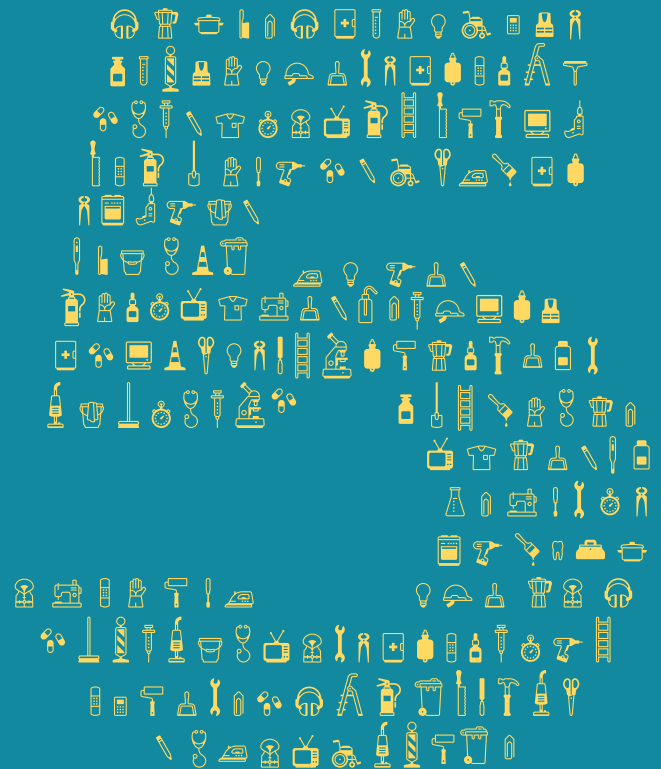


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New Digital Health Challenges: development of a Help Community for the cancer patient



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Abstract

The crisis generated by the pandemic has made it clear the need to redefine the strategies relating to the fulfilment of goal 3 of Agenda 2030 (*Good Health and Well-being*) according to the new model of sustainable development. It considers the protection of environmental, social and economic resources, thanks also to the increase of digital societies. Within the healthcare context, to cope with the difficulties of carrying out healthcare services in the presence of and reducing hospital access, there has been a greater diffusion of new digital tools, accelerating the *digital health* race.

In a hospital-territory integration strategy, taking care of the patient is fundamental. He needs not only continuous monitoring but also a relational comparison with others.

Therefore, the work proposed in this article presents the results of a project developed by a multidisciplinary team within the Department of Medical Oncology of the Papardo hospital in Messina. The goal is to respond to the need to *bring treatments closer, bring people*

together and bridge the physical and relational distance through developing new digital solutions.

In particular, the methodological approach of Ergonomics for Design and Human Centered Design, adopted in this work, has provided an effective strategy in allowing the development of a *patient-centered*, sustainable and innovative platform aimed at patients with breast cancer. The goal is to provide continuity between the hospital journey and the return home and to allow the patient, even at a distance, to feel supported in their needs, requests and expectations.

Introduction

The crisis generated by the pandemic has made it clear the need to redefine the strategies relating to the fulfilment of goal 3 of Agenda 2030 (*Good Health and Well-being*) according to the new model of sustainable development. The promotion of this model is based on an approach that considers the protection of environmental, social and economic resources, thanks also to the increase of digital societies (Collicelli & Cascelli, 2021).

In particular, the efficiency of the health service is often linked to digitisation. Today, the use of technology in the health sector is concretely translated into benefits for the patient but also for health facilities. As early as 2005, the 58th World Health Assembly in Geneva recognised the potential of e-Health to strengthen health systems and improve quality, safety and access to care and encouraged Member States to take action to introduce digitalisation into health systems and services.

With the onset of the Covid-19 emergency, to cope with the difficulties of providing healthcare services in the presence of and reducing hospital access, there has been a greater diffusion of new digital tools, which inevitably led to what is defined as “*digital health*”.

Through apps, telemedicine and Industry 4.0, digitisation has firmly established itself in the healthcare sector. The new information and communication technologies (ICT) are revolutionising health systems and contributing to their future sustainability.

Focusing on a sustainable, resilient and equitable health system, the National Recovery and Resilience Plan (PNRR) provides for significant investments in the health sector. These investments make it possible to exploit digitisation’s benefits to all users involved.

