3 elements

## Individual characteristics:

- Nutritional status
- GI conditions
- Others...



## Food characteristics:

- Matrix properties
- Interactions among nutrients
- Type of fat...

PERT dose

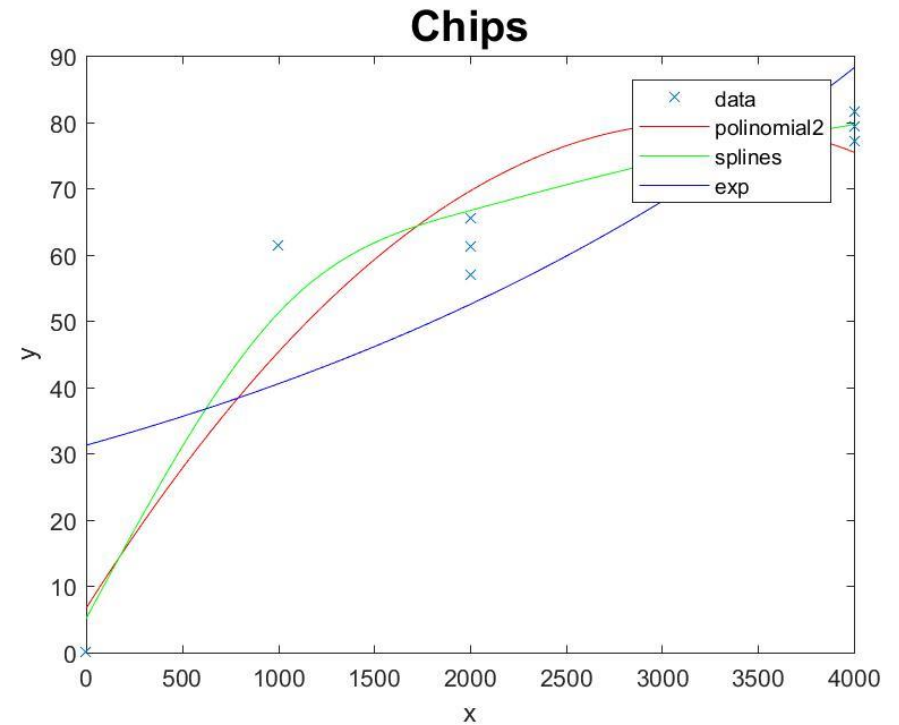
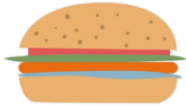
*If we are able to identify the role of food properties in the scenario of a CF digestion, we'll be able to predict the optimal dose of PERT*

