



# STRATEGIC PLAN 2023-2027

PEDIATRIC CANCER CENTER BARCELONA

**A centre by all and for all**

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# Foreword

Alongside our motto, **“A centre by all and for all”**, this strategic plan reflects our **commitment over the next five years to continue improving care, research and teaching** in the Hospital.

The Pediatric Cancer Center Barcelona (PCCB) is a one-of-a-kind, state-of-the-art facility in Spain, and a pioneer in Europe, as it is specifically designed to care for children and teenagers with cancer, as well as their families. Our goal is to offer a comprehensive, cross-disciplinary service that combines care and research in one facility.

It must be stressed that, throughout the whole co-creation and implementation process of the PCCB, we have counted on the **active participation of patients, their families, and our professional staff members** in the design of our facilities, for example. This has allowed for better, more efficient adaptation of the services and activities we offer, thus allowing us to **humanise healthcare**.

Our methods are built on a **multidisciplinary, super-specialised, highly complex and comprehensive** care model.

Not only do we provide care for patients with active disease, but also their families and surviving patients. One of the PCCB's goals is to provide **comprehensive care** that can help improve quality of life for both patients and their families.

There are currently a huge number of innovative and successful projects being carried out to help improve the quality of life of children.

Our Strategic Plan is a **roadmap** for the coming five years. In our plan, we have laid out our strategy and the steps that have to be taken, but we have also left room for flexibility so we can respond to new needs and opportunities that arise.

In short, our centre is an **innovative and forward-thinking** organisation that has a **commitment to society** to provide pediatric oncological care. Here we bring healthcare and research together; focusing on more than just active patients and following a work methodology which patients, their families, and professional healthcare providers **actively participate in**.

This Strategic Plan will allow us to solidify our place as a **national and international role model** and upkeep our **commitment to scientific excellence, humanism, hospitality, innovation, and professional medical competence**.

**Working together**, we will reach our goals.

# 0\_

Executive summary

# Executive summary

With **more than 1,200 new cases per year in under-14's, pediatric cancer** (or childhood cancer) is the **leading cause of childhood mortality** from disease in Spain—**with no known causes**—and is one of the healthcare system's greatest challenges.

The creation and implementation of comprehensive, single-specialty centers is widespread across the United States and in other European countries. In Spain, however, it is practically non-existent. Within the context of childhood cancer, it has been shown that the single-specialty model improves clinical results and is of clear benefit, as it promotes **case grouping** and grows **professional and research staff** expertise. By working together, these two entities can combine and improve on their shared knowledge.

At **SJD Barcelona Children's Hospital**, the need to tackle pediatric cancer head on is reinforced by five factors, as introduced by **the PCCB**: 1) **the large, ever-increasing number** of oncology patients being attended to (40% aggregated annual increase over the last 5 years), with more than a third of patients coming from abroad; 2) the **good results obtained**, which lead to survival rates akin to those of large international facilities and centres—although, at present, there is still a long way to go with certain types of childhood cancer—; 3) the **healthcare and research trajectory**, which has been consolidated via a translational model; 4) **the correlation with the mission of The Hospitaller Order of St. John of God**, which seeks to provide exceptional care, especially to vulnerable individuals; and finally, 5) the huge amount of support from wider society, on which we frequently rely at the Hospital, and which has played a crucial role in being able to proceed with this ambitious initiative, raising 37 million Euros from donations.

The **starting point in the healthcare plan is already promising**: around 420 new patients per year (of which, 153 are from abroad), more than 160 healthcare professionals and a significantly increased satisfaction rate among patients and their families (NPS of 89.9), thanks to an innovative, comprehensive healthcare model. With regard to translational research, we have several innovative therapies at our disposal, such as CAR-T 19 for patients in leukemia relapse, Naxitamab® for patients with high-risk neuroblastoma, or Oncolytic Viral treatment methods for patients with advanced retinoblastoma. All this, alongside a significant number of **publications in influential journals**, with an IF score of 513. At the same time, our **Pediatric Oncology and Hematology Specialist Training Programme** is the highest ranked in the country.



# Executive summary

The PCCB is the first single-specialty childhood cancer hospital in Spain, and a pioneer in Europe. It has a total of 37 hospital rooms, 8 isolation rooms for hematopoietic stem cell transplants (HSCT), 26 day hospital rooms, 21 outpatient consultation rooms, a surgical wing with two surgeons, its own dedicated pharmacy, a nuclear medicine unit, a rehabilitation gym, family-centred spaces and research laboratories. All of this, as well as being designed in collaboration with patients, families, and professionals, who have been involved in the process from the outset, using design thinking methods. The healthcare model offers **multidisciplinary, super-specialised, highly complex and comprehensive healthcare**, contributing not only to eradicating the disease in question, but also restoring the patient's health and wellbeing, as well as that of their family. Finally, the governance model **will allow patients and their families to be naturally involved in decision-making processes**.

The PCCB's strategy stems from the fact that it is a centre that is open to the world; where the quality of the healthcare we provide and our patient experiences are of utmost importance, hence the motto of "A centre by all and for all". We want to become an internationally acclaimed oncology facility for children and adolescents, that can guarantee its patients the best possible health outcomes and quality of life.

To make this vision a reality, we have laid out four clearly defined goals alongside their respective indicators:

- 1. Increase our capacity to cure childhood cancer while reducing side-effects by providing forward-thinking, personalised, comprehensive care.**
- 2. Develop targeted, innovative, effective treatments for currently incurable cancers.**
- 3. Share and transfer knowledge and skills through teaching and training.**
- 4. Have a global impact.**

This strategy will be based on **four pillars: healthcare, research, teaching, and training, and being open to the world**. It will have **four facilitators** to ensure each objective is achieved: **an innovative, participative organisational and management model, attracting and retaining talent, infrastructures and digital transformation tools, and a sustainable finance model**.

1. Spanish Registry of Children with Tumours RETI-SEHOP. Statistics 1980-2020: 3,594 recorded cases between 2018 and 2020.

2- Spanish National Statistics Institute (2020). Number of deaths per cause of death (1-19 years of age).

3. The Net Promoter Score (NPS) divides respondents into: "promoters", who gave scores of 9 or 10; "passives", who gave scores of 7 or 8; and "detractors", who gave scores of 6 or less. The NPS index can be as low as -100 (where everyone is a detractor) or as high as 100 (where everyone is a promoter).



# 1\_

Why do we need a healthcare facility dedicated to pediatric cancer?

# Why do we need a healthcare facility dedicated to pediatric cancer?

## Pediatric or childhood cancer

Pediatric cancer, also known as childhood cancer (both terms are used interchangeably throughout this document), consists of the abnormal, rapid growth of stem cells, which in contrast to adult cancer, originates during fetal development.

It is linked to several rare diseases. There are currently 1,200 new cases diagnosed in Spain each year, and it has a prevalence of 155 cases in every one million children, similar to the European mean. There are around 250 new cases diagnosed in Catalonia each year.

Although research into childhood cancer has led to an increased survival rate in recent years (the 5-year survival rate being around 80%), pediatric cancer is the leading cause of death in the pediatric age group over the age of 1 in Spain. Furthermore, while there is evidence that suggests adult cancer is closely related to lifestyle and one's environment, childhood cancers stem from spontaneous genetic mutations during the rapid fetal growth stage. As a result, there are no methods to help prevent this type of cancer.

## The need for single-specialty healthcare facilities for childhood cancer

There are several shortcomings regarding how childhood cancer is handled within the wider Spanish National Health System:

**Few cases, spread out across several facilities:** In Spain as a whole, there are many hospital facilities that treat children and adolescents with cancer, many of which have a very low number of patients. The fact that cases are so widely dispersed makes it difficult for healthcare professionals to develop true expertise and creates high degrees of variability in results.



# Why do we need a healthcare facility dedicated to pediatric cancer?

**Lack of specific diagnosis and personalised treatment:** A precise diagnosis is key to improving treatment efficacy, increase survival rates and reduce the number of subsequent side-effects. In addition, having access to advanced, state-of-the-art therapies is key to offering a truly personalised treatment plan.

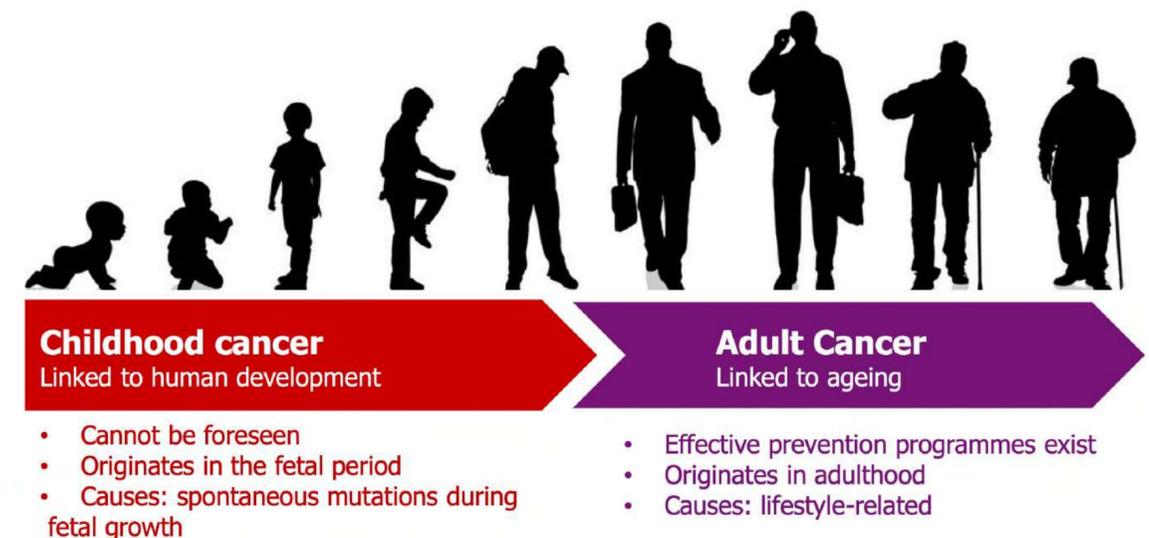
**Little mental, social, or emotional support for patients and their families:** Attention is often focused on medical diagnosis and treatment, relegating social and emotional support to second place, especially for patients and their families.

**Numerous side-effects:** While current oncological treatments increase survival rates, side-effects from procedures and treatments are still far too common.

**A fragmented care model:** There are often difficulties coordinating healthcare, both within the Hospital environment and in various other healthcare settings, making it difficult to provide consistent, comprehensive care.

