



PALLIATIVE CARE

A co-housing project for people with serious illnesses

REPORT



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This document seeks to use language that is inclusive and respectful of gender differences. However, when it was not possible to find a stylistically appropriate neutral formulation, the masculine form was used, in accordance with traditional Italian linguistic conventions.

Executive Summary

According to the World Health Organisation (WHO, 2015), **palliative care (PC) should be initiated early** in the course of any chronic condition with a poor prognosis, in parallel with treatments aimed at prolonging survival, with the aim of improving the quality of life of patients and their families. PC plays a key role in **ensuring dignity for people with incurable diseases**, as recognised at national level by the National Recovery and Resilience Plan (PNRR) and Ministerial Decree No. 77/2022, which highlight its strategic function in the reorganisation of local care. However, the response to end-of-life needs is often fragmented, delayed and characterised by a predominantly medical-hospital approach, factors that make it difficult to ensure early and comprehensive care.

As part of the PNRR, the *Tuscany Health Ecosystem (THE)* promotes **Health Community Labs (HCLs)**: co-creation initiatives developed in collaboration with local stakeholders in the Tuscany region.

The aim of this HCL is to understand whether the early and comprehensive approach to PC, implemented through support pathways for caregivers and operators, sharing spaces and initiatives aimed at well-being, can evolve from a local initiative to a scalable territorial model. To this end, the report illustrates the HCL's experience in PC services, with a focus on **the Casa del Grano (CdG)** project.

Promoted by *the Tutto è Vita Foundation* in Cantagallo (PO), the CdG project, a co-housing facility for people with serious illnesses, proposes an **innovative model of early care centred on mind, body, relationships, nature and spirituality**, with the aim of fostering a sense of community and mutual support.

In this context, HCL has launched a **participatory process** involving healthcare professionals, volunteers and institutions, with the aim of co-creating guidelines aimed at innovating the care of patients in PC, so as to improve the services offered by the CdG project and, at the same time, promote its more effective integration and dissemination within the Regional Health System (SSR) and replicability in other territorial contexts.

The HCL covered in this report identified the CdG as its pilot model, from which the key elements of scalability were identified — such as **integrated care pathways, clear communication, continuous training of operators and sustainability** — which guided the definition of the guidelines.

Key Messages

- The traditional approach to palliative care (PC) is often characterised by late activation and a predominantly medical-hospital setting.
- The CdG proposes a model of early, comprehensive and simultaneous care. This approach integrates body, mind, relationships, nature and spirituality, improving the quality of life (QoL) of people with illness;
- Co-creation with doctors and specialists in PC, Medici di Medicina Generale - general practitioners (MMG), psychologists, nurses, spiritual assistants and volunteers in PC has made it possible to identify solutions consistent with the needs of the community, increasing shared awareness of the real needs in the area.
- The guidelines for replicating the model include the creation of integrated care pathways, the enhancement of communication and socialisation between patients, carers and operators, and the creation of accessible, welcoming and inclusive recreational and wellness spaces.

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'Accompany' is a verb that derives from a wonderful word: companion. A noun of great spiritual significance, which literally means 'one who shares bread'. It is by accompanying others that we become more human.

1. Introduction

Palliative care (PC) plays a key role at European and national level, representing a priority area for ensuring dignity, equity and quality of life for people with incurable diseases. Accordingly, the PNRR (National Recovery and Resilience Plan) and Ministerial Decree No. 77/2022 have recognised its strategic role in the reorganisation of local social and health care.

Among the Italian regions, Tuscany is one of the most advanced in the field of PC. As highlighted in the report by the Agenzia Nazionale per i Servizi Sanitari Regionali - National Agency for Regional Health Services (Agenas, 2024), the region has a comprehensive and integrated network of services, with a steady increase in the number of patients receiving care¹ both at home and in *hospices*, an increase in the number of beds and regional planning fully aligned with national objectives. In particular, the Florence area stands out for its innovative initiatives aimed at strengthening collaboration between the public and third sectors, with the aim of increasing accessibility and improving the quality of services offered.

Nevertheless, in Tuscany, Italy and Europe, a traditional approach to palliative care still prevails which, although effective in many respects, has limitations in responding early to the needs of people with illness, in combating the loneliness and social isolation frequently associated with illness, and in promoting the overall and integral well-being of the person.

This is the context for the CdG project, promoted by *the Tutto è Vita* Foundation, which proposes a new approach to the care of patients in PC: a comprehensive, early and simultaneous model. At the same time, the initiative aims to combat loneliness by offering *co-housing* solutions dedicated to patients and their families and/or *carers*, with the aim of fostering a sense of community and mutual support.

Some studies (Temel et al., 2010; Smith et al., 2017; Hui et al., 2014) show that this approach helps improve patients' *quality of life*, reduce their psychological and existential *distress*, and prolong their survival. At the same time, it provides valuable support in treatment choices, encouraging less use of aggressive therapies and reducing healthcare costs thanks to more appropriate interventions.

The Health Community Lab (HCL) on PC in Tuscany aims to analyse and capitalise on the experience of the existing pilot project, the CdG, promoting a process that involves healthcare professionals who are active and/or interested in the topic, *hospice* volunteers, and institutional representatives. Starting from an analysis of what has worked and what needs to be improved in the CdG project, the HCL intends to co-create guidelines aimed at innovating the care of patients in PC, so as to improve the services offered by the project and, at the same time, promote its more effective integration and dissemination within the SSR and replicability in other territorial contexts.

¹ In this document, we have chosen to use the expression "taking care" instead of "taking charge" to promote a change in language in line with a vision of promoting the humanisation of care.

The Tuscany Health Ecosystem and the Health Community Lab

The *Tuscany Health Ecosystem (THE)* is a research project promoted **by the Tuscany Region and all Tuscan universities**, including the University of Florence, funded by the MUR (Ministry of University and Research) through the National Recovery and Resilience Plan (PNRR funded by the European Union - Next Generation EU, Mission 4, Component 2, CUP B83C22003920001). THE has been **divided into 10 macro research themes**, assigned to the spokes, all related to life sciences issues. In particular, spoke 10 has been named 'Population Health'. The universities and public and private bodies participating in spoke 10 (Scuola Superiore Sant'Anna, University of Florence, University of Pisa, University of Siena, University for Foreigners of Siena, Dedalus spa) aimed to **integrate methods and tools to improve the ability to implement the innovations that will be introduced in the coming years in our health service**, especially through the involvement of the population and the community.

The Department of Economics and Management (DISEI), together with the Department of Architecture (DIDA), the Department of Education, Languages, Intercultural Studies, Literature and Psychology (FORLILPSI), and the Department of Health Sciences (DSS), conducted research in the field of '*Community engagement and social innovation for health and well-being of individuals and territories*', developing the **Health Community Lab (HCL)** methodology, i.e. a collaborative space involving citizens, institutions, businesses and universities to **co-create innovative solutions dedicated to the health and well-being of a community or territory**. As part of the project, each HCL developed tested the methodology in different contexts (for further information, see Biggeri et al. 2025a and Biggeri et al. 2025b), specifically testing certain parts of the process. The HCLs thus made it possible to **verify and refine the methodology through concrete cases**, even though these were **partial applications**, limited to specific areas, problems or topics of intervention.

The primary target audience of the project is doctors and trainees in palliative care, general practitioners (MMG), psychologists, nurses, spiritual assistants and volunteers specialising in palliative care. The secondary, indirect target audience is people with serious illnesses, families and *carers* who may have access to the services offered by these pathways.

This report is divided into six sections. After a general introduction (Chapter 1) and an in-depth analysis of the topic of PC and the CdG project (Chapter 2), the methodology adopted is illustrated (Chapter 3). This is followed by an analysis of *the co-creative workshops* (chapter 4) and the data emerging from the evaluation questionnaire (chapter 5). The document concludes with a summary of the results and operational recommendations (chapter 6).

