



PID GENIUS

A MOBILE APPLICATION BY PATIENTS FOR PATIENTS
A PERSONAL ASSISTANT FOR PATIENTS
WITH A PRIMARY IMMUNODEFICIENCY

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BACKGROUND

PIDs are a group of over 300 different rare genetic diseases that occur when components of the immune system do not work properly. Once diagnosed, PID patients need lifelong personalised treatment in order to lead their lives as normally as possible. These treatments can be heterogeneous, such as immunoglobulin (IG) replacement

therapy, anti-infectious prophylaxis, growth factors, anti-fungal medications etc. PIDs being chronic diseases, adherence to treatment and medical follow-up are especially important. Regular visits to specialist(s) are even more beneficial when patients are able to report their tolerability to treatments, and occurring adverse events. Keeping records of

their treatment history often require patients to do a lot of paperwork, especially for those patients getting IG therapy which are human plasma derived medicinal products and as such require rigorous compliance to reporting measures. This documentation is burdensome to maintain and also often difficult to manage during a medical appointment.

PROJECT LEADER

IPOPI, the International Patient Organisation for Primary Immunodeficiencies, has launched the

first mobile application developed by a patient organisation for people with primary

immunodeficiencies (PIDs) for worldwide use.

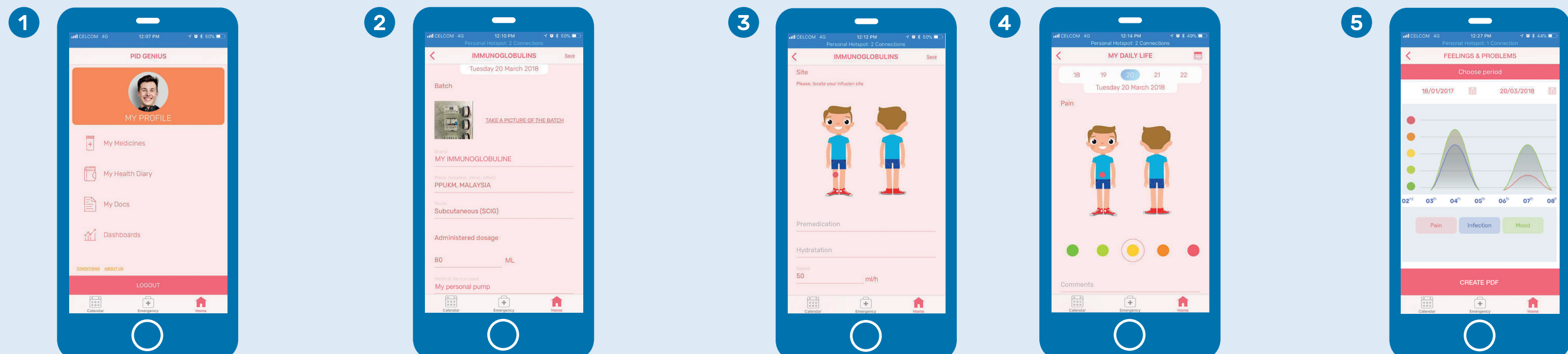
OBJECTIVES

PID Genius is aimed at assisting patients in:
- coping with their condition and treatment,

- making the discussion easier with their specialists during appointments,

- keeping track of their key data and documents, especially in case of an emergency or when traveling.

PID GENIUS: DIFFERENT SERVICES



- A profile with a summary of the patient and condition characteristics.

- A health diary where patients can record their:
 - treatment
 - different parameters (physical, infections, mood, absences)
 - vaccines
 - appointments.

- A description of the different treatments the patients are receiving.

- Dashboards displaying stored information on a timespan and facilitating patients' discussions with their medical specialists.

- A document section (medical or administrative) so patients always have them at hand.

METHOD

IPOPI set up two working panels, one made up of patients and one made up of physicians, so as to release its app based on patients' needs whilst

incorporating physicians' views. Both panels were composed of people emanating from different regions of the world. Therefore, the app ad-

resses different issues that patients are facing comprehensively and regardless of the country where they live.

TECHNICAL AND LEGAL ISSUES

PID genius complies with the European community regulation which is considered as one of the most rigorous legislations on personal data protection worldwide. PID Genius works on Android and iOS

systems. Data are at disposal on the patient's device, in order to be accessible offline. They are also stored on Azur cloud, run by Microsoft which offers the highest level of security measures so

as to avoid any breach in patient privacy. The cloud is based in the European Union. Nobody but the patient can access the patient's personal data.

NEXT STEPS

This app is registered worldwide. The language of the app is English.

IPOPI intends to translate it into different languages within the forthcoming months.

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