**Lack of targeted research:** Despite increased patient survival rates, there are still between 15 and 20% of childhood cancers that have no cure. The low occurrence of pediatric cancer results in few resources being invested into researching these diseases.

One solution to these issues that is implemented on an international scale is single-specialty facilities dedicated to childhood cancer. This means all healthcare and clinical or lab-based research resources (basic and translational) are combined in one singular facility. The aim of these facilities is to effectively and efficiently provide the appropriate level of care to a large volume of patients through a personalised, comprehensive care model. This is done by concentrating a large volume of patients—who would otherwise be spread across the country in facilities with much less capacity, both in terms of infrastructure and care provision—into the one premises with a highly-specialised team of healthcare professionals.



4. Spanish Registry of Children with Tumours RETI-SEHOP. Statistics 1980-2020: 3,594 recorded cases between 2018 and 2020.

5. Spanish Registry of Children with Tumours RETI-SEHOP (2014). "Childhood Cancer in Spain". Available at <https://www.uv.es/rnti/pdfs/B1.05-Texto.pdf>

6. Spanish National Statistics Institute (2020). Number of deaths per cause of death (1-19 years of age).

# 2\_

Why the SJD barcelona children's hospital?

# Why the SJD barcelona children's hospital?

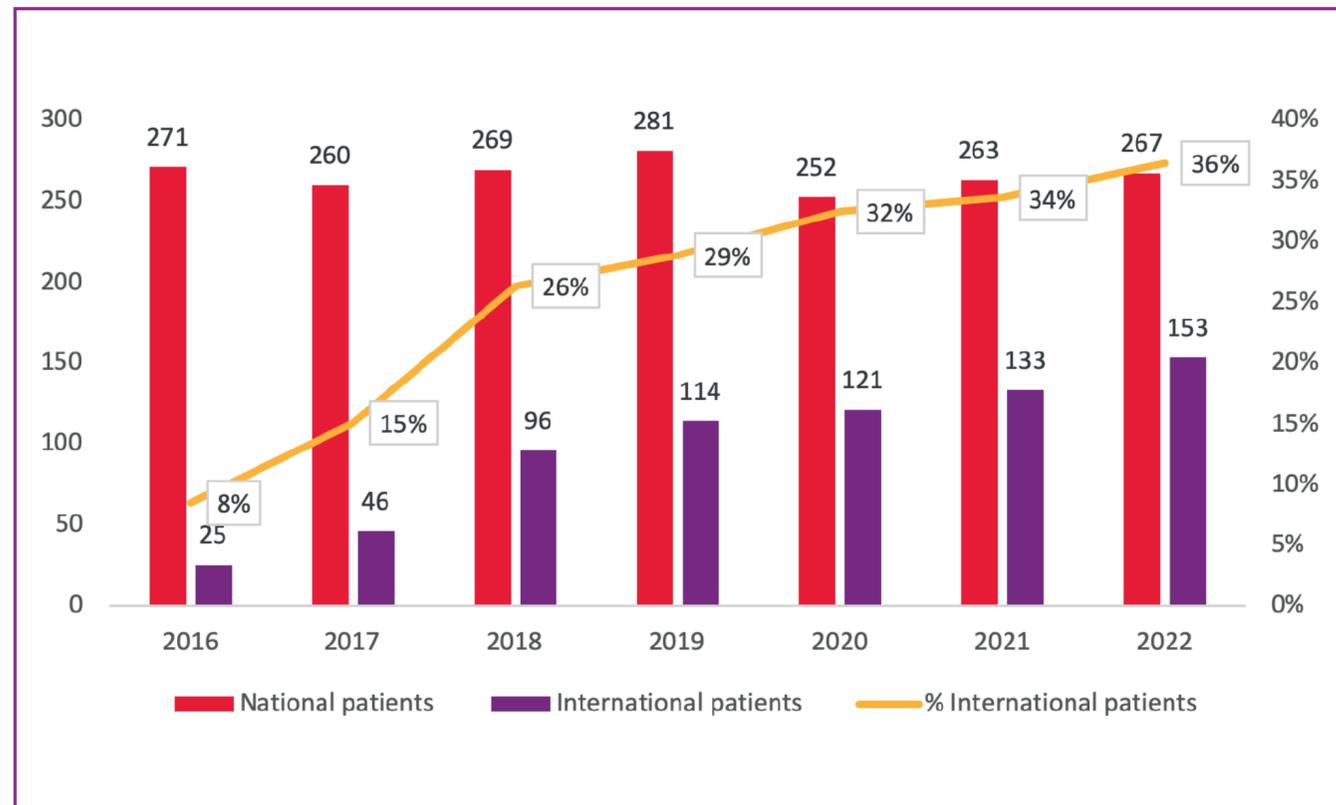


Figure 1. Number of new pediatric oncology patients in the SJD Barcelona Children's Hospital between 2016 and 2022, grouped by origin.

Source: SJD Barcelona Children's Hospital Registry.

There are five key factors that have encouraged the Hospital to proceed with the creation of a single-specialty childhood cancer centre:

**The huge increase in patients:** The total number of new patients in the Hospital's Oncology Service has seen a significant increase, with an overall annual growth rate of 40% in the last five years, primarily due to the increase in international patients. These patients have gone from making up only 5% of cases to 34% of cases in the last five years.

The **good results obtained**, which result in survival rates akin to those of large international facilities and centres—although, at present, there is still a long way to go with certain types of childhood cancer.

**High-calibre healthcare and research groups working within a translational investigative model.** The healthcare team in the Hospital's Oncology Service is distinguished for their excellent levels of care and research. They are pioneers on a European scale thanks to state-of-the-art therapies such as CAR-T therapy for type-B lymphoblastic leukemia, or their use of anti-GD2 immunotherapy to treat patients with high-risk neuroblastoma, with a 40% increase in survival rates in the first instance, and a 20% increase in the second.

# Why the SJD barcelona children's hospital?



Figure 2. Number of treated patients, grouped by tumor type (only new patients).

\* The COVID-19 pandemic did not significantly affect the number of patients.

In the investigative sphere, for the last 20 years, the Hospital has had a childhood cancer research lab with a translational outlook. Currently, it is staffed by more than 50 professionals. The research team focuses on: 1) molecular diagnosis and prognosis; (2) pre-clinical models; and (3) targeted therapies and new therapies. The lab has one of the largest pediatric tumor banks in Europe, giving researchers access to primary tumor samples stored in several formats, with which they can experiment and study cell behaviour in response to new therapeutic approaches, both in vitro (on the slide), and, later, in vivo (on animals). It also has a clinical trials unit, with 50 active clinical trials in progress.

As such, it is relevant here to boast some of the Hospital's successes. With regard to diffuse brainstem tumors (DIPG)—which have a higher than 90% mortality rate in the two years post-diagnosis—the first international clinical trial has been carried out to investigate the safety of using dendritic cell-based vaccines to treat these tumors. Another example within this area would be the use of the humanised anti-GD2 antibody Naxitamab® in patients with high-risk neuroblastoma. The Hospital was the first in Europe to test this treatment, which has increased survival rates to figures in the 90% range in the last ten years (vs. ~70% in the 1990s) for high-risk cases. More than 200 patients from around the world have received this treatment at our facility.

# Why the SJD barcelona children's hospital?

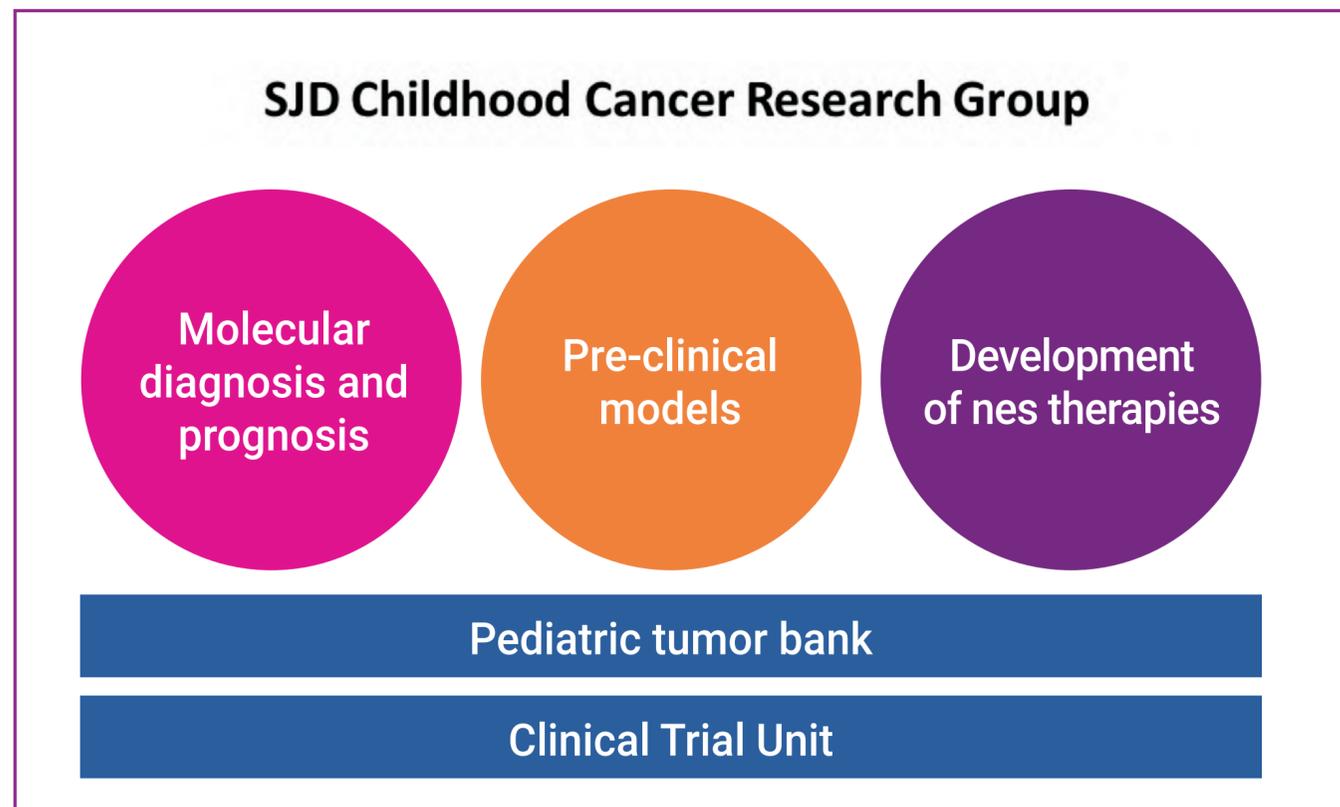


Figure 3. Structure of the Hospital's childhood cancer research group.