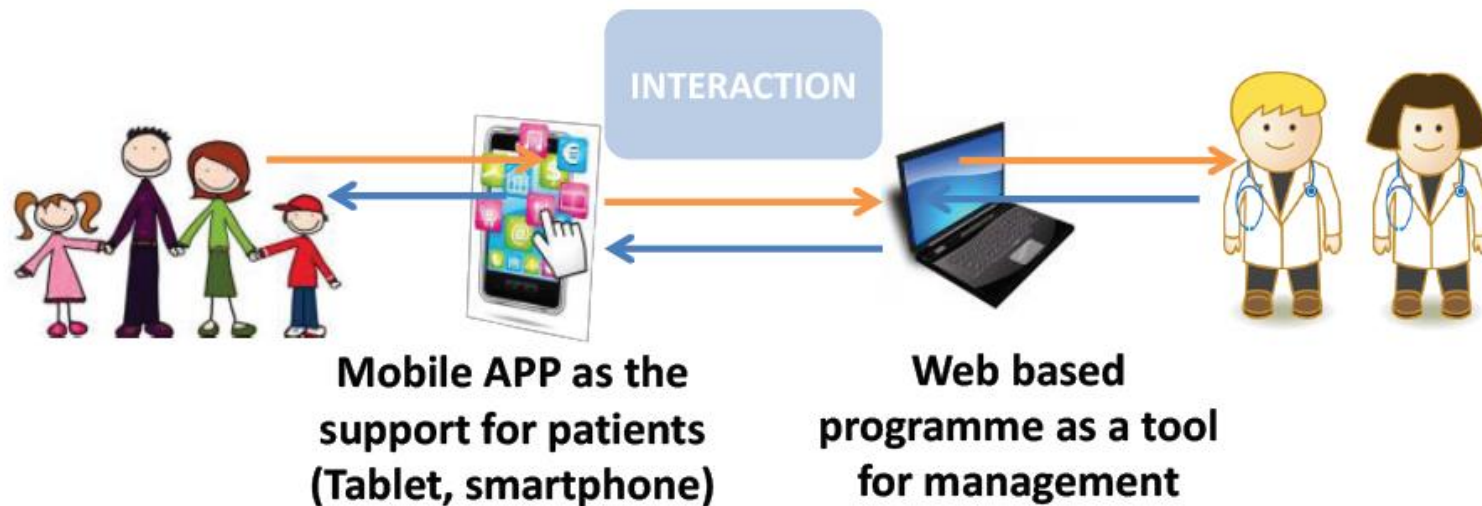


Horizon 2020  
European Union funding  
for Research & Innovation



# Vision - PERT

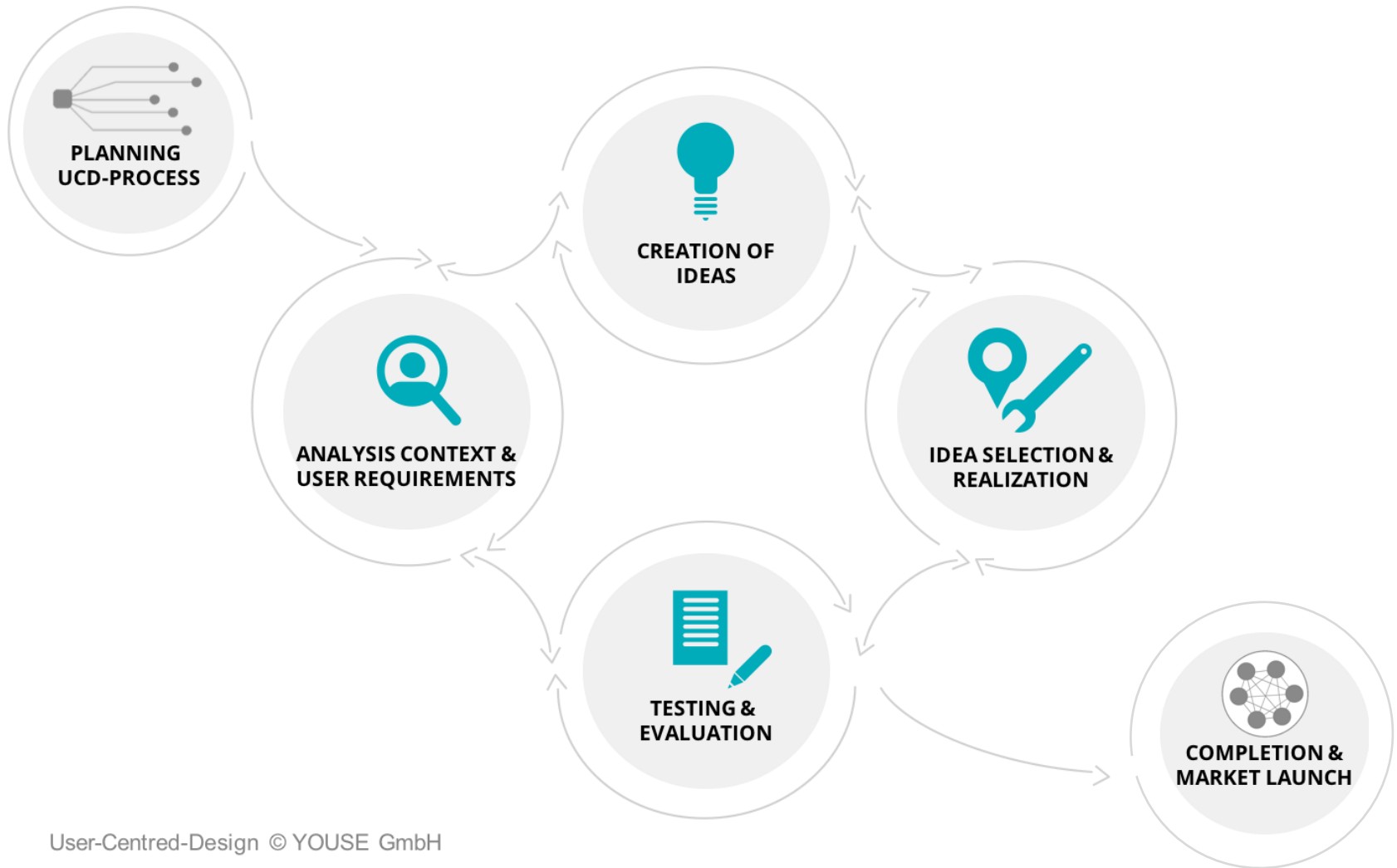




- Games for CF management
- Country specific food databases
- Self-report of food intake, signs and symptoms
- Interactive educational material

- Remote follow-up
- Nutritional composition of patient's food intake
- Response to PERT
- Direct secured messages to patients
- Charts, graphs and visual information

