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

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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.

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) methodology1,2,3, 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 where involved in the activities.

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

<table>
<thead>
<tr>
<th>Area</th>
<th>Main requests</th>
<th>N°</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient’s clinical information - diary</td>
<td>Report fever attacks and symptoms Repository of health information</td>
<td>12 5</td>
</tr>
<tr>
<td>Community</td>
<td>Online chat, blog and forum- patient to patient Direct connection with the physician</td>
<td>14 11</td>
</tr>
<tr>
<td>Personal agenda</td>
<td>Calendar for therapy, visits, exams scheduling Alerts (appointments, deadlines, reminders)</td>
<td>13 4</td>
</tr>
<tr>
<td>Clinical and practical information</td>
<td>Information in medical language Information in plain language Legal information- patients’ rights</td>
<td>13 7 7</td>
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</tbody>
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Table 1 – Most expressed needs

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.

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Figure 1 – Double Diamond Process

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”.

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.