2. Context analysis

2.1 *The early care model in palliative care*

The WHO (2015) indicates PC as a model for caring for the needs associated with terminal illnesses through the early identification, assessment and treatment of the physical, psychosocial and spiritual problems of patients and their families. Of particular importance in this field are the *Early Palliative Care* (EPC) and *Simultaneous Care* (SC) models, which promote, respectively, early care for the patient's needs, starting from the diagnosis of a potentially incurable disease, and the provision of PC to people with the disease and their families. PC should therefore be initiated early in the course of any chronic condition with a poor prognosis, even simultaneously with treatments that can prolong survival, with the aim of improving the quality of life of patients and their families, reducing psycho-existential *distress* and reducing the use of aggressive therapies, promoting more appropriate interventions.

Data from the scientific literature show that early introduction of PC not only has statistically significant benefits for patient survival but also has beneficial effects for *family members/caregivers*. This data is extremely important, suggesting that the early introduction of PC during the course of the disease improves the overall quality of care. Early identification of patients with PC needs is therefore a fundamental aspect for initiating an appropriate clinical care pathway for chronic disease. Furthermore, assessing prognosis and how to communicate it is one of the most delicate moments in the relationship between the healthcare team, the person with the disease and their family members. In this context, the early integration of a care model that includes PC represents a significant opportunity to improve the quality of care. This early integration is useful for a number of reasons: it offers the person with the disease and their family greater awareness of the disease and their prospects for the rest of their lives; it allows *the care team* to plan appropriate and proportionate care interventions; it facilitates the adoption of a common language, which is also useful for scientific research.

In conclusion, the model of early and simultaneous palliative care promotes comprehensive care for the sick person, especially in contexts where the main objective is no longer just the survival of the person with the disease. This model has multiple objectives: to optimise the quality of life of people with the disease at every stage of the disease by focusing on the physical, functional, psychological, spiritual and relational needs of the sick person and their *carers and* family members; to ensure continuity of care through flexible management of the person with the disease and their needs; to avoid feelings of abandonment in the advanced and terminal stages of the disease (Associazione Italiana di Oncologia Medica - Società Italiana di Cure Palliative - Italian Association of Medical Oncology & Italian Society of Palliative Care [AIOM-SICP], 2015).

2.2 *Palliative Care in Tuscany*

In recent years, palliative care has been expanded and disseminated in the Tuscany Region, both in terms of *hospice* care and community-based care. In 2024, Agenas highlighted in its annual report that the Tuscany Region is among the best equipped and most attentive in terms of palliative care planning, thanks to a regional plan consistent with the main guidelines of the PNRR (National Recovery and Resilience Plan) and supported by the resources provided by the latter for the enhancement of services.

In this regard, Tuscany has implemented the establishment and accreditation of the local palliative care network and the presence of an integrated care pathway that is uniform across the region. From 2023 to 2024, the number of patients cared for at home or in dedicated facilities grew from 10,395 to 11,154: an increase of more than 7 per cent. The number of *hospice* beds for adult patients was 185 in 2023 and rose to 206 in 2024, an increase of 21 beds. The number of people receiving palliative care also increased: 8,400 patients were cared for in 2024, an increase of 6.4 per cent compared to the previous year. A total of 4,167 patients were cared for in *hospices*, residential and semi-residential facilities: 371 more than the previous year (+9.8 per cent) (Fortini, 2025).

Overall, the Region's interest in palliative care and the number of people receiving care is growing, as demonstrated by the strengthening of services and the consolidation of home-based palliative care. The guidelines for the reorganisation of local healthcare (as per Ministerial Decree No. 77/2022) provide for the implementation of strategies to enhance the service so as to reach 90 per cent of the population concerned by 2028. In addition to this, during 2025, the Region emphasised the particularly important role of the third sector in supporting the local care network. This is the context for the CdG care pathway, which we present in the next paragraph, promoting early intervention.

2.3 The Casa del Grano project: co-housing for people with serious illnesses in Tuscany

The CdG project, promoted and managed by the *Tutto è Vita* Ets Foundation², is part of the care philosophy proposed by *EPCs* and *SCs*. Although early and simultaneous care is recommended in many documents from important institutions in the field of care, it is often very difficult to implement this model.

However, many of the most important organisations in the field of PC and care in general have conducted research with interdisciplinary working groups that have strongly highlighted the value of comprehensive care for people (European Association of Palliative Care, 2020; Sulmasy & Bledsoe, 2019; Miccinesi, 2019). In 2021, the Italian Association of Psychogeriatrics published a document on the quality of end-of-life care in nursing homes, in which it states: *'If human beings are cared for in their entirety, and their essential dimensions are interconnected, the existential needs they express always have ethical and spiritual implications, and even those that are simply biological are often manifestations of other, deeper aspects'* (Bormolini, 2021).

Another aspect that the CdG project attempts to address is loneliness. The alert issued in 2023 by Vivek Murthy, head of the *Public Health Service Commissioned Corps* and chief spokesperson on public health for the US federal government, speaks of a veritable *'epidemic of loneliness and isolation'* (Lingiardi, 2023), which affects contemporary society as a whole (Biggeri et al., 2025c, Chapter 1). The CdG project therefore also aims to respond to the need to combat the loneliness experienced by people affected by serious illness, which is often even more acute than that experienced by the general population. In fact, serious or terminal illness profoundly changes a person's life and social relationships: think, for example, of the loss or suspension of one's job, or the difficulty or impossibility of leaving the house. Furthermore, we know that, epidemiologically, degenerative and incurable diseases most frequently affect older age groups (Istituto Superiore di Sanità, n.d.), where patients are more likely to already be living in social isolation and economic hardship.

² www.tuttovita.it

One of the aims of the CdG is therefore to place people in the facility for a period of 'regeneration' of variable duration (up to three months) so that people with illness can live in a community (in the form of *cohousing*), so that illness and suffering are not relegated outside the social and community fabric but harmonised in all aspects of social life. The creation of a social fabric in which illness and health, life and death return to being equal conditions and part of a single 'existence' is, in fact, an integral part of the innovations proposed by the CdG.

2.4 The structure of the project

The CdG project in Borgo Tutto è Vita (Mezzana, Municipality of Cantagallo, Province of Prato) involves *co-housing* based on the concept of 'integral care' (Istituto Superiore di Sanità, 2024; Bormolini et al, 2024), offering every opportunity to create a community around the sick person and their carers/family members.

Through the programmes offered within the CdG, a process of reflection and awareness of the experience of illness is encouraged, which can also help in the development of Disposizioni Anticipate di Trattamento - Advance Treatment Directives (DAT) open to a holistic dimension of the person that includes aspects related to the body, mind and spirit.

The methodology used, with a view to holistic care, alternates between moments dedicated to the psyche and the processing of emotions; to the body (with breathing and yoga techniques); and finally, spaces for teaching meditation and internalisation practices.

The CdG facility consists of a building surrounded by greenery in the Bisenzio valley, with a maximum of 40 beds in single, double and triple rooms, designed to accommodate people with illnesses and their *carers* and/or family members, including children and adolescents. The premises have small communal kitchens, while the rooms are private and not shared.

Attached to the facility are a fully equipped gym and the building called 'Casa Peter Pan', a space dedicated to programmes for children and young people connected to patients. The aim of these programmes is to strengthen and promote the empowerment of children facing the anticipatory grief that accompanies the serious or terminal illness of a family member, helping them to become aware caregivers in a manner appropriate to their age, level of maturity and personal resources.