Regarding CAR-T cell therapies, the Hospital was the first in Spain to use them when treating children and young adults. We were also the first to treat infants with an academic CAR-T, ARI-0001 cells. Since 2016, we have treated over 80 children and teenagers with this therapy in 7 different clinical trials. This makes the Hospital one of the leading European facilities using CAR-T therapies on pediatric patients.

In recent years, scientific output from our Oncology Service has been increasing, and in 2020, there were 79 publications referenced in the Journal Citation Reports (JCR), with an impact factor of 698, and more than 80% of publications in first-quarter journals.

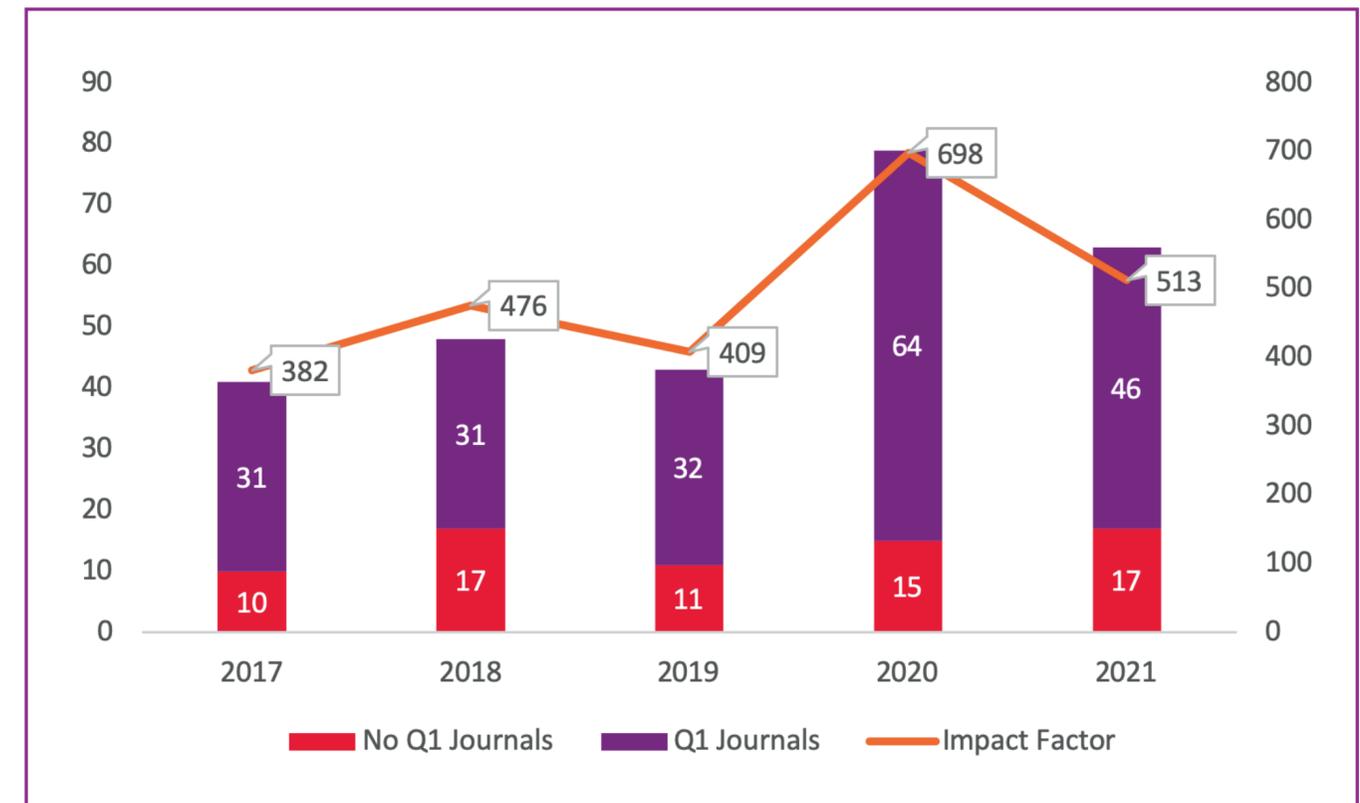


Figure 4. Number of JCR publications and impact factor of the Childhood Cancer Research Group.

# Why the SJD barcelona children's hospital?

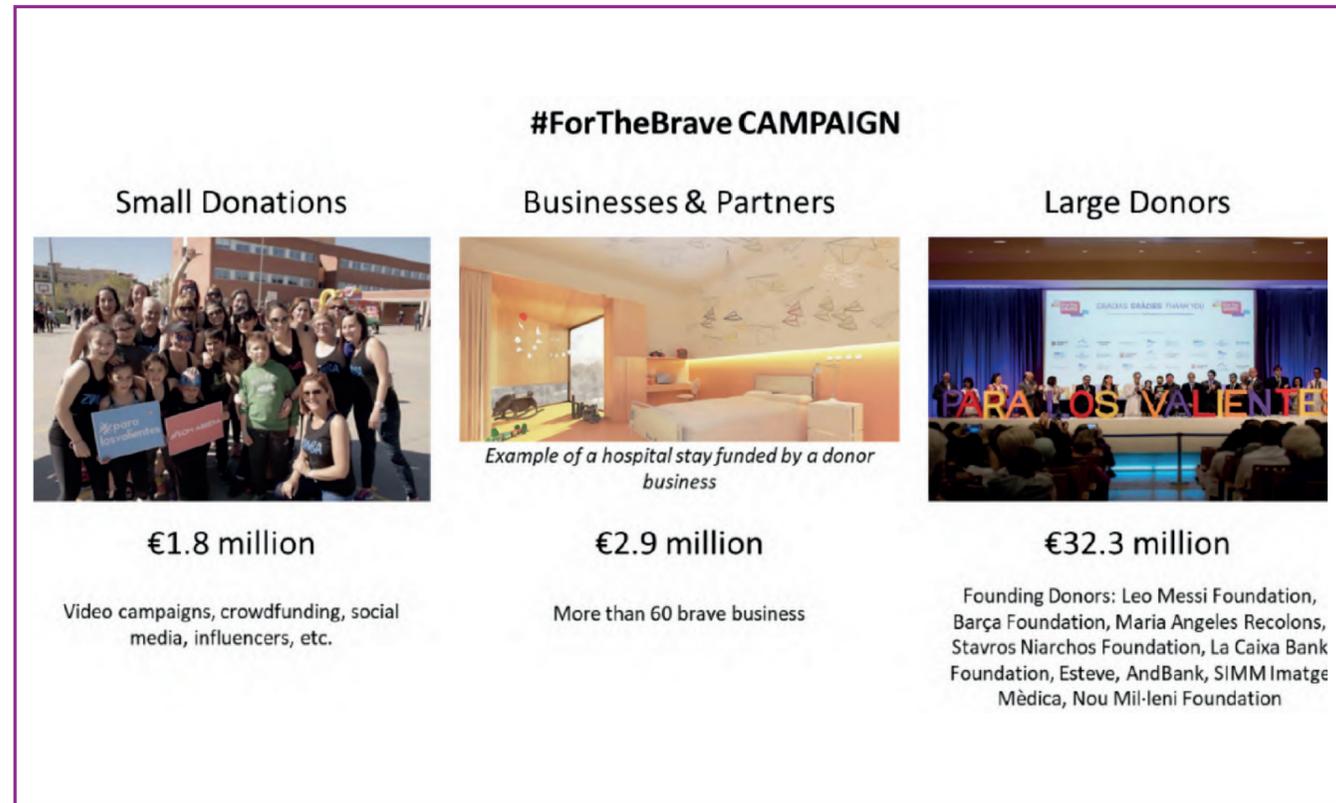


Figure 5. Infographic showing donors who helped fund the initial investment into the PCCB.

**The correlation with the institution's mission:** The mission of The Hospitaller Order of St. John of God (HOSJG), which is shared by the Hospital, is “to provide comprehensive care to people in vulnerable situations, thereby contributing to the creation of a more just and supportive society”. As such, having a single-specialty childhood cancer centre contributes to supporting children and families in vulnerable situations as a result of the disease. What’s more, the humanist care model that characterises the Hospital does not only focus on improving survival rates, but also on improving patient quality of life, which is equally as important.

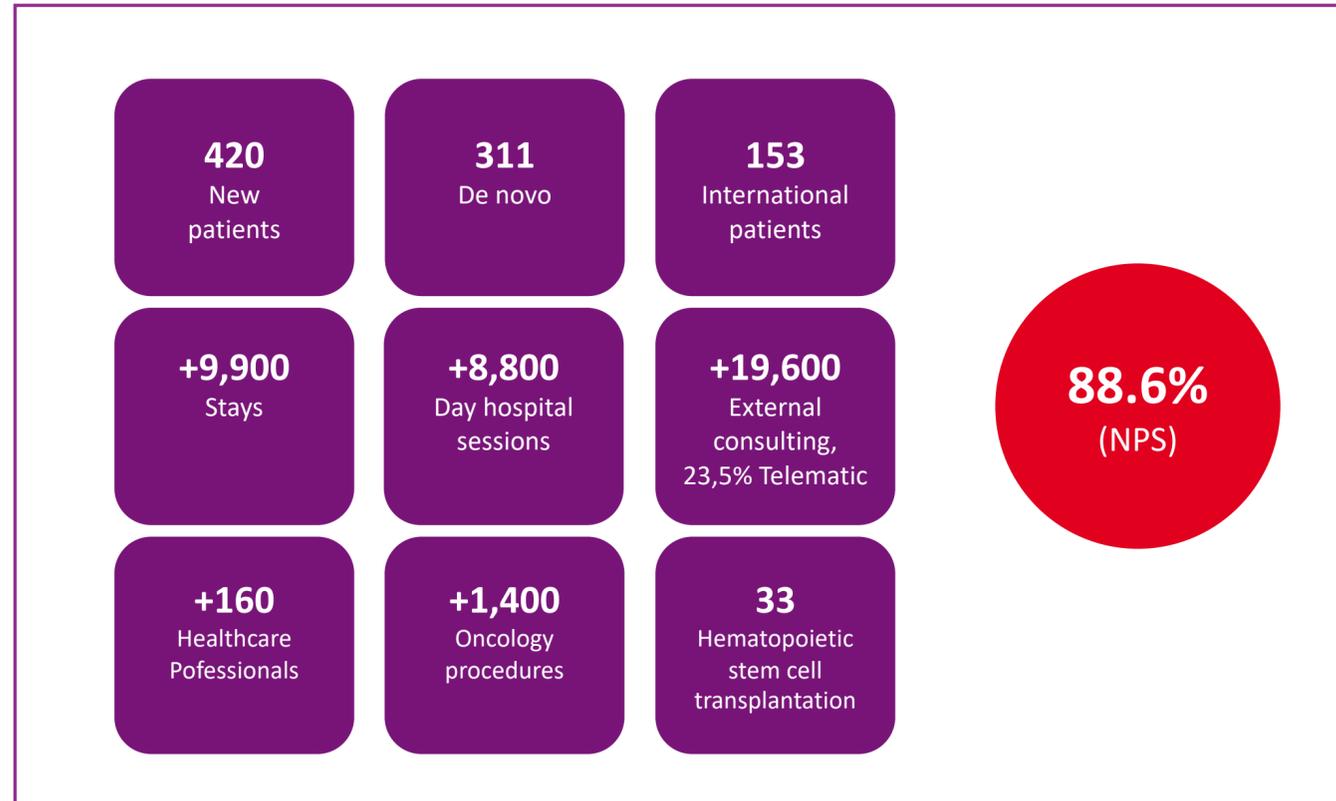
**Support from wider society:** Traditionally, HOSJG has been part of wider society in a diverse manner of ways and has counted on widespread support for many years. This support was clear to see during the #ForTheBrave fundraising campaign, which began on the 15th of February 2017, and managed to raise 37 million Euros to build the Pediatric Cancer Center Barcelona. This centre has been funded by small donations (5%), donations from businesses and partners (8%) and from large donors (87%).