# User Integration



User-Centred-Design © YOUSE GmbH



# User Integration – Requirement Analysis

## Netnography



## Shadowing



## Interviews: Patients & Parents



## Interviews: Health Professionals





# User Integration – Idea development GAME

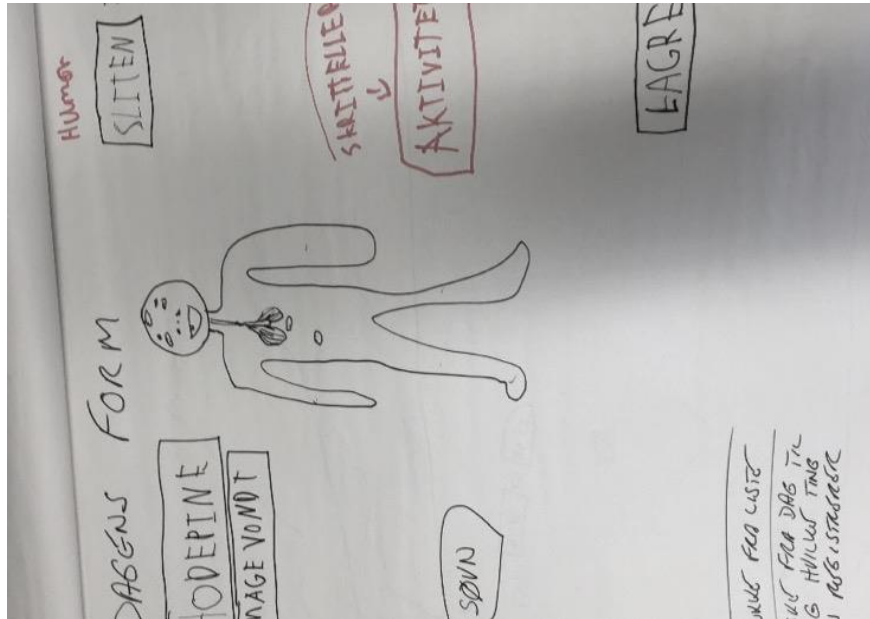
## Co-Design with children & teenagers



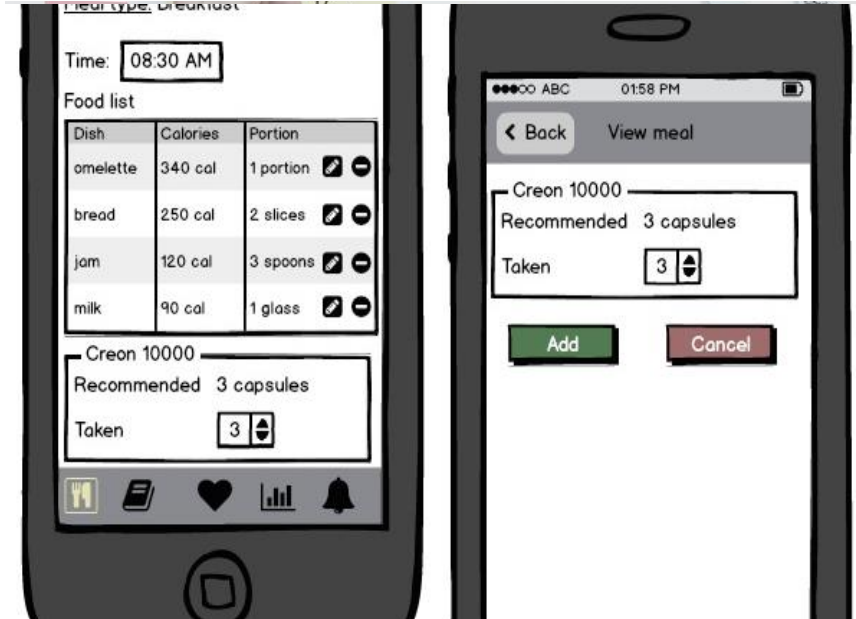
## Prioritisation of learning content



# User Integration – Idea development SMA



Iterative Co-Design with teens & parents

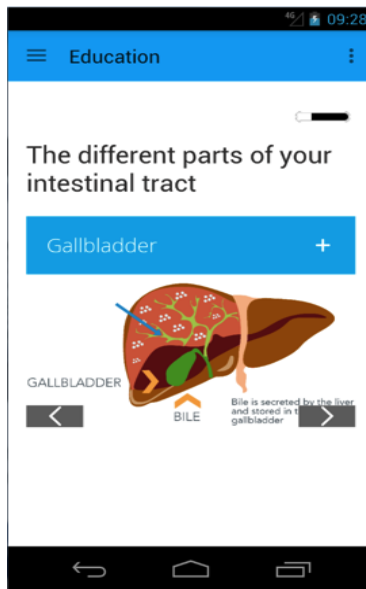


Mock-Up Evaluation with teens, parents & HP Teenagern, Eltern & med. Fachpersonal

# User Integration – Testing



**Iterative usability tests with children & teens**



**Iterative usability tests with teens & parents**



**Iterative usability tests with Health Professionals**



**Clinical trial in 7 European CF centers**



A business card for each of the 9 **products**.