Within the scope of *EPCs* and *SCs*, the CdG is therefore a pilot project that could be replicated throughout Tuscany and beyond. The project is being carried out in close collaboration with the local AUSL (Azienda Unità Sanitaria Locale), the Prato Health Authority, the PC network, the Tuscany Region, the Province of Prato, the Union of Municipalities of the Bisenzio Valley and the Municipality of Cantagallo. The project has already been submitted for supervision to the director of the PC of the AUSL Toscana Centro and the director of the Prato *hospice*, with a view to establishing a collaboration that could also be institutionally sanctioned. All this with a view to possible replication in other places, where the third sector could offer beds in the form of *co-housing*, introducing an intermediate structure between home care and *hospice* care that would alleviate the pressure exerted by patient demand in the face of insufficient bed availability compared to what was planned.

At present, the project is entirely funded by the third sector organisation *Tutto è Vita Foundation* and the Foundation's volunteer network.



Figure 1 and Figure 2 - Current configuration of the Casa del Grano project.

2.5 Services offered and future proposals

The CdG facility aims to provide participants with the services of a number of operators: an Operatore Socio Sanitario - healthcare worker (OSS) (available 24 hours a day) and a nurse (8 hours a day) for the entire community in case of need for assistance. In addition to this basic support staff, other care providers will be regularly present with a view to providing comprehensive care for the individual: 2 physiotherapists, 3 psychologists, 3 art therapists, 1 social worker, 5 spiritual assistants, and 9 yoga instructors, who will gradually cover 50 hours per week with their presence at the CdG.

The innovative idea behind the project is to return to the original spirit of the PC, in which the *pallium*, the cloak of care, embraces all dimensions of the human being: physical, but also emotional, existential, social and spiritual.

In this regard, within the CdG project, the third sector will offer assistance for people's physical needs (non-medical), existential and spiritual support. All this will be integrated with medical care and psychotherapy for people with serious and terminal illnesses provided by the National Health Service's home care service, who will thus have a collective home at their disposal.

Below are some *renderings* of the project's facilities within the Borgo *Tutto è Vita*, which, upon completion, will also include the construction of a *hospice* with a particular focus on spirituality, to be called *the Spiritual Hospice*.



Figure 3 - Rendering of the future Spiritual Hospice.



Figure 4 - Rendering of the lower part of Borgo Tutto è Vita, with art studio, refectory and large room for silence, prayer and interfaith meditation



Figure 5 - Rendering of Borgo Tutto è Vita, overview from above.

2.6 Evaluation of participants in the Casa del Grano programme

During the HCL, data was collected on the first participants in the CdG's comprehensive programmes. These first participants followed the experimental programme by completing a questionnaire at the beginning and end of the experience. The questionnaire used for the evaluation was FACIT-Pal (Functional Assessment of Chronic Illness Therapy – Palliative Care) (Lyons et al., 2009), a multidimensional tool developed to assess the quality of life of patients undergoing palliative care. It derives from the integration of the FACT-G (Functional Assessment of Cancer Therapy – General) questionnaire, which explores physical, functional, emotional and social well-being, and the FACIT-Sp, which adds the spiritual and existential meaning component.

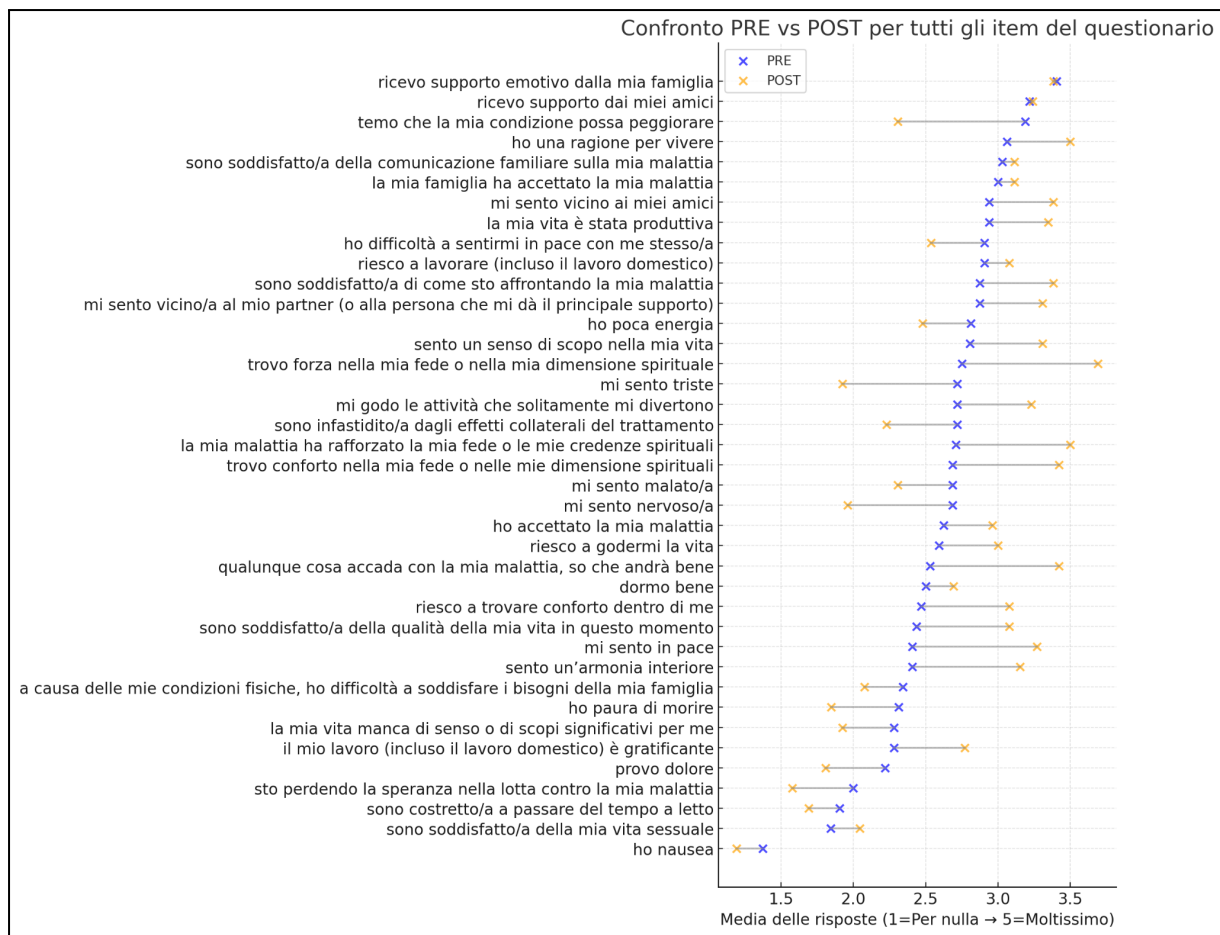


Figure 6 - Questionnaire results. The graph shows the change in scores before and after the programme.

Analysis of the questionnaires administered before and after the programme shows an overall positive picture, with signs of improvement especially in the spiritual dimension and, to a lesser extent, in the psychological dimension. The average scores, expressed on a scale of 1 to 5, indicate that after the intervention, patients tend to perceive a greater ability to cope with their condition and a stronger sense of personal meaning.

In the psychological sphere, there is an increase in the sense of satisfaction with the way patients cope with their illness, a sign of a progressive strengthening of resilience and greater acceptance of the situation. At the same time, there remains a slight difficulty in feeling fully at peace with oneself, suggesting that the emotional dimension, although improved, remains fragile and requires ongoing support. Palliative care therefore seems to promote greater awareness and a more solid ability to adapt, even if it does not completely eliminate anxiety or inner tension.

On a social and relational level, the scores are stable. The emotional support perceived by the family remains high in both phases, while the family's acceptance of the illness shows slight progress. This suggests that emotional and supportive relationships were already strong before the intervention and that the shared experience of the illness has helped to further consolidate family cohesion. No significant changes were recorded, but a protective and stable relational environment was confirmed, which is essential for the overall well-being of the person with the disease.

