

Development of an App for the management of Autoinflammatory Diseases using an innovative patients-clinicians codesign approach

Silvia Federici*¹, Camilla Santu*², Marta De Munari², Fabrizio De Benedetti¹, Ruggero Di Maulo^{2*}*these authors contributed equally to the work

¹Reumatology department, Bambino Gesù Hospital, Rome ²Cloud-R s.r.l.

Background: Autoinflammatory diseases are rare conditions characterized by recurrent episodes of inflammation with fever associated to elevation of acute phase reactants and symptoms affecting mainly the mucocutaneous, musculoskeletal or gastrointestinal system. These diseases affect negatively the quality of life of patients and their families.

Objective: Aim of this project is to develop a tool able to ameliorate patients' management of the disease and to enhance patient-physician communication.

Results: All participants actively expressed various needs, that we subsequently summarized in 4 main areas (Table 1).

Area	Main requests	N°
Patient's clinical information - diary	Report fever attacks and symptoms Repository of health information	12 5
Community	Online chat, blog and forum- patient to patient Direct connection with the physician	14 11
Personal agenda	Calendar for therapy, visits, exams scheduling Alerts (appointments, deadlines, reminders)	13 4
Clinical and practical information	Information in medical language Information in plain language Legal information- patients' rights	13 7 7

Table 1 – Most expressed needs



Methods: In order to develop a tool based on real-life needs, we involved patients and caregivers since the initial phase of the project. A first workshop designed to capture their needs and desires was organized. Innovative co-design activities were performed through “Lego Serious Play™” (LSP) methodology^{1,2,3}, in a pure “divergence” phase (Figure 1). 13 patients and caregivers (from teen-agers to adults) affected by different AIDs (FMF, TRAP, CAPS, MKD) and 2 physicians were involved in the activities.



Conclusion: While in few cases LSP has been used as a method to manifest the physicians' and healthcare workers ideas and creativity¹, to the best of our knowledge this approach has never been used with patient in the field of autoinflammatory diseases. Our project shows that active involvement of patients and caregivers in the design of a mobile-App can be achieved through innovative approaches.

Participants of the LSP activities will be further involved and their opinion will be taken into consideration in the following App development activities (including User Experience and User Interface definition).

The objective is to obtain an App tailor-made on the patients' real needs – including the required functionalities with consequent high satisfaction and long-term adoption of the tool.

Acknowledgment: Project realized thanks to an unrestricted sponsorship from Novartis.

REFERENCES: 1. Frick, E., Tardini, S., & Cantoni, L. (2013). White Paper on LEGO SERIOUS PLAY. Lugano, Switzerland: Università della Svizzera italiana. 2. Kristiansen, P., Hansen, P., & Nielsen, L. (2009). Articulation of tacit and complex knowledge, In P. Schönsleben, M. Vodicka, R. Smeds, & J. Ove Riis (Eds.). 13th International Workshop of the IFIP WG 5.7 SIG, (p. 77-86). Eidgenössische Technische Hochschule Zürich. 3. Rasmussen, R. (2006). When you build in the world, you build in your mind. Design Management Review , 56-63.

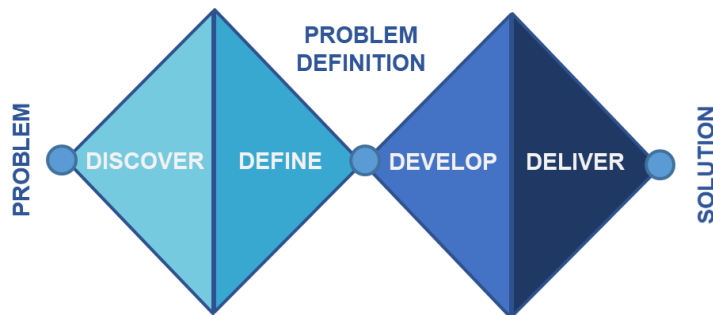


Figure 1 – Double Diamond Process

Participants were asked to describe, through LEGO and metaphors:

- 1)The disease,
- 2)Themselves in comparison with the disease,
- 3) Solutions and supports which could help them in managing the disease.

After each step they presented their model and everyone was engaged in the discussion. The ideas collected during the three phases allowed to have, at the end of the workshop, a list of functionalities identified as necessary for the app, the so-called “Killer-Features”.