

CROWDFUNDING

The BLACKSWAN Foundation RE(ACT) Community

An international example of value innovation related to the world of scientific research of rare diseases.

BLACKSWAN Foundation is a Swiss organization founded by Dr. Olivier Menzel. The activities of the Foundation began in February 2010 thanks to the efforts and the help of the Board of multidisciplinary management composed of experts in the fields of finance, law and health sciences. The main mission is to support the research on rare and orphan diseases. Another objective is to improve the public understanding of these diseases.

A disease or disorder in Europe is defined as rare when it affects less than 1 in 2000 individuals. Together, rare diseases affect only about 30 million people in Europe. 80% of rare diseases are genetic in origin, and often are chronic and life-threatening.

Together with strategic partners Eurordis, Findacure, E-Rare and Association Enfance et Maladies Orphelines, in 2014, the BLACKSWAN Foundation designed and launched in beta version the RE(ACT) Community. Initially designed to stimulate and to continue conversations, the exchange of knowledge, and mutual support between the different participants - researchers, leaders in thinking, professionals - on the RE(ACT) Congress (International Congress on Research of Rare and Orphan Diseases), the RE(ACT) Community soon became a digital hub dedicated to the exchange of value regarding orphan and rare diseases. It is an area of, so far, more than 8,000 diseases mapped by scientific research and with a growth rate of 5 new diseases reported weekly in the medical literature that, however, taken individually, are not of economic/financial interest and are there-

fore often neglected by the R&D activities of the big players of the international pharmaceutical industry. Right from the start, the RE(ACT) Community has been designed and developed with the aim of achieving several synergistic objectives, summarized in the following 4 keywords:

- **Meet:** connecting and networking between scientific researchers interested in the subject, coming from all over the world
- **Share:** exchanging experiences both between the researchers (indirectly) and between patients and researchers
- **Learn:** sharing innovative studies and discoveries by researchers, testimonies from patients about the diseases
- **Support:** presenting scientific projects by researchers that, if accepted by the Scientific Advisory Board of the community, can be financed by all the members through the dynamics of crowdfunding.

The RE(ACT) Community has positioned itself right from the start as a virtuous case and of high innovative potential in a particular context - that one of innovations in scientific research - which is in great ferment and at the peak of a deep digital disruption, characterised - to mention just two examples - 1) by the recent birth of new collaborative platforms (social networks, communities, ...) dedicated to medicine and/or specific sub-areas of scientific interest, and 2) by the increasingly frequent organization of events with a disruptive format (hackathons, makeathons, barcamps, ...) both by small local groups as well as by

large international entities, such as General Electric, Massachusetts Institute of Technology and Philips.

After two years of testing and fine-tuning, 2016 marked a turning point for the RE(ACT) Community: the platform has indeed begun an important process of redesign and revamping, in order to locate and seize new opportunities. There were three main challenges to overcome, linked to macro-indicators of platform success:

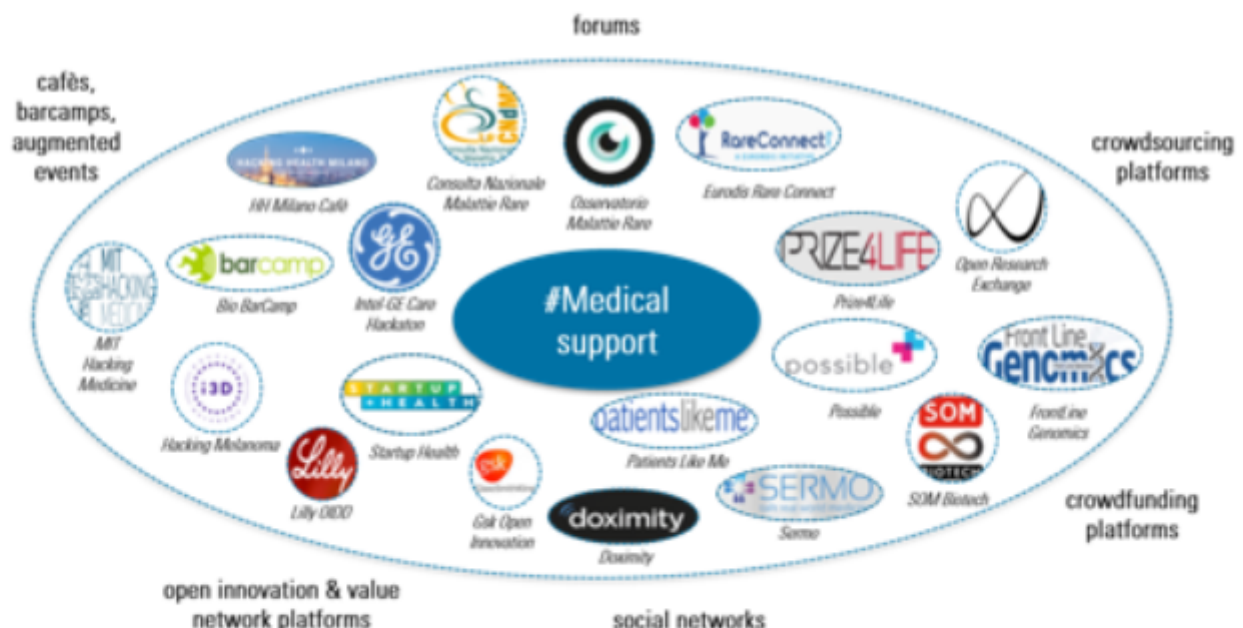
- Awareness: the data from the network showed a clear problem with the (lack of) knowledge of the platform of the interested audience – and in general of the online audience
- External Engagement: because of the low awareness, the platform remained a niche project, but it didn't even appear capable to connect between and activate its stakeholders as the "sounding board" of the project
- Inner Involvement: the final result consisted of consumption by the community and a total of donations that was below the predefined target.

