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Executive summary

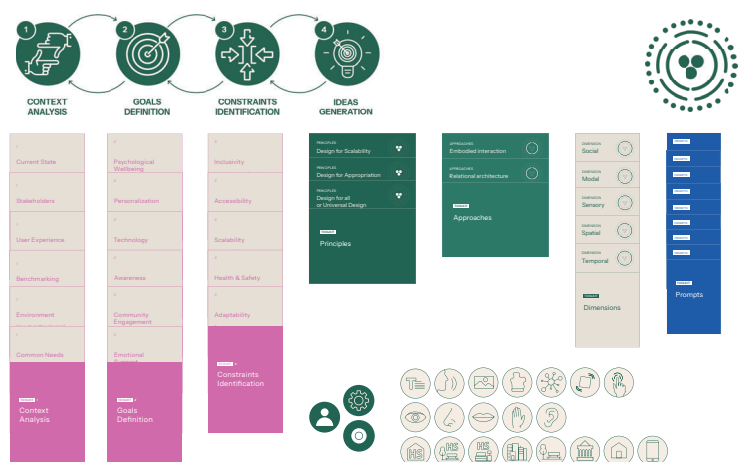
Children's Palliative Care (CPC) is a specialized area of adult palliative care tailored for children with diverse and complex conditions, including neurological, oncological, and congenital disorders. CPC focuses on enhancing the quality of life for children and their families through comprehensive care that addresses physical, psychological, relational, and social needs. Despite the significant need, with over 21 million children worldwide requiring palliative care, approximately 95% lack adequate access. The Bologna Paediatric Hospice, an initiative by the Fondazione Hospice MT Chiantore Seràgnoli Onlus, addresses this gap by providing CPC in Italy: this project aims to improve the quality of life through a holistic approach, integrating scientific best practices with technological innovation. A collaborative effort known as the FoSCHe (Fondazione Seragnoli Children Hospice Healthcare) project involves students from PoliMi and the Seràgnoli Foundation: its primary objectives are the development of a system approach as a model for Paediatric Hospices globally and the creation of positive social impact within the Bologna Pediatric Hospice ecosystem.

The project team developed **Liber-**, a meta-design framework intended to support innovative and inclusive CPC projects. Liber- makes use of a holistic approach to wellness by focusing on emotional, psychological, social, and spiritual needs: it promotes human connection and relationship-building, aiming to improve the overall well-being of children and their families. **Liber-** was operationalized into a toolkit, a versatile resource designed for use by children's hospitals, specialists, and designers in CPC. This toolkit catalyzes the creation of projects that adhere to the framework's principles and approaches, including *Design for Appropriation*, *Design for All*, *Design for Scalability*, *Embodied Interaction*, and *Relational Architecture*. The effectiveness of the **Liber-** framework was demonstrated through the development of the pilot project Heartrings: an interactive installation inspired by ferrofluid, which visualizes the impact of community and relationships inside Bologna Paediatric Hospice. As more people engage with the system, it creates evolving, structured forms, symbolizing the strength of relationships.

In summary, Liber- represents an innovative and adaptable framework for developing CPC projects that enhance human connections and well-being. Its successful application in Heartrings underscores its potential to positively influence Paediatric Hospices globally. By fostering projects that focus on the holistic needs of children and families, Liber- aims to become a best practice model, improving the quality of life in complex care environments.

Key Words

Meta-design framework, Children Palliative Care, Human-centered design, Holistic Approach.



Liber- meta-design framework and the operational toolkit



Project description written by the Principal Academic Tutor

The FoSCHe project represents an innovative advancement in the field Children's Palliative Care, by proposing to integrate a design-driven methodology in such a delicate healthcare environment. At the core of this initiative is the Liber- meta-design framework, which serves as a comprehensive tool for developing innovative and inclusive design projects: it emphasizes a holistic approach, addressing the emotional, psychological, social, and spiritual needs of children and their families, trying to promote human connections and interpersonal relationships. Liber- must be intended as a generative and operational tool. For this reason, the team has operationalized it into a toolkit intended for use by pediatric hospices, specialists, and designers: this toolkit facilitates the development of projects grounded in essential design principles, found to be crucial for the development of significant and effective projects. The first example of the Liber- application is the pilot project Heartrings, an installation, to be placed within the Bologna Pediatric Hospice, which translates the interactions of the hospice people into the collective work of a dynamic digital visualization, symbolizing the metaphor of aggregation and the building of relationships within the hospice environment.