Rethinking services and processes by integrating them with digital technology, making them practical, efficient and centered on the

needs of the players operating in the health sector, becomes one of the main prerogatives for developing the “*Connected Care*” model. The latter represents the ecosystem that, through web-based digital platforms, guarantees the patient access and sharing of health information with all those involved in the treatment process (Sgarbossa & Locatelli, 2022).

However, in a strategy of hospital-territory integration, taking care of the patient is fundamental, who needs continuous monitoring and a relational comparison with others. The gap, created on both fronts, can be bridged by applying new technologies. Augmented reality, gamification, and technologies at the service of emotions and knowledge become helpful tools capable of guaranteeing more effective services.

Therefore, the work proposed in this article presents the results of a project developed by a multidisciplinary team within the Cracking Cancer Hackathon initiative to respond to the need to *bring treatments closer, bring people together* and fill physical and relational distance through the development of new digital solutions.

Breast cancer: between Breast Unit and post-hospital care

According to the latest survey carried out by the Italian Cancer Registries Association (AIRTUM), breast cancer is still the most frequently diagnosed cancer in women in Italy today. About 55,000 women get sick annually, one-third of the total cancers affecting the female population (AIRTUM-AIOM, 2021).

According to the Breast Cancer Research Foundation, two million women worldwide are diagnosed with breast cancer annually. It is estimated that one in eight women will develop the disease in their lifetime. However, thanks to increasingly sophisticated diagnostic tools and cutting-edge therapies, the chances of recovery are always higher. Today, breast cancer has an excellent average prognosis, with a survival of 88% five years after diagnosis (Gori, Miglietta & Modena, 2021).

The care of women affected by this disease deserves excellence. Therefore, establishing multidisciplinary breast cancer centres, or Breast Units, was fundamental. From diagnosis to follow-up, it provides for taking charge of all breast cancer patient's physical and psychological needs. As a model of assistance, specialised in the diagnosis, treatment and psychophysical rehabilitation of women, the

Breast Unit provides that the management is entrusted to a multi-disciplinary group of experienced professionals in the breast and oncology field. They support the patient in the different phases of his path of care, from taking charge to managing the therapeutic assistance process, promoting clinical-experimental research activities with innovative drugs and at the same time guaranteeing information activities and specific initiatives through the involvement of patients' associations.

From 18 December 2014, through the approval of the "guidelines on the organisational and assistance methods of the network of breast care centres", the Italian Breast Units have a reference to offer women the best services and care (Europa Donna, 2020).

Breast cancer patients, therefore, by turning to individual centres that operate in synergy on the territory just like a network, can take advantage of services that guarantee prevention and continuity of care. In this context, the establishment of a network of breast centres in Sicily has seen the creation of as many as 17 Breast Units (Figure 1), which pursue the following goals:

- prevention and information on correct lifestyles;
- mammography screening and level II investigations with the most advanced technologies and highly specialised personnel;
- genetic counselling and psychological support;
- treatment with the most innovative surgical techniques and drugs;
- continuity of treatment and management of complications, as well as oncological nutrition.

Despite the support guaranteed by the Breast Units, the rapid spread of Covid-19 and the consequent restrictions on access to hospitals have inevitably conditioned the dynamics of the management of oncological diseases in all phases of the diagnostic and therapeutic process, as well as inevitably creating a distance physical and relational in post-hospitalisation.

Therefore, the need for patients to interface with health professionals has amplified the need to take advantage of remote patient-therapy monitoring systems (telemedicine), accelerating the *digital health* race.

In addition, following the spread of social media, a different patient approach emerges to information and comparison with other patients and healthcare personnel (Taylor et al., 2020).