# 3\_

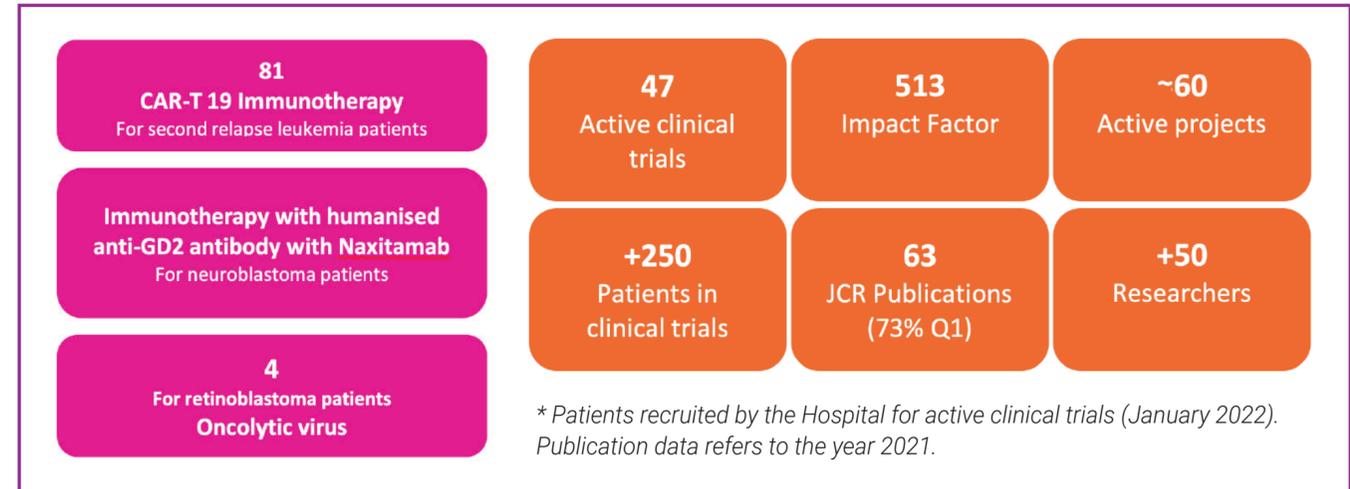
What is our starting point?

# What is our starting point?

## The Oncology Department in numbers (2022)

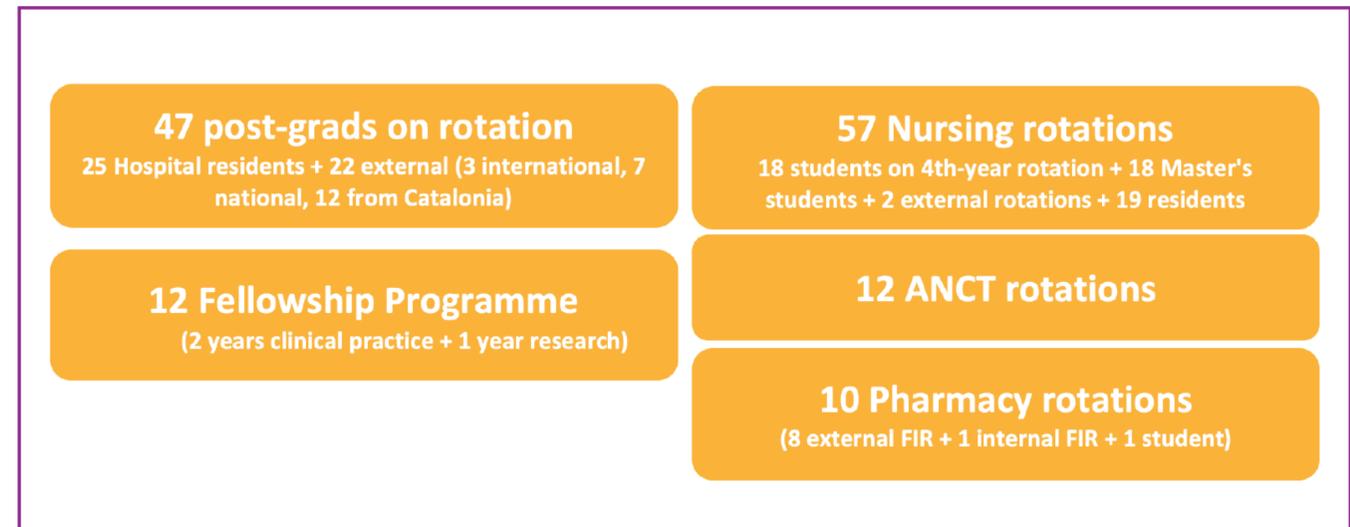


\* The Net Promoter Score (NPS) divides respondents into: "promoters", who gave scores of 9 or 10; "passives", who gave scores of 7 or 8; and "detractors", who gave scores of 6 or less



Innovative therapies

Research



Teaching

# 4\_

## What is the PCCB?

# What is the PCCB?

- 1** Unic in Spain and a **pioneer** in Europe
- 2** Entirely from **philanthropic funds**
- 3** Care and **research** in a single space
- 4** **Multidisciplinary, super-specialised, highly complex and comprehensive** care model
- 5** Aspires to have a **global impact**

The PCCB is a single-specialty service for children and teenagers with cancer and their families, designed to provide integrative and translational care. The facility has two functions: on the one hand, it provides healthcare services to patients who are suffering from childhood cancer; on the other hand, it is a space where research and investigation efforts can be focused and executed.

**It is based on a multidisciplinary, super-specialised, highly complex and comprehensive care model. The PCCB: a one-of-a-kind centre.**

The building is located next to the Hospital and is connected by a covered walkway. The PCCB is made up of five wards, and has all of the required infrastructure to provide comprehensive care to its patients:



- |                              |                                      |  |   |                                   |
|------------------------------|--------------------------------------|--|---|-----------------------------------|
| <b>37</b><br>Hospital rooms  | <b>8</b><br>Isolation rooms for HSCT | <b>21</b><br>Outpatient consultation rooms | <b>26</b><br>Day hospital rooms &<br><b>2</b> blood sample cubicles | <b>1</b><br>Rehabilitation gym    |
| Games room and family spaces | Surgical wing                        | Pharmacy: dispensary and cleanrooms        | Research Laboratory   | Nuclear medicine and radiotherapy |

# What is the PCCB?

The following table shows the services and tools available at the PCCB:

Scope of care	Diagnostic protocols	Therapeutic protocols
Hospitalisation ICU Outpatient department Day hospital Home Care Palliative care unit Procedure rooms Operating theatre Physiotherapy and rehabilitation Psychotherapy Social care Integrative medicine Pharmaceutical services	Laboratory Diagnostic imaging Diagnostic nuclear medicine	Surgery Basic Pharmacology Chemotherapy Radiopharmacy Radiotherapy Nuclear Medicine Advanced therapies (HSCT and CAR-T)

It should also be highlighted that the PCCB has an advantageous location, being next to the Collserola Natural Park. To make the most of this natural landscape, we want to renovate the area directly surrounding the centre to give it a therapeutic purpose for cancer patients and their families. When they visit the PCCB, they need to be able to go for a walk and relax, get in touch with and take in nature, stimulate their senses, play, share the space and reminisce together. We want to fulfil these needs by transforming the outside areas of the PCCB.

# 5\_

Where do we want to go?

# Where do we want to go?

Our motto is “**Pediatric Cancer Center Barcelona:  
A Centre by All and For All**”

Our vision is to become a leading international **child and teenage cancer care centre that guarantees best health outcomes and patient quality of life**

Our mission is to **provide excellent healthcare to children and teenagers with cancer, applying the knowledge generated in research to clinical practice**

## Our values:

- **Excellence:** to be able to offer the highest quality services possible, both in terms of healthcare and in research and education.
- **Humanism:** to be able to put patients and their families at the centre of our caregiving, giving them what they need in an integral way.
- **Hospitality:** to be able to welcome patients and their families with dignity, respect, responsibility, and spirituality, making them feel at home.
- **Innovation:** to be able to offer early diagnoses and treatments that are adapted to each patient.
- **Professional skills and competence:** to be able to guarantee responsible, high-quality care to our patients.



# Where do we want to go?

The following section details the PCCB 2023-2027 Strategic Plan.