Through the collaboration of students from PoliMi and the Seràgnoli Foundation, the project aims to influence CPC practices globally. The Liber- framework aspires to serve as a best practice model, enhancing the quality of life for children facing complex medical challenges. By combining scientific best practices with innovative design, the initiative aims to establish a pioneering approach in the field of pediatric palliative care.

Team description by skill

The project team FoSCHe is a well-rounded group of professionals and academics, bringing together a diverse range of expertise crucial for the successful development and implementation of the Liber- framework.

Sabrina Morelli (Communication coordinator) and **Maria Vittoria Faravelli** (Team Controller), both master's students from Politecnico di Milano, contribute their specialized skills in Communication Design and Architecture Built Environment Interiors, respectively. Sabrina Morelli's background in Communication Design equips her with the ability to create compelling visual and interactive elements that effectively communicate complex ideas and enhance user engagement. Her expertise is vital for designing intuitive and impactful interfaces and experiences that resonate with the needs of children and their families. Maria Vittoria Faravelli's architectural skills are instrumental in developing the spatial and environmental aspects of the project: her knowledge allows her to approach design challenges from multiple angles. Her background in architecture enables her to consider both functional and emotional aspects of design, integrating practical spatial solutions with a deep understanding of human experiences.

Chiara Di Lodovico and **Rebecca Squeri**, the project's tutors from Politecnico di Milano, bring advanced expertise in Product Design. Chiara Di Lodovico, with a PhD in Design, provides deep insights into user-centered design and innovation processes. Her experience is crucial in guiding the team through complex design challenges and ensuring that the solutions align with best practices in the field. Rebecca Squeri, holding a Master's degree in Product Design, complements this with practical skills in translating conceptual designs into functional products and services. Together, they mentor the students and help refine the project's focus and direction.

At the helm of the team is **Manuela Celi**, an associate professor in the Department of Design at Politecnico di Milano. Her role as the main academic tutor involves overseeing the project's strategic direction, ensuring academic rigor, and integrating interdisciplinary approaches into the framework. Her extensive experience in design education and research provides a strong foundation for guiding the project towards innovative and practical outcomes. Supporting her are **Daniela Sangiorgi** and **Christian Campagnaro**, both associate professors at Politecnico di Milano and Politecnico di Torino, respectively.

The team also benefits from the insights of external tutors from the Fondazione Seragnoli, including **Marco Dolera**, **Alberto Bortolotti**, and **Deborah Bolgonesi**. Marco Dolera, Lead Experience Designer at MAIS Tech, offers specialized knowledge in creating engaging user experiences, while Alberto Bortolotti's role as Chief Innovation Officer provides strategic guidance on integrating cutting-edge technologies. Deborah Bolgonesi's expertise as Project Manager and Team Coordinator ensures that project management and coordination are handled efficiently, facilitating smooth collaboration and execution throughout the project phases.

Goals

The FoSCHe project is born with the mission of advancing the field of Children's Palliative Care (CPC) through a multidisciplinary holistic approach, focused on people's well-being. Collaborating with the non-profit M.T. Hospice Foundation Chiantore Seragnoli Onlus and academia from Politecnico di Milano and Politecnico di Torino, the project has established three primary goals:

1. **Develop a Systemic Model:** The project aims to identify and create a comprehensive model for Pediatric Hospices that can be applied both nationally and internationally. This model will serve as a blueprint for integrating best practices and innovative solutions, ensuring an adaptable holistic approach to pediatric palliative care.
2. **Integrate Innovative Technologies:** The team plans to incorporate advanced design technologies and processes to enhance the scalability of the project. By leveraging these innovations, the project seeks to optimize service delivery and expand its impact, making high-quality CPC accessible to a broader audience.
3. **Generate Positive Social Impact:** A central objective is to produce a tangible positive social impact. The project will focus on developing a service system that prioritizes the well-being of patients, their families, and caregivers, ensuring that the enhancements contribute meaningfully to their quality of life.