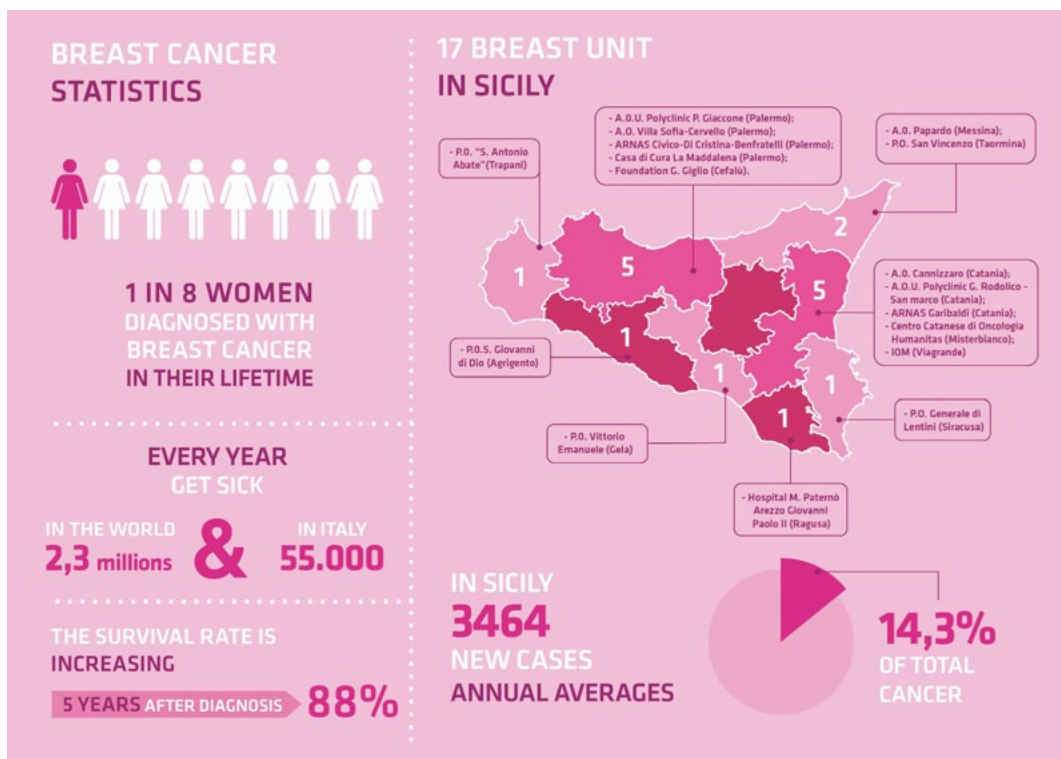


Figure 1. Graphical elaboration of data on breast cancer worldwide, in Italy and the Sicilian Breast Units. (Source: AIRTUM-AIOM, 2021; Europa Donna, 2020).

In particular, the so-called *Health Online Communities* have created new ways of remote interaction to overcome patients' loneliness. Indeed, scientific studies highlight how much patients approach communities initially in search of support and information. However, over time they also find gratification in providing support to others (Shaw et al., 2000).

Therefore, emotional support and respect for autonomy are fundamental elements for providing correct information to the patient (Piazza et al., 2021).

Membership in online cancer communities can eliminate the inhibitions deriving from face-to-face confrontations and foster equal relationships (Crook & Love, 2017). Furthermore, lower rates of depression and stress occur among patients included in these communities (Winzelberg et al., 2003).

Despite the numerous advantages, we should recognise the risks behind the communities, where it is possible to find information

that is only sometimes provided by professional and competent users on the subject.

Therefore, the present research aims to create new therapeutic tools and methods of remote interaction (support community) that allow for overcoming the patient's sense of loneliness and satisfying his needs and expectations alongside physicians, behavioural psychologists, and other experts supervised by a moderator. However, these forms of communication, resulting in the possibility of health improvement, require new measurement tools. Therefore, specific goals were:

1. investigate the criticalities and difficulties encountered by cancer patients in the post-hospital path;
2. develop innovative solutions capable of facilitating the post-hospital path, reducing the distance created when the patient leaves the hospital.

Methodology

The research used the theoretical and methodological tools of Ergonomics for Design (Tosi, 2020), specifically those of Human-Centered Design (ISO 9241-210: 2019) which, including data, information and knowledge collected on and with people in real life and work contexts allow the definition of design solutions.

The study, developed in stages, involved a multidisciplinary team of professionals (oncologists, nurses, computer scientists, communication and digital technology experts, designers, psychologists, data managers, case managers, trainees, project managers, designers and patients). With a participatory design approach, it was possible to encourage dialogue and comparison between the various parties involved. This involvement has made it possible to focus on the needs and expectations of cancer patients and the skills and points of view of the professionals involved in planning and managing services relating to care in the various Breast Units.

The research precisely developed the following operational phases:

- i) phase 1: Literature analysis relating to digital technologies for healthcare (gamification, technologies at the service of emotions and knowledge, etc.);
- ii) phase 2: Analysis of the critical issues in the post-hospital path;
- iii) phase 3: Development of the design concept and scenarios;
- iv) phase 4: Evaluation of the feasibility of the project.

