Sugar Program
Fall Report 2019
Team Polimore

SUGAR

UNIMORE
UNIVERSITÀ DEGLI STUDI DI MODENA E REGGIO EMILIA

POLITECNICO
MILANO 1863

Executive Summary

This report aims to show the job done by the students of the University of Modena and Reggio Emilia, together with the students of Politecnico di Milano, for the SUGAR Project, in its first phase.

The SUGAR Project is a Design thinking challenge launched yearly by the SUGAR Network in conjunction with partner companies. Our challenge was proposed by Sanofi Genzyme, the speciality care global business unit of Sanofi, a worldwide pharmaceutical company with offices also in Italy. The company requested us to ideate solutions to improve the quality of life of Cancer and Multiple Sclerosis patients.

To fulfill our challenge, we are applying the Design Thinking methodologies used by IDEO and Stanford, which are rooted in human-centricity and practice-based learning. Meaning, our team is not only constantly learning through research, prototyping, testing, and iteration, but that in every step of the process, we are keeping our patients in top of mind.

What emerged from this first discovery and definition stage is a very clear vision of all the environments and people affecting patients' quality of life. Within this area, we discovered social inclusion and the role of loved ones and caregivers as key elements to patient wellbeing, especially senior patients. Fatigue and self-perception surfaced as the two main trends affecting both Cancer and Multiple Sclerosis patients throughout their journeys, and not only on specific stages, as was the trend with most patient struggles.

Now that we have a more narrow scope, we will continue to search for our patients' needs, while we kick-start ideation, and initiate rapid testing of possible solutions to the issues we have identified.

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Section 1

Context

Context

SUGAR is a global network that brings together students, universities and companies for the future of innovation through a new learning experience.
The SUGAR Network facilitates human-centered design to young talented minds. SUGAR aims to create impact by uniting universities and industries across the world to promote an alternative education, where students have ownership of the projects and are encouraged to be passionate about learning. SUGAR provides a platform for students to solve real company problems through the application of human-centered design and the use of design thinking tools and methodologies.

Picture of the SUGAR GKO in Hefei, China.
Source: SUGAR Network

How might we improve the quality of life of patients living with Cancer and Multiple Sclerosis?

Problem statement

During the SUGAR 2019-2020 programme, students from the Politecnico di Milano and the University of Modena and Reggio Emilia are collaborating to solve a challenge for the Italian headquarters of Sanofi Genzyme. The challenge was stated as follows: “How might we improve the quality of life of patients living with Cancer and Multiple Sclerosis?”

The company proposed this area of focus as they identified one common issue amongst both diseases: with recent improvements in treatments, patients are living much longer than before. Which means they are now facing the challenge of living with physical, emotional, and social issues that persist over long periods.

Moreover, while treatments can help speed recovery from attacks, modify the course of the disease, and manage symptoms, patients could be left alone to deal with all other consequences of their condition. Additionally, the amounts of information available on the internet can leave them vulnerable to fake news or perplexed in the face of contrasting suggestions.

Corporate partner

Sanofi Genzyme is the specialty care global business unit of Sanofi, focused on rare diseases, multiple sclerosis, oncology, immunology, and rare blood disorders. The company helps people with debilitating and complex conditions that are often difficult to diagnose and treat.

The branch dedicates to discovering and advancing new therapies and providing hope to patients and their families around the world. For over a decade, they have been working to develop novel treatments for MS. They also have a portfolio of medicines indicated across a variety of cancers.

The company was founded in 1981 and is based in Cambridge, Massachusetts. Genzyme was acquired by Sanofi in 2011, and has a presence in approximately 65 countries, with 17 manufacturing facilities and 9 genetic-testing laboratories.

SANOFI GENZYME

Pictures of the Sanofi logo
Source: Sanofi.it

The Universities

Politecnico di Milano

Politecnico di Milano is a scientific-technological university founded in 1863, focusing on the training of engineers, architects, and industrial designers. It focuses on the quality and innovation of its teaching, drives research, and develops a fruitful relationship with the business and productive world through experimental research and technological transfer.

Università di Modena e Reggio Emilia

Founded in 1175, it is one of the Italian oldest universities, with campuses located in Modena and Reggio Emilia. The university is committed to high-quality research, and it is large enough to offer all the facilities expected from a major university but small enough to retain a personal and friendly learning environment.

Design team

Teaching Assistants

Our teaching assistants will support us throughout the duration of the project, along with the other university staff.

Silvia Remotti

Service Designer
POLIMI

Mario Di Nauta

Innovation Coach
UNIMORE

On the left, picture of the whole team of Politecnico di Milano and UNIMORE during the egg hurl challenge in China.
Source: Matteo Vignoli

Polimore

Given the favourable geographic location of the two teams, we had the chance of working together as a whole group for the whole development of this research phase, meeting multiple times even in person in the cities of Milan and Bologna.
The opportunity to work together was especially useful to take advantage of all the competences of each team member.

POLIMI

Pratyush Dadhich

Design & Engineering

I am a Design and Engineering master's student. I study this because growing up, I was always keen to know the ideas behind the products we create. I chose to be part of SUGAR to learn new things, to work on real projects, and deliver a working solution for our partner.

Daniela De Sainz

Product-Service System Design

I am a UX/UI Designer, studying Product-Service System Design. I'm glad to bridge my backgrounds in visual and human-centered design to create better experiences; and my curiosity and passion for storytelling, research, and problem-solving have led me towards SUGAR.

Chiara Pacchiarotti

Product-Service System Design

I am a Product-Service System designer with a Visual Design background. I see design as a tool for building meaningful innovation. I value leaving the desk to talk to people and explore the context. I'm curious, and I like to discover new cultures and learn about new topics.

UNIMORE

Ludovico Cavazzuti

Management Engineering

I'm a Management Engineer, and according to my career choice, I like for everything to always be well organized, so I always plan my work and respect timetables. I'm really competitive, so when pressure increases I do my best to reach my goals.

Eugenia Dessì

International Management

I'm a final year master's degree student in International Management. I really enjoy being part of a team with people from different backgrounds and I hope this experience will lead us to a very innovative and useful solution for our partner.

Mirco Tincani

Physics

I'm a master's student in Physics. I'm attracted by the underlying mechanism of all sorts of complex systems and relational networks. I am curious and I'm used to make experiments and prototype solutions. I truly believe in the potential of interdisciplinary teamwork.

Ugo Vergallo

Computer Engineering

I'm a Computer Engineer specialized in Cyber Security and Artificial Intelligence. I love staying fit and going to the gym, and to travel to crazy places where I try to take wonderful pictures of the world. I hope to achieve a solution that will make us proud of our work.

Section 2.1

Design Development

2.1

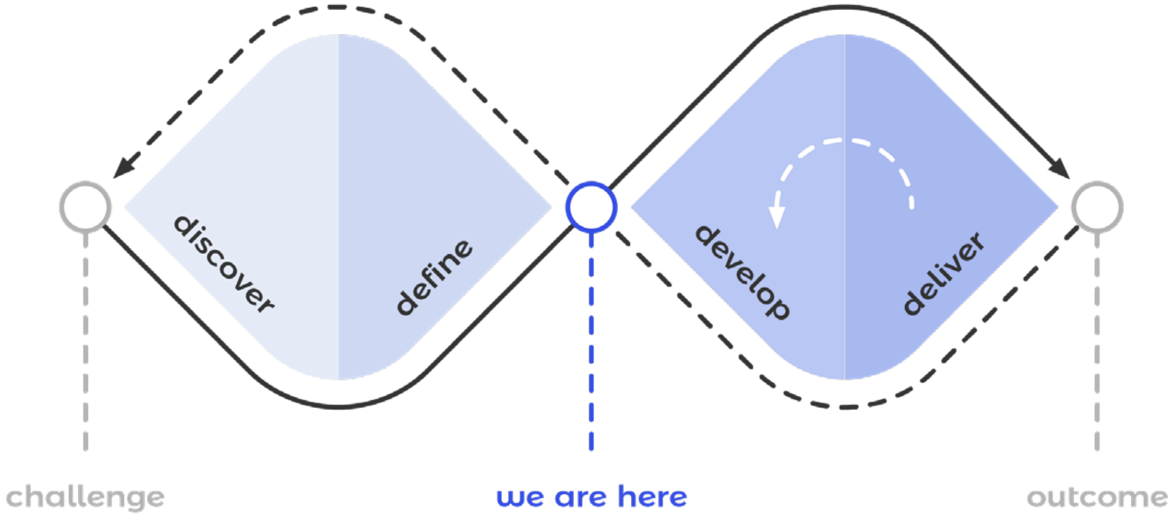
Introduction

Design thinking is a non-linear, iterative process that seeks to understand users—the patients, challenge assumptions both companies and designers might have, redefine problems, and create innovative solutions to prototype and test. The method consists of 4 phases—Discover, Define, Develop, and Deliver—and is most useful for tackling problems that are ill-defined or unknown. During the first stage of this challenge, the Discover and Define phases were put into practice.

During the Discover phase, we gained an empathetic understanding of the challenge through understanding our assumptions and the issues we wanted to find out with the use of six tools: Challenge Deconstruction, Design Space Mapping, Ecosystem Mapping, Desk Research, Field Research or Needfinding, and Brainstorming. Empathy is crucial to a human-centered design process like design thinking because it allows people to set aside their assumptions about the world and gain real insight into users and their needs.

During the Define phase, we accumulated the information created and gathered during the Discover phase. We analyzed our observations and synthesized them to define the new core problems, ones that were more narrow and specific than our initial challenge. Here, three main tools were used: Empathy Maps, Personas, and Benchmarking.

Now, we will explain each of the tools we have used during our process, and the insights gained through each of them.



The double diamond. Adapdet by the model created by the Design Council

Brainstorming session

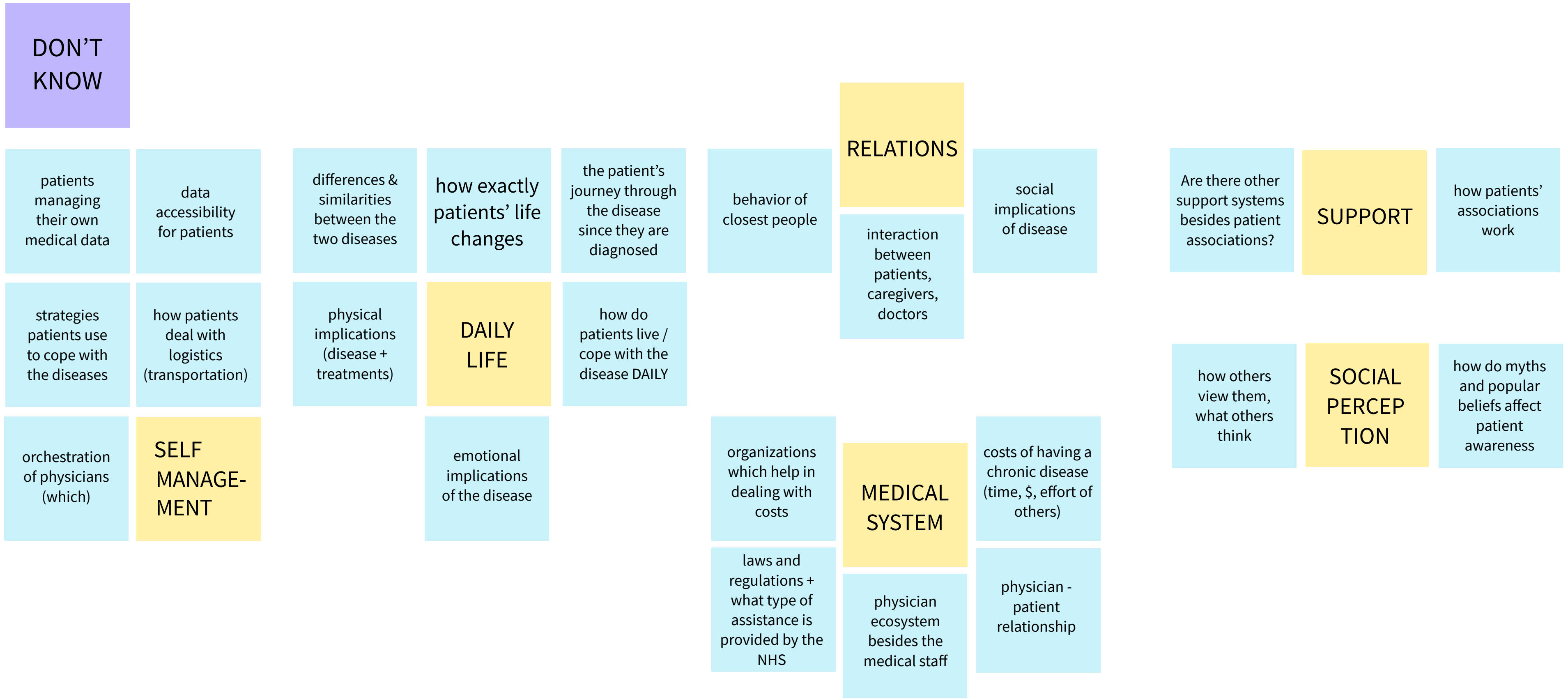
Brainstorming

Brainstorming is a design thinking tool that allows teams to generate new ideas and solutions around a specific topic. When using this tool, we noted all our ideas individually and then shared as a group without criticism. We used this technique throughout the whole process, as it allowed team members to think more freely and generate spontaneous new ideas instead of focusing on ideas that we already mentioned. Since our team consists of people from different backgrounds, brainstorming helped us to listen to and be open to new ideas.

Challenge deconstruction map

Challenge deconstruction

This was the tool that kick-started our process. We used it to understand the real meaning of the challenge, deconstructing each word, and what it really meant for the team through writing down the keywords for each challenge keypoint. It helped us to know where to start our research and to get a rough idea of the areas in which we needed to focus.