To achieve these goals, the project involves two key phases: the first is a comprehensive research phase that examines existing service offerings within and beyond the CPC field, focusing on personal care and well-being. The second phase entails the conception, design, and development of an innovative service concept that addresses identified needs and opportunities, ensuring that the proposed solutions are both practical and impactful.

Understanding the problem

The FoSCHe project is designed to address critical challenges within the field of Children's Palliative Care (CPC), focusing specifically on the newly established Pediatric Hospice in Bologna. CPC is a vital area of healthcare dedicated to improving the quality of life for children with life-limiting and life-threatening conditions. It involves a holistic approach that addresses physical, emotional, social, and spiritual needs, aiming to alleviate suffering and enhance the overall well-being of patients and their families.

The M.T. Foundation Chiantore Seragnoli Onlus Foundation, a leader in palliative care, manages several hospices in Italy and is spearheading the establishment of the country's first Pediatric Hospice marked by the approach of putting the advancements of technological innovations in the service of an ethical mission. This facility aims to integrate excellence and innovation into every aspect of its operation, emphasizing both functional and aesthetic values in its design. Developed by the renowned firm Renzo Piano Building Workshop (RPBW), the hospice embodies a vision of beauty and efficiency, creating a supportive environment that resonates with the idea of alleviating pain by elevating the human experience.

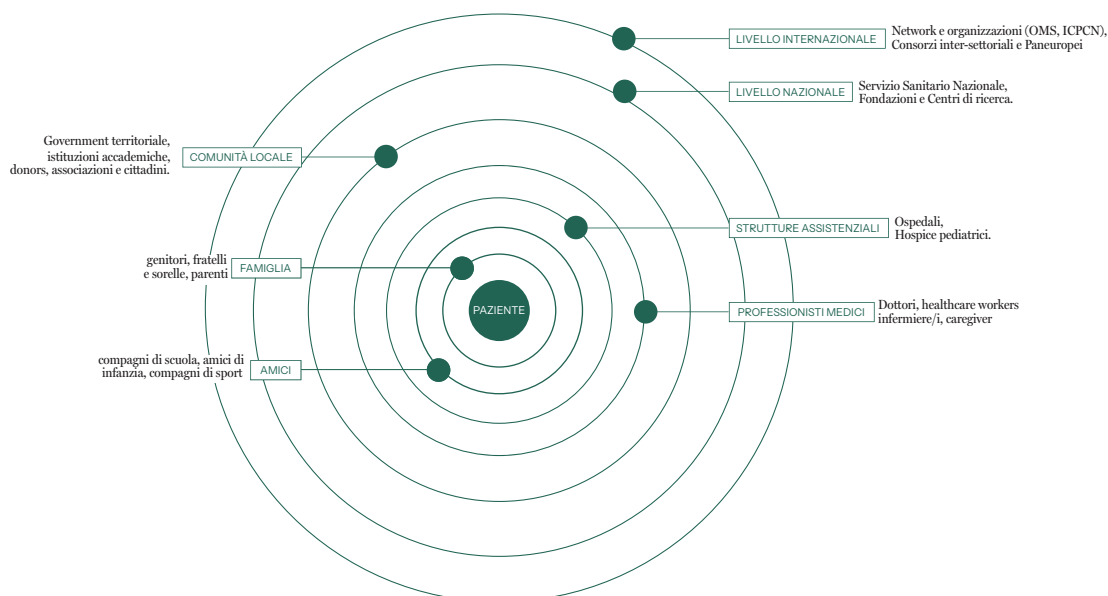


Figure 1: Stakeholders' map

The field of CPC is complex, involving a diverse array of stakeholders. These include primarily patients, their families, medical professionals, care facilities, local communities, and various national and international organizations. Each stakeholder interacts with the palliative care system in unique ways, creating a multi-layered environment that requires careful consideration. Families, for instance, are intimately involved in the care process, while medical professionals and care facilities provide essential services. The broader community and institutional stakeholders also play significant roles in supporting and shaping the palliative care landscape. The disparity between the global need for pediatric palliative care and its availability highlights the significance of the FoSCHe project. Even in advanced countries, CPC services are often underfunded and underutilized. By addressing these gaps and showcasing innovative, scalable solutions, the project has the potential to make a substantial social impact. It aims to set a best practice for pediatric hospices worldwide, promoting a message of innovation, care, and humanity in the field of CPC.