The spiritual dimension shows the most evident change. The increase in the score relating to the perception that the disease has strengthened faith or personal beliefs indicates a process of inner maturation and existential growth. During the course of their treatment, patients seem to have found new sources of meaning and comfort, recognising in their experience an opportunity for deep reflection on life and their values. Spirituality emerges as an important factor of support, capable of accompanying the person on their journey through illness with greater serenity and meaning.

2.7 International Classification of Functionings (ICF), capability approach and PC

The capability approach allows us to reflect on adherence to PC as the possibility of choosing how to live the last part of life to the fullest, possibly even giving up some physical functions in favour of others that are relational and spiritual. Such choices, if considered exclusively in the light of the International Classification of Functioning, Disability and Health (ICF), may appear inconsistent, since the main objective of this classification system is to promote an increase in individual functionality, while providing a standardised language and framework for describing health and related states. However, when the ICF is integrated with the *capability* approach, respect for individual *agency* (rather than autonomy) takes priority and translates into recognition of the freedom to choose how to live and, if necessary, how to approach the end of one's life (Biggeri, et al. 2025d). As Sen (1999) observes, the achievement of a person's *agency* concerns, in fact, 'the realisation of goals and values that they have reason to pursue, whether or not they are related to their own well-being' (Sen 1992: 56).

The Capability Approach

The capability approach, developed by Amartya Sen (1999), is a conceptual framework that defines development and well-being not in terms of wealth or resources, but in terms of real freedoms.

- **Capabilities** (Real Opportunities and Abilities): These are the real opportunities/abilities and substantial freedoms that a person has to do and be what they have reason to value (e.g. having the opportunity to be healthy, to access quality social and health services, to be educated (in health *literacy*), to participate in decision-making).
- **Functioning**: These are the states and actions that an individual actually achieves (e.g. being well nourished, participating in a debate).
- **Agency**: This is the ability of individuals to act and bring about change based on their own goals concerning their own well-being and that of others.

The approach emphasises that **participation** (in politics and various decision-making processes) **has intrinsic and instrumental value**, as it expands human freedoms and individual and collective *empowerment*. *Capabilities* are highly dependent on conversion factors that are personal, territorial and contextual (similar to the social determinants of health), making the removal of local barriers crucial for full well-being.

However, it should be borne in mind that, as social beings, our decisions are often guided by the impact they may have on others, just as our capabilities are, in turn, influenced by the choices of others. The *capability* approach also considers the impact of individual choices on the capabilities of others, such as family *caregivers*, and, more generally, *on* collective *agency*. In this way, it avoids reducing human agency to individual interests, while affirming the freedom of individuals to determine how and to what extent the interests of others enter into their own ends.

Applied to the end of life, the *capability* approach embraces the idea of flourishing, which can manifest itself in different ways in the final stage of existence. For example, as Donaldson (2024) observes, palliative care, both in hospices and through supporting the desire of the sick person to die at home, involves a teleological shift in medicine: from the goal of prolonging life at all costs to that of ensuring a 'good death' through acceptance of its inevitability. The end of life is not, in fact, a simple matter of choice (e.g., euthanasia vs. palliative care vs. non-palliative care), but a journey that involves the body, the psyche and spirituality. For this reason, the process through which one decides how to live this moment, and what care to receive, is as important as the choice itself.

The CdG is a tool that facilitates the comprehensive care of the person at the end of life and their family *caregivers*, giving them the opportunity to make informed choices and embark on an integrated and shared process.

3. Methodology

HCLs are based on the concept and rules of *the Living Lab*³ (Leminen *et al.* 2012), i.e. an environment of innovation in which citizens, businesses, universities and public bodies co-create innovative solutions and apply them in real-life situations. Each HCL represents an innovation project in which these actors collaborate, co-create and implement initiatives and solutions related to the health and well-being of a specific community⁴. The main theoretical reference is the perspective of sustainable human development (Biggeri *et al.* 2023), which recognises the centrality of the individual and the community in transformation processes and is based on five pillars - *productivity, equity, environmental sustainability, participation & empowerment, human security* - while emphasising the role of human *collective agency*, which is expressed through interactions between different social actors and guides transitions towards sustainability.

The methodology is divided into three phases:

1. *Preliminary phase*: begins with the identification of needs related to a specific health or well-being issue (*conceptualisation*), followed by a context analysis in which the key stakeholders and⁵ s to be involved in the subsequent phases are identified and data useful for the successful implementation phase are collected (*context analysis and planning*).
2. *Implementation phase*: consists of the co-creation of a prototype together with the stakeholders identified in the previous phase (*design*).
3. *Evaluation phase*: this involves evaluating the process, the prototype created, as well as the dissemination, possible scalability and maintenance over time of the solutions developed, with particular attention to their sustainability.

The structure of the paragraph follows the three operational phases of the project: preliminary phase, implementation phase and evaluation phase, providing details for each phase on the activities carried out, the actors involved, and the data collection and analysis techniques used. Section 3.1 is dedicated to the design of the study, while sub-sections 3.1.1, 3.1.2 and 3.1.3 present the three phases of the project respectively. Each phase is analysed from both an operational and methodological point of view in order to provide a clear and systematic overview of the participatory process undertaken. A short final section is dedicated to ethical aspects.

³ According to the European Network of Living Labs (ENoLL), *Living Labs* are '[...] user-centred, open innovation ecosystems based on a systematic user co-creation approach, integrating research and innovation processes in real-life communities and settings'. See: <https://enoll.org>.

⁴ For more information on HCLs, see Biggeri *et al.* 2025a.

⁵ A stakeholder is an individual, group of people or organisation actively involved in an initiative, whose interests are negatively or positively affected by the outcome of the implementation or progress of the initiative, and whose actions or reactions in turn influence the stages or completion of a project or the fate of an organisation. See: <https://dictionary.cambridge.org/dictionary/english/stakeholder>.

What is co-creation?

Co-creation is an approach based on **active collaboration between a variety of stakeholders** (Vargas et al., 2022), aimed at **creatively resolving shared issues** (McCaffrey et al., 2025; Messiha et al., 2023). This process develops throughout all stages of the initiative, from the exploration and identification of needs or critical issues to the design, implementation and evaluation of solutions or interventions.

In recent years, co-creation has become increasingly important in the context of strengthening health systems. In its global strategy for integrated health services 2016-2026, the World Health Organisation (WHO) promotes a co-creative process for the development of integrated and people-centred health services through the involvement of governments, service providers and citizens (WHO, 2015). Co-creation therefore plays a central role in this area, as **the challenges faced by contemporary public systems, often characterised by increasing social complexity, require the active involvement of a wide range of social actors in public governance** (Torfing & Ansell, 2021).

What is the difference between co-planning, co-design and co-creation?

Co-planning and co-design (Art. 55, Legislative Decree 11/2017) are structured and regulated forms of public-third sector or public-citizen collaboration, while co-creation is a more recent and broader concept that takes on a wider, horizontal and participatory dimension involving all stakeholders - users, communities, professionals, institutions and research.

- **Co-planning** refers to the phase in which administrations and other actors jointly identify needs, priorities, methods of intervention and resources.
- **Co-design** concerns the following phase, in which the actors involved define and implement specific projects or interventions on the basis of shared planning.
- **Co-creation** goes even further: it involves the participation of all actors from conception, design, implementation and evaluation, with the aim of generating together.

3.1 Study design

Following the HCL approach, the study was divided into three main phases.

In the first phase (*preliminary phase*), a review of the state of the art of PC in the Tuscany Region was conducted, with particular attention to the CdG project. The aim was to gain an in-depth understanding of the context, the main challenges and the actors involved.

In the second phase (*implementation phase*), four co-creative *workshops* were held involving healthcare professionals active in the field of PC, aspiring spiritual assistants, volunteers, postgraduate students and organisational and institutional figures. Based on the evidence

that emerged, guidelines were co-created to improve the care of PC patients and the services offered within the CdG.