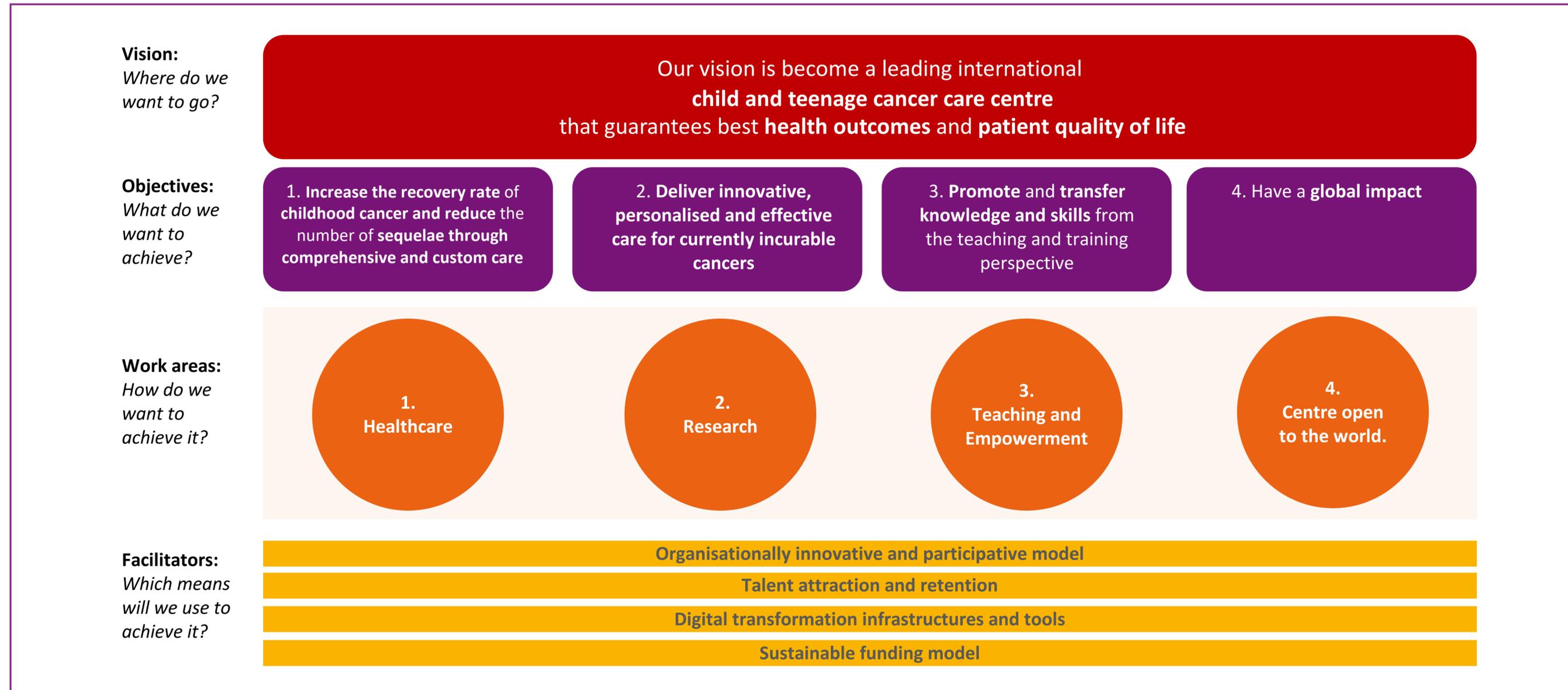


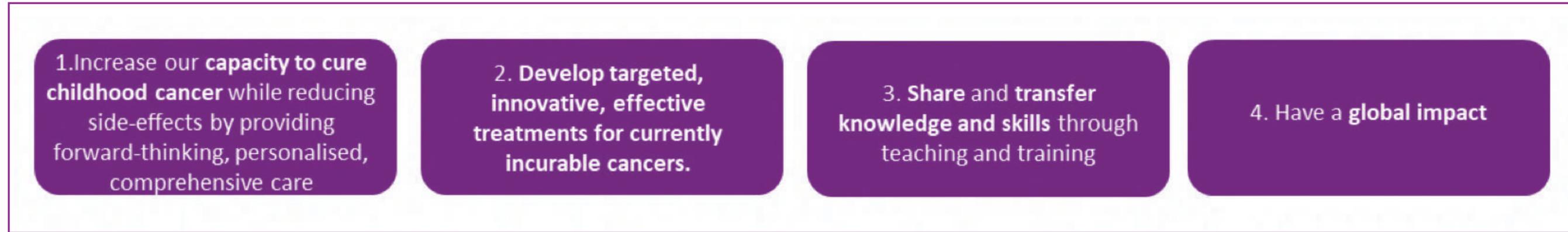
Figure 6. Infographic showing a conceptual breakdown of the Pediatric Cancer Center Barcelona 2023-2027 Strategic Plan.

# 6\_

What do we want to achieve?

# What do we want to achieve?

The PCCB has set four strategic goals for the next five years (2023-2027):



We will now present each of these goals in greater detail.

**a. Goal 1: Increase our capacity to cure childhood cancer while reducing side-effects by providing forward-thinking, personalised, comprehensive care**

Over the last few years, the survival rate of pediatric cancer patients has increased substantially. However, it remains the main cause of death by disease in children over the age of 1 in Spain.

The PCCB wants to make sure that all children who have been diagnosed have access to the best therapies available, guaranteeing the highest survival rate and the lowest chance of any potential physical or emotional side-effects. That said, we consider the best treatment to always be linked to patient experience and quality of life. That is why both our facilities and the staff who treat our patients are equipped to fulfil any and all patient needs, including those that go beyond purely health-related matters. This will therefore allow us to meet social, recreational, or familial needs, up to and including fulfilling needs related to understanding who the child is as a person, for example, through psychosocial care or spiritual guidance.

# What do we want to achieve?

## What will we consider a success?

## How will we measure success?

**Increase in number of new patients treated**

• Number of new patients

**Increase in survival rates of patients treated**

- Survival and event free survival of patients with acute lymphocytic leukemia
- Survival in patients treated with CAR-T
- Event free survival in diffuse midline glioma
- Survival in high risk neuroblastoma
- Eyes with RB saved using active immunotherapy/oncolytic virus
- Mortality associated with Allogeneic Hematopoietic Stem Cell Transplant

**Reduction in side-effects and improved quality of life**

• Change in the mean quality of life score of patients (scaled, pre- vs. post-treatment).

**Maintenance or increasing in user satisfaction**

• Net Promoter Score in the Oncology Department

# What do we want to achieve?

## b. Goal 2: Develop targeted, innovative, effective treatments for currently incurable cancers

The survival rate for pediatric cancer in Spain is around 80% after five years. This figure also means that 20% of children and teenagers who are diagnosed do not overcome the disease, as some tumors still do not have any effective treatments. The causes of lack of treatment are related to the fact that these tumors are extremely rare, or due to genetic or epigenetic differences within a single tumour, making existing treatment responses vary wildly. This is made worse by the fact that research is not sufficiently funded.

### What will we consider a success?

### How will we measure success?

#### Development of new treatments that increase survival rates

- Number of clinical trials in advanced therapies (cell therapy, gene therapy, oncolytic viral therapies and vaccines)
- Number of clinical trials (hospital-run) that have progressed from phase I to II.
- Number of patients in advanced therapy clinical trials (cell therapy, gene therapy, oncolytic viral therapies and vaccines)
- Number of research lines
- Number of international multi-site clinical trials
- Number of clinical trials in personalised medicine
- Number of clinical trials in CAR-T
- Clean room productivity
- Number of patents registered
- Number of animal-testing models developed

#### Treatment personalisation

- Number of patients studied in the oncology precision platform
- Number of personalised treatment plans
- Number of massive tumor sequencing procedures
- Number of tumor methylation analysis

# What do we want to achieve?

## c. Goal 3: Share and transfer knowledge and skills, both through continued professional training and by teaching and empowering patients and their families

In line with the institution's principles, we want the knowledge discovered at the PCCB to be shared. That is why we will focus on three areas: firstly, on continued professional training around the world in pediatric oncology; secondly, on promoting healthy habits in patients and in their environments, to live as healthily as possible; and finally, on educating patients and their families about their future lifestyle and the needed maintenance, which will really empower the patient with regard to their disease and in their day-to-day life.

What will we consider a success?	How will we measure success?
Expansion of our educational offer	<ul style="list-style-type: none"><li>• Number of courses and Master's programmes offered</li><li>• Number of virtual content sessions developed</li><li>• Number of fellows and their destination</li><li>• Number of areas/fields of knowledge we provide training in</li><li>• Development of an educational itinerary for each functional unit (IFU)</li></ul>
Increase in number of professionals trained	<ul style="list-style-type: none"><li>• Number of students and specialists who come to PCCB for training</li></ul>
Ability to assess the quality of educational offer	<ul style="list-style-type: none"><li>• Establish a learning commission at the PCCB</li><li>• Index of University of Barcelona/other university professors and teaching partners</li><li>• Assessment of integration of time set aside for training activities by fellows and personnel</li></ul>

...

# What do we want to achieve?

## What will we consider a success?

### Implementation of the VIDA project

### Ensure cancer patients empowerment

## How will we measure success?

- Number of activities developed
- Qualitative assessment of the impact of the project

- Number of patients/families who have undertaken training in/taken on board healthy habits
- Number of structured training programmes
- New training formats
- Evaluation of results from training programmes; their impact and quality

# What do we want to achieve?

## d. Goal 4: Have a global impact

From a healthcare standpoint, the Hospital's Oncology Department is already globalised: currently, almost a third of cancer patients treated are of international origin. However, we want to attract more patients from all over the world. We have also developed an Outreach programme that we want to continue building on, such as through the inclusion of collaboration agreements with third-party institutions and organisations, training and education programmes, and collaborative investigation and research projects. We have set our sights wider. We understand the term “global” as the footprint we leave in our environment with the work we do. In that sense, our facility will deliver the best possible care to its patients, having as little environmental impact as possible, all while promoting real, tangible initiatives to help support and advance the United Nations’ Sustainable Development Goals plan.

### What will we consider a success?

### How will we measure success?

**Increase in international patients treated**

• Percentage of international patients treated

**Increase in collaboration agreements with various countries and international institutions**

• Number of active agreements

**Increase the number of international training programmes we launch**

• Number of programmes

**Increase the number of collaborative research projects with other facilities and institutions**

• Number of national, European and international projects  
• Representation in the project: involvement as a collaborator or as a member of the project's management group.