Figure 2: Arca sull'albero: Bologna Pediatric Hospice

The team's visit to the Pediatric Hospice facility provided valuable insights into the physical and emotional context of the hospice. Key reflections included the need to enhance the human dimension of care through technology, using it to address the unique needs of patients and families, and develop flexible design solutions. These observations brought to light the idea of a meta-design framework and guided its development. The name of the framework is Liber- and it aims to create a replicable and impactful Design-driven and Human-centred model for pediatric palliative care. The framework is designed to stimulate and amplify design opportunities, enhancing the human dimension within the hospice ecosystem and ensuring that the project's benefits extend beyond the local context to have a global influence.

Exploring the opportunities

The FoSCHe project stands at the forefront of enhancing pediatric palliative care by focusing on enriching human interactions within the hospice environment. This endeavor uncovers several promising opportunities, guided by a Bottom-Up approach that prioritizes the lived experiences and needs of users over prescriptive solutions.

The main opportunity, core of the counterbrief, was found during the research activity: it lies in enhancing the human dimension of care. The aim is to design services/products/systems that foster meaningful interactions among children, families, and hospice staff. By integrating elements that encourage sharing, bonding, and mutual support, the project can transform the hospice into a more welcoming and socially engaging environment that feels like home. This approach aligns with the need for projects that are not only functional but also resonate with the emotional and social needs of users, offering comfort and a sense of community.

Another significant opportunity is the integration of advanced technologies to support and enhance human connections. Including Technologies such as interactive platforms and digital visualizations could be used to create engaging and supportive environments that transcend physical limitations. For instance, technology could facilitate virtual meetups for families or interactive play experiences that cater to diverse needs and abilities.

Strengthening community ties both within and outside the hospice presents another opportunity for the project: by engaging with children and adults, with patients, families and hospice personnel, but also with local communities and other hospices around the world, the project can create a network of support that extends beyond the hospice walls. This broader engagement can help build a supportive ecosystem where families and patients feel more connected and less isolated.

The opportunity to develop flexible and adaptive design is also crucial. The project aims to create systems and spaces that are not only inclusive but also adaptable to the diverse and evolving needs of children and their families, guaranteeing inclusivity for different abilities and backgrounds.

In summary, opportunities can be translated into design practice through the application of design principles and approaches, which are ultimately at the very heart of the Liber-meta-design framework: Design for Appropriation, Design for Scalability, Design for All, Relational Architecture and Embodied Interaction. By harnessing all these opportunities, Liber aims to foster an environment where human connections and emotional well-being are at the core of care delivery.

Generating a solution

The solution generated by the team is *Liber-*, a meta-design framework aimed at enhancing the emotional and psychological well-being of children and families in pediatric hospices. Its open structure offers adaptable guidelines for designing innovative systems that foster human connections and community within the pediatric hospice ecosystem. Instead of prescribing specific solutions, *Liber-* provides a flexible framework that encourages creative, design-driven approaches, amplifying personal voices and interactions. The name "*Liber-*" reflects its core principles: freedom, autonomy, and community-centered design, emphasizing user empowerment and emotional support and resonating with the latin root meaning "children".