These challenges, strongly based on (and enabled by) human dynamics and social networking, immediately made evident the need to proceed with the redesign and revamp the of the RE(ACT) Community to turn it into a real Platform, following some phases that characterize all the steps of the Platform Design &

Delivery Journey designed by OpenKnowledge:

- Platform Thinking & Designing: redrawing the existing platform and user experience in line with an approach capable of putting at the centre the expectations of the people towards the value generated by the project, their behaviour, the mechanisms and the most appropriate specificity in order to stimulate virtuous digital interaction.
- Platform Deploying: structuring a plan of content marketing and interaction-first digital communication. In other words, integrating with one another and taking advantage of content, messages and channels able to stimulate the motivation, genuine involvement and direct activation of individuals towards the project, its peculiarities and its objectives, in order to make it grow in terms of social audience, relevance and overall range.

Figure 1
An overview of initiatives and projects that are deeply revolutionizing the world of medical and scientific research





Innovative tools and methods that support Platform Thinking & Designing

The first step to redesign the RE(ACT) Community in line with expectations, needs, stories, perspectives of users required a commitment to two initial activities.

First, an online survey was launched for all the members already registered on the platform, in order to analyse the level of knowledge of the community, its valuation and the desired future. The respondents (about 15% of the total population involved) provided feedback, suggestions and insights necessary to understand the main areas of concern and still unexpressed potentialities on which to act, in relation to each of the 4 objectives of the project listed previously (meet, share, learn, support).

Simultaneously, a collaborative workshop was organized that involved a group of stakeholders composed of representatives of organizations dedicated to fundraising to support research, doctors, scientists, close relatives of people affected by a rare disease. The use of innovative and highly immersive/experiential methodologies enabled the collectivism of a wealth of stimuli necessary to think about the Massive Transformative Purpose of the RE(ACT) Community, or the aspirational statement that describes its purpose,

encoded at a latter moment of work in the phrase “we are the RAREvolutionary people. Stand up for scientific research”.

As anticipated, these two actions allowed the collection, organisation and use of a range of fundamental stimuli for redesigning the RE(ACT) Community, stressing the components - dynamic, mechanical, graphic and functional features, ... - in major added value for users of the platform, facilitating, simplifying and stimulating their interactions and the most virtuous behaviours at the same time.

Platform Deploying: redesigning the content strategy in an interaction-first perspective

After the phase of redesigning the RE(ACT) Community, a consequent necessity seemed obvious: to design a content strategy (characterised by an ecosystem consisting of channels, content and digital messages) capable of engaging the best of the audience of fans, followers, and subscribers, of stimulating the intrinsic motivational drivers of individuals pushing them to action in terms of engagement, enrolment and the effective use of the platform, financing projects published by the researchers with micro-donations gathered according to the crowdfunding model.

Figures 2 and 3
The transformation of the home page of the RE(ACT) Community before and after

From its launch in beta phase in 2014, the RE(ACT) Community appears on Facebook, Twitter, Google Plus and LinkedIn through dedicated accounts - company page and groups. A cumulative audience on social networks composed of more than 5,000 users is in constant growth, and whose involvement was stimulated through the optimization of the editorial plan (with a strong focus on publishing updates that could relate the valuable benefits of the platform and multi-channel promoting of the hashtag #RAREvolution) and the design of the media strategy of Facebook advertising to support the content distributed on the latter company network. These actions generated an average increase in social engagement of 90%.