DON'T KNOW

SELF MANAGEMENT
patients managing their own medical data
data accessibility for patients
strategies patients use to cope with the diseases
how patients deal with logistics (transportation)
orchestration of physicians (which)

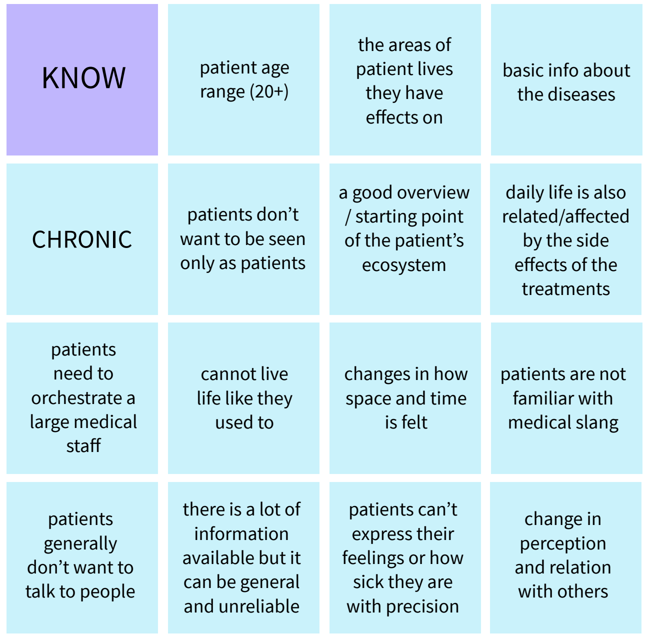
DAILY LIFE
differences & similarities between the two diseases
how exactly patients' life changes
the patient's journey through the disease since they are diagnosed
physical implications (disease + treatments)
how do patients live / cope with the disease DAILY
emotional implications of the disease

RELATIONS
behavior of closest people
social implications of disease
interaction between patients, caregivers, doctors

MEDICAL SYSTEM
organizations which help in dealing with costs
costs of having a chronic disease (time, $, effort of others)
laws and regulations + what type of assistance is provided by the NHS
physician ecosystem besides the medical staff
physician - patient relationship

SUPPORT
Are there other support systems besides patient associations?
how patients' associations work

SOCIAL PERCEPTION
how others view them, what others think
how do myths and popular beliefs affect patient awareness



KNOW
patient age range (20+)
the areas of patient lives they have effects on
basic info about the diseases

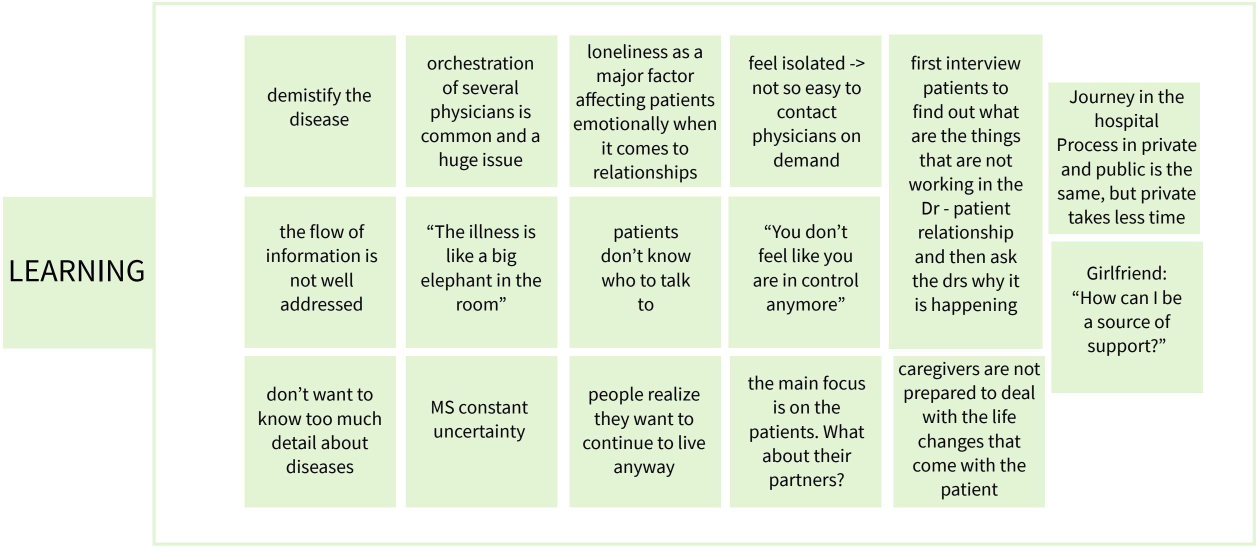
CHRONIC
patients don't want to be seen only as patients
a good overview / starting point of the patient's ecosystem
daily life is also related/affected by the side effects of the treatments
patients need to orchestrate a large medical staff
cannot live life like they used to
changes in how space and time is felt
patients are not familiar with medical slang
patients generally don't want to talk to people
there is a lot of information available but it can be general and unreliable
patients can't express their feelings or how sick they are with precision
change in perception and relation with others

On top, mapping what we know and what we don't

Design space mapping

Next, we listed the facts we knew and we did not know about the challenge. Then, we classified these facts into subcategories to define the topics related to our challenge, and finally, we identified the areas we needed to learn more about through desk research.

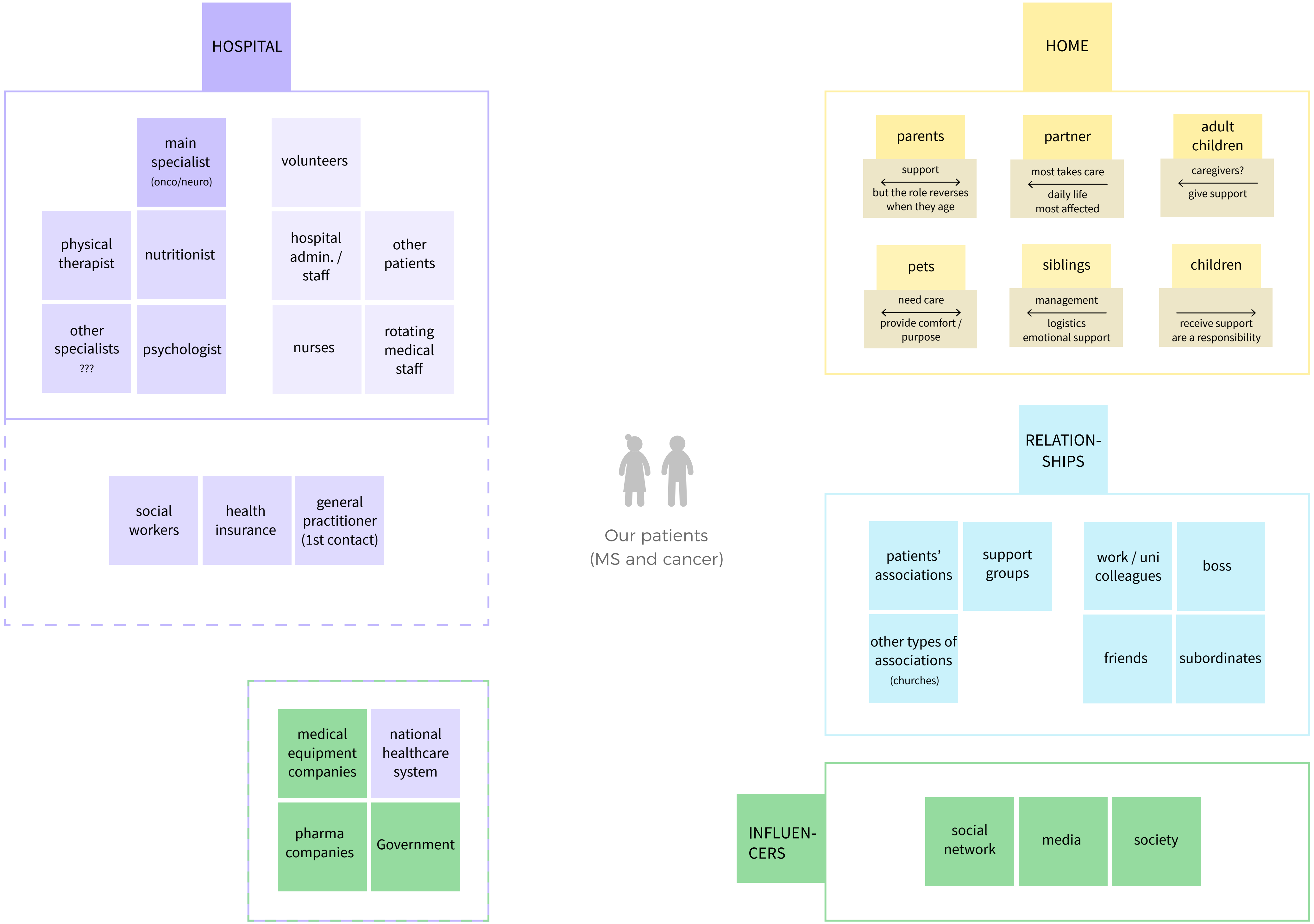
Below, the areas of focus for the desk research



LEARNING
demistify the disease
the flow of information is not well addressed
don't want to know too much detail about diseases
orchestration of several physicians is common and a huge issue
"The illness is like a big elephant in the room"
MS constant uncertainty
loneliness as a major factor affecting patients emotionally when it comes to relationships
patients don't know who to talk to
people realize they want to continue to live anyway
feel isolated -> not so easy to contact physicians on demand
"You don't feel like you are in control anymore"
the main focus is on the patients. What about their partners?
first interview patients to find out what are the things that are not working in the Dr - patient relationship and then ask the drs why it is happening
caregivers are not prepared to deal with the life changes that come with the patient
Journey in the hospital Process in private and public is the same, but private takes less time
Girlfriend: "How can I be a source of support?"

Ecosystem mapping

Before starting desk research, we mapped the patient's ecosystem by identifying all the environments and people that play a role in the patient's life and how they interact with each other and the patient. This, to gain a better understanding of which elements had a larger influence on the patients and also to identify which people we needed to interview during needfinding.



HOSPITAL

main specialist (onco/neuro)
volunteers
physical therapist
nutritionist
hospital admin. / staff
other patients
other specialists ???
psychologist
nurses
rotating medical staff

social workers
health insurance
general practitioner (1st contact)

medical equipment companies
national healthcare system
pharma companies
Government

Our patients (MS and cancer)

HOME

parents
support ↔ but the role reverses when they age

partner
most takes care ← daily life most affected

adult children
caregivers? ← give support

pets
need care ↔ provide comfort / purpose

siblings
management ← logistics emotional support

children
→ receive support are a responsibility

RELATION-SHIPS

patients' associations
support groups
work / uni colleagues
boss
other types of associations (churches)
friends
subordinates

INFLUEN-CERS

social network
media
society

Section 2.2

Desk research

Desk research

Even though human-centered design centers around talking with people about their challenges, ambitions, and constraints, we still need context, history, and data that interviews are not able to provide. This is why we turned to research scientific papers, websites, books, and social media support groups for information about our challenge's topics.

Besides Cancer and Multiple Sclerosis, the main topics we researched during this phase were: the public medical system in Italy, Italian patient associations, and other forms of support, challenges patients face when living with the diseases, patient self-management, and social inclusion of patients. This, to better understand what issues affect the "quality of life" of a patient living with a chronic disease.

We will now proceed to share our main findings of each of these categories.

2.2

Multiple sclerosis

Multiple sclerosis is a nervous system disease with a wide range of symptoms that affect the self-care ability of patients in their daily activities of life.

It is one of the most common neurological disorders and causes of disability in young people. The disease is not curable and treatments can only decrease the frequency of attacks or symptoms perceived by a person in a given period, as treatments can only decrease the rate of worsening of the illness.[1]

The most common symptoms of the disease are sensory disturbances, walking difficulties (due to fatigue, weakness, spasticity, loss of balance and tremor), vision problems (diplopia, blurred, and pain on eye movement), intestinal and urinary system dysfunctions (constipation and bladder dysfunction), cognitive and emotional impairment (inability to learn and depression), dizziness, and vertigo.[2] There are four types of Multiple Sclerosis:[3]

- **Clinically isolated syndrome (CIS)**: the first episode of Multiple Sclerosis symptoms that patients experience. It results from inflammation and damage to the myelin sheath.
- **Relapsing-remitting Multiple Sclerosis (RRMS)**: appearing around the age of 30, it is the most common among patients, as around 85% suffer from it. This type of Multiple Sclerosis is characterized by attacks of new or worsening symptoms called relapses. After each attack, patients have an extended period in which their symptoms improve or disappear until the next relapse. The severity of symptoms varies depending on the extent and location of the nerve damage.
- **Primary progressive Multiple Sclerosis (PPMS)**: it is less common than RRMS, with patients aged 40 years or older being the most affected. This type of Multiple Sclerosis is characterized by patients experiencing symptoms throughout their life without recovery or remission, instead of suffering from attacks or a sudden onset of symptoms.
- **Secondary Progressive Multiple Sclerosis (SPMS)**: it is the progression of RRMS. When a patient suffers from SPMS, symptoms will gradually become more severe without any further distinction between attacks and remission.

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[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6614347/

[2] https://www.healthline.com/health/multiple-sclerosis/early-signs

[3] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6614347/

Even though Multiple Sclerosis does not have a cure, there are medicines to treat its symptoms. The common infusion treatments are listed below[4]:

- **Natalizumab (Tysabri)**: designed to block the movement of potentially damaging immune cells from the patient's bloodstream to their brain and spinal cord. This medication increases the risk of a potentially serious viral infection of the brain known as progressive multifocal leukoencephalopathy (PML) in people who are positive for antibodies to the causative agent of the PML JC virus.
- **Ocrelizumab (Ocrevus)**: this humanized immunoglobulin antibody medication is the only disease-modifying therapy (DMT) approved by the FDA to treat both the relapse-remitting and primary-progressive forms of MS. Side effects include irritation at the injection site, low blood pressure, fever, and nausea, among others. Ocrevus also increase the risk of some types of cancer, particularly breast cancer.
- **Alemtuzumab (Campath, Lemtrada)**: helps reduce relapses by targeting a protein on the surface of immune cells and depleting white blood cells. Treatment consists of five consecutive days of drug infusions followed by another three days of infusions one year after the first treatment is completed. This drug increases the risk of infections and autoimmune disorders, including a high risk of thyroid autoimmune diseases and rare immune-mediated kidney disease.