In the final phase (evaluation *phase*), the results of the questionnaire administered to workshop participants during the implementation phase were analysed. The questionnaire aimed to detect changes in participants' perception of *agency* and to assess their level of satisfaction with the experience.

HCL phase	Prototype creation activities	Actors involved			
		Public actors	Private actors	Research bodies	Civil society
<i>Preliminary phase</i>	Conception		x	x	
	Context analysis and planning		x	x	
<i>Implementation phase</i>	Design	x	x	x	x
<i>Evaluation phase</i>	Distribution/ Dissemination	x	x		
	Evaluation		x	x	
	Maintenance	x	x		

Table 1 - Stakeholders involved in the HCL phases (based on Laurisz et al. 2023).

3.1.1 Preliminary phase

In this phase, a review of the PC system in the Tuscany Region was conducted, with a focus on the CdG project. The analysis emphasised the elements that make this project an innovative experience in the regional landscape. The review covered both the services currently active within the CdG and the vision that guides its work.

Based on this analysis, the working group identified the thematic areas on which to focus the subsequent co-creative *workshops*. The information gathered also guided the selection of *workshop* participants, which included healthcare professionals, volunteers, aspiring spiritual assistants, postgraduate students, and organisational and institutional figures, with the aim of ensuring a broad and diverse representation of the different actors and perspectives involved in the PC system.

3.1.2 Implementation phase

The *Tutto è Vita Foundation* was responsible for identifying and engaging the stakeholders identified in the preliminary phase, inviting them to participate in the implementation phase. This phase involved the implementation of co-creative *workshops*, which took place through four *Focus Groups* (FGs) (Kitzinger, 1995), each lasting approximately one and a half hours. In order to ensure in-depth discussion and encourage participants to express themselves

freely, the groups were organised homogeneously by professional role: healthcare professionals and aspiring spiritual assistants, volunteers, PC trainees, and organisational and institutional figures. This methodological choice made it possible to explore a wide range of perspectives, reducing the risk of inhibitions or imbalances linked to the presence of hierarchically different roles. In fact, despite the homogeneity of roles, the groups included participants from different *hospice* contexts, thus ensuring a reduction in power asymmetries among participants and, at the same time, a rich variety of experiences and points of view.

The four *workshops* were held in June, July and September 2025 at three locations: Villa al Palco (Prato), Borgo *Tutto è Vita* (Vernio) and the headquarters of the *Tutto è Vita Foundation* (Florence). The sessions were led by a facilitator with the support of one or more observers.

A total of 39 people participated. Ten people (one man and nine women) took part in the FG dedicated to healthcare professionals and aspiring spiritual assistants; 11 people (one man and ten women) participated in the volunteer group; the FG for postgraduate students saw the participation of seven people (four men and three women); and finally, 6 men and 5 women participated in the FG with organisational and institutional figures. The following table shows the main socio-demographic characteristics of the *workshop* participants, with reference to number, gender, average age and distribution by age group. In this regard, it is interesting to note that the composition of the groups shows a significant gender difference in participation, with a clear prevalence of women among healthcare professionals and volunteers.

Workshop	No. of participants	Gender	Average age	Age range	Age	Role
1	10	9F/1M	53	39-61	0 < 35 10 (35-65) 0 > 65	Healthcare workers
2	11	10F/1M	62	46 - 77	0 < 35 6 (35-65) 5 > 65	Volunteers in PC
3	7	3F/4M	40	27	2 < 35 5 (35-65) 0 > 65	PC medical residents
4	11	5F/6M	58	43 - 72	0 < 35 6 (35 - 65) 3 > 65	Organisational and institutional figures

Table 2 - Socio-demographic characteristics of participants in the implementation phase. Source: our own elaboration.

After a brief presentation of the CdG project by some members of the *Tutto è Vita Foundation*, the semi-structured FGs focused on three main themes:

1. The difficulties most frequently encountered by patients in PC (social, relational, psychological, cognitive, etc.) and how the CdG project could help to overcome them;
2. The strengths of the CdG project and areas for improvement;
3. Operational suggestions for improving the CdG project.

Based on an analysis of the first three FGs, a number of guidelines were drawn up to innovate the care of PC patients, developed from the ideas that emerged from the discussion between the participants and conceived as a reference for the development of practices and organisational models. These guidelines were subsequently discussed and validated in the last FG, which was attended by organisational and institutional figures.

In addition, at the end of the first three *workshops*, a concluding activity was proposed in which participants were invited to write on a piece of paper a word or short phrase that expressed what PC meant to them.

The *workshops* were recorded and transcribed *verbatim*.

3.1.3 Evaluation phase

During the *workshops*, participants were given two online questionnaires to complete at the beginning and end of the meetings (Participation Questionnaire). The questionnaire aims to detect changes in participants' perception of agency and to assess their level of satisfaction with the experience. Each response was recorded using an anonymous code. The three areas assessed concern the following areas:

- Perception of factors that impact well-being in PC;
- Assessment of participants' *agency*;
- Satisfaction with participation.

Responses were coded using 5-point *Likert* scales. The concept of *agency* refers to an individual's ability to act deliberately to pursue goals that they have reason to value (Biggeri & Ferrannini, 2014). In other words, a person is an agent (*agency*) when they are able to make autonomous decisions and actively influence their own life and the surrounding reality, based on their own values, preferences and goals (Crocker & Robeyns, 2009).

The activities carried out in *the workshops* were analysed through a thematic analysis: describing the categories that emerged and summarising the main results. The questionnaire was analysed on the basis of the different dimensions assessed. The average *agency* values were estimated according to the validated scale and by performing a t-test on the measurements before and after the *workshops*. Similarly, pre- and post-changes in individual *items* related to factors influencing well-being in PC were analysed in order to assess any changes in perception on this issue. The level of satisfaction, on the other hand, was measured exclusively at the end of *the workshops*.

3.2 Ethical protocol

All participants received oral and written information about the study, its objective, research design and privacy, with the opportunity to ask questions and withdraw from the study at any time. Written informed consent was obtained prior to their inclusion in the study.

4. Co-creative workshops with healthcare professionals, aspiring spiritual assistants, volunteers, postgraduate students, and organisational and institutional figures

The context analysis of the preliminary phase provided important insights into the topic of PC, proving essential for outlining a clear and detailed picture of the needs and requirements of those involved. The data collected guided the identification of topics of particular relevance, which were subsequently explored and discussed during the co-creative workshops. The following key themes emerged from these workshops.

4.1 Humanisation of Palliative Care

During the FG involving volunteers, a number of limitations of the current model of palliative care were identified, including the predominantly medical-hospital approach, partly determined by the delay with which patients normally access this service. In this way, the experience of illness is reduced to clinical management alone, neglecting fundamental aspects related to identity, emotions and the need for existential support. The result is a care system that is unable to fully respond to the profound needs of those facing a difficult phase in their lives.

"Last year, the average length of stay went from 21 days, which is still short, to 14. So when we welcome people into our hospice, sometimes we try to run for cover, sometimes we take what we have and maybe we only have to intervene to manage the urgent symptoms."

(Volunteer hospice nurse)

To overcome these limitations, FGs participants highlighted how early care in PC, activated at the time of a poor prognosis, is the essential starting point for the humanisation of care. Early care allows the person with the disease to develop a greater awareness of their clinical condition and to make informed choices about how they wish to deal with the course of the disease, independently evaluating the various treatment options available.

Self-determination, closely linked to clear, transparent information that respects the person's needs, allows the person with the disease and their family to access services early on, focusing on the possibility of playing an active role in their own life and care journey. In this sense, the CdG stands out as a place where the person does not feel reduced to their clinical condition, but recognised in their entirety, with their bonds, values and desires.

"The fact that it is not a hospital environment, but effectively a home, does not give you the feeling of being in a place where sick people go, and so you realise that you are definitely among lots of people who may be family, friends or relatives. You are not the illness, you are the person."