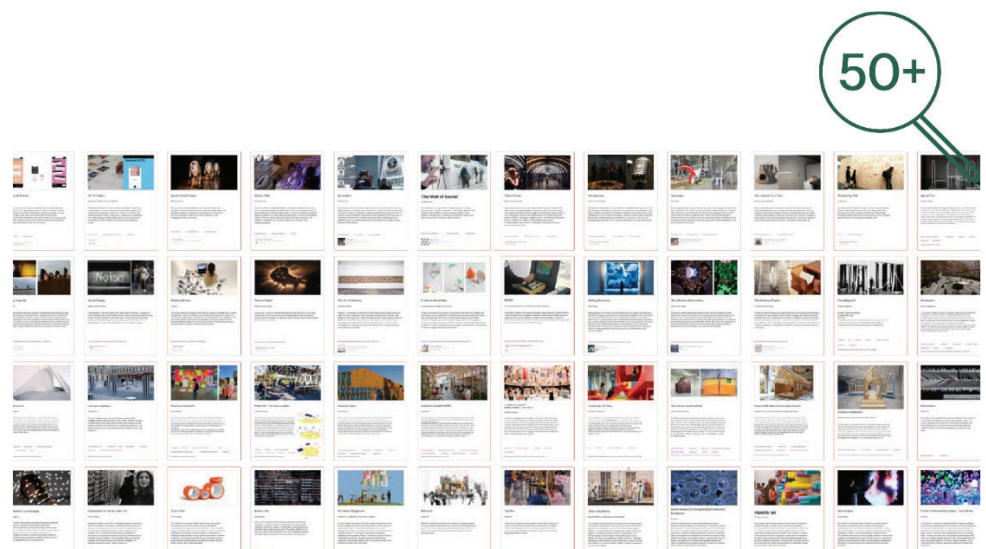


Figure 3: The collection of case studies from the art, design and architecture field

Developed from an analysis of approximately 50 case studies, the framework draws on art and design examples that prioritize human-centered and design-driven approaches. The framework was initially structured as a tree diagram, breaking down complex design systems into key components such as input, system, and output. While this analytical approach proved effective in mapping existing systems, it was less suited for creating new designs. Therefore, the framework evolved into a more flexible, circular structure, which better supports generative and dynamic design processes.

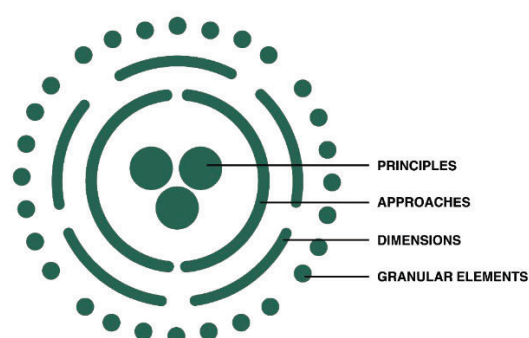


Figure 4: The structure of the Ideas Generation phase

CONTEXT ANALYSIS



It is a preparatory and crucial moment to fully understand the scope: it is essential to understand needs, challenges and opportunities and to perform informed decision-making

<p>1</p> <p>Current State</p> <p>What services are currently offered? To whom are they addressed? What are their strengths and weaknesses?</p> <p>Context Analysis</p>	<p>1</p> <p>Stakeholders</p> <p>Who are the internal and external stakeholders? What is the relationship between them? What are their needs, expectations, objectives?</p> <p>Context Analysis</p>	<p>1</p> <p>User Experience</p> <p>What is the users' journey through hospice? What emotions, of comfort and discomfort, are generated during the experience?</p> <p>Context Analysis</p>	<p>1</p> <p>Benchmarking</p> <p>What services are offered by other hospices? What are the best practices in CPC?</p> <p>Context Analysis</p>	<p>1</p> <p>Environment</p> <p>How does the physical, emotional, cultural environment influence the hospice experience and work?</p> <p>Context Analysis</p>	<p>1</p> <p>Common Needs</p> <p>What are the common needs of the various users? Are there, in addition to specific needs, cross-cutting and universal needs?</p> <p>Context Analysis</p>
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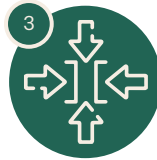
GOALS DEFINITION



Setting goals helps to guide and give clarity and consistency to the whole design process. This moment helps to stimulate discussion and reflection of the team.