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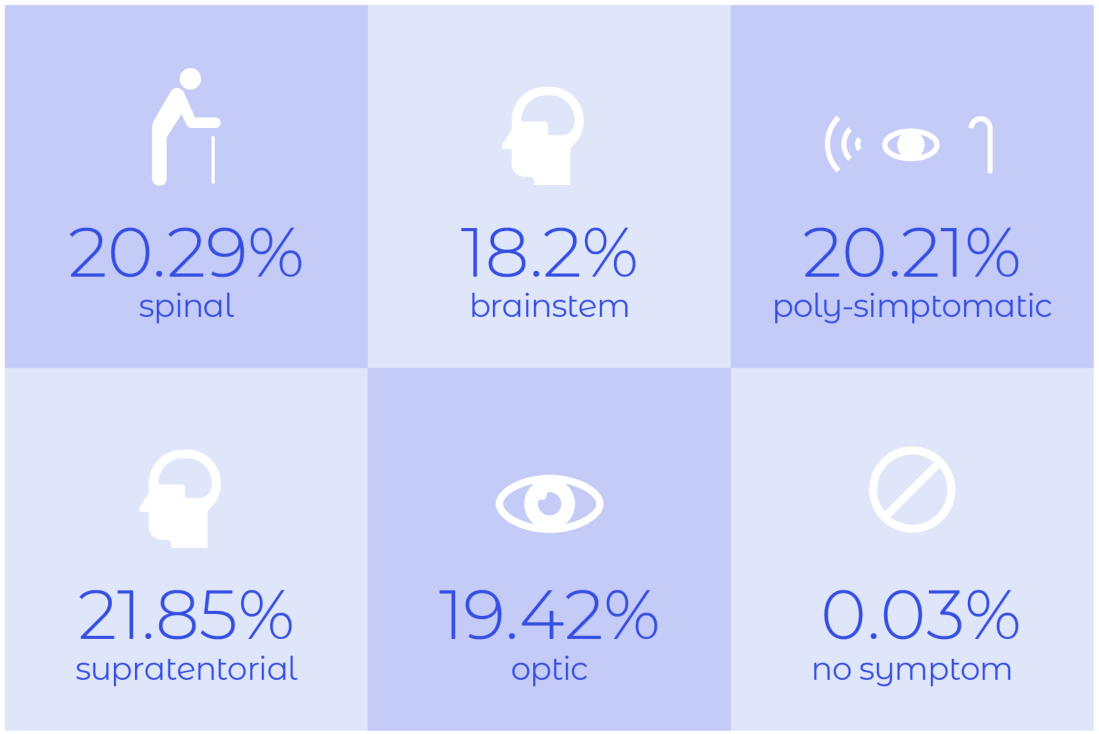
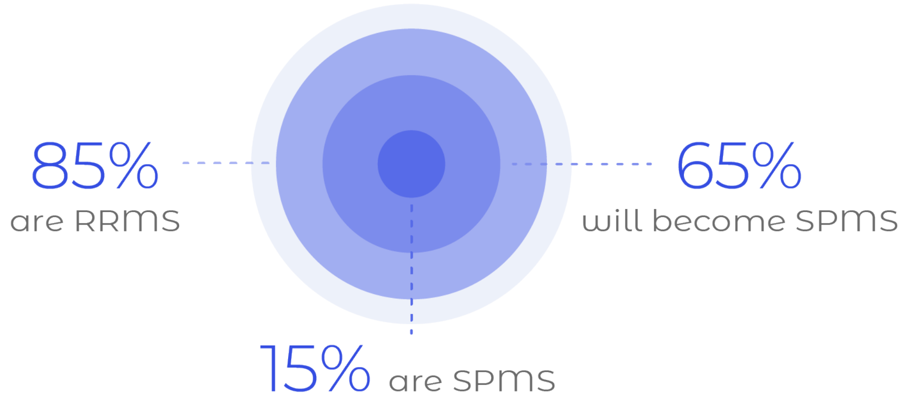
[4] https://www.mayoclinic.org/diseases-conditions/multiple-sclerosis/diagnosis-treatment/drc-20350274

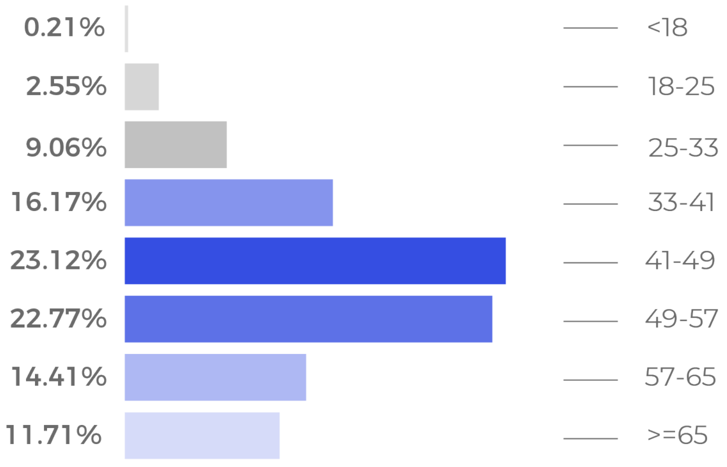
Distribution of symptoms at onset *(Italy, 2019)*




Multiple Sclerosis Cases in Italy


Patients by gender

> In 2018, AISM reported 122,000 Multiple Sclerosis cases in Italy.


Percentage of patients by age

Source of the graphs: Registro Italiano MS, 2019

Cancer

Cancer is a disease caused when cells divide uncontrollably and spread into surrounding tissues.

There are more than 100 different types of cancer, named for the organ or type of cell in which they start: for example, cancer that begins in the colon is called colon cancer.[1]

Cancer symptoms vary according to the cancer type. However, there are several known common symptoms, such as eating problems, fatigue, fever, night sweats, changes in the color of the patient's tongue, neurological problems, and skin changes.[2]

Different stages identify the severity level of cancer a patient has, stage four being the most serious[3].

- **Stage 0**: identified as a no cancer stage, though there is a potential of abnormal cells to transform into cancer cells.
- **Stage 1**: this is early-stage cancer, in which the cancer cells have grown into a small, unique area.
- **Stages 2 and 3**: cancer cells have grown into nearby tissues and lymph nodes.
- **Stage 4**: also known as advanced or metastatic cancer, in this stage, the cancer cells have spread to other parts of the body.

There are many treatments available for cancer. The treatment given by a physician depends on the type of cancer and its stage[4].

- **Surgery**: a procedure in which a surgeon removes cancer from the body.
- **Radiation Therapy**: uses high doses of radiation to eliminate cancer cells and shrink tumors.
- **Chemotherapy**: uses drugs to eliminate cancer cells.
- **Immunotherapy**: a type of cancer treatment that helps your immune system fight cancer.
- **Targeted Therapy**: targets the changes in cancer cells that help them grow, divide, and spread.
- **Hormone therapy**: slows or stops the growth of breast and prostate cancers that use hormones to grow.
- **Stem Cell Transplant**: a procedure that restores blood-forming stem cells in cancer patients who have had theirs destroyed by very high doses of chemotherapy or radiation therapy.
- **Precision Medicine**: aids doctors when selecting treatments that are most likely to help patients based on a genetic understanding of their disease.

Patients who have had cancer treatment have a risk of developing long-term side effects, which can happen months or years after treatment. Evaluating and treating late effects is an important part of cancer survivorship care[5]. The most common long-term side effects of cancer treatments are:

1, 2, 3 https://www.cancer.gov/about-cancer

4 https://www.cancer.gov/about-cancer/treatment/types

5 https://www.cancer.net/survivorship/long-term-side-effects-cancer-treatment

- **Fatigue**: a constant feeling of physical, emotional, or mental tiredness. It is the most common side effect of cancer treatment. Some cancer survivors have fatigue for months or even years after finishing treatment.
- **Heart problems**: both chemotherapy and radiation therapy to the chest can cause heart problems.
- **Brain, spinal cord, and nerve problems**: chemotherapy and radiation therapy can cause long-term side effects on the brain, spinal cord, and nerves.
- **Learning, memory, and attention difficulties**: chemotherapy and high-dose radiation therapy to the head and other areas of the body may cause cognitive problems for adults and children.

Italian numbers at a glance

60,550,075	total population
175,741	number of deaths
1,180,472	prevalent cases *(5-year)*

New cancer cases *(Italy, 2018)*

13.9%	breast
12%	colorectum
10.7%	prostate
9.8%	Lung
6.3%	bladder
409 808	total case number

Source: WHO, 2018

The National Medical System

The services offered by the National Medical System cover all direct costs of the two diseases, but patients have to cover many indirect costs.

The services offered by the National Medical System change depending on regions. In the search for better healthcare, patients residing in the South often migrate North, specifically to the Lombardy region.

In Italy, the National Medical System covers all direct costs related to Cancer and Multiple Sclerosis. These are related to diagnosis, treatments, and hospitalization. However, patients must cover indirect costs. In 2018, the costs sustained for diagnosis, treatments, and hospitalization of both diseases were almost 20 billion euros.[1]

These indirect costs concern all the support patients need while coping with the disease, such as psychological support, nutritionists, physiotherapy, logistic support, and drugs to deal with the side effects of the treatments.

> In 2018, the costs sustained for diagnosis, treatments, and hospitalization of both diseases were almost 20 billion euros.
>
> Source: Fondazione Veronesi

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[1] https://www.fondazioneveronesi.it/magazine/articoli/oncologia/quanto-costa-ammalarsi-di-cancro

The cost of Multiple Sclerosis in Italy

5B €
yearly cost
to the NHS

45,000 €
the average cost
per year, per patient

84,000 €
the average cost for an
advanced stage patient

2,620 €
cost of a relapse

38%
of patients
do not get
free drugs
for treating
all of their
symptoms

1,325 €
min average yearly
cost per patient

6,500 €
max average yearly
cost per patient

148m € yearly pension expenditure

67m €/y	58m €/y	22m €/y
living allowance	disability checks	disability pensions
8,800 beneficiaries	*7,300 beneficiaries*	*1,650 beneficiaries*

Source: AISM, 2018

The indirect cost of Cancer in Italy

7,145 €
direct costs

3,235 €/y
medical expenses

1,960 €
medicines

546 €
specialists

323 €
private nurses

3,910 €/y
non-medical expenses

1,491 €
transport

720 €
assistance

284 €
special diets

34,052 €
indirect costs

10,978 €/y	6,668 €/y	15,038 €/y
missing income from patient's job	missing income from caregiver's job	value of caregiver assistance

Source: Rapporto Aiom Airtum, 2017

Patient support

Besides relying on family and friends, patients can access other forms of support like Patient Associations and Social Media groups. Furthermore, patients affected by chronic illnesses can access juridical support.

Juridical Support[1]

Besides treatment, Multiple Sclerosis and Cancer patients need juridical and economic support. In Italy, the most important law for protecting patients living with a chronic disease and disabled persons are the Civil Disability Law and the 104 Law. The 104 Law applies to patients with a disability or handicap and their families, allowing them to perform caregiving duties.

These two laws can guarantee patients: instruments to treat impairments, home rehabilitation, tax deductions, disability allowance, the right to study, logistic support, and work support in the form of leave permits, priority in the choosing of a workplace, refusal to transfer, aid to be hired, moving to part-time employment, and performing a job according to the patient's medical condition.

To obtain the rights established by the laws, a commission will evaluate and recognize the patient's percentage of disability. Based on this percentage, the patient is given benefits.

Patient Associations[1]

For Multiple Sclerosis and Cancer patients, the world of Italian Patient Associations varies greatly. When it comes to Multiple Sclerosis, only AISM exists, while for Cancer, there are multiple associations, each one specialized in a different cancer type.

Patient Associations are distributed across Italian territory, and their role has been fundamental in encouraging the country's targeted policies, disease research, and healthcare operations.

Many advancements in the field of rare diseases, at different institutional levels, are due specifically to the activities of these organizations, as they have allowed civil society to gain awareness about the peculiarities of these illnesses and the problems they imply.

The work of the associations has contributed to modifying the relationships between central, regional, and local institutions and the communities of patients, removing many existing barriers.

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[1] https://www.aism.it/invalidit%C3%A0_civile

[1] http://www.salute.gov.it/portale/temi/p2_6.jsp?lingua=italiano&id=709&area=Malattie%20rare&menu=vuoto

> For Multiple Sclerosis and Cancer patients, the world of Italian Patient Associations varies greatly. When it comes to Multiple Sclerosis, only AISM exists, while for Cancer, there are multiple associations, each one specialized in a different cancer type.