**Participation in global health initiatives**

• Number of initiatives

**Growth of the Charity Fund programme, which allows international patients with few resources to be treated**

• Number of patients funded through Charity Fund  
• Money invested in Charity Fund

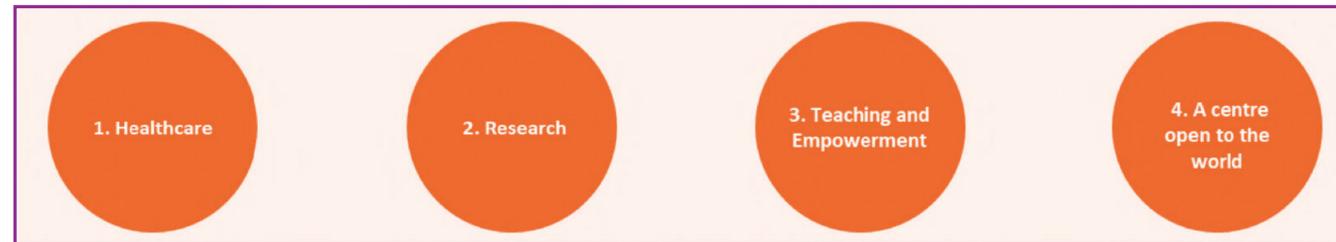
**Achieving SDGs (within the Hospital's SDG project)**

• Measured impact of the Hospital's SDG project.D

# 7\_

How do we want to achieve it?

# How do we want to achieve it?



To meet our strategic objectives, we have established four lines of work: 1) healthcare, which is based on the 4P model (personalised, predictive, preventative and participative); 2) research, which will focus on creating knowledge and making progress towards new therapies; 3) teaching, wherein we will work to consolidate the PCCB as a global leader in pediatric cancer education and in patient and family training; and 4) having a global impact as a centre that is open to the world.

## 7.1 First Line of Work: Healthcare

Healthcare at the PCCB will be provided in line with the Hospital's own style and the centre's values:

- **Multidisciplinary:** A diverse team of professionals will create a personalised, coordinated treatment plan. The teams involved will include: the oncology team (pediatric oncology/hematology and nursing); neurosurgery; pediatric surgery; nuclear medicine-specialised orthopedic surgery; pharmacy; the social work team; rehabilitation; psychosocial support; nurse case managers; clinical assistants, etc.

- **Super-specialised:** Organised by functional units per tumor type, which allow us to reach the level of knowledge required for optimal care provision on a case-by-case basis.
- **Highly complex:** Given the patients' fragile state, this line of work is always looking for innovative solutions in diagnostic and therapeutic procedures.
- **Comprehensive:** Understanding care from a biological, psychological and social viewpoint, as well as the need to promote healthy habits. This is especially the case for diet, physical exercise, adequate rest and reducing stress. Patients will have access to all available services, ensuring a comprehensive level of care so that all of their needs are covered.
- **Quality and safety:** At present, we have indicators to measure the impact of our actions at the PCCB. The NPS is a useful scale to get information about patient and family satisfaction, and subsequently, take the necessary steps to improve their experience. By keeping an eye on patient safety, any and all incidents that may occur are always reported to the safety committee, where they are identified, assessed and handled appropriately. This allows us to improve our protocols and prevent future accidents. One of our objectives is to develop a targeted quality plan for the PCCB which will safeguard patients and uphold high-quality care.

# How do we want to achieve it?

## Healthcare organisation

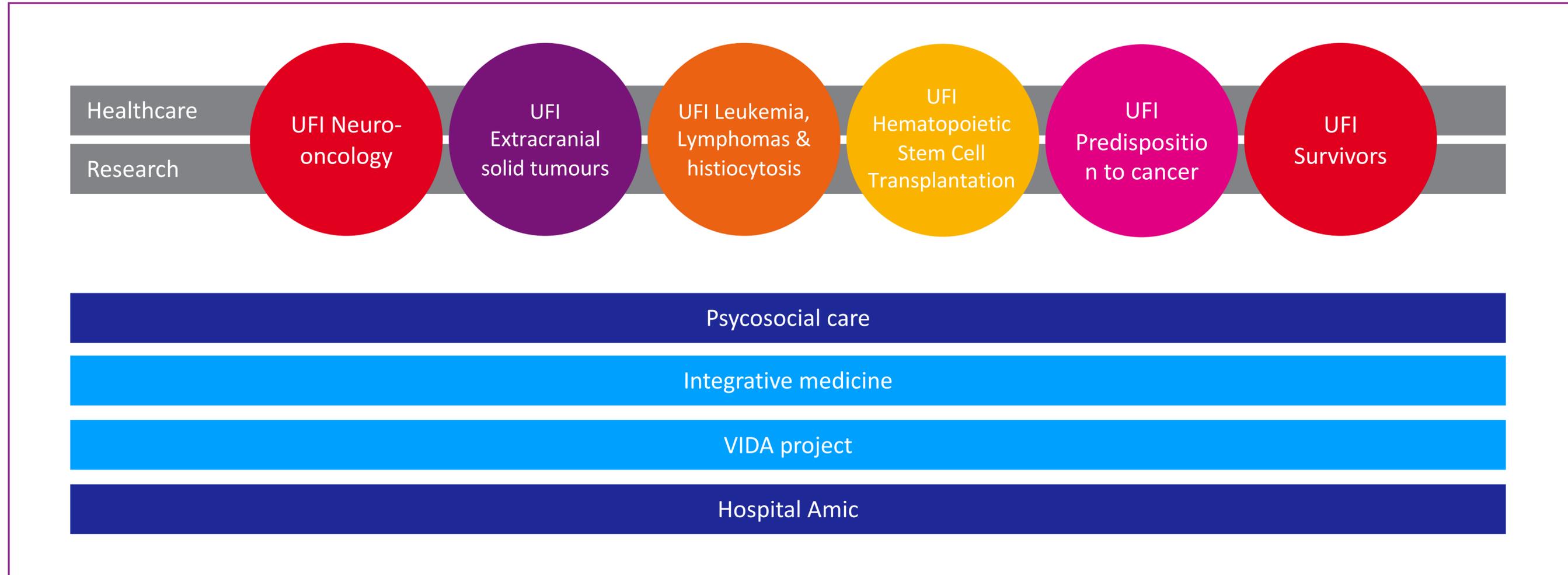


Figure 7. Functional infrastructure of healthcare organisation

# How do we want to achieve it?

The healthcare organisation at the PCCB consists of six integrated functional units (IFUs), which guarantee a high-calibre care model that combines research and healthcare. The functional units are as follows:

- **Neuro-oncology:** for patients with tumors in the central nervous system.
- **Extracranial solid tumors:** this unit covers patients with solid tumors outside the central nervous system.
- **Leukemia, lymphoma and histiocytosis:** this focuses on patients who have leukemia, lymphoma, histiocytosis and congenital bone marrow failure.
- **Hematopoietic stem cell transplants:** this unit focuses on children and teenagers who require a bone marrow, umbilical cord blood or peripheral blood transplant during their treatment. It applies to both patients with oncological diseases and hematological or genetic diseases (such as immunodeficiencies, hemoglobinopathies or metabolic disorders).
- **Predisposition to cancer:** covers patients with hereditary syndromes that predispose them to cancer, such as neurocutaneous disorders (neurofibromatosis type 1 and 2), tuberous sclerosis or Li-Fraumeni syndrome, for example.

- **Follow-up with cancer survivors:** this unit handles care, support and any other services necessary to monitor surviving patients and improve their quality of life, as well as helping them transition to the adult healthcare system.

Aside from these functional units, the PCCB also offers several other cross-disciplinary healthcare services to all patients at the centre. They are:

- **Psychosocial care:** this provides psychological, emotional and social support to patients and their families, both for patients in therapeutic care and those in palliative care.
- **Integrative medicine:** provides several services aimed at improving patient wellbeing and quality of life, such as acupuncture, nutrition or manual support therapies.
- **VIDA Project:** this service aims to educate patients and their carers, empowering them to get involved in managing the disease and encouraging healthy habits, both in the hospital environment and at home.
- **Hospital Amic:** this programme aims to humanise the hospital experience for patients and their families, making it as positive as possible. The service employs various strategies, such as adapting spaces to the needs of the patients and their families, including them in the patient's treatment plan, or logistical support for families.

# How do we want to achieve it?

## Actions that will be carried out in the coming years:

- Consolidate the multidisciplinary management model for cancer patients by opening up single-specialty departments, among others.
- Provide a precise diagnosis (with genetic screening) to all patients, as well as implementing all diagnostic and monitoring techniques called for in national and international protocols.
- Identify areas for improvement in services which support diagnosis, and implement them.
- Arm nursing teams with targeted, specific training across several units.
- Develop, expand and evaluate the service offering of the home care programme for cancer patients (SJD at Home – Oncology).
- Redesign/repurpose the Survivors Unit, adding psychosocial care to its services, among others.
- Design and implement the Adolescent and Young Adult Unit.
- Improve/implement a psychosocial support service for families (family request).
- Create and implement a psychosocial care service for cancer patients.
- Integrate psychosocial care into functional units, and carry out case assessment and decision-making in a joint manner.
- Expand and assess the Integrative Pediatric Oncology Unit's (IPOU) service portfolio, adding mindfulness and yoga.
- Consolidate the model and implement a targeted Hospital Amic programme within the PCCB, wherein we promote and organise group activities to help patients socialise.
- Coordinate with personnel in the local area, both in and outside the healthcare environment (e.g., schools and primary healthcare services), and include them.
- Obtain and maintain Quality Standard Accreditations awarded by external agents (e.g. ISO 15189, JACIE for HSCT and CAR-T).
- Create a therapeutic green zone around the PCCB (Collserola Park).
- Introduce new technology that improves quality, safety and comprehensive care in the patient's pharmacotherapeutic process.
- Launch the VIDA programme.

# How do we want to achieve it?

## 7.2 Second Line of Work: Research

The research that is carried out at PCCB is translational, meaning it focuses on both developing precise diagnostic techniques, as well as more effective, less aggressive therapies. The main research groups are as follows:

- **Pediatric Cancer Epigenetics group:** childhood tumors are biologically different to those found in adults and are characterised by epigenetic deregulation. This group focuses on studying the biology of these tumors—especially malignant rhabdoid tumors—with their ultimate goal being to find personalised therapies that can reverse the damage caused by the tumor and improve the patient's wellbeing and prognosis. To do this, they characterise and sequence tumors stored in the Hospital's pediatric tumor bank.
- **Translational Genomics group:** this group focuses on studying genetic and epigenetic abnormalities in order to identify new biomarkers. This means that not only can they improve diagnostic procedures and prognoses, but also best predict how each patient will respond to treatment. Additionally, they can identify potential therapeutic targets by studying these abnormalities. They also research how to utilise these biomarkers in clinical practice.
- **Sarcomas and Histiocytosis group:** this group studies pediatric sarcomas and histiocytosis of Langerhans cells to develop effective drug treatments.
- **Pediatric Cancer Treatments group:** despite the increased survival rates, there are still some pediatric cancers which have no cure, such as diffuse midline gliomas (DMG). This research group is focused on finding treatments for these types of cancers through both pre-clinical projects and clinical trials of new treatments.
- **Pediatric Blood Diseases and Leukemia group:** this group studies these specific types of childhood cancer to improve diagnosis (improved genetic/epigenetic characterisation), monitoring and follow-up (using more sensitive techniques to monitor measurable residual disease), prognosis (by developing new biomarkers) and treatments (such as cell immunotherapy with CAR-T, or improvements to hematopoietic stem cell transplant procedures).