A second content marketing tool at the disposal of the RE(ACT) Community right from the release in beta phase consists of the news area of the platform, visible on the home page: a very interesting digital place, if read in terms of narrative potential of the entire project. Talking of that, the editorial format #RARETalk was conceived and launched, which provides for the monthly publication of an interview with a prominent champion of the issue of orphan and rare diseases. The first interviews involved the high-calibre personalities Nicolas Sireau (The AKU Society Chairman and Chairman/Founder of Findacure) and Heather Etchevers (Research Scientist at the French National Institutes of Health - INSERM). An innovative way to apply the methodology of storytelling to subject matter that is neither trivial nor banal, through a direct point of view and the direct perception of people who do not give up when faced with often very complex problems. The pages containing those interviews are still strongly impacting some indicators of web analytics, generating peaks of visits to the community 4 times greater and double the length of stay in comparison to average performance indicators on which the RE(ACT) Community is usually evaluated.

After completing the content strategy aimed to make the RE(ACT) Community grow in terms of social audience, relevance and overall range, it was designed and launched again, an initiative of social advocacy with the aim of transforming the restricted and selected number of about 100 stakeholders of the platform (researchers, collaborators of partner organisations of the project, patients who were particularly involved, ...) in direct amplifiers of the messages and communication about the project. By using specific software, these users have been invited and are still

encouraged to periodically share through their own profiles on social networks, and in a few clicks, the dedicated content - Facebook and LinkedIn updates, tweets, ... - 'pre-packaged' and suggested by the Community Manager. The first data available shows interesting results in terms of the reach of such content on all the major social networks.

A revolutionized (and revolutionary) path of the RE(ACT) Community

The transformative path of the RE(ACT) Community towards the paradigms and idiosyncrasies of the Platform is 'only' at the beginning, but the first insights already show the virtuosity of this roadmap.

The different actions implemented for each of the steps of the Platform Design & Delivery Journey projected by OpenKnowledge (Platform Thinking, Platform Designing, Platform Deploying) are proving capable of overcoming the main challenges related to macro-indicators of success of the platform - or, of stimulating awareness, external and internal involvement of the RE(ACT) Community again.

In the immediate future, the project will need to continue to capitalize on the innovations generated daily from the social logics and digital technologies in scientific research, consistently with an approach of continuous design & delivery which requires a constant optimization and examination of the platform and its peculiarities. Overall, remaining firmly anchored to the facilitation/stimulation of the interactions and the real exchange of value between the members and the stakeholders, in line with the 4 fundamental purposes (meet, share, learn, support) defined from the beginning.

Crowdfunding for scientific research

Interview with Olivier Menzel, Founder and President of the BLACKSWAN Foundation.

How did the idea to design and develop the RE(ACT) Community come about?

The idea of the creation of the RE(ACT) Community was born in 2012 after the first edition of the RE(ACT) Congress, the first international scientific congress about the research into orphan and rare diseases started by the BLACKSWAN Foundation. During the congress, in fact, we noticed that the meeting of the researchers from different specializations, but united by a common interest in rare diseases, had allowed the creation of a number of co-operation projects - to be exact, at least twelve in the first edition.

They were (and still are) important collaborations, particularly in an area where even the researchers themselves are 'rare' and the financial support is insufficient. This also helps to avoid creating duplicates in research projects, thus optimizing the exploitation of resources. So we asked ourselves: why wait for two years? The RE(ACT) Congress in fact is a bi-annual event. On the contrary, a practical possibility to develop further collaboration and sharing of scientific knowledge in a virtual way existed, but on an ongoing basis, thanks to an interaction platform such as the RE(ACT) Community. We then added the ability to fund research projects through a crowdfunding mechanism: in this sector it is often difficult to find funds to start research that can then be attractive to its financing entities.

What are the main value benefits that a platform like the RE(ACT) Community brings to various stakeholders in the world of orphan and rare diseases?

The RE(ACT) Community is a project with a non-profit purpose that creates a network of the main actors in the field of orphan and rare diseases, allowing them to benefit from all points of view and to receive different input supporting the research. The patients,

who in this field are often the true experts of a disease, may for example share their health experiences by providing the information and insights that are very important to researchers. In turn, the same researchers can exchange information between themselves, at the same time entering indirectly into contact with patients and/or with patient organizations to realize future clinical trials.

What are the objectives achieved today by the RE(ACT) Community, and what are the future developments?

The RE(ACT) Community has a database with more than 6,000 diseases and today counts around 600 members including researchers, patients and supporters of the research of rare diseases. It has already financed a research project that contributed to the creation of a national registry of giant congenital melanocytic nevus. Other research projects are being evaluated by the Scientific Advisory Board (SAB) of the community, and will probably soon be financed on the platform. The future goal of the RE(ACT) Community is to increase furthermore the trade between the researchers with the contribution of the patients, becoming in that way a reference point for the promotion and distribution of scientific research on rare diseases at the global level. The goal to strive for is to help to find therapies for the treatment of millions of people suffering from a rare disease, (too) often ignored by the different health systems. To carry on with these objectives, the RE(ACT) Community is constantly looking for donors and corporate partners which would support its action: we are available for any information or a proposal via our e-mail address contact@react-community.org.