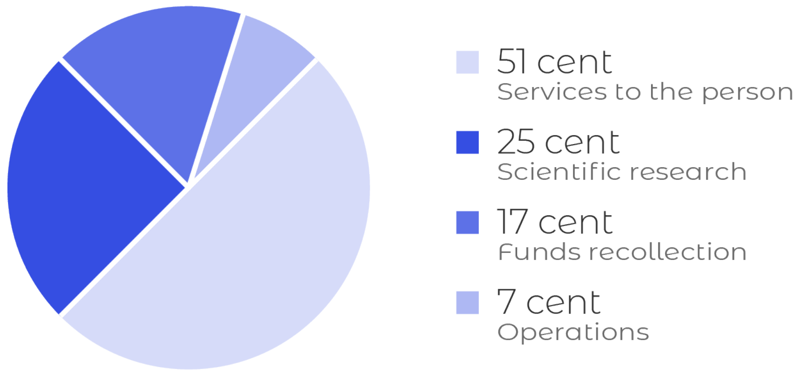
What Patient Associations do for the Patients

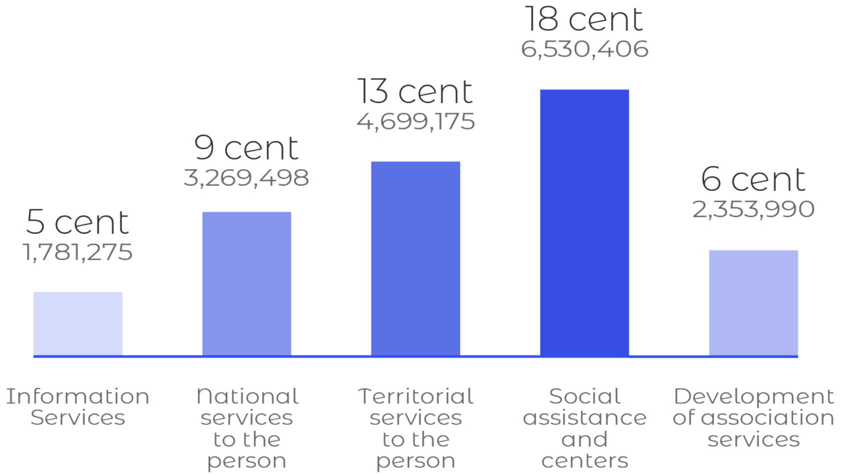
- Offer housing for patients and relatives that need to be close to healthcare facilities during the acute phase of the illness
- Help patients and people living with disabilities to deal with everyday necessities
- Take charge of terminal patients at home and in hospice, were they get palliative cures and pain management
- Provide information on patient needs in the illness in different phases.
- Psychological support in treatment centers
- Physical treatments for people with disabilities
- Rehabilitation treatments
- Provide information through dedicated phone lines

What Patient Associations do for Healthcare Advancement

- Collect funds for research
- Cooperate in public healthcare programs
- Cooperate to study projects
- Find patients for clinical studies
- Produce informative material about the illnesses, available treatments, and clinical networks
- Often create networks between specialists and other structures to start research activities and support projects

AISM investment figures for 2018





Source: AISM

Patient Support Groups

These are groups made for patients by patients, most commonly on social media platforms like Facebook. Through these groups, people can share their stories, ask questions, and meet others facing similar issues. There are Italian Facebook groups with more than 10.000 subscribers, and members of these groups appear to be very active, as a daily average of more than 50 posts is posted and discussed. For example, in Italy, the number of patients subscribed to 5 Facebook Groups is 30.000, more than the patients subscribed to AISM.

Life with a chronic illness

For patients, experiencing a chronic disease requires adjustment across multiple aspects of their life. These adjustments unfold over time because they depend on the patient's context. So, we can state that adapting to a chronic illness is neither a linear or a stable process.

For patients, experiencing a chronic disease requires adjustment across multiple aspects of their life. These adjustments unfold over time because they depend on the patient's context. So, we can state that adapting to a chronic illness is neither a linear or a stable process.[1]

Moreover, how patients adjust to chronic illness varies greatly, since adjustment encompasses multiple components that cross interpersonal, cognitive, emotional, physical, and behavioral domains. The main contributors to adjustment to chronic disease are socioeconomic status, culture and ethnicity, gender-related processes, interpersonal support, and personality attributes.

> “
> The patient's socioeconomic status affects their health directly, through access to healthcare, and indirectly, through the behaviors they learn and practice.
>
> Source: Annual Review of Psychology

The patient's socioeconomic status affects their health directly, through access to healthcare, and indirectly, through the behaviors they learn and practice.

Culture plays a key role as well since significant differences emerge in the way different ethnic groups deal with the disease. For instance, African American and Latin cancer patients are more likely to endorse spiritual practices than Western European patients.

Differences in the way men and women adapt to the disease have also been observed. For example, when it comes to cancer patients, women generally report more depressive symptoms than men. However, men tend to reduce work activities more and are nurtured by their partners. In contrast, after returning home from the hospital, women take on household responsibilities more quickly.

When adjusting to major life transitions, patients can perform different adaptive tasks. From a strictly physical and medical point of view, patients can learn how to regulate distress or how to manage pain

We have understood that adjustment to chronic illness is a complex and dynamic process, where patients face every single step of the journey with different attitudes and strategies. We have to keep in mind that a disease that disrupts a patient's life does not exclude the experience of joy. And finally, that chronic illness can be seen as an opportunity for finding positive meaning, altering health behaviors, enriching emotional life, and deepening personal relationships.

and symptoms. But they can also change and adapt their social relationships and behaviors and their way to enhance self-esteem, for instance by finding new meanings for their life and by trying to maintain paid employment or routine activities during the different stages of their illness.

Patients can learn effective coping strategies through social support. Social support can also offer patients a better understanding of their problems, it can diminish physiological reactivity to stress, and can act as a source of encouragement to learn positive behaviors. However, considering the patient-partner relationship, the beneficial effect of intimacy appears to fade over time as providing support becomes burdensome to the partner.

Personality can both be seen as a risk or as a protective factor. For example, patients showing optimism shortly after hospital discharge predicted fewer depressive symptoms a year later. Moreover, they also predicted faster in-hospital recovery and returns to normal life activities. Optimism's benefits have been demonstrated in people with various cancers and at several periods in the disease trajectory.

How patients view their disease is a fundamental determinant of their later coping efforts and adjustment. Perceived threats to health and life goals, disease-related expectancies, and finding meaning in the illness experience are processes that seem to impact patients' views of their disease.

> Optimism's benefits have been demonstrated in people with various cancers and at several periods in the disease trajectory.
>
> Source: Annual Review of Psychology

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[1] https://www.researchgate.net/publication/6858444_Health_Psychology_Psychological_Adjustment_to_Chronic_Disease

Challenges faced in ADLs

The Cambridge Dictionary defines ADLs, or activities of daily living, as "the basic activities that people need to be able to do in order to take care of themselves, for example, getting in and out of bed, getting dressed, and eating."

> "
>
> The main challenges associated with a chronic disease are confronting physical, emotional, psychological, cultural, and behavioral changes, the fear of becoming crippled, and facing the financial burden of the disease.

Source: "Challenges in ADL for patients living with Multiple Sclerosis"

Self management

Self-management can be defined as the decisions and behaviors that patients with chronic illness engage in what affects their health.[1]

Sometimes the need for self-management is a result of physical necessity because patients understand that making real changes is essential for their health. As a result, demand for self-management tools is increasing (self-care, mobile care, and home-care) outside the walls of formal institutions.[2] However, at the same time, not all patients are up to the task of managing their data, particularly senior patients, who are sometimes lonely and in a worse stage of the disease, or those without internet access.[3]

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1 http://www.improvingchroniccare.org/index.php?p=Self-Management_Support&s=39

2 https://www.chcf.org/wp-content/uploads/2017/12/PDF-PatientSelfManagementToolsOverview.pdf

3 https://www.fiercehealthcare.com/tech/are-all-patients-up-to-task-managing-their-own-health-data-some-cios-say-no

> "
>
> Not all patients are up to the task of managing their data, particularly senior patients, who are sometimes lonely and in a worse stage of the disease, or those without internet access.

Source: FierceHealthcare

Patient-generated health data or PGHD is health-related data created, recorded, or gathered by or from patients, family members, or caregivers to help address a health concern. It provides value to both patients and health care professionals. For the patients, it is important because they can keep track of their status, their treatment, and the medical progress of their aggravations. For the physicians, it is a fundamental resource as it helps them choose the right treatment and to be able, step by step, to adapt and fit the clinical plan to the current needs of the patients.[4]

Patients are willing to donate their health data to research as long as there is a transparent system where they are fully in control of their data and where the relationship with companies, authorities, and doctors is based on mutual trust. However, in many countries, patients do not always have access to their medical records because of legal issues. Furthermore, many scientists have argued that patients having access to their own medical record has pros and cons. On the one hand, it can enhance the relationship between doctor-patient, patient empowerment, and patient education, but, on the other, patients can become more worried and have pessimistic thoughts after have understood everything about their disease.[5]

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4 https://www.healthit.gov/topic/otherhot-topics/what-are-patient-generated-health-data

5 https://www.reuters.com/article/us-health-hipaa-charts/patient-cant-always-access-complete-medical-records-doctors-say-idUSKCN0YE2PY

Work

One important aspect to consider in patients facing these diseases is the loss of productivity. In 2018, almost 45% of cancer patients declared they couldn't maintain the same income because of the disease, and one of two Multiple Sclerosis patients couldn't perform the job they wanted because of the symptoms, while 27% had to change jobs.[1]
This issue not only affects patients but their caregivers, as most of them have to change their work or even leave it because of their caregiving role.[2]

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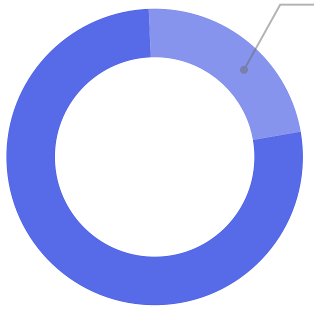
1 https://www.aism.it/stato_di_handicap

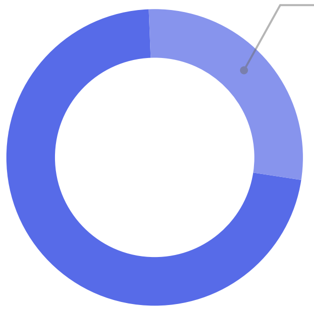
2 https://www.aism.it/invalidit%C3%A0_civile

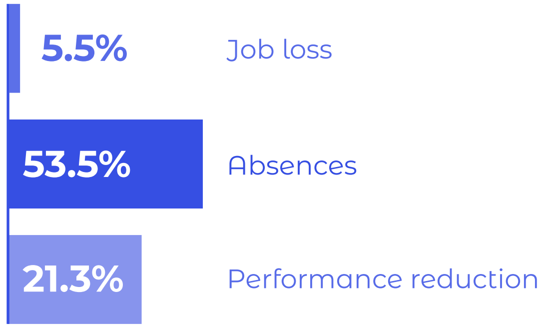
Changes in the work life

78%
of patients
experience a
sudden change in
their work life



72.4%
of caregivers
experience a
sudden change in
their work life





Source: corriere.it

Social inclusion

When it comes to affecting a person's quality of life, it appears social inclusion is a very relevant factor, as being part of a community gives people purpose, makes them feel needed, and with a scope in life.

When it comes to affecting a person's quality of life, it appears social inclusion is a very relevant factor, as being part of a community gives people purpose, makes them feel needed, and with a scope in life.

Social inclusion is defined as “the ability to take part in the activities of a society and to feel a part of that society.”[1] Social inclusion plays an important role in a person's life not only because social relationships are fundamental to a person's emotional fulfillment, behavioral adjustment, and cognitive function[2], but because communities tend to reinforce a person's will to maintain healthy habits, leading to an overall better level of health. If a person is surrounded by people conducting a healthy lifestyle, they are more likely to follow their group's example to fit in. Moreover, the homogeneity of the shared value amongst the group reinforces this mechanism[3].

Social integration is critical to development across the lifespan, but it is likely to be particularly important in later life. Recent research has shown that emotional closeness in relationships increases with age. However, at the same time, the number of social relationships decreases.[4]

Social perception is key to social inclusion. However, studies have found that patients suffering from the physical effects of diseases like Cancer are likely to be stigmatized and estranged from their communities, increasing their sense of loneliness and triggering isolation.[5]

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[1] https://www.macmillandictionary.com/dictionary/british/social-inclusion

[2] https://www.researchgate.net/publication/236081883_Social_isolation_loneliness_and_all-cause_mortality_in_older_men_and_women

[3] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4822264/

[4] https://www.researchgate.net/publication/236081883_Social_isolation_loneliness_and_all-cause_mortality_in_older_men_and_women

[5] https://www.ncbi.nlm.nih.gov/pubmed/22628419

Relationships

According to research and clinical practice, family involvement during the care of patients with long-term illnesses facilitates the patient's acceptance of the disease and improves compliance with the therapeutic program.[1]

However, caring for the patient creates a lot of work burden on the caregiver, and this burden depends on the type of assistance the patient needs. For example, caring for a patient with dementia is more challenging than caring for a patient with physical disabilities alone.[2]

Moreover, when caregivers feel they can manage the practical difficulties of caring for patients with chronic illnesses, they can consider positive aspects of caregiving despite the burden. Whereas when tasks become too demanding, their perceptions of positive aspects may decline, while the psychological consequences of caregiving may increase here caregiver burden refers to the physical, financial, and psychosocial hardships of caring for a loved one.[3]

People caught in poor relationships tend to develop and maintain negative perceptions of self, find their life to be less satisfying, and often lack the motivation to change their behaviors.[4]

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[1] https://www.sciencedirect.com/science/article/pii/S1090513816300721

[2] https://www.researchgate.net/publication/225293255_Caregivers_Burden_of_Older_Adults_with_Chronic_Illnesses_in_the_Community_A_Cross-Sectional_Study

[3] https://www.researchgate.net/publication/225293255_Caregivers_Burden_of_Older_Adults_with_Chronic_Illnesses_in_the_Community_A_Cross-Sectional_Study

[4] https://www.researchgate.net/publication/324838778_Preventing_Social_Isolation_in_Older_People

Social isolation

We have shared that when a patient is diagnosed with a chronic illness, the disease and its treatments change their daily life. However, it has been observed that chronic illness patients are also more likely to isolate themselves.[1]

Loneliness often is regarded as the psychological embodiment of social isolation, reflecting a person's experienced dissatisfaction with the frequency and closeness of their social contacts or the discrepancy between the relationships they have and the relationships they would like to have.[2]

When a person's intimate and social needs are not adequately met, a complex set of feelings termed loneliness occurs. Feelings of loneliness are not synonymous with being alone but instead involve feelings of isolation, feelings of disconnectedness, and feelings of not belonging.[3]

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[1] https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/HomeCare_Guidelines_FINAL.pdf

[2] https://www.ncbi.nlm.nih.gov/pubmed/18504506

[3] https://www.researchgate.net/publication/324838778_Preventing_Social_Isolation_in_Older_People