# How do we want to achieve it?

## Actions that will be carried out in the coming years:

- Start new studies based on solid tumor cell therapies.
- Start immunotherapy clinical trials for solid tumors.
- Start clinical trials involving CAR-T with new therapeutic targets to increase the number of hematological diseases that can benefit from this therapy (such as T-cell lymphoblastic leukemia, type-B lymphoma, myeloblastic leukemia)
- Promote research programmes into nurse-led treatments.
- Support specific research into pediatric psycho-oncology.
- Investigate biomarkers in bodily fluids to be able to non-invasively identify therapeutic targets.
- Develop and validate biomarkers in solid pediatric tumors, as well as design our own analysis tools and implement them in clinical practice.
- Collaborate with other research groups to improve tumor characterisation alongside professionals and new technologies based at other facilities.
- Integrate the IRJC basic research group into the clinical and translational research carried out by the Pediatric Blood Diseases and Leukemia group at the IRSJD.
- Develop tools and methods based on real world evidence (RWE) to create new treatments.
- Forge partnerships to facilitate multi-centre studies and take part in international, multi-centre clinical trials.
- Encourage participation in international collaboration groups and the inclusion of patients in clinical trials for first line treatment.

# How do we want to achieve it?

## 7.3 Third Line of Work: Teaching and Empowerment

The PCCB wants to continue promoting the Hospital as a leading educational hub in the field of pediatric oncology. Educational training projects will be developed at the PCCB that will make it the first choice for pediatric oncology training in Latin America. Furthermore, the offering of English-language training will be increased to cement HSJD's position as a learning hub, both with online and in-person training events.

We will also work to foster healthy habits, as well as teach and empower patients and their families, as this will have a positive effect on both their health and their quality of life. The educational resources available at present for patients are made up of a combination of activities relating to: the promotion of healthy-lifestyle habits; education on nurse-led caregiving; and informative, training materials about disease management. These resources will have a plan of action that is specific to the PCCB.

### Actions that will be carried out in the coming years:

- Organise pediatric oncology training courses with an international, multidisciplinary focus.
- Create a Master's programme with international participation to specialise in pediatric oncology nursing.
- Develop a continuing professional development programme for PCCB personnel, and implement simulation-based learning technologies in a routine manner.
- Develop specialised training programmes about psychosocial care in pediatric cancer
- Broaden educational collaboration efforts with international partners and promote knowledge exchange between healthcare professionals and predoctoral individuals.

- Consolidate the TeLeo program for national and international training, specific to the PCCB.
- Include simulation-based activities in training programmes and routine training in the PCCB.
- Expand the pediatric oncology Fellowship Programme with a focus on radiotherapy, as well as creating new programmes in other areas (e.g., IPOU, HSCT – CAR-T or oncological pharmacy).
- Initiate positioning efforts with the key entities involved (SEHOP, ITCC, etc.)
- Design and implement the VIDA project.
- Review, restructure and update existing training and empowerment programmes.
- Promote patient empowerment in clinical trials by making research co-participative, digitalised, and humanised.

# How do we want to achieve it?

## 7.4 Fourth Line of Work: A centre open to the world with a global impact

The activities that are carried out in the centre are intended to have a global impact. We hope to continue expanding the centre's international reach, by working towards offering care to patients from other countries in the world and adding to the list of countries from where we treat patients. Furthermore, we want to build on both the Outreach and the Charity Fund programmes so we can treat patients from abroad with fewer resources who cannot access the treatments they need. Finally, the PCCB will work towards providing sustainable healthcare in line with the United Nations' 2030 Sustainable Development Agenda, both from an environmental stance and an economic, social point of view.

### Actions that will be carried out in the coming years:

- Develop new national and international partnerships, securing influential new “referees” through contracts or agreements with government entities.
- Increase patient intake from Latin American countries.
- Establish an international training programme to teach both our staff about situations elsewhere in the country and the world, and those from the rest of the country or international individuals about our centre, funded by grants.
- Explore new treatment funding routes for international patients (e.g., bank loans, insurances, and internal payment plans, among others).
- Expand both the international strategic alliances research programme with ad hoc consulting services and our offering of doctorate and post-doctorate roles, among others.
- Expand the CLOSER project for leukemia (developing teaching material for both staff, and patients and families).

- Collaborate in healthcare and training projects in mid to low-income countries.
- Establish the Charity Fund programme, which raises funds for families in vulnerable circumstances and also helps to improve clinical capacity in the places of origin.
- Bolster the Hospital's position as a leading facility in performing and analysing different diagnostic techniques, focusing on developing countries.
- Expand and solidify agreements with foundations who refer international patients with fewer resources.
- Establish a positioning and branding plan across various channels with adequate professional representation.
- Open a Hospital residence to house patients and families who do not habitually reside in Barcelona.
- Establish a plan for successful implementation of the United Nations' Sustainable Development Goals in line with the Hospital's own strategy.

# 8\_

What will we use to achieve it?

# What will we use to achieve it?

**An innovative and participative organisational and management model**

**Attracting and retaining talent**

**Infrastructures and digital transformation tools**

**A sustainable funding model**

We will make use of several facilitators that will guarantee each of our goals are achieved. These facilitators can be split into four groups: 1) an innovative, participative organisational and management model, (2) attracting and retaining talent, (3) infrastructures and digital transformation tools, and (4) a sustainable finance model.

## **8.1 Facilitator 1: An innovative and participative organisational and management model**

The organisational and management model of the PCCB will be state-of-the-art and will encourage active participation of all involved parties. It follows the FLAT organisation model promoted by the Hospital: Facilitative, to aid decision-making; Low-Complexity, to make various aspects of management run more smoothly and quickly; Autonomous, with groups being able to make their own management decisions; and Transparent, to encourage accountability.

### *8.1.1 Applying the EMC2 model*

The EMC2 model encompasses the idea that excellence is achieved through operations management, evidence and standardisation-based medicine and knowledge, and a patient-focus, meaning the experience of the patient or the user. Both the Hospital and the PCCB use this model to ensure consistent clinical excellence. .

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### *8.1.1.2 Huddles*

Huddles will be incorporated into PCCB protocols, as they are already running in the wider Hospital. They consist of short meetings at the start of the workday, in which we discuss various indicators and information about safety and quality, facilitating information exchange between professionals working in different areas and disciplines.

### *8.1.1.3 Patient experience*

As is already routine in the Hospital, the PCCB will also integrate tools to ensure the best possible patient experience: from satisfaction surveys that help us work out our net promoter score (NPS), to building PROM (patient reported outcome measures) and PREM (patient reported experience measures) measurement systems, which will allow for a transition to a more value-based healthcare model.

# What will we use to achieve it?

## 8.1.1.4 Participation

As we did already during the PCCB design stage, both patient and staff opinions will be taken into consideration during decision-making processes at our centre. We will do this using surveys, single-speciality meetings and family consultations.

### Actions to carry out in the coming years:

- Create systems of participation, coordination, and communication to consolidate the FLAT management approach
- Clarify and define the participation model for patients and families, including them in decision-making and protocol-creation processes.
- Integrate patient-specific factors into our care model, for example, the patient's culture, their country of origin, their native language, their religion, etc.
- Open a suggestion box for the PCCB.
- Increase management capacity for functional units.

## 8.2 Facilitator 2: Attracting and retaining talent

Attracting and retaining talent is vital to ensure excellent provision of care and research for patients and their families. The healthcare team is key to creating the appropriate atmosphere, giving a precise diagnosis, and providing appropriate treatment to patients and families.

### 8.2.1 Encourage educational stays

For example, in international centres, through collaborations with other leading healthcare centres. This will allow professionals to share their knowledge and experience, as well as access new, innovative resources and technology.

### 8.2.2 Healthcare/research professionals

Reduction in the number of healthcare-related tasks for a specified timeframe with the aim of developing lines of basic, translational, or clinical research.

Promote or recognise professional career trajectories within the PCCB

### 8.2.3 New professional roles

We continue to push for the development of new roles, making the most of the vast experience and expertise of our personnel and bringing added value to our teams. In this sense, each functional unit has one clinical and one administrative contact person. Additionally, we will solidify the role of nurse case managers and advanced practice nurses. Furthermore, we will consider the possibility of adding more roles, so we can provide the highest quality care to our patients, and so their experience is the best that it can be.

# What will we use to achieve it?

## 8.2.4 Cocreació en la definició dels processos

In pursuit of ongoing improvement within our centre, we will continue to keep the needs of our patients and their families in mind, just as we have done in the design of the centre. We will make use of the design thinking method, based on observation (to understand), idea generation (through co-creation), prototyping and testing. There will be daily interviews, focus groups, etc., with families, patients, and staff.

### Actions that will be carried out in the coming years:

- Create systems of participation, coordination, and communication to consolidate the FLAT management approach
- Make progress in developing new professional roles (patient manager, healthcare educator, data manager, bio-IT-tech, etc.).
- Establish and implement a specialised nursing figure in each functional unit.
- Incorporate case managers and patient managers in routine healthcare tasks.
- Guarantee healthcare professionals time away from active care so they can focus on research and education.

## 8.3 Facilitator 3: Digital transformation tools and infrastructures

To be able to offer high-calibre, efficient healthcare that addresses both our patients' specific needs and healthcare results, the PCCB will make use of several new technologies. Various initiatives will be implemented, focusing on technology integration and process digitalisation. We will also create databases, as well as new predictive models.

### 8.3.1 Cortex

Cortex is a data monitoring centre in which healthcare staff can gain access to huge volumes of key data on how the centre functions that is evaluated in real-time, with the goal of optimising patient flow and improving hospital management. Staff will have access to data that updates in real-time, such as number of beds or resources, which will help with decision-making in complex situations, such as saturations or bottlenecks. The PCCB will have its own Cortex system, allowing for easier understanding of centre-specific dynamics. In addition, the digitalisation process and the data processing model that will be used by the centre will be coordinated from this system.