Phase 1: Literature analysis relating to digital technologies for healthcare.

Through the review of the literature and state of the art, the first operational phase involved the analysis of the leading scientific contributions and the most recent experiments relating to the application of digital technologies within the world of healthcare.

Starting from the keywords “e-health” and “digital health”, it was possible to select the research contributions that, nationally and internationally, were the most significant for research, especially about the experiments/studies of technologies used in the oncology field.

This phase allowed the collection of helpful material to identify reference models and start the subsequent analysis phases in the field.

Phase 2: Analysis of the critical issues in the post-hospital path.

The second phase of the research involved an “expert patient” and various professional figures to activate dialogue and participation processes that would allow the analysis of the context and, specifically, the analysis of the critical issues encountered during the post-hospital path.

For this purpose, the methodologies used in this phase were the following:

- i) *focus group* with professionals who work within the medical oncology department (oncologists, nurses, trainees, psychologists, case managers, data managers, etc.), which allowed the collection of suggestions and information regarding the various hospital dynamics, activities and services offered within the departments, as well as indications regarding the functions to be implemented and included in the post-hospital care path;
- ii) *semi-structured interview* (Wilson & Sharples, 2015) with an expert patient (PE) able to extrapolate, from his own health experience, the value of valuable knowledge for orienting decision-making and organisational choices both in the field of assistance, both research and social responsibility. What the interviewee reported made it possible to bring out critical issues and unexpressed needs common to many women who have cancer treatments.

The focus groups and interviews were crucial for defining the next phase, which involved developing the design concept and defining possible intervention scenarios.

Phase 3: Development of the design concept and scenarios.

The development of design concepts and the definition of intervention solutions in phase 3 were possible thanks to the application of the following methodologies:

i) *co-design workshop* with a graphic rendering of the results involved designers, project managers, IT experts, communication and digital technology experts and figures suitable for taking charge of the patient and professionals with experience in the breast and psychological field. Furthermore, the workshop, through brainstorming sessions (Nunnally & Farkas, 2017), concept maps (Wheeldon & Faubert, 2009) and the development of mockups, allowed to analyse of existing criticalities and encouraged the emergence of new ideas through discussion and creation of shared collective knowledge.

ii) *design-orienting scenarios* (Manzini & Jégou, 2004) have been useful for the development of "plausible" and "questionable" visions and proposals. For example, this tool made it possible to represent the team's strategic vision regarding developing an innovative and patient-centered community.

Overall, these methodologies were used to conduct activities aimed at:

- Analysis of the critical issues and difficulties encountered by cancer patients in the post-hospital path;
- Generation of ideas and definition of the platform's contents and the language used in the digital service.

Phase 4: Evaluation of the feasibility of the project.

For the project evaluation, elaborating a SWOT Analysis (von Kodolitsch et al., 2015) was fundamental. It is a methodology aimed at evaluating the opportunities and strengths, but also the criticalities and weaknesses, to determine the most appropriate management methods concerning the internal and external context in which the planning is developed (Figure 2). Furthermore, from an economic and sustainability point of view, it was possible to evaluate and calculate the costs of implementing the platform in the first year of life, analysing the expense items. In order to plan the implementation of the project and the necessary related resources, giving a consequentiality and timing to each phase, a chronogram of activities has also been developed, which extends for eight weeks and includes: the development of the project, the portal, of informative materials, the publication of contents, multidisciplinary meetings, shared interventions, activation of the toll-free number, fundraising, etc.