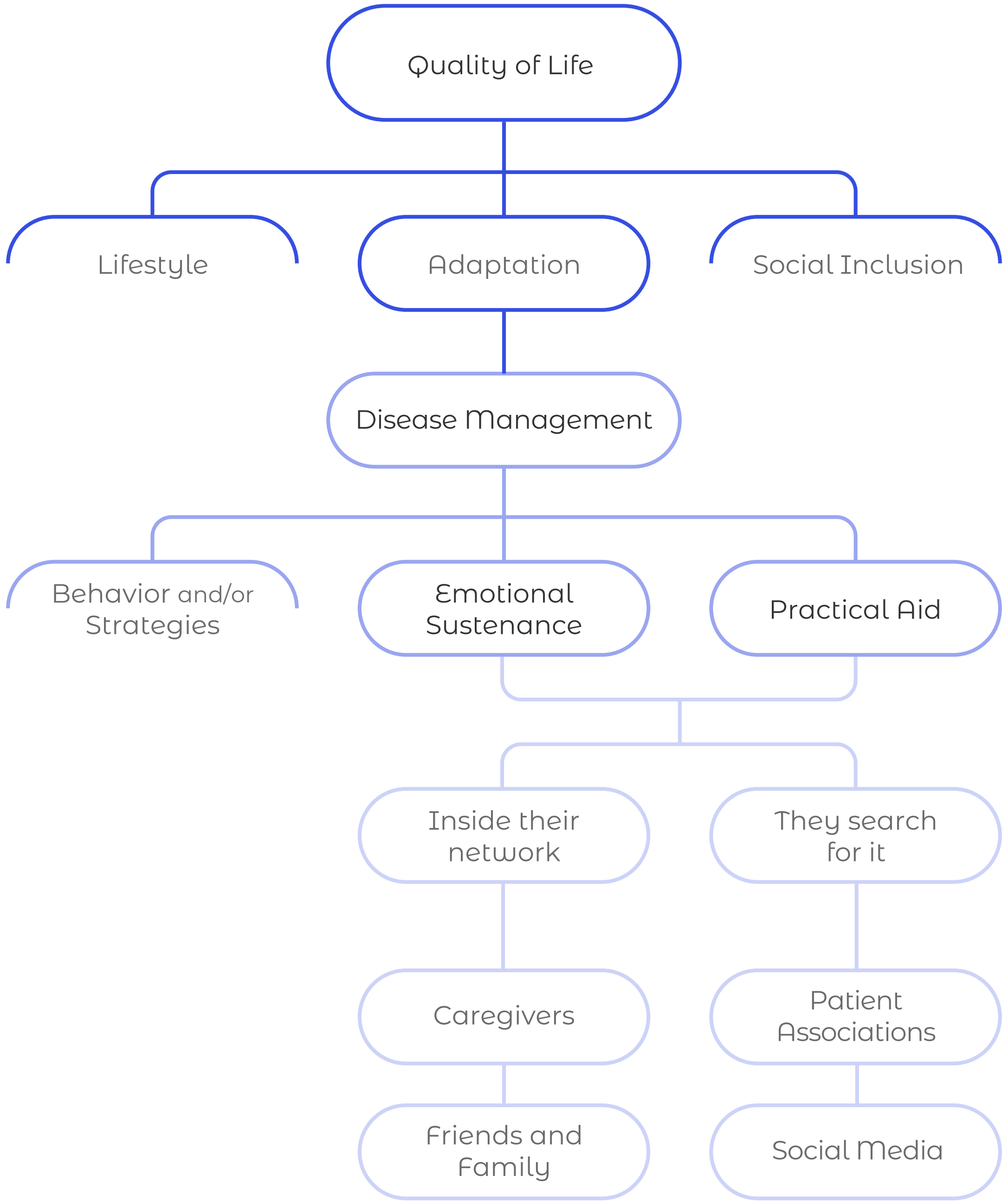
Outcomes

Through desk research, we were able to understand which aspects have the most powerful impact on the everyday life of Cancer and Multiple Sclerosis patients. Furthermore, we were also able to map how these aspects interact with each other to affect the patients' quality of life.

We identified that the patients' quality of life is influenced by several factors that can be clustered into three categories: lifestyle, social inclusion, and the person's ability to adapt to life with a chronic illness.

We have found adaptation to be directly related to how patients manage their disease. However, disease management varies greatly, as it is the result of the patient's behavior and strategies, emotional sustenance, and practical aid.

Patient behavior is affected by the patient's ability to self manage, self-perception, and sense of control. Whist the patients obtain emotional sustenance and practical aid with the help of caregivers, family, friends, patient associations, and other social-related strategies like joining Facebook groups.



The final diagram resulting from our desk research

Section 2.3

Needfinding and benchmarking

2.3

Needfinding

Our goal in this phase was to talk with patients, their families, caregivers, and medical staff; empathize with them and, through the story of their journeys, catch their hidden needs.

After having identified from the desk research the main possible areas which could, in different ways, affect the patient's quality of life in Italy, we went more in-depth in the daily lives of our patients, as we needed to understand the hopes, desires, aspirations, and challenges of the patients we would be creating a solution for. Hence, our goal in this phase was to talk with patients, their families, caregivers, and medical staff; empathize with them and, through the story of their journeys, catch their hidden needs.

Interviews Methodology

Our research was conducted mainly through face-to-face and online interviews. The actors involved in this process were patients, both of Multiple Sclerosis and cancer, and all the people who cross their path during the disease: physicians, caregivers, relatives, friends, partners, support groups, and patient associations. Each of them plays a crucial role in different phases of the patient's journey, from diagnosis to social support, and this is the reason why we decided to include them in our research. They could give us a broad overview of the needs and problems of our main target and, as a consequence, more detailed hints.

Our teammate Eugenia reading the biographical book written by one the patients that we interviewed.

Facebook Support groups became a source for our local and remote interviews, almost 100% of those outside our networks. People we interviewed from these groups were mostly young adults (under 40).

We interviewed 40 people:16 patients (8 for MS and 8 for Cancer), 11 caregivers, 9 family members, 1 friend, 1 neurologist, and 2 oncologists. The interviews lasted around an hour, and the structure and questions were created to address the person who was interviewed.

Since our challenge touches a sensitive topic, one of our main goals was to make interviewees feel comfortable to talk to us, so we gave them space to answer our questions.

We listened carefully to their stories, and we even got the opportunity to read about the deepest thoughts and worries of some patients, since they shared their writings with us.

Some insights we got from interviews matched our information from desk research, others, opened new areas of opportunity.

> “
> Facebook Support groups became a source for our local and remote interviews, almost 100% of those outside our networks. People we interviewed from these groups were mostly young adults (under 40).

40	structured interviews performed
16	patients interviewed (8 MS, 8 cancer)
1h	was the average interview time
15	other patients contacted on FB

Empathy maps

An Empathy Map consists of four quadrants that reflect four key traits which the interviewees demonstrated during the research stage and a central part showing their pains, gains and feelings.

An Empathy Map consists of four quadrants that reflect what a person thinks, sees, says, and does, and a central part showing their pains, gains, and feelings. We chose empathy maps as a tool to summarize our learnings from the interviews performed during the field research and to 'put ourselves in the shoes' of the interviewees. We customized the maps for each category of people interviewed - cancer patients, MS patients, caregivers, friends, and family - so that they could represent an overview of their experiences and feelings.

We developed these maps to cluster and analyze the insights gained from interviews, as to get a deeper understanding of our interviewees. It was fairly easy to determine what the interviewees said and did. However, determining what they thought and felt was based on careful observations as to how they behaved and responded to specifically targeted questions we made.

The first quadrant on top is about WHO our interviewee is and what they need to change in their lives, the decisions they need to make, the tasks they need to do differently, and what is their overall situation.

The quadrant on the right is about what the interviewee SAYS and SEES around them. We wanted to understand the things they see others doing in their hospital, house, and work environments, and the things they say about their diagnosis, coping with the illness, their loved ones, medical staff, and about support.

The quadrant on the bottom is about the interviewee's actions and what they DO. We wanted to know about their behaviors, their decisions, coping strategies, and routines. It is particularly in this quadrant, along with the top one, where we can notice the differences between how different types of people behaved and reacted to the illness according to their character and personal inclinations.

The quadrant on the left is dedicated to the influence of external factors, what the interviewees HEAR. Which comments did they hear from family and friends? And from others? What did they hear from the media?

Finally, the central section of the map addresses the interviewees' PAINS and GAINS. In this fundamental section, we have their fears, frustrations, and anxieties, along with their wants, needs, hopes, and dreams.

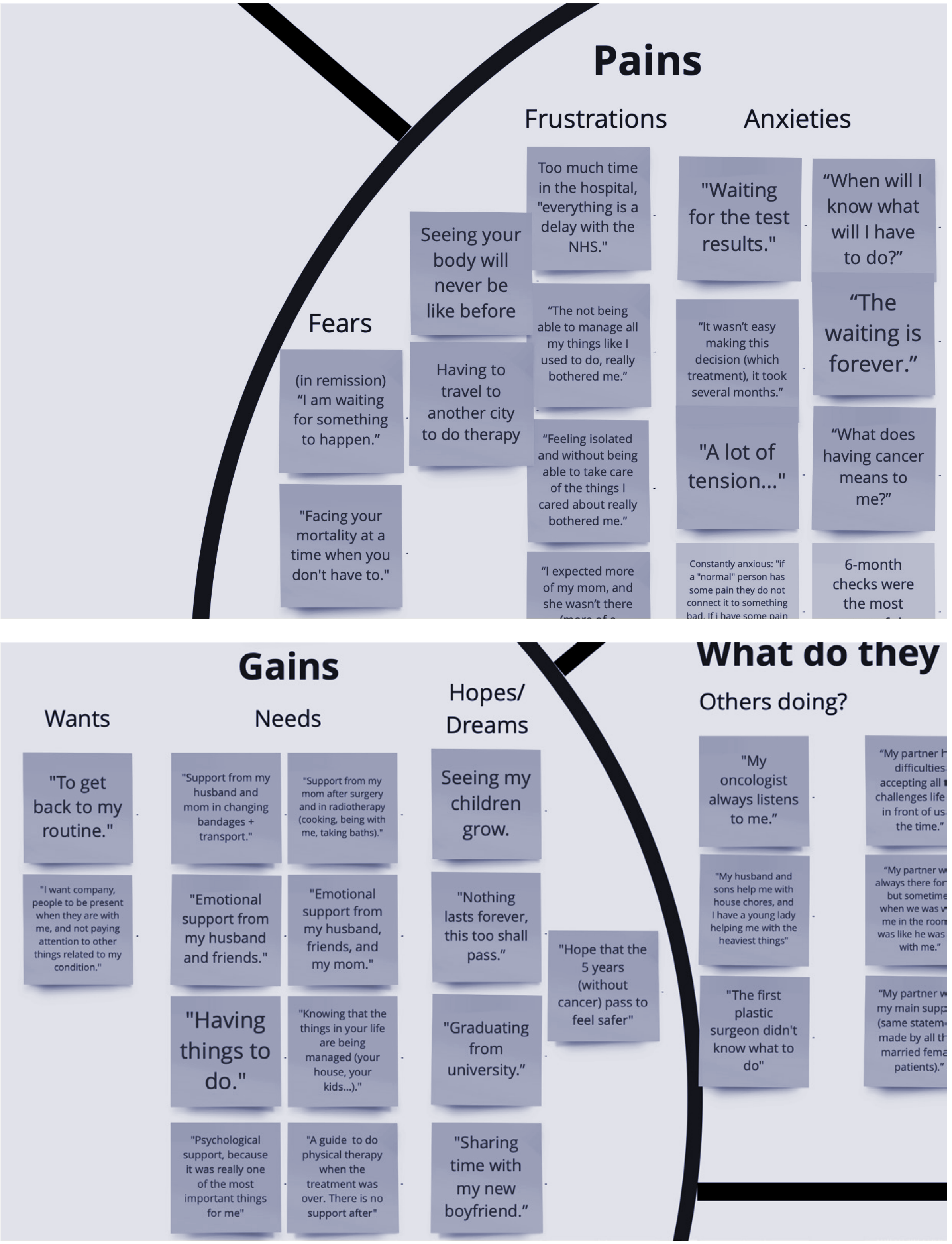
The creation of empathy maps required the effort of the whole team. We created the empathy maps template on a digital board used for remote collaboration, where each team member could place the information gained through his or her interviews, allowing the whole team to get an overview of the results.

These maps were a way for us to dissect the single interviews into small insights, making sense of them in a way that allowed us to, at the same time, look at the bigger picture. Empathy Maps helped us validate findings from previous research while bringing up new insights from interviews. With this tool, we identified patterns that would later help us create our persona profiles.

The template used for our empathy maps.

> These maps were a way for us to dissect the single interviews into small insights, making sense of them in a way that allowed us to, at the same time, look at the bigger picture.

Patients with different life backgrounds and different characters showed a different attitude and behavior towards their disease, and the same was noticed for caregivers. For this reason, this exercise prepared the background for the construction of the personas that we later created.



A sneak peak of the thoughts and feelings reported on the cancer patients' empathy map. The full empathy maps can be found clicking on THIS LINK.

Personas

Fictional characters, real stories.

Personas are fictional profiles, often developed as a way of representing a particular group based on their shared interests. They can provide a range of different perspectives, allowing the design team to segment their target into different, smaller groups. Each persona represents a "character" with which the client and the design team can engage, providing a deeper understanding of the users' needs and behaviors.

Even though the personas themselves are fictional, the motivations and reactions they exhibit are real, being a collation of feedback gained during the research phase of the project and the reflection of what real people said and felt.

A common way of developing personas is to cluster research insights into common-interest groupings, which can then be developed into a workable character. We created our personas based on the information collected during desk research and from the interview insights we organized in the empathy maps

Creating our personas.

We chose to represent personas for both Cancer and Multiple Sclerosis patients, as well as for caregivers. This, because even though our research targets are patients, caregivers have a fundamental impact on their lives. Moreover, it is important to understand also caregivers' needs and behaviors, gaining useful insights for a future solution that might involve also their participation in the process.

Some characteristics of our personas, such as gender and age, reflect actual demographic data. For example, cancer is prevalent in men rather than women, so we have two male cancer personas and one female, and two female Multiple Sclerosis personas as this disease is more common among women.