<p><b>MyFoodFACTS</b></p> <p>Nutritional composition of meals obtained in MyCyFAPP</p>	<p><b>MyFoodCAL</b></p> <p>The platform and engine to elaborate recipes based on nutritional composition of meals</p>	<p><b>Nutritional Recommendations Handbook</b></p>
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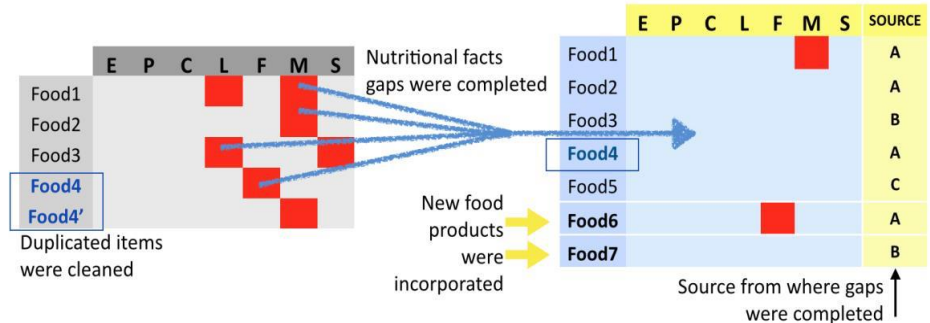




**MyFoodFACTS** is a set of country-specific nutritional composition databases. Foods are classified in a formal taxonomy and each entry contains comprehensive and complete nutritional information

- Includes specific products consumed by children with CF.
- More than 14 nutritional facts for each food.
- Contains country specific food and meals.
- food naming and classification easy to understand.