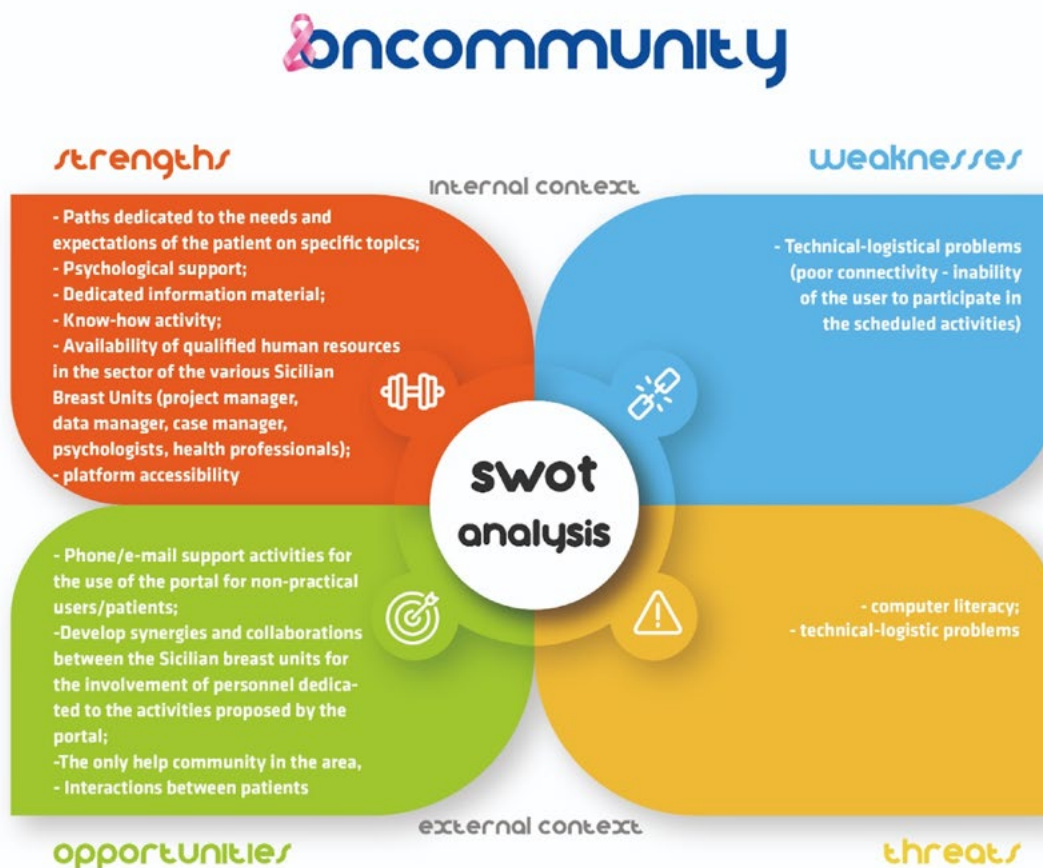


Figure 2. Processing of the Swot Analysis for the evaluation of the Oncommunity platform.

Results

During the processing of the collected data, it was possible to identify the following critical issues:

- Need for support, from a distance, of professionals such as doctors, psychologists, etc., able to alleviate the sense of fear, frustration and loneliness.
- Need for comparison, at a distance, between cancer patients who live the same situation/experience to be able to share and empathise with finding comfort, advice, etc.
- Need for more information on the part of the patient on the aspects concerning the therapy: symptoms, toxicity, duration, etc. and on his care path.

Therefore, based on the critical issues that emerged, it was possible to develop *Oncommunity*, a web-based platform entirely created in-house, with a responsive layout. Maximum compatibility with any computer system, accessibility from any device connected to the network, simultaneous access by multiple users to facilitate teamwork, centralised maintenance and updates of the platform, and reduction of management costs are all attributes that characterise this type of platform (Figure 3).