<p>2</p> <p>Psychological Wellbeing</p> <p>How is it possible to contribute to the psychological well-being of all users? What is the balance sought between serious and leisure moments?</p> <p>Goals Definition</p>	<p>2</p> <p>Personalization</p> <p>What role can personalisation of spaces and activities play within the hospice system?</p> <p>Goals Definition</p>	<p>2</p> <p>Technology</p> <p>How can technology be used to improve the hospice experience for children and families? How can it be involved in facilitating and enriching the environment?</p> <p>Goals Definition</p>	<p>2</p> <p>Awareness</p> <p>What is the level of awareness in society? How can it be raised? What are the main taboos and myths in this area?</p> <p>Goals Definition</p>	<p>2</p> <p>Community Engagement</p> <p>What strategies can increase community involvement in hospice processes? What is the role of the community in the use of the service?</p> <p>Goals Definition</p>	<p>2</p> <p>Emotional Support</p> <p>How can the emotional support service for users be guaranteed and enhanced? At what times and places is it most needed?</p> <p>Goals Definition</p>
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CONSTRAINTS IDENTIFICATION



The ecosystem of a paediatric hospice is extremely complex and includes many obstacles which, if not taken into account, can really hinder the success of the project.

<p>3</p> <p>Inclusivity</p> <p>How is respect for the social and cultural values of the various users ensured? How is it possible to involve different age groups?</p> <p>Constraints Identification</p>	<p>3</p> <p>Accessibility</p> <p>How is accessibility to the service guaranteed for users? Is its fruition independent of motor and cognitive limitations? What are the main barriers?</p> <p>Constraints Identification</p>	<p>3</p> <p>Scalability</p> <p>Is it possible to scale up the project in other places, times and contexts? How is its replicability facilitated and ensured?</p> <p>Constraints Identification</p>	<p>3</p> <p>Health & Safety</p> <p>How does the design meet the standards of hygiene and safety so necessary in a hospice? What materials and forms are appropriate?</p> <p>Constraints Identification</p>	<p>3</p> <p>Adaptability</p> <p>Does the service evolve over time or does it remain the same? How does it adapt in the present and future to changing needs?</p> <p>Constraints Identification</p>
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IDEAS GENERATION



It's time to unlock creativity and begin the Idea Generation phase. This is the time to let your thoughts run free, challenge assumptions, and come up with fresh, original concepts.

Liber- proposes a specific workflow for this phase, structuring the process in 3 principles, 2 approaches, 5 dimensions, and many specificities. This structure provides non-prescriptive guidelines to facilitate and catalyze the design process.

<p>PRINCIPLES</p> <p>Design for Scalability</p> <p>aims to create solutions, products or systems that can be easily expanded and adapted to handle an increase in project size or complexity. This may include implementing scalable technologies and designing processes that can be easily replicated on a larger scale.</p>	<p>PRINCIPLES</p> <p>Design for Appropriation</p> <p>rather than creating rigid and predefined solutions, it develops open and non-prescriptive projects designed as platforms that respect and activate people's agency, the characteristics of which are shaped by users who through their practices give the project its own meaning.</p>	<p>PRINCIPLES</p> <p>Design for all or Universal Design</p> <p>aims to create products, environments and services that are accessible to and usable by all people, regardless of their physical, sensory, cognitive or age capabilities. The goal is to promote social inclusion, enabling as many people as possible to participate, without discrimination or barriers.</p>		
<p>APPROACHES</p> <p>Embodied interaction</p> <p>considers the body as an integral part of the interactive experience. Rather than being limited to interactions through technological devices, this approach involves interactive systems that encourage movement and sensoriality; it is based on the idea that physical action can amplify interactive and learning experiences.</p>	<p>APPROACHES</p> <p>Relational architecture</p> <p>revisiting the spaces we normally inhabit to create new human and sensory relationships, to increase our perception of the surrounding context, changing the usual dynamics that govern our relationship with the environment around us, revealing the possible inter-relationship between real space and virtual space.</p>			
<p>DIMENSION</p> <p>Social</p> <p>Those participating in the experience.</p>	<p>DIMENSION</p> <p>Modal</p> <p>Through what mode can one contribute to the experience.</p>	<p>DIMENSION</p> <p>Sensory</p> <p>What senses are involved in the experience.</p>	<p>DIMENSION</p> <p>Spatial</p> <p>From which location one can participate in the experience.</p>	<p>DIMENSION</p> <p>Temporal</p> <p>When and how long one can participate/access the experience.</p>