## Other Data Bases



**Endorsed by food scientists and nutritionists**

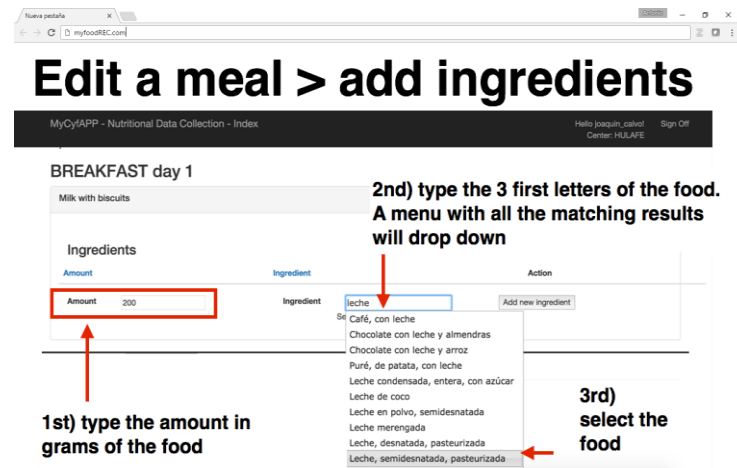






**MyFoodREC** is an online tool which allows compiling case reports specifically designed for clinical trials involving patients, food intake records and laboratory tests.

- ❑ Quick and smooth data introduction.
- ❑ Integrated with MyFoodFACTS
- ❑ Advance reporting and data analytics on nutritional facts
- ❑ Data can be exported for further processing (csv and xls)



**Edit a meal > add ingredients**

MyCyFAPP - Nutritional Data Collection - Index

Breakfast day 1

Milk with biscuits

Amount	Ingredient	Action
200	leche	Add new ingredient

1st) type the amount in grams of the food

2nd) type the 3 first letters of the food. A menu with all the matching results will drop down

3rd) select the food





MyFoodCALC is a tool specifically designed to create recipes on the basis of strict nutritional guidelines.

- Predefined dishes for specific clinical endpoints
- Personalization and tagging recipes
- Integrated with MyFoodFACTS
- Recipes can be edited
- Reliable nutritional information for different portion sizes

## Paella



Overview of the ingredients and amounts of a dish

Amount	Ingredient	Action
80,00	Arroz	<input type="button" value="Delete"/>
10,00	Ajo	<input type="button" value="Delete"/>
60,00	Cocostilla de cerdo	<input type="button" value="Delete"/>
50,00	Tomate	<input type="button" value="Delete"/>
50,00	Tomate frito	<input type="button" value="Delete"/>
30,00	Patata	<input type="button" value="Delete"/>
25,00	Garbanzo cocido	<input type="button" value="Delete"/>
30,00	Morcilla	<input type="button" value="Delete"/>
10,00	Aceite de oliva	<input type="button" value="Delete"/>
10,00	Caldo Polo	<input type="button" value="Delete"/>

As we add new ingredients the nutritional facts calculation is performed automatically.

Values

Kcal	P	PSL	L	L%	HC	HC%	FIBT	CA	FE	FAMS	FAPU	FASAT	NA	STARCH	SUGAR
791	26	4%	40	14%	82	13%	7	4	0	19	5	13	1	74	8

We see here the nutritional facts calculated for this meal.

E.g. lipids in this meal represent 14% of the total daily intake of a 2500kcal diet. If the recommendation is "40% of the energy coming from lipids, there would still be 26% remaining..."

**Endorsed by food scientists and nutritionists**

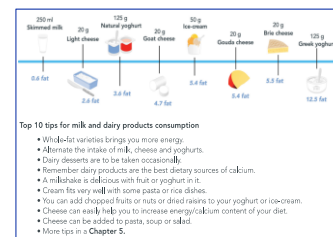
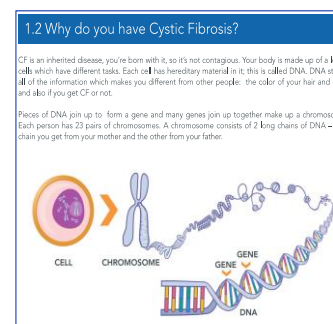
**Endorsed by clinicians**





**Nutritional Recommendations Handbook** is a compilation of information related to what Cystic Fibrosis is and the nutritional therapy, focused on nutritional education and practical tips.