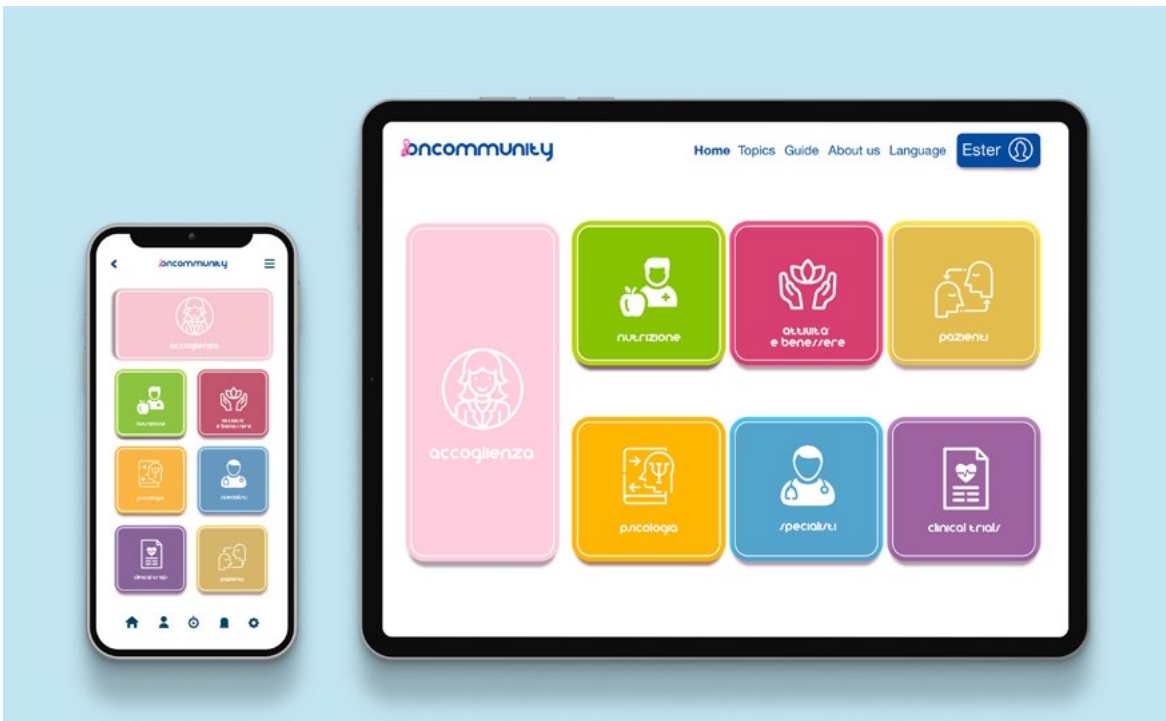


Figure 3. The graphic interface of the web-based platform is compatible with any computer system and accessible from any device connected to the network.

Specifically, it is a cloud-based web server platform with dedicated sub-tools and routines for each activity, i.e. tools made available to users and technologies tailored to the patient's needs. *Oncommunity* is a *patient-centered* platform aimed at patients diagnosed with breast cancer to provide continuity between the hospital path and the return home and to allow the patients, even at a distance, to feel supported in their needs, requests and expectations.

The platform aims to ensure that patients are cared for by professional figures in the post-hospital path to promote greater awareness in dealing with the disease from a medical, nutritional and bio-psycho-social point of view.

Therefore, it requires various human resources, such as Surgeons, Radiologists, Pathologists, Oncologists, Radiotherapists, Nurses, Case managers, Radiology technicians, Data managers, Psycho-oncologists, geneticists, Plastic surgeons, Nuclear doctors, and Data analysts. Conceptually, this *Help Community* is presented as a virtual tour consisting of 7 dedicated rooms (from reception to nourishment, trials, and specialists), which the patient can access, after registration, through his page (Figure 4). The latter requires indicating one's mutational status (for example, if the disease is in an early or advanced stage) in compliance with privacy and current regulations (GDPR). In this way, the user will be automatically redirected to the most relevant rooms/activities at the time of the illness.



Figure 4. How to register and access the patient's page to take advantage of the services offered by Oncommunity.

