

1 su 30 e non lo sai: information on Cystic Fibrosis Carrier Test

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Background and rationale

Introducing carrier testing for Cystic Fibrosis (CF) means promoting a conscious parenting choice. This study investigates the main issues, limits and needs of communication

related to carrier testing in the general population, as well as the impact and satisfaction of a website and a communication campaign for users.

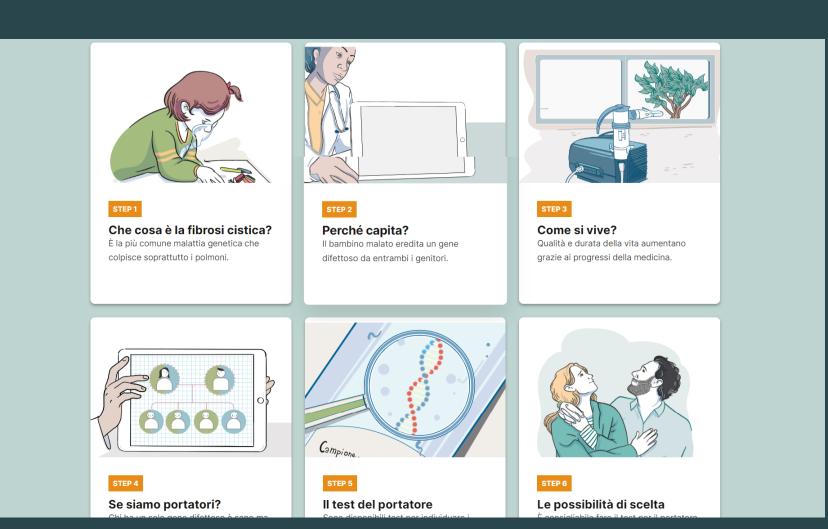
Hypothesis and objectives

A website built according to health decision support aids can be a handy tool for communication between health practitioners and patients, increasing CF and carrier testing awareness, even among those who do not have known cases in their families.

Essential methods and results

- Scientific literature and online competitors analysis to identify the contents, the narrative format and the textual and visual languages of the website
- 14 semi-structured interviews, a chat conversation (10 participants) and a minifocus group (sample 3) on a selection of people of childbearing age





Main themes

The general practitioner: a trustable source of information



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However, if I were to find material on my own or this brochure, but on the web, I wouldn't make decisions based on that, no. I would always need a doctor who could somehow go more specific. And then I always need this relationship of trust that I have created.



 Workshop with Fondazione Ricerca Fibrosi Cistica staff (both of communication and scientific communication department)

Fondazione Ricerca Fibrosi Cistica Value Promise

To be the reliable point of contact between people and the world of Cystic Fibrosis scientific research

Insight 1 in 30 is a healthy carrier and doesn't know it

A little-known disease and test

I'd rather have had some information, because to find out only now, because I'm participating in a study and after having a child... It's better to have a little more information campaign, I think

Decision criteria

- General attitude toward health choices
- Risk estimation
- Costs
- Reliability of the test
- How and where the test is done
- Patient's quality of life

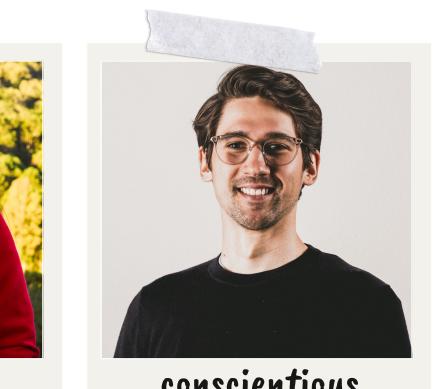
Is it worth it or not? Also because there are millions of tests that can be done, in my opinion, it has to be made an assessment of the risk

Since both of us are young and neither of us has mutation in our family or anything like that, it was unnecessary money that we could have put into the baby carriage

Personas



informed young





mother of CF child with no known cases

Brand story

Are you 1 in 30? Thanks to science, you have a tool to know in advance and approach parenting consciously



Activation plan definition

defining specific strategic communication activities based on the identified touch points for the target population

Bibliography

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