(Doctor)

This description highlights how the environment of the CdG itself contributes to humanising care, making the patient feel central and recognising them as a person and not as a disease.

"The person can take the time to think that they are a person with an illness and not just their illness."

(Thanatologist)

The CdG has therefore been recognised as a particularly effective example of innovation in the humanisation of PC, especially for the possibility of allowing time thanks to early treatment: a relaxed time that allows one to stop, reflect and process what is happening, opening up the possibility of reworking one's experiences and giving new meaning to one's existence. Time thus becomes a fundamental tool: it allows people to reflect, rework emotions and prepare themselves to make informed choices about their lives and their care pathway.

"[...] time to choose how to live and how to die, because this also gives us time to talk about end-of-life decisions, which are often made with a person who has more energy, more strength, more capacity and more lucidity."

(Thanatologist)

These contributions emphasise how early care not only improves quality of life, but also encourages the sick person to be proactive and maintain their personal resources, enabling more meaningful and integrated management of the disease.

4.2 The relational dimension in care

In the context of PC, the relational dimension plays a fundamental role. Many patients and their families, when faced with a serious or degenerative illness, experience a profound sense of emotional loneliness and relational fragmentation. In addition to its physical impact, the illness often has the effect of disrupting the rhythm of daily life, creating a void not only in spaces but also in relationships. It is precisely in this context that the *co-housing* model proposed by the CdG project takes shape, not only as an effective logistical solution, but also as a therapeutic and humane choice, capable of giving new centrality to the relational dimension in the care pathway.

All the FGs highlighted the need to cultivate open, authentic and ongoing dialogue between patients and family members, *carers* and healthcare professionals, which is considered essential for building a truly personalised and person-centred care pathway.

"[...] ask them 'what do you expect from this hospitalisation, what have they told you, what have they explained to you, how do you feel', and start a dialogue from there."

(Volunteer hospice nurse)

Dialogue and exchange between patients themselves is also considered crucial in encouraging the sharing of emotions, experiences and fears related to the experience of illness. In a safe and welcoming space, such as that offered by the CdG, it becomes possible to freely express deep feelings, such as fear of pain or death, without the fear of having to protect one's family or be judged.

"[...] discussion and dialogue, and therefore relationships, are, I think, the basis for opening up about one's personal experience. So I think that La Casa del Grano is a great opportunity for discussion."

(Volunteer hospice nurse)

Living together, even if only for a few days, in a protected and familiar environment, can generate new, authentic and deeply healing bonds. It is through daily interaction, a shared meal, a walk, a kind word, that inner resources are reactivated and a sense of belonging is rebuilt.

A key element in the success of this approach is the organisation of small group meetings, which avoid the risk of intrusiveness and foster intimate and welcoming relationships. In fact, not everyone feels comfortable with social exposure, especially in fragile stages of the disease: this is why it is important that the community dimension is limited. This approach not only combats isolation, but also generates meaning, a fundamental element in facing the journey of the disease with dignity and humanity.

'There are people for whom a group that is too large can be intrusive. Instead, Casa del Grano, made up of small units, offers the opportunity for people who have things in common at that moment to interact, thus creating a more welcoming microcosm.'

(Volunteer hospice nurse)

However, some participants highlighted the ambivalent nature of *co-housing* and peer relationships. On the one hand, they represent a valuable opportunity to authentically express one's emotions, develop awareness and feel less alone in one's experience. On the other hand, they can generate anxiety or suffering, especially in those who perceive the experience of others as a painful anticipation of their own journey. In order for socialising to truly have therapeutic value, it is necessary to find a balance between these two extremes: valuing the generative potential of peer encounters and providing a safe and supportive environment where sharing is facilitated by competent figures capable of containing and managing possible negative emotional repercussions.

'(Sometimes it is possible) to find benefit in the experience of others, or to start feeling a great fear, [...] because you think, 'Wow, that will be my end. [...] if I meet someone who has the same illness as me and who eventually recovers, then it's natural to feel positive energy. If I meet someone who may have had exactly the same experience as me but who actually comes here and dies [...] I may [...] feel anxious, because I see a preview of what may soon be my reality [...]'.

(Volunteer hospice nurse)

4.3 Caring for family members, carers and healthcare professionals

In the care process, it is essential that attention is not only focused on patients, but also on those who accompany them closely. Family members, *carers* and social and healthcare workers are fundamental figures, but with distinct roles and needs.

Family members and *carers*, who are often emotionally involved, offer emotional support, closeness and constant presence, while facing a psychological, relational and economic burden that is sometimes overlooked. Caring for them means recognising the profound impact that illness has on the entire family unit.

Healthcare professionals, on the other hand, whether doctors or nurses, ensure the physical, psychological and, in some cases, spiritual well-being of the person with the disease. Here too, in order to provide genuine and competent care, it is necessary to devote time to caring for them, listening to them and helping them to decompress.

4.3.1 Family members and carers

In accompanying family members and *carers*, the burden on them is emotional, physical, organisational and financial, and often the healthcare system fails to provide adequate tools to support them effectively. The risk is that, while caring for the person with the illness, the family's need for support is neglected. Unlike other healthcare facilities, the CdG is described by participants as a 'healing community', i.e. a space for the entire family to rebuild. It offers a chance to take a breather, a break from treatments, emergencies and anxiety. It is a place where families can stop and come together in a time of extreme difficulty.

'A place like the Casa del Grano is like giving these families a breather, because I imagine that from the moment of illness, everything is very hectic, with treatments, anguish and despair, so stopping, taking these families to heart and giving them a breather, reuniting them with their children and relatives, means reorganising and removing some of the anxiety. It creates a new horizon and therefore a new stability, allowing them to start again with strength and resources.'

(Psychologist)

The time and space offered by the CdG also encourage conscious processing of the imminent separation, allowing family members to benefit from a support programme that enables them to consciously face the final stage of their loved one's life. This process of emotional and psychological preparation is essential to reduce the trauma of separation and promote a healthier and less conflictual grieving process.

"Often, patients do not tell their families that they are approaching death until the very end, and this is a huge trauma for those close to them [...] if such a case is taken on early, awareness-raising work can be done."

(Director of the Health Authority, Prato)

"This would allow family members to prepare themselves so that they can say goodbye and bring closure."

(Director of Palliative Care, Prato and Pistoia)

Nevertheless, according to the healthcare professionals who took part in the FG, even in a welcoming and protected place such as the CdG, family members may find themselves experiencing a form of 'secondary' isolation, which is less obvious but equally impactful. Far from their homes, work, friends and daily lives, they often find themselves putting their lives on hold to be with their loved one, with a significant impact on their emotional and organisational stability. Being close to the person with the illness can bring comfort, but at the same time it can create a forced disconnection from the outside world which, if not supported by a solid network, risks becoming alienating.

This suspension becomes even more complex when there are other children or relatives in the family who continue their lives elsewhere, making it difficult to maintain active contact with their local area and established habits. In particular, for children and young people, continuity in activities such as school, sport, or even simply their daily routine, represents an essential anchor to normality.

'The family around them may have difficulties travelling (to and from the CdG). [...] Because it is true that sometimes having a place where you can [...] suspend everything and devote yourself to that (is a positive factor), but it is also true that [...] maintaining daily habits (remains an important aspect). [...] so I imagine that the location (of the CdG) also requires this aspect to be taken into consideration.'

(Psychologist)

Offering free accommodation and meals, or at least providing more extensive financial exemptions, could make a difference in making this treatment truly accessible to all, without adding further pressure.

4.3.2 Healthcare professionals

In addition to family members and *carers*, those who work daily in contact with suffering, such as healthcare workers, doctors and nurses, also need to be listened to and supported. All too often, however, these individuals experience a sense of abandonment and emotional overload, which risks compromising not only their health but also the quality of care they provide. As highlighted in the FG with healthcare workers, it is not just a question of physical fatigue: it is a suffering that settles in, accompanying the worker even outside the workplace, to the point of draining them of energy and motivation.

