

POSTER PRESENTATION

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APTIC: a social network to improve the quality of life of members of patients' associations

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The APTIC social network has been developed by PSINET research group at the Universitat Oberta de Catalunya together with Hospital de St. Joan de Déu and Fesalud Foundation, and has been partially funded by Tic Salut Foundation (health department of the Catalan government). Our social network aims at enabling the individual members of patients' associations (mostly parents of children with chronic and rare diseases) to share experiences, information, advice and, ultimately, to offer them on-line tools to improve the quality of life of the entire family.

Participation in specialised social networks like APTIC offers a great opportunity to use technology to improve quality of life with low cost and with a large impact on health. From the health psychology perspective, variables such as the perception of self-efficacy, empowerment and social support are key to improving quality of life. For this reason, like health psychologists we are interested in the analysis of these variables and in their impact on the quality of life of members of patients' associations. We are examining these variables and network usage in order to establish whether social networks are indeed useful for parents.

Our social network has been built on open source software and through collaborative work between organisations (the hospital itself, patients' associations...) and individual users.

We will offer our first results and some thoughts about the work with patients and families through social networks. Our goal is to enhance their positive effects,

for instance using them as a tool to overcome the fragmentation of knowledge in the field of rare diseases.

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