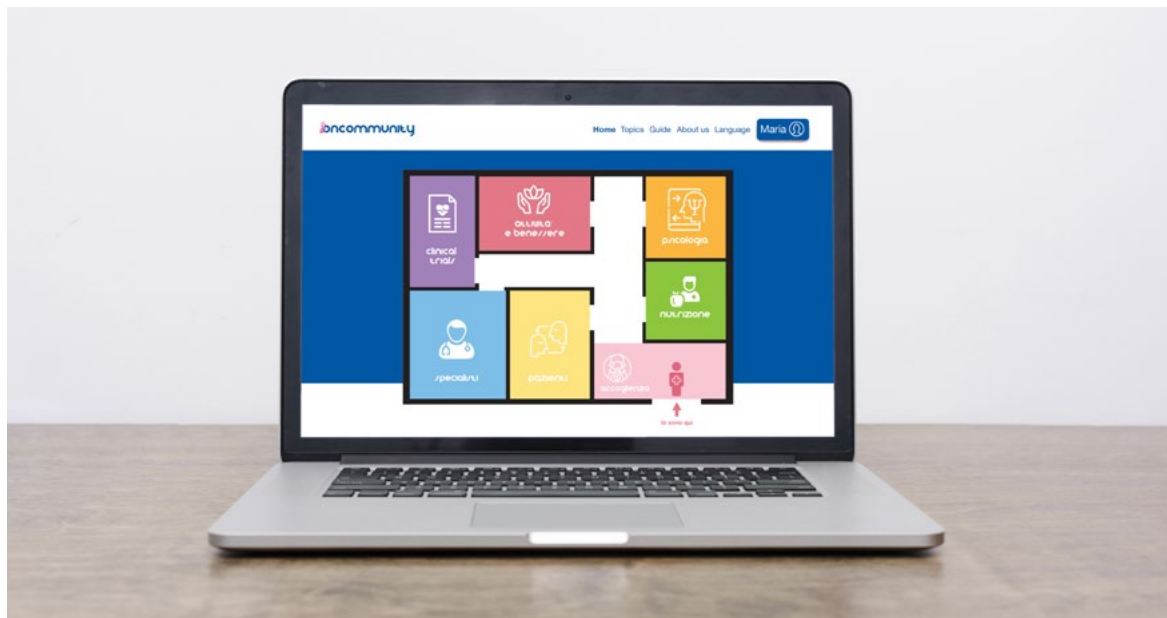


Figure 5. Graphical interface of the virtual tour with the possibility of accessing the various rooms (Nutrition, Activity and Wellness, Patient, Psychology, Specialists, Clinical Trials).

The virtual tour (Figure 5) begins in the first Reception room, where the patient is welcomed, taken by the hand and accompanied along the entire path, which includes the choice of the six subsequent rooms (Nutrition, Activities and Wellness, Patient, Psychology, Specialists, Clinical Trials).

Precisely, the Nutrition room satisfies the need for discussion; that is, it allows the patient to retrieve information on the correct diet to be followed during the treatment and participate in organised activities with chefs or experts in the sector.

On the other hand, the room regarding Activities and Wellness favours close collaboration with various associations, which, through meetings with professionals in the sector (hairdressers, make-up artists, etc.), respond to the patient's needs about lifestyles, physical well-being, and body care.

The need to share one's personal experience with other patients suffering from the same pathology is satisfied by switching on instead in the Patient's room. The discussion sessions are coordinated and moderated by a "guide patient" who has already experienced and overcome the disease.

The possibility of accessing the *Psychology room* is also fundamental, which allows greater awareness of what is being experienced through the support of psycho-oncologists and psycho-education laboratories. No less important is the *Specialists' room*, which guarantees effective communication between patients and healthcare professionals regarding the risks, and benefits of therapy, genetic tests and diagnostic tests to be performed.

Finally, the virtual tour allows access to the *Clinical Trials room*, which involves the patient in clinical-experimental activities, guaranteeing more information and discussion with the specialists in the sector.

Furthermore, to be more inclusive, the platform provides an email and a dedicated telephone number to contact if the patient needs to get used to technology.

Ultimately, Oncommunity:

1. Favours the creation of a remote multidisciplinary network for breast cancer patients.
2. Allows the patient to be taken in charge, supporting him in his care path.
3. Ensures human support to promote a better quality of life.
4. Guarantees a greater involvement of patients as actors and protagonists of their care path.

Conclusions

Although the research has allowed the identification of future and possible intervention scenarios within the oncology field, a further study that includes a larger sample of respondents would be desirable. Furthermore, this approach would allow us to understand the relational and emotional aspects of the patients. For this reason, further studies and analyses in the field (participatory and co-design processes) involving a diversified and enlarged user of patients and professionals in the sector should be launched to create an even more inclusive, sustainable and centered platform on the needs of the actors involved. Possible future steps of the research include the development of the platform and further usability testing phases that allow testing and improving the contents conceptualised in this survey. However, the results of this study highlighted the need for the following:

- create a new remote multidisciplinary network for the cancer patient who has breast cancer to provide continuity between the hospital path and the return home;

- have professionals who deal remotely with taking charge of the patient in his post-hospital path to promote greater awareness in dealing with the disease from a medical, nutritional and bio-psycho-social point of view;
- involve the patient more in clinical-experimental activities also through correct information and updates on the risks/benefits of the innovative treatments proposed;
- ensure adequate human support for the patient in his clinical path, a world unknown to him, to promote adherence to therapies and a better quality of life.

Therefore, the study highlighted the effectiveness of applying Ergonomics for Design, Human Centered Design and participatory design methodologies to identify sustainable and innovative intervention solutions within the hospital context. Specifically, the involvement of the Medical Oncology department of the Papardo hospital in Messina and a network of experts in different disciplines (psychology, medicine, computer science, etc.) has allowed underlining the importance of better combining the multidisciplinary dimension between multiple spheres of knowledge, to promote sustainability and well-being in the health sector.

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