We also took into account the different ecosystems that can revolve around a patient, understanding their family context and the relationships that they have to manage.

On the other hand, personas reflect also the different personalities and attitudes that the interviewees had.

For this reason, there is a mentally stronger patient, whose main concern comes mainly from the physical disability that the illness has comported, while there are other patients mainly in need of emotional support.

The complete persona profiles are visible at THIS LINK

Main insights

1.

Since we started with an extremely broad target, that is all cancer patients (with solid tumors) and MS patients, aged 20 years old onwards, the creation of personas allowed us to understand which problems occur in different age groups and which are their different needs, besides the differences based on personality.

2.

Since we have the task of finding a solution that can be applied to both types of patients, personas allowed us to map their needs across their journeys and compare which were repeating among different personas and which were most recurrent. This helped us focus on the most relevant needs.

PERSONA PROFILE | CANCER PATIENT

The routine seeker

Carla

40, university professor
Cancer patient in remission

🏠 lives in Milan with her husband and their child

♥ her husband (main caregiver) and mother take care of her

Frustrations

- Not being able to manage all the aspects of my life like I used to.
- Coping with my husband's emotional difficulties in dealing with my disease.
- Feeling constantly under a microscope, and waiting for the cancer to reappear.
- Not being able to take care of my daughter like I used to. Often my husband takes care of all of us.

Needs

- Performing my daily routine without my physical impairment stopping me.
- When I was ill, I needed to know my house and children were taken care of.
- When I was ill, I wanted company; for my loved ones to be present when they were with me, and not paying attention to other things related to my condition.

NEEDS THROUGHOUT THE JOURNEY

Diagnosis

- Find reliable information on my type of cancer and a specialized hospital
- **Find a way to mange the relationship with my partner**
- Deal with the fact that I might not make it

Surgery

- A direct contact with patients to prepare logistically and mentally to my surgery
- Knowing that my child is going to be taken care of while I can't be there

Treatment

- **Manage my daily routine to deal with fatigue and still have energy for my child**
- Company from my loved ones

Recovery

- **Manage my daily routine to do physical therapy exercises**
- **Manage my daily routine to keep having energy throughout the day**

PERSONA PROFILE | CANCER PATIENT

The sad loner

Mario

68, bakery owner on hiatus
Cancer patient in stage 4

🏠 lives by himself in Reggio Emilia

♥ his two adult daughters take care for him

Frustrations

- Not feeling like myself when looking into the mirror.
- Feeling like I cannot go on with my life as usual, I have to be healthy to do things.
- Turning down the things and people who used to bring me joy.
- My daughters and friends asking me out. I'm tired, I don't want to go.

Needs

- Trusting my medical team because I'm not keen on informing myself.
- Having my daughters manage my appointments for me.
- Having others manage my daily activities, since I don't feel like doing them myself.
- Getting out of my depression, but I don't want help from others.

NEEDS THROUGHOUT THE JOURNEY

Diagnosis

- Recognize the symptoms early
- **Manage my relationship with my daughter caregiver**
- **Get support for my depressive tendencies**
- Deal with the fact that I might not make it

Surgery

- **Managing my relationship with the paid caregiver hired by my daughter**
- Knowing how to look for psychological support

Treatment

- **Help in performing daily tasks that I am not strong enough to do because of fatigue**
- Strong psychological support because I cannot cope with the disease

Recovery

- **Having a psychological support after the treatments didn't have the expected results**

PERSONA PROFILE | CANCER PATIENT

The anxious researcher

Paolo

65, retired
Cancer stage 2

lives in a small town near Rome with his wife

his wife takes care of him at home, his son is his caregiver

Frustrations

- Taking medications and dieting is often hard to follow.
- Travelling long distances to get to the hospital, and depending on my wife to do this.
- Feeling anxious about the future, searching for answers, and then not knowing which answers I should trust.

Needs

- Turning my doctor's indications into habits.
- My appointments not being a hassle or burden to my son.
- A trustworthy source of information to calm my recurring anxiety.
- Knowing that I am going to recover and win back my retiree life.

NEEDS THROUGHOUT THE JOURNEY

Diagnosis

- Find reliable information on my type of cancer, **reliable and detailed, instead of random articles found online**
- Help from my son for going to visits

Surgery

- A direct contact with patients to know more information about my surgery, to get advice on practical things from more experienced patients

Treatment

- **Manage my daily routine to deal with fatigue and still have energy for the things I love**

Recovery

- **Need a way to follow my medicines routine without forgetting to take them**
- **Need help in following a new routine**
- Manage the fear of having cancer again

PERSONA PROFILE | MS PATIENT

The life planner

Alice

25, computer engineering student
Living with RRMS

lives in Bologna with her parents

engaged to Luca, but now her mother is her caregiver

Frustrations

- I struggle to envision my future.
- Which are the best treatment options?
- Which part of my body will fail tomorrow?
- My symptoms and how they affect my daily life and social relationships.
- I don't have the energy to do all the things I would like to do in a single day.

Needs

- I want to adapt my new house to my future needs.
- Having easy-to-access and more detailed info about planning for my future needs.
- Reaching my life goals, no matter how the disease changes me.
- For others to understand my physical symptoms and effects, I can't go out as much as my friends do.

NEEDS THROUGHOUT THE JOURNEY

Discovery

- Life tailored information, not medical, such as about home planning, family, and **how to deal with fatigue**

Diagnosis

- **Learn how to change my habits/ behaviors to not make the symptoms worse**
- Need to find all the specialized centers for MS patients

Treatment

- **To know the "tricks" and "work-arounds" of more experi-enced people**

Follow up

- **I need to experience my body at its fullest now that I can**

Remission

- **Being aware and mentally prepared for when a relapse will occur**
- Having an emergency plan (life insurance, home adaptations...)

PERSONA PROFILE | MS PATIENT

The overwhelmed patient

Giulia

45, public administration employee
Living with RRMS

🏠 lives in Milan with her family

♥ her husband and mother care of her

Frustrations

- Feeling too tired to play with Matteo.
- Needing more rest after work hours, than I was used to.
- Having the other moms understand that even though I am less present, I am a good mother like them.
- Feeling confident with my body.
- Not feeling that I am in control of my life anymore.

Needs

- Wanting my coworkers to understand my symptoms and how they affect my performance.
- Finding a way to better manage my routine to support my family.
- Managing how my fatigue affects me.
- Knowing that I'm always going to be taken care of without being a burden to my family.

NEEDS THROUGHOUT THE JOURNEY

Diagnosis

- Life tailored information, not medical, such as about home planning, family, and **how to deal with fatigue**

Relapse

REPEATING IN CYCLE

- **I need help from others to perform the activities that I used to do on my own**
- I need others to understand what I am going through, especially in my work environment
- **I need emotional support**

Remission

- **I need to learn to cope with my cognitive and physical impairments**
- **I need to learn how to deal with fatigue and life tailored, experience based advice**

PERSONA PROFILE | CAREGIVER

The worried mother

Marcella

55, consultant
Mother of Alice

🏠 lives in Bologna with her family

♥ caregiver of her daughter

Frustrations

- I worry for my daughter's future
- Information on the internet is in english and is also not well organized.
- I had it hard to find a specialized center near our home.
- I am worried that Alice gets sick before I manage to buy her a new house, because now we live in a house on two floors with stairs.
- I find it hard to balance work with the time I spend with Alice and my wife.
- Sometimes I feel powerless, my plans for the future have also changed.

Needs

- I need more free time for my hobbies.
- I need to know that Alice will be fine.
- I need information about the best medical staff and treatments in Italy.
- I do not find reliable information about the diseases and the drugs without wasting time over internet.
- I need to understand how my husband is dealing with it, because we had a different way of reacting to this change in our life.

PERSONA PROFILE | CAREGIVER

The multitasking daughter

Lucia

35, bank employee
Daughter of Mario

🏠 lives in Modena with her family

♥ caregiver of her father, but she has to take care of her child too

Frustrations

- I am not happy with my life, I don't have enough time for myself
- I don't know how to deal with my father's depressive behaviour, I don't know what to do or to tell him to truly make him feel better.
- I have to make important decisions on my father's behalf because I am the one taking his appointments and dealing with his cancer, since he doesn't want to know anything about it, and I feel the responsibility.

Needs

- I want to take care of my father like my daughter.
- I want to manage my free time
- I need a paid caregiver for my father so that I can also manage my family and my house
- I would like to have a way to take my father to the medical appointments without having to travel a lot.

PERSONA PROFILE | CAREGIVER

The supporting partner

Roberto

54, works in a design studio
Husband of Carla

🏠 lives in Milano with his wife and their child

♥ caregiver of her wife, he has to take care of their daughter too

Frustrations

- Don't know how to deal with my wife
- Relationship is different than before
- I do not know what to do in certain situations
- I sometimes feel tired too, but Carla and our daughter need me.
- I always need to plan my day according to my wife's needs.

Needs

- I need to manage work hours to have time for my family and for myself
- I need to replace Carla with our daughter when she can't take care of her
- I need to balance how to manage Carla's and our daughter's needs at the same time

Benchmarking

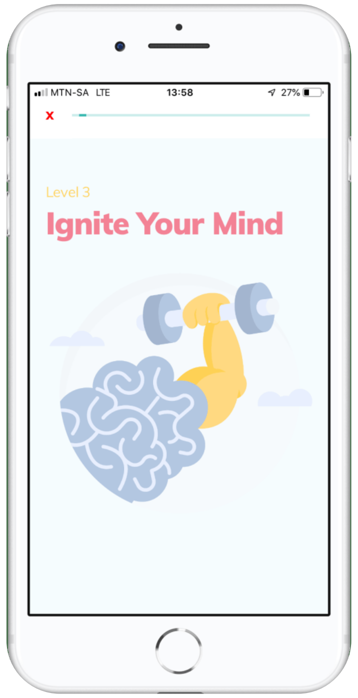
Benchmarking is a vital part of the design process that can, and should, be performed during all stages.

Benchmarking is a vital part of the design process that can, and should, be performed during all stages. Benchmarking helps teams understand key issues that revolve around their challenges. Through benchmarking, we discovered the existing solutions that are working in the healthcare field and positively impacting Cancer and Multiple Sclerosis patients worldwide.

Our benchmarking research was made online, as we took inspiration from articles, newspapers, websites, and social networks. And it allowed us to understand which aspects of patients' quality of life are already being addressed in the market today.

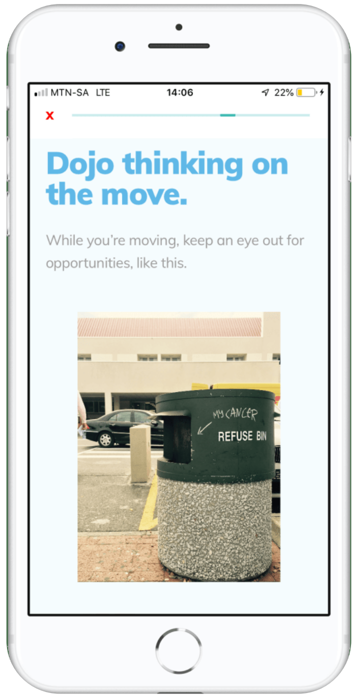
BENCHMARKING

Cancer Dojo



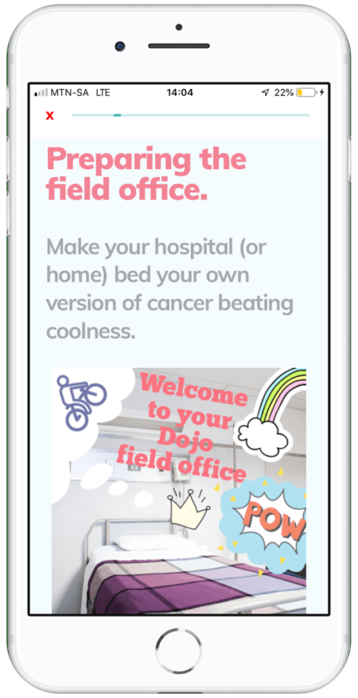
Level 3

Ignite Your Mind



Dojo thinking on the move.

While you're moving, keep an eye out for opportunities, like this.



Preparing the field office.

Make your hospital (or home) bed your own version of cancer beating coolness.

What

A digital solution which provides a simple, informed, user- friendly journey that teaches patients how to actively engage with their chosen treatments, stay motivated, generate their own meditations, learn how to visualize, be more mindful, eat better, live better, laugh more and ultimately become happier, healthier and Harder To Kill.

Why

Studies show that playing an active role in your own healing has beneficial effects on your well-being, resilience and positive cancer outcome.

Created for

Cancer patients

When

Mid-2010s

Where

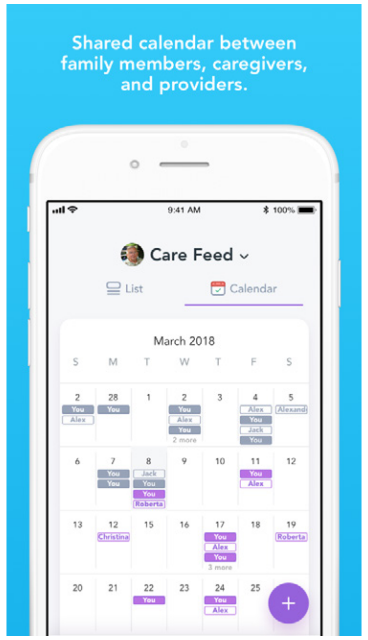
South Africa

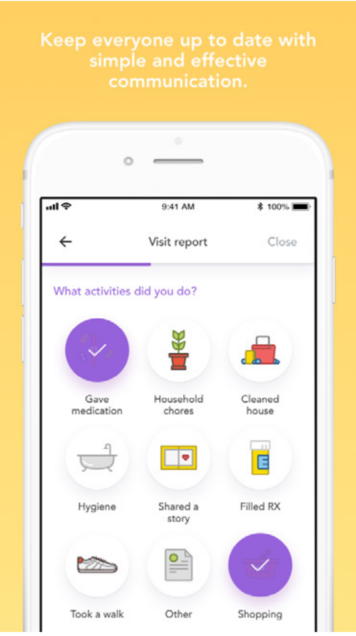
Source

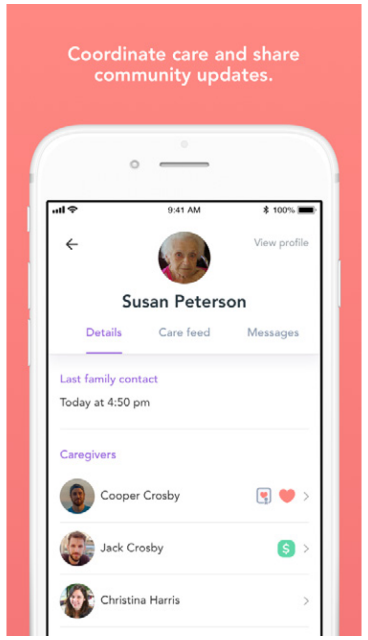
https://cancerdojo.com/

BENCHMARKING

Carely







What

A free app that brings families together around the care of a loved one. It enables families to organize and track a loved one's activities and appointments by planning and sharing visits, send direct messages to members of your care circle and your loved one's care teams, and explore local resources to support the caregiving journey.