"The huge problem is that workers are completely abandoned [...] and absorb all the discomfort. There is very little care for these poor workers who find themselves immersed and overwhelmed by these problems, which they then take home with them. [...] In my opinion, entering a reality where both the patient and the worker are cared for makes all the difference."

(PC doctor)

Taking care of the team means recognising the reciprocal nature of care. No one can support others if they themselves are neglected. It is therefore essential to build an environment that also protects those who provide care, through training, emotional decompression and discussion.

4.4 Accessibility

In order for the CdG, and similar experiences, to be truly accessible places, it is necessary to consider practical and logistical aspects, but also more subjective and personal ones.

4.4.1 Location

Despite the CdG project's intention to offer a space surrounded by nature and tranquillity, physical, geographical and organisational barriers can be a significant obstacle to access for many patients and families. In particular, those who are physically impaired or come from outside the region may encounter difficulties in reaching the facility or receiving ongoing healthcare.

'One critical issue I see in Casa del Grano al Borgo is the road, the fact that it is difficult to reach.'

(Nurse)

The problem is not only about getting there, but also about managing medical emergencies and complex needs, which increase with early access to the facility. The distance from equipped healthcare facilities, the fragmentation of care between different regions or healthcare areas, and the difficulty in coordinating existing services can compromise the effectiveness of the care pathway, while generating insecurity and fear in those who are already struggling to cope with a difficult illness.

'Practical aspects such as the management of health emergencies here. The earlier the patient, the person and their family have access, the more necessary it is to ensure a clear approach to the management of complex symptoms and medical emergencies. I can hardly imagine how health emergencies would be managed here. And then a second aspect is that almost all of us come from Florence. My general practitioner here might have problems, but integrated home care might also have other problems. And if I came from outside the region, it would be even worse, meaning I wouldn't even be able to set foot in a healthcare facility here in Prato.'

(Medical director of PC specialisation school)

In light of these observations, some participants argue that it is necessary to rethink the location criteria for the CdG and all facilities for seriously ill patients, seeking a balance between immersion in nature and practical accessibility, especially for those in critical condition.

4.4.2 Spiritual prerequisite

In addition, according to the opinion of most FGs participants, the CdG is not a suitable environment for all patients, nor is it a valid solution in every case. It appears to be more suitable for those who have already embarked on a personal journey of spiritual search and introspection, as only they are truly able to fully embrace and appreciate what is on offer, as well as the natural environment that surrounds them. On the contrary, those who have never confronted the spiritual dimension or cultivated inner reflection throughout their lives may find it difficult to access this experience, risking perceiving it as distant or insignificant in relation to their needs.

'In my opinion, spirituality is a double-edged sword. In this sense: if someone has already embarked on their personal and spiritual journey, then it can be a great help, but some people who may never have explored this aspect may be traumatised, in the sense that they say, "Oh my God, if they talk to me about this, then I'm really at the end of my life.'

(Hospice volunteer)

In addition, it is not always possible to continue or start a spiritual journey, especially in cases where patients are in a phase of clinical deterioration, have cognitive impairments, as in degenerative diseases, or are in conditions that do not allow them to embark on a path of inner awareness. Therefore, it may be appropriate to rethink the paths, adapting them also to those who have not had previous spiritual experience, thus ensuring greater accessibility and inclusiveness of the CdG project.

4.5 Difficulties and strategies for integrating the early and comprehensive care model into the Regional Health System

In conclusion, the FG participants highlighted the importance of promoting the dissemination and integration of the early and comprehensive care model, such as that of the CdG, within

the SSR. At the same time, several critical issues were identified regarding the application of this model, which emerged above all in the last FG with organisational and institutional figures. These difficulties concern organisational, procedural and cultural aspects.

4.5.1 Critical issues

The early and comprehensive care model requires a holistic approach to the person with the disease, as part of a cross-cutting and interprofessional process, capable of overcoming the logic of individual services to promote a comprehensive vision of the person's care and well-being. However, the current organisation of the healthcare system makes it difficult to implement this model due to its structure and characteristics.

In particular, the 'silo' organisation of healthcare companies, which is not very cross-cutting and is hierarchically oriented, limits the continuity and integration of care pathways, making it difficult to offer people with illnesses a multidimensional model of care. This structure often results in a focus on individual services. As a result, operators may find themselves working in a fragmented manner, with poor coordination between the various professionals involved. In fact, most of the critical issues reported concern insufficient communication between professionals and the absence of a structured network capable of supporting the sick person and their family from the moment of diagnosis, hindering the full implementation of the integrated model.

'[...] Our healthcare system pushes us [...] to work hard for services [...] and if I provide a service, it is me, my organisational structure, my office, my department, my service, my head physician, it is me. If, on the other hand, I have to worry about being part of a process of taking care of a person who needs many things [...] it is no longer me and my service, but I have to be able to imagine a cross-cutting process, not a one-way thing.'

(Director of the Health Authority, Prato)

In fact, at the time of diagnosis, the MMG is often the only point of reference for the person with the disease. However, the limitations related to the time and resources available to them highlight the need for their more structured involvement, together with other operators, in the care pathways.

"At that stage, the public service is not very well organised because, clearly, the only person often involved at that stage is the general practitioner."

(Director of the Health Authority, Prato)

Added to these difficulties is the limited capacity of the healthcare system to guarantee the care of patients for prolonged periods. As highlighted by the FGs participants, some diseases with potentially uncertain outcomes, such as amyotrophic lateral sclerosis (ALS), require long-term support, while the current system is designed for short-term interventions, which consider PC as the last stage of life, with rapid progression towards the end of the care pathway.

"This completely different (longer) time frame requires all those who work in this field to make significant changes to their internal organisation, because we are designed to support efforts in a short time frame."

(Coordinator of the Palliative Care Federation, Tuscany)

In addition to structural and procedural issues, there are also cultural ones. Early and comprehensive care requires that all aspects of the well-being of the person with the disease (physical, psychological, social and spiritual) be considered within a complete care pathway. This means addressing not only medical and clinical issues, but also psychological and social ones. According to the organisational and institutional figures participating in the last FG, the healthcare system is not yet fully equipped to manage this type of need, focusing mainly on medical and health care at the expense of other dimensions.

'The people we are addressing (patients in palliative care) have enormous social problems, and I think we all know from experience that [...] healthcare collapses in the face of social needs that you are unable to address (manage).'

(Coordinator of the Italian Society for Palliative Care, Central Italy)

Finally, there are further obstacles to the implementation of the model in the SSR, including the public perception of *hospices* as environments closely associated with death. This perception limits the usability of the places where the model proposed by the CdG should and could be applied and hinders its dissemination. This is compounded by often limited knowledge of the services available and a reduced ability of patients to navigate the range of palliative care services offered in their area. For example, there have been reports of comprehensive and simultaneous palliative care clinics whose frequency of use remains very low, mainly due to insufficient communication about their presence in the area.

4.5.2 Strategies

Taking into account the difficulties highlighted above, thanks to the contribution of the participants in the last workshop, a number of operational proposals were formulated, aimed at outlining possible strategies for the concrete integration of the early and comprehensive PC model within the SSR.

With regard to the organisational criticalities of the SSR, a crucial issue concerns the identification and training of coordinators capable of accompanying the person throughout the entire process, from diagnosis to PC. MMG were identified by participants as possible intermediaries in care pathways, although their more structured involvement and support from family and community nurses is necessary. The latter should provide continuous support from the moment of diagnosis, connecting the various professionals.

"In my opinion, we need a community nurse, a family nurse who accompanies the patient from the moment of diagnosis and is able to connect the various skills."