- Addressed to patients with Cystic Fibrosis and their caregivers
- Aimed to the empowerment of the nutritional self-management
- Based on scientific evidence and EU clinical guidelines
- Plenty of practical examples and applicable recommendations
- PDF, online and mobile version



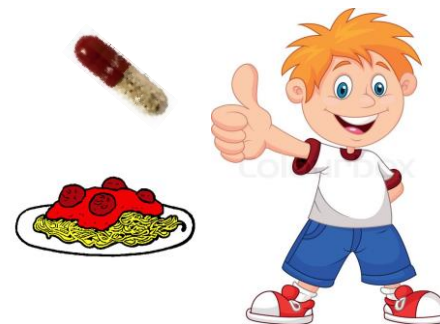
**Edited by top level CF Units  
across Europe**





**Theoretical Optimal Dose Data base** contains information about the enzymatic supplements needed to optimize the fat digestion among a subset of foods

- Food-oriented dose of enzyme replacement.
- Based on the nutritional composition in MyFoodFACTS
- Expressed on lipase units per gram of fat (LU/g fat)
- Prevents over/under dose direct and side effects



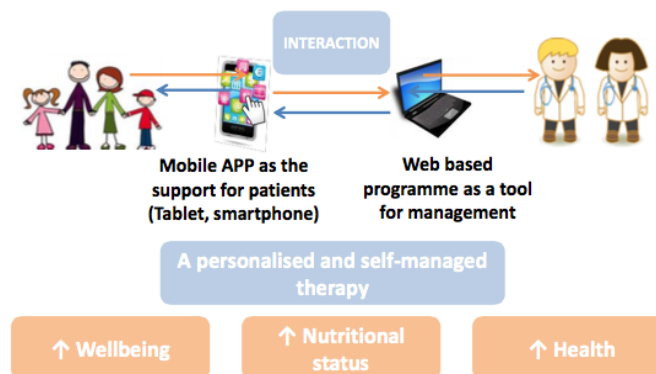
**Endorsed by food scientists  
and nutritionists**

# MyCyFAPP Self-management app



The **self-management app** is a mobile application to support CF patients and caregivers on the self-management of the health status and to share information with health professionals.

- Designed and developed with patients and caregivers
- Supervised by health experts
- Supports multi-language
- Includes enzyme replacement calculation, follow-up and educational content.
- Management of reminders



**Endorsed by patients and clinicians**







The **Gaming application** is a mobile game for tablet designed for young patients (4-11 y) with cystic fibrosis aimed to provide relevant education about the disease

- Specifically developed with and for children with CF.
- Use of an avatar to learn how to take care of personal needs, related to CF.
- Based on the importance of food intake, hydration and well-being
- Different difficulties and adaptation to achievements.
- Supports multilanguage



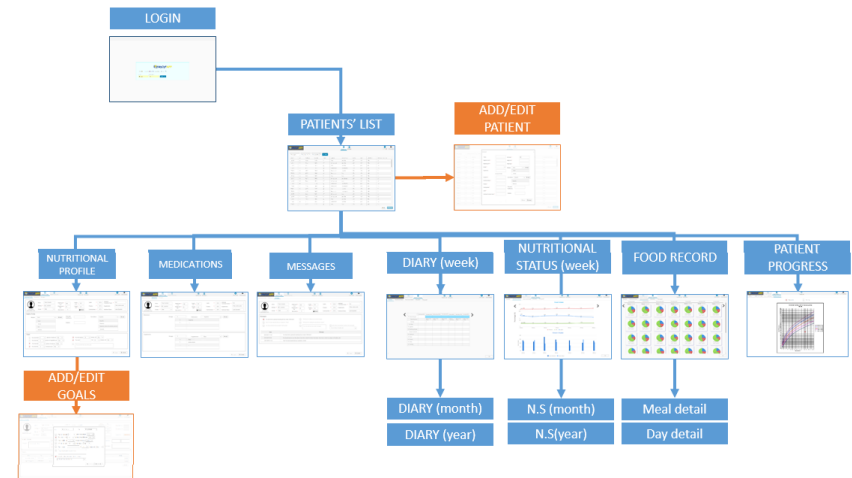
**Endorsed by kids with CF and parents**

# Professional Web Tool



The **Professional Web Tool** is a dashboard to perform an accurate follow-up of CF patients

- Integrated with the self-management mobile application
- Monitors nutritional status, medications and adherence
- Insights, trends and analytics on several variables
- Fashionable and fast web-interface
- Can be integrated with Electronic Medical Record



**Endorsed by clinicians**



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