# What will we use to achieve it?

## Actions that will be carried out in the coming years:

- Incorporate patient-focused digital tools: platform creation and personalised care, among others.
- Incorporate digital tools that will facilitate communication between patients and families in the centre.
- Incorporate safety systems for storing and prescribing medication (e.g., Pixys, cytostatics).
- Create digitalised pathways that allow for multidisciplinary care, facilitated by the digitalisation of clinical support services (e.g., diagnostic imaging and diagnostic anatomic pathology).
- Integrate PCCB digital initiatives with those implemented in wider Catalonia, Spain and Europe.
- Establish a data system for the PCCB which includes access to medical history records, creation of data clusters and the collection of genetic data, among other possibilities.
- Install a Cortex system in the PCCB.
- Define and launch a telemedicine model for pediatric oncology.
- Facilitate multi-channel, multi-language access for cancer patients through the Contact Center.
- Set up a technology environment that focuses on the educational needs of patients and families.

## 8.4 Facilitator 4: Sustainable funding model

The funding model will be adapted to the four fundamental lines of work at the PCCB. In terms of income, we hope to strike a balance between funding from public bodies and payment by private patients, relying on donations in the form of large-scale investments and partnership systems with the wider industry to guarantee a diverse funding repertoire. Regarding cost management, we will always aim for efficient resource use, assessing new technologies we have acquired and the healthcare protocols we have in place using pre-established methods within the Hospital, for example, the MACANT group, without sacrificing quality nor patient or staff experience.

## Actions that will be carried out in the coming years:

- Innovate the payment system for pediatric oncology patients alongside public entities.
- Increase the number of partnerships we have with different territories for increased international patient intake.
- Develop and implement a fundraising plan to finance ongoing research and healthcare projects.

# 9\_

## Governance model

# Governance model

## A governance model that involves families

The PCCB governance model consists of four bodies: the SJD Management Committee, the PCCB Management Committee, the External Advisory Board, and the Family Association.

- **SJD Management Committee:** approves the PCCB strategy, the yearly management plan, and the plan for the research and healthcare model; and monitors yearly objectives.
- **PCCB Management Committee:** creates the PCCB strategy plan and the yearly management plan; and monitors healthcare, research, and teaching activities.
- **External Advisory Board:** consulting for both clinical and research strategies, scouting international alliances and positioning.
- **Family Association:** consulting on how the centre is run. In this way, we want to take a step forward with patient and family inclusion in how the centres of the Hospital are run.



# Governance model

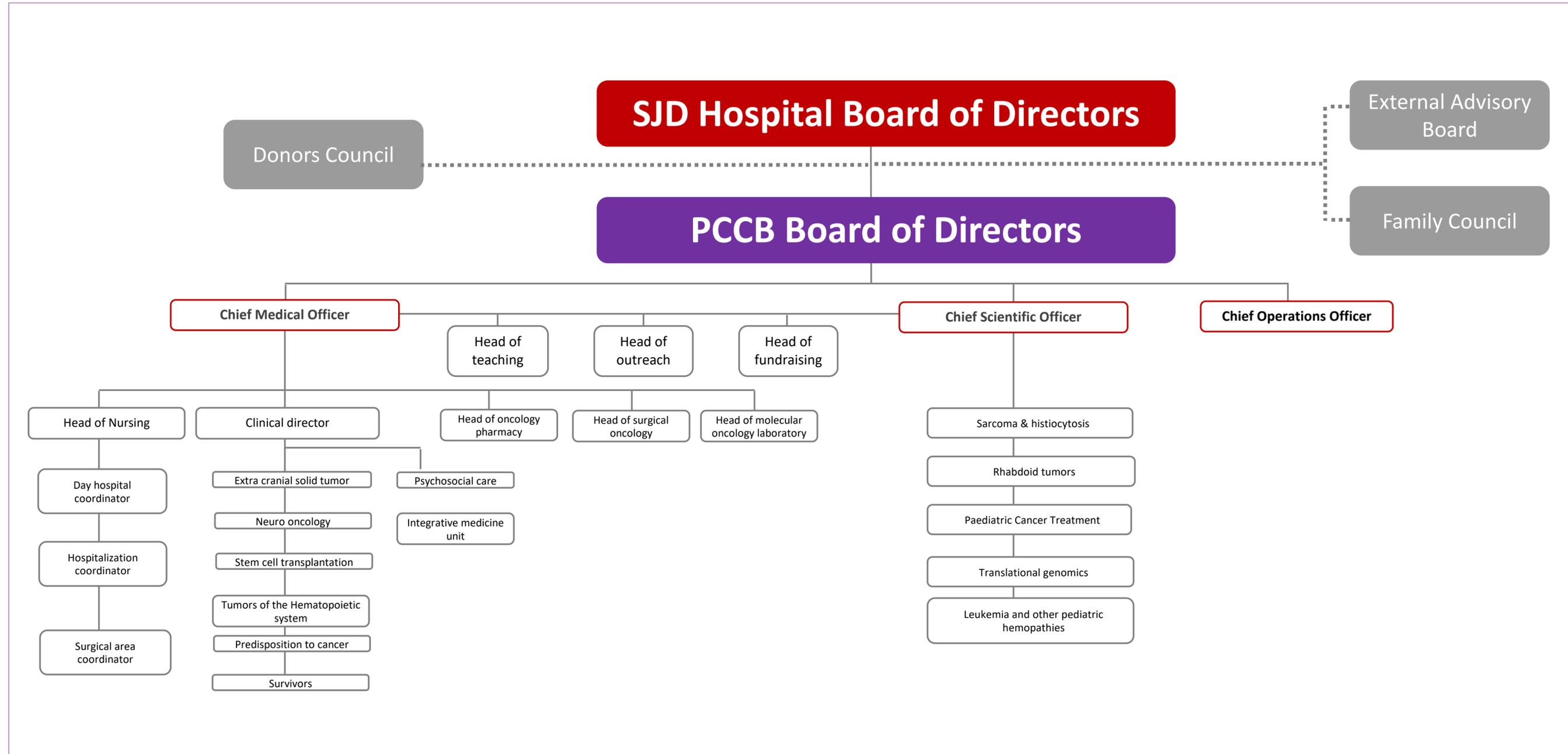


Figure 8: PCCB Organisation Chart

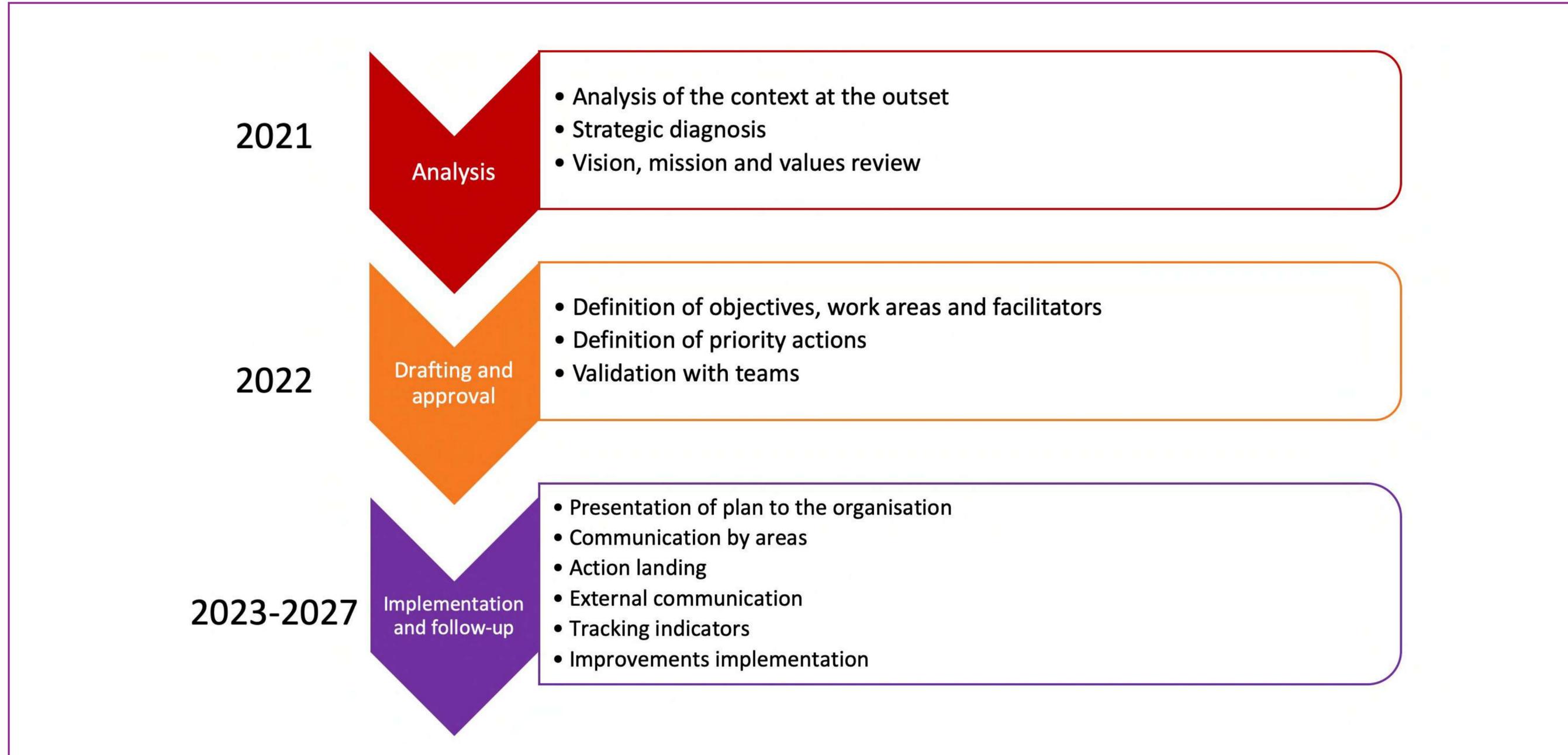
# Methodology used for creating and implementing the plan

This Strategy Plan has been created in a participative way, giving a voice to several collectives present in the centre. To do this, the following has been carried out:

- Two surveys, in which we asked for the opinion of staff about the motto, the vision, the values, the objectives, the lines of work and the facilitators in this plan. 175 staff members took part.
- Personalised interviews with staff members, with a total of 30 in-depth interviews.
- Group sessions, with more than 150 personnel members (annual PCCB session).
- Activities involving patients and families. During the month of April 2022, two focus groups were organised, which focused on acclimatisation, spaces, and care models. Participants included 6 parents and 5 children who had been treated for cancer and who had also taken part in the entire participative process for the new PCCB.



# PCCB strategy plan timeline



# Donors and collaborating partners

## Donors



## Collaborating Partners





**Pediatric Cancer Center**

Barcelona Children's Hospital