Created for

Patient, caregivers and family members

When

2013

Where

United States

Why

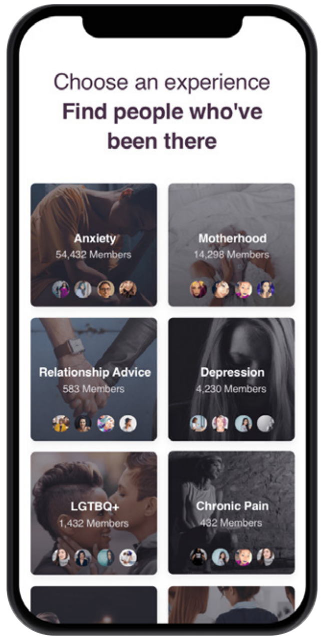
Families need to feel supported throughout their caregiving journey. The aim of the app is simplifying the care communication for families and connecting them to the information they need to make informed care decisions with their loved ones.

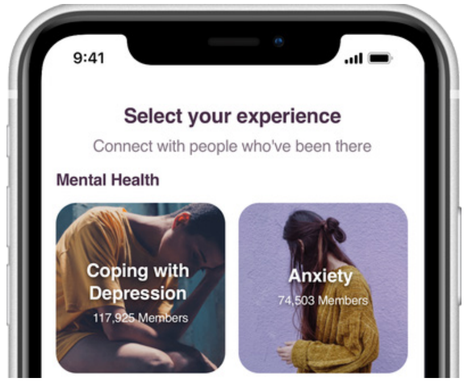
Source

https://www.care.ly/for-families.html

BENCHMARKING

Wisdo





What

A platform that allows people to take on life's greatest challenges and opportunities by tapping into the wisdom of those who've already experienced them. It allows you to connect with people who've walked your path, get advice and share your own. Using private messaging, it provides peer support without the exposure involved in posting on traditional social media sites like Facebook.

Created for

people having a hard time overcoming obstacles in their lives

When

mid-2016

Where

Israel

Why

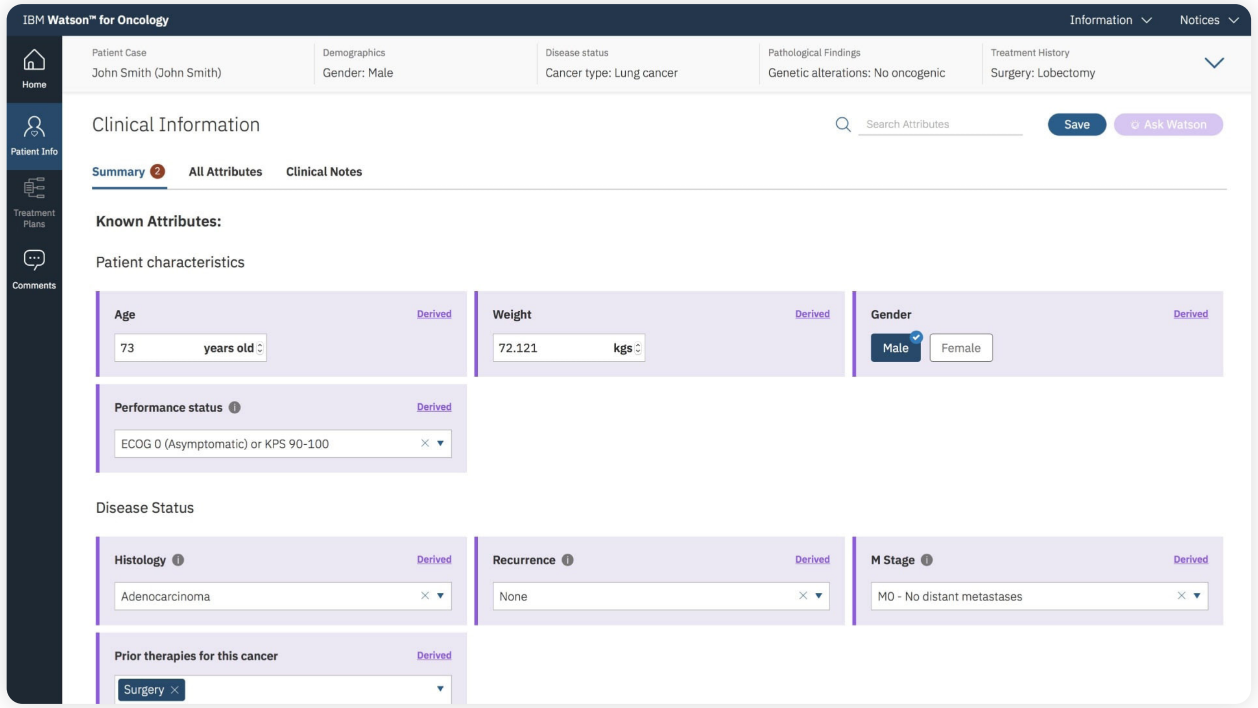
Knowledge gained from the experience of others who have been through the same difficulties and the same path, is powerful and useful to face everyday issues. Sharing stories and helpful advice, or just talking with someone who understands, helps people get through the hard times.

Source

https://wisdo.com/

BENCHMARKING

IBM Watson for Oncology



Patient Case: John Smith (John Smith)
Demographics: Gender: Male
Disease status: Cancer type: Lung cancer
Pathological Findings: Genetic alterations: No oncogenic
Treatment History: Surgery: Lobectomy

Known Attributes:

Patient characteristics

Age: 73 years old
Weight: 72.121 kgs
Gender: Male
Performance status: ECOG 0 (Asymptomatic) or KPS 90-100

Disease Status

Histology: Adenocarcinoma
Recurrence: None
M Stage: M0 - No distant metastases
Prior therapies for this cancer: Surgery

What

A platform that helps physicians quickly identify key information in a patient's medical record, surface relevant evidence and explore treatment options.
Watson for Oncology is a solution that is fueled by information from relevant guidelines, best practices, and medical journals and textbooks. The solution assesses information from a patient's medical record and displays potential treatment options ranked by level of confidence based on training with supporting evidence. The oncologist can then apply their own expertise to identify the most appropriate treatment options for their patients.

Why

Synthesizing the latest research and best available information to improve patient care poses a great challenge for oncologists.

Created for

oncologists

When

Mid-2010s

Where

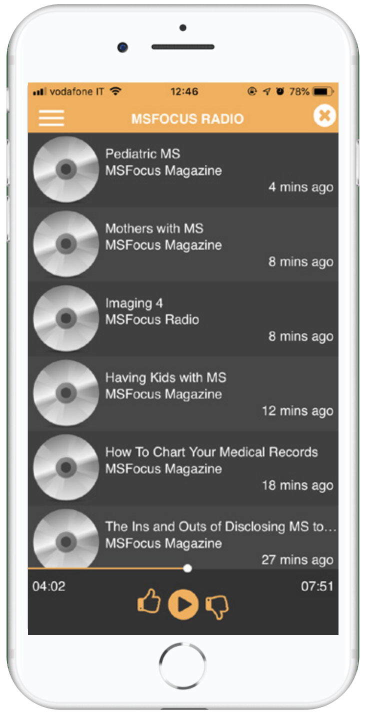
United States

Source

https://www.ibm.com/products/clinical-decision-support-oncology

BENCHMARKING

MS Focus Radio



Pediatric MS
MSFocus Magazine
4 mins ago

Mothers with MS
MSFocus Magazine
8 mins ago

Imaging 4
MSFocus Radio
8 mins ago

Having Kids with MS
MSFocus Magazine
12 mins ago

How To Chart Your Medical Records
MSFocus Magazine
18 mins ago

The Ins and Outs of Disclosing MS to…
MSFocus Magazine
27 mins ago

04:02 07:51

What

A 24/7 online radio station that broadcasts content specifically designed for Multiple Sclerosis patients. Focusing on assisting patients with visual or cognitive impairments, their audio programming delivers current information about the disease to those who may want something different than the digital or traditional outlets.

Why

To empower those affected by Multiple Sclerosis with reliable information necessary to make the most complete and educated decisions concerning their health.

Created for

Multiple Sclerosis patients

When

2017

Where

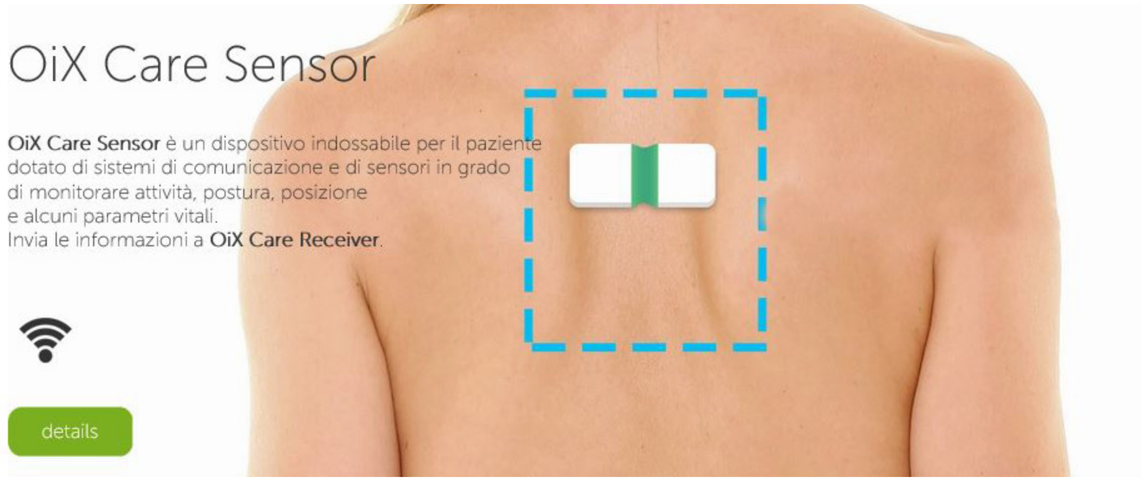
United States

Source

https://www.healthline.com/health/multiple-sclerosis/top-iphone-android-apps

BENCHMARKING

Oxy Care



OiX Care Sensor è un dispositivo indossabile per il paziente dotato di sistemi di comunicazione e di sensori in grado di monitorare attività, postura, posizione e alcuni parametri vitali.
Invia le informazioni a **OiX Care Receiver**.

What

an integrated ecosystem that allows caregivers to have constant monitoring of people affected by dementia. A wearable device with sensors (OiX Sensor) collects information about the patient's condition and behavior in their environment (posture, movements, temperature, humidity) and submits it to a Receiver.

Why

The control and management of elderly people with dementia brings about many issues. These people usually are in good physical condition but in need of constant monitoring (24/7) because of their mental condition. They can get lost or wander around, have uncontrolled behavior, fall and forget about it, misuse household appliances or other objects.

Created for

caregivers of dementia patients

When

2014

Where

Italy

Source

https://www.avanix.it/solution.asp/l_en/p_4/our-solutions.html

BENCHMARKING

The Savvy Caregiver

What

It is a 12-hr course to introduce family caregivers to the caregiving role, providing them with the knowledge, skills, and attitudes needed to carry out that role, and alerting them to self-care issues. The program increases the skill, knowledge, and confidence of future caregivers and prepares them to better respond to the challenges they can potentially face.

Why

The caregiver role is hard to adopt, caregiver's attitudes and behaviors highly affect patients emotionally and vice versa.

Created for

caregivers

When

Mid-2010s

Where

United States

Source

https://www.caregiver.org/savvy-caregiver-program

My MS Diary

What

The app tracks the injection sites automatically and manages the stock of injections. It also gives alerts and reminders related to drug buying, storage, use, and application. The application also contains a handy notepad to help patients remember things they'd like to discuss with their doctor or symptoms they may want to keep track of.

Why

People who are diagnosed with a chronic illness have to suddenly change and adapt to a new life. Technology has come a long way with tools that make managing MS — and life in general — a bit easier.

Created for

Multiple sclerosis patients

When

2015

Where

United States

Source

https://www.healthline.com/health/multiple-sclerosis/top-iphone-android-apps

Section 3

Narrowing our focus

3

Narrowing our focus

Most of the problem statements were linked to each other by a common theme.

After learning about current solutions for our patients on the market, we focused on their needs through personas. We found out that their needs are not homogenous among their journeys, but that they are changing with each step and new challenge the disease brings to their lives.

To better understand our personas' needs, we created Problem Statements. These are sentences that describe the main need of the persona, followed by the main issue that prevents them from fulfilling it. By performing this exercise, we realized the main issues we needed to tackle when creating solutions.

After listing all our problem statements, we realized that most of them were linked to each other by a theme, so we grouped them to form these main trends:

- Support through information
- Self-management
- Mental preparation
- Relationships and communication

Now, we will briefly describe each theme and present the main persona needs and pain points in the form of problem statements.