<p>PRINCIPLES</p> <p>Who contributes and generates/input s data into the system?</p>	<p>PRINCIPLES</p> <p>What type of data is collected by the system?</p>	<p>PRINCIPLES</p> <p>Where and when can you contribute to the system?</p>	<p>PRINCIPLES</p> <p>How does the system work?</p>	<p>PRINCIPLES</p> <p>What kind of information is provided to participants?</p>	<p>PRINCIPLES</p> <p>Where and when can the data generated by the system be accessed?</p>	<p>PRINCIPLES</p> <p>How are data translated by the system?</p>	<p>PRINCIPLES</p> <p>Who benefits and receives/ experiences data from the system?</p>
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Liber-'s new structure is composed by core design principles (Design for All, Design for Appropriation and Design for Scalability), guiding approaches (Relational Architecture and Embodied Interaction), and five dimensions (social, modal, sensory, spatial, and temporal), addressed also by prompts that pose specific questions to define the concept. These elements offer designers a toolbox for developing projects that can be created from scratch or modified to suit different hospice environments. The *Liber-* framework has been translated into a practical toolkit, to easily guide users through its four key steps—context analysis, defining objectives, identifying constraints, and generating ideas—making *Liber-* a valuable resource for creating emotionally impactful and inclusive designs.

To verify and demonstrate the effectiveness of such a meta-design framework, the team also focused on the development of a pilot project, called *Heartrings*.

Heartrings is an interactive installation designed for the waiting room of the Pediatric Hospice in Bologna, aiming to foster human connections and community building. The installation consists of three 3D-printed, sensor-equipped interactive objects, which respond to blowing, touch, and rotation (*Embodied Interaction*). These interactions are visually represented on a screen through a dynamic particle display, accompanied by sound. Initially inspired by the metaphor of ferrofluid, whose particles move and aggregate in response to external magnetic fields, the particles visualized on the screen move, change colour and cluster together in response to user actions, symbolizing the formation and dynamics of relationships within the hospice environment. A prototype of *Heartrings* was realized with the support of prototyper and programming experts. The interactive objects were 3D-printed: this production method not only enables the creation of different installation's objects but, in line with the *Design for Scalability* and *Design for All* principles, also encourages replication, modification, and customization of the shapes of the project, making it more inclusive, dynamic and accessible. Also, following the *Design for Appropriation* principle, the ambiguous shapes chosen for the 3D-printed objects encourage personal interpretation and exploration, while the ferrofluid-inspired display visualizes the building of connections between users, manifesting the *Relational Architecture* approach. For what concerns the system architecture, a Message Queuing Telemetry Transport (MQTT) broker was used to manage data flow: this choice allows for the decoupling of inputs and outputs, making it possible to seamlessly delocalize sensors and expand the system by adding more input devices and multiplying interactive visual or physical outputs, if wanted: this flexibility ties into the broader goals of the project by facilitating scalability and adaptability. Similarly, the choice of open-source electronics and software, including a Raspberry Pi to power real-time interaction visuals, aligns with the *Liber-* framework's principles of scalability, inclusivity, and accessibility.

Heartrings embodies the core objectives of *Liber-* by focusing on emotional well-being, inclusivity, and the promotion of community engagement. But it is only one of the infinite design possibilities generated by the *Liber-* framework. Launching Call for Projects and/or Design Workshops remains an open and interesting option for the future continuation of the project: it represents a concrete and fresh possibility to scale the project and expand its resources and opportunities. Such an event would be the perfect time to test on new ground the generativity and operativeness of *Liber-* and have in a short time a large number of concepts.



Figure 5: *Heartrings*



Figure 6, 7, 8: The interactions of the prototype, touch, rotation and blowing

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