1 Support through information

This theme addresses the patients' need of accessing non-medical, but reliable, information sources, and other types of information that are difficult to access through the internet or other sources like Patient Associations. Recurrent themes we found related to information where the avoidance or extreme usage of social media networks and internet sites.

Journey stage	Problem statement
From diagnosis onwards	**Paolo wants** to find not strictly medical-related information **because** he feels anxious, **however**, since he doesn't know how to research, his searches are random and finally, gets an information overload that amplifies his anxiety.
From diagnosis onwards	**Carla wants** to find not strictly medical-related information **because** she wants to know which are the next steps to follow and feel prepared, **however**, she doesn't want to join patient groups because her personal network is already strong.
During diagnosis and relapses	**Alice wants** to find not strictly medical-related information **because** she needs to adapt her environment and plan for the future, **however**, this information seems to not be available anywhere she looks.
During treatment	**Alice wants** to know strategies on how to cope with her treatment's side effects **because** she wants to feel in control of her body, **however**, this information seems to not be available anywhere she looks.
During remission	**Carla wants** guidance to perform her physical therapy exercises, **because** she needs to recover as much mobility as possible, **however**, she feels left alone in comparison to the constant medical follow-up she had during treatment.

2 Self-management

This theme addresses the patients' need for learning and integrating new habits and strategies related to lifestyle changes and medical instruction. Moreover, one recurrent struggle of patients was activity management concerning their energy, as their energy levels decrease considerably because of their illness and the treatments.

Journey stage	Problem statement
From diagnosis onwards	**Alice wants** to have energy **because** she needs to perform all her daily activities, **however**, she is struggling to keep up with the tasks she used to perform every day.
From diagnosis onwards	**Paolo wants** to follow his doctor's indications **because** he needs his body to be strong and working properly, **however**, he is struggling to stick to his new routine as he is not held accountable daily.
During treatment	**Carla wants** to have energy, **because** she needs to perform all her daily activities, **however**, she is struggling to keep up with the tasks she used to perform every day.

3 Mental preparation

This theme addresses the patients' need for being mentally prepared to tackle the changes that the disease has brought or will bring in the future. These changes are related to self-perception, how the disease changes how patients look and what they do, affecting the way they view themselves.

Journey stage	Problem statement
During and after treatment	**Mario wants** to feel like himself before the illness **because** he wants to perform his daily activities and keep on with his social life, **however**, he does not feel comfortable outside of his room.
From diagnosis onwards	**Giulia wants** to be mentally prepared to the fact that a relapse will happen, **because** she needs to still feel in control of her life, **however**, she doesn't have a strategy or knows in which way the relapse will affect her.
After relapse and onwards	**Giulia wants** to keep up at work, **because** she doesn't want to lose her job, **however**, she has to cope with her cognitive impediments.
After relapse and onwards	**Giulia wants** to continue to fulfill her tasks and responsibilities, **because** it gives her purpose, **however**, she is having trouble completing them and is now needing help from others to do so.

4 Relationships and communication

This theme addresses the patients' need for social inclusion, belonging, and understanding. Issues that revolve around co-workers and loved ones understanding their condition, the struggle to voice their disease-related problems to medical staff and others, and romantic relationship struggles arise here.

Journey stage	Problem statement
From diagnosis onwards	**Giulia wants** her coworkers to understand her symptoms and how they affect her performance, **because** she does her 100%, **however**, her 100% is not what it used to be and she is expected to perform as usual.
From diagnosis onwards	**Giulia wants** to share and communicate her symptoms effectively to her doctor, **because** she needs to get the best medical attention possible, **however**, she forgets about them and she is imprecise when describing them.

Choosing our two main focuses

After analyzing our themes, we decided to narrow our focus by selecting them through a set of parameters:

- Does the theme involve a potentially realistic solution?
- Does it have the potential to affect a large number of patients from both diseases?
- Does it have a true and tangible impact on the lives of patients?
- Will it be of interest to our corporate partner?

We then decided to focus on fatigue as a shared struggle and the changes in self-perception patients have. Then, we reframed our challenge by creating two How Might We questions.

How might we help patients spend their energy in an efficient way throughout their activities so they do not feel drained at the end of the day?

We chose this question because:

- For cancer patients, fatigue is one of the most common side effects of chemotherapy (oral or infusions) and radiation therapy, especially when the two are combined.
- Fatigue is one of the most common side effects of MS, affecting the patients' ability to perform daily tasks
- It is described as "if the total amount of energy that a healthy person has per day equals to 10 bricks, an MS patient would have at most 5 of these bricks per day." Even after 10h of sleep an MS patient is not able to recover the 10 bricks of energy he used to have before the disease
- When in working environments, MS patients struggle to keep up with tasks as they are expected to perform at their 100%, since the world and rhythms around them have been shaped by and for "100% energy people". This issue can be compared to that of an infrastructure barrier for people in wheelchairs, but much more invisible and less understandable by people who are not in touch with MS.
- When planning daily activities people are not used to considering they might have a limited energy resource.
- Fatigue can be either physical or mental, or both at the same time. Physical fatigue is when your muscles can't perform at their 100%, whereas mental fatigue can be described as an overwhelming tiredness or decrease in attention.

How might we help patients with evolving body limitations to find a fulfilling daily routine?

We chose this question because:

- Physical limitations are common as MS progresses and as Cancer becomes metastatic or the patient undergoes surgery.
- Performing daily tasks while struggling with a physical impairment, even if these are as simple as opening your purse to take out your metro card, poses a big challenge.
- People tend to identify themselves through the tasks they perform: their jobs as professionals or as house managers, their roles as caregivers for their loved ones, the activities they enjoy doing often.
- A common coping strategy of Cancer patients is returning to their "normal professional or house routine" after and during treatment, and physical impairments make this difficult to fulfill.
- Relying on others to perform or fulfill the tasks they were used to doing by themselves, weighs heavily on patients' self-perception and sometimes makes them feel worried or anxious.
- When a person is unable to fulfil their previous roles, and these are filled by someone else, this role change might affect the way their relationship unfolds.

Section 4

Conclusions

4

Conclusions

At the project start, our team assumed that both diseases were very different and that finding a meeting point or common struggles for patients was not attainable, especially since our partner requested us to focus on addressing the largest number of patients.

In this sense, our biggest opportunity area (the possibility of exploring such a big scope with our challenge) became our biggest constraint. This, because we spent a lot of time performing desk research to understand the elements affecting the quality of life and the types and stages of each disease.

While performing research and interviews, Multiple Sclerosis posed a bigger challenge than cancer, not only because of the rarity of the disease but because working in conjunction with Patient Associations is difficult and cumbersome. However, through Social Media, mainly Facebook Groups, we have found a way to talk to patients. Even though gaining the trust of strangers through the internet is not easy, we believe that these groups will help us during the rest of our project.

During this same stage, we realized that loved ones and caregivers play a major role in patients' lives, and we identified this discovery as an opportunity for creating innovation. Moreover, since through benchmarking, we discovered that most solutions in the market address patients or caregivers alone, but not together, and the number of solutions addressing caregivers was little and focusing on the same pain points. However, this opportunity area was dissuaded by our partner, as their focus of interest relies especially on the patients.

Finally, creating a solution addressing both Cancer and Multiple Sclerosis patients is difficult. This is why our partner requested us to develop solutions for both. Even though this is a great learning opportunity for our team, this can become a constraint when it comes to team members' capabilities and timelines.

Next steps

After the winter presentation, our corporate partner narrowed and modified our challenge, which means that before kick-starting the second stage of the project, we will again be working on the discovery and definition stages, going more in-depth in the two areas we defined. To accomplish this, we will talk again with the patients we already interviewed, with new patients, and other actors like the Associazione Italiana Malati di Melanoma (A.I.Ma.Me).

Moreover, as our corporate partner suggested, we will find a way to split into two different groups so we can address solutions to both diseases. Given the complexity of our challenge, this idea could lead our team to more innovative opportunities, as each of us will have the opportunity to focus solely on one disease.

Finally, benchmarking and prototyping activities will become more vital for us as we create ideas and generate solutions.

Personal reflections

Pratyush

It was an amazing experience to work in a team with different backgrounds, as you get ideas from different perspectives. Working for university projects does not help you to adapt to corporate environment, but sugar is a platform where you work in a university for a corporate and you learn a lot of things before entering into the corporate world. Sanofi Genzyme is an amazing company and has always supported us by giving valuable suggestions at every moment of the project.

Daniela

When we first received our brief, I was convinced that our main challenge was to work to create a viable solution for it. However, when we started working, I realized that the challenge was going to be working as a unified and effective team. Now, after three months since PoliMore was created, I feel positive we will overcome the challenges ahead.

Throughout this experience, I've had the opportunity to see my team members work together, share ideas, and grow professionally and personally. This is the reason why I joined SUGAR: real progress can only be achieved if we work together and try to develop real understanding between professionals and the people that we work for.

Chiara

Since the beginning of the project, I was extremely motivated by our challenge, since it gives us the possibility of developing a meaningful project that might help patients in overcoming their difficulties. However, the process for designing a good solution is long and complex, and it will require patience and dedication to see its results.

Starting with a very broad How Might We question, our challenge was to address all the patients of two different and complex diseases, so we needed to choose a direction to follow. In doing this, we didn't opt for an arbitrary selection of a topic to focus on, but we rather followed a process from which to get as much knowledge as we could on the whole issue, in order to build a solid foundation for the months to come. We reached people who are currently living in these conditions, trying to empathise with them and to understand their actual needs, and we finally got to have a new direction that has the potential to address the needs of many.

From now on, we will start the design phase, taking advantage of the different competences and personal attitudes that we have in the team and that we got to discover in these first months working together. I believe that this project wouldn't be possible without the collaboration of the whole team and I am pretty confident in that everyone's role will be fundamental in getting to the final result.

Ludovico

In my opinion, with the 2 HMWs we found out, we have decided to focus our attention on two really interesting and important fields: in particular in my opinion for what concerns fatigue management we can develop some innovative product to measure the fatigue at the beginning and at the end of the day so that a person could understand how much fatigue every activity of life requires and better manage the distribution of his energy during the day; this idea could be useful to everyone, not only to MS patients: I think for example a professional sportsman or a busy manager that has to manage different works during the day and he wants to do all of them at his best. For sure the most complex aspect concerns the fatigue measure in a structured and analytical way.

For what concerns the second HMW, referred to body limitations, I think we should first discover which are the most common and limiting damages of the cancer that our corporate partner asked us to focus on and then, based on this, we could think a service/product that could help patient to overcome the limitations deriving from it or that could help them to readapt their routine according to it.

Until now we couldn't do it because we explored all the field of cancers but every cancer has its own damages and it's difficult to find something in common between all of them but now that we have a specific area of focus we can identify a patient sample, understand a specific limitation and work specifically on it.

Eugenia

In these four months of activities, different feelings and thoughts have gone through my mind. At the beginning, I remember I was excited about the challenge and I could not stop thinking about the SUGAR project. Even if I knew the challenge we had was really complex and intense, I could not wait to start!

I think that talking with people, understand which are the most frequent needs, but also some hidden ones, is the best way to create and ideate something very innovative which can really improve the life of patients. Our topic is very sensitive, and for me, the most challenging part so far, but at the same time the most satisfactory, was running the interviews. We talked with people who suffers and who are facing difficult times in their lives, and for this reason the key point of our conversations with them is “empathy”. Of course touching some topics was painful, both for me, because I was not used to listen to such stories, and for them, but I learned how to deal with my emotions and to try to act more as professional as possible. For this reason I am strongly convinced that this project is going to be a great opportunity for me, and for all of my team, to improve ourselves not only as future employees, but also as humans. Also the work between us, within the group, went fine most of the time and I hope the next part of the project will be even more satisfactory than these past four months, since now we have a more specific goal and all the process is becoming clearer and clearer.

Ugo

In these 4 months of research and interviews we discovered a lot on the patients whose life we need to improve on their strengths and weaknesses. We empathize with them and now we are ready to try to do something that can really change their daily life. Sometimes it was very difficult to listen to some of the stories of the people we interviewed and there were some tears, but we also saw a lot of enthusiasm about the research that we were doing. We discovered a lot of unmet needs where we can work to create something valuable for them.

Working as a team enables us to tackle a lot of different stories, different points of view and do a lot of work that would have been impossible for a small team. Living all in Italy and meeting in person every month we are capable of working as a team of 7 and not as two teams of 4 people, working better than others. Unfortunately we don’t speak all Italian and sometimes for the interviews it was difficult, but we managed to do all the work that we needed to do. Now we can’t wait to put in practice what we learned in our studies mixed with the needs of the patients to create something that will make us proud of our work and the company happy to have invested in this project.

Mirco

The whole project offered us a really interesting opportunities and way to approach such an interesting field of innovation:

The task really involves us since it is really actual, indeed it is not so rare to have a reasonably close parent or friend with one of these diseases, especially cancer. Or, hopefully not, but ourselves could be a patient.

In addition we acquired interesting and useful knowledge that may help us to prevent errors or to have a better approach toward this kind of patients

We feel that we have the opportunity to really make a difference in the lives of these people, we feel really motivated by the challenge

Make us understand a field which otherwise we might not interact with: the world of being a patient of a chronic disease. Speaking with patients tucht our way of thinking really deeply

We have the opportunity to put in practice our most creative attitude beside the specific knowledge of our learning field.

We are learning by doing how to interact in an interdisciplinary group in order to reach a common goal, but also we’ve learnt new techniques and sharing opinion give us the possibility to open our view towards new furtner boundaries

Interacting with such a professional and organized structured like Sanofi, but also the sugar network make us enter in the mindset hierarchical cooperation

Also all the initiatives included during the course of the project like reports or public speeches needed to share our work and ideas gave us the opportunity to improve our skills for an efficient communication, by doing and receiving feedback.

Also events like the kick-off in China, make us work in a really different environment, testing and improving our capability of adaptation and integration. Not only, we also met many other motivated students like us in a really fertile and multicultural environment, that stimulate us in the exchange of ideas and future inspiration or to build new links for future developments

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