(Coordinator of the Italian Society for Palliative Care, Central Italy)

However, the most desirable model remains that of integrated multidisciplinary *teams*, in which doctors, nurses, psychologists and other professionals share responsibility for the care pathway, avoiding placing the entire decision-making burden on the MMG.

"We don't need a single doctor or a single nurse, but an integrated team where everyone contributes their expertise, otherwise everything remains on the shoulders of the family doctor.

(President of the Italian Society of General Practitioners, Tuscany)

With regard to cultural issues, it is considered essential to improve the information provided to citizens, promoting a shared culture of PC and helping to overcome the cultural resistance that still exists. It is therefore essential to make care pathways explicit and adequately publicised, so that they are known not only by professionals but also by patients and their families.

'Care pathways must be established and made known [...] because often patients are abandoned by hospitals without a clear understanding of the care pathway.'

(Vice-President of the Order of Nurses, Florence and Pistoia)

4.6 Economic and organisational sustainability

Finally, one of the crucial issues for the future of CdG and for the dissemination of the early and comprehensive care model in the SSR and other local contexts concerns economic and organisational sustainability.

The lack of public funds and the reluctance of the healthcare system to invest in alternative models to traditional care are significant obstacles. Institutions often respond to any innovative proposal with the constraint of 'equal resources', i.e. without additional financial commitment.

'Healthcare also has a huge problem [...] there is a need for resources [...] (but) they never put any money in. So if you propose something to them, they panic or reject it immediately [...]. I don't know what it's like in Tuscany now, but in other places, the best word for them is 'isorisorse', meaning 'What you have, if I don't have to spend anything, if you do everything on a voluntary basis, if I don't have to put in a penny, maybe I'll let you do it'. Maybe.'

(Doctor)

This attitude reflects a rigid mindset that is not very open to innovation, which hinders the emergence of new, person-centred experiences.

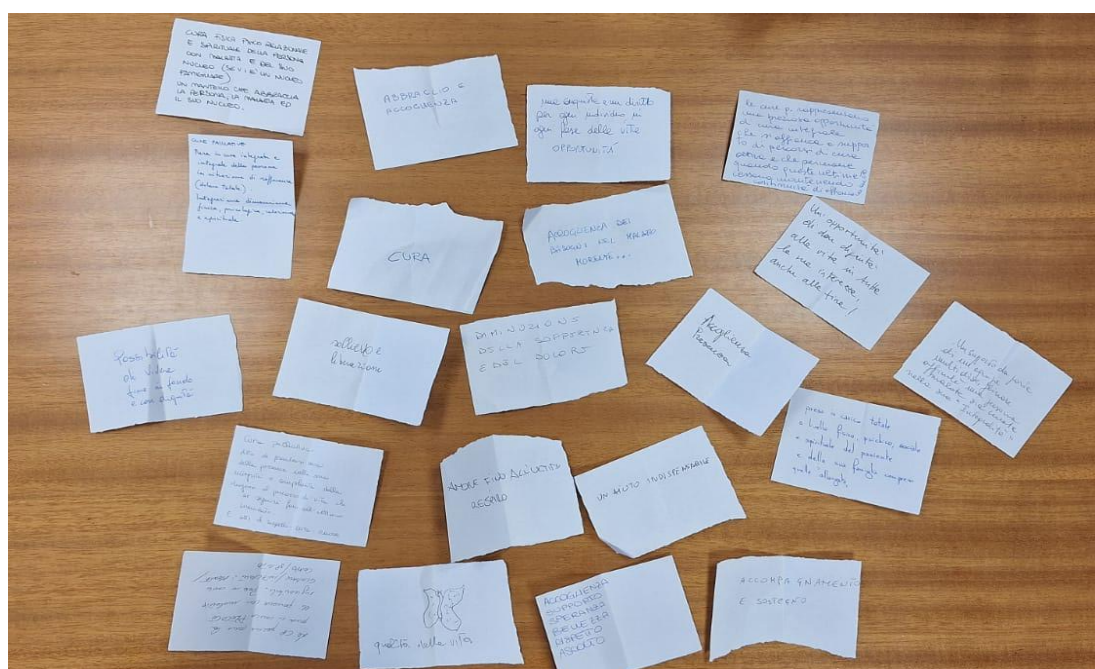
However, participants highlighted how a more widespread use of the early and comprehensive care model, made possible by timely intervention at the time of diagnosis, could lead to a significant reduction in healthcare expenditure, limiting hospital admissions and ineffective aggressive treatments. This approach allows resources to be used more efficiently, redirecting them towards forms of care that are more useful for patients and their families, such as greater support for *caregivers* through home care, improving the overall quality of care.

"Specialist palliative care has proven its effectiveness both in clinical practice and in generating economic savings [...] above all because it helps to reduce hospital admissions, which are currently one of the main factors driving up healthcare costs."

(Coordinator of the Italian Society for Palliative Care, Central Italy)

To address these challenges, there is a strong need to develop a sustainable economic plan that includes *partnerships*, institutional networks and self-financing tools. This approach would not only ensure continuity but also allow access to be extended to people from different areas.

The final activity of the workshops highlighted a variety of meanings and values associated with PC, as perceived by the participants. The words and phrases collected confirmed that PC is considered an integrated care pathway, involving not only the body but also the emotional and spiritual spheres of individuals.



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5. The prototype generated: guidelines

The co-creative process made it possible to outline some guidelines aimed at implementing the early and comprehensive care approach proposed by the CdG in other contexts and within the healthcare system. These include:

- Promoting comprehensive care pathways⁶ that are not limited to medical and clinical aspects but also take into account fundamental dimensions related to identity, emotions and the need for existential and spiritual support. Such pathways may include complementary services such as pet therapy, mindful breathing, contemplative and meditative practices, art therapy, horticultural therapy and contact with nature, as well as the creation of spaces dedicated to psychological and physical wellbeing, including massage rooms, educational activities, music workshops and tools to support creativity and relaxation.
- Defining strategies aimed at identifying patients' needs early on, at the time of hospital diagnosis, ensuring timely support and facilitating access to dedicated facilities, including by strengthening the role of MMG and family and community nurses;
- Promote clear, transparent and respectful information for people with the disease, so as to encourage informed choices between the various options available, enabling the timely activation of treatment and personal growth pathways;
- Encourage open and ongoing dialogue and empathetic listening between patients, carers and healthcare professionals, providing opportunities not only for medical and clinical communication, but also for listening to social, existential and spiritual needs;
- Create spaces dedicated to discussion between people diagnosed with serious illnesses, facilitated by competent figures, who encourage the sharing of experiences and mutual support;
- Offering support to carers, family members and healthcare professionals through dedicated programmes, opportunities to process emotional, existential and spiritual experiences, also taking into account the economic dimension;
- Promoting a culture of continuous training for social and healthcare professionals working in palliative care, conceived as a permanent and shared process, integrated with cultural and awareness-raising initiatives, involving medical specialists, support staff, schools and the community, in order to foster a broad and widespread cultural dialogue;
- Open *hospices* to the community, promoting an inclusive, participatory environment that is closely integrated with the local area, which can help to redefine this reality as a context not exclusively linked to a tragic outcome, but to the rediscovery of self-care;
- Design accessible and inclusive facilities, ensuring coordination with the main healthcare facilities and existing services, guaranteeing continuity and integration of care;
- Develop an economic plan to ensure the economic and financial sustainability of dedicated initiatives based on:

⁶ By 'integral', we mean that they encompass all dimensions of the human being: physical, mental and spiritual.

- The establishment of strategic *partnerships*;
- The activation of institutional networks;
- The development of self-financing tools, without relying exclusively and continuously on contributions from the third sector.

6. Questionnaire results

The Participation Questionnaire administered to the 39 FG participants showed a high level of *agency*, which was further enhanced by co-creative interaction. Satisfaction with the workshops was rated high in all areas, particularly in terms of interaction with other participants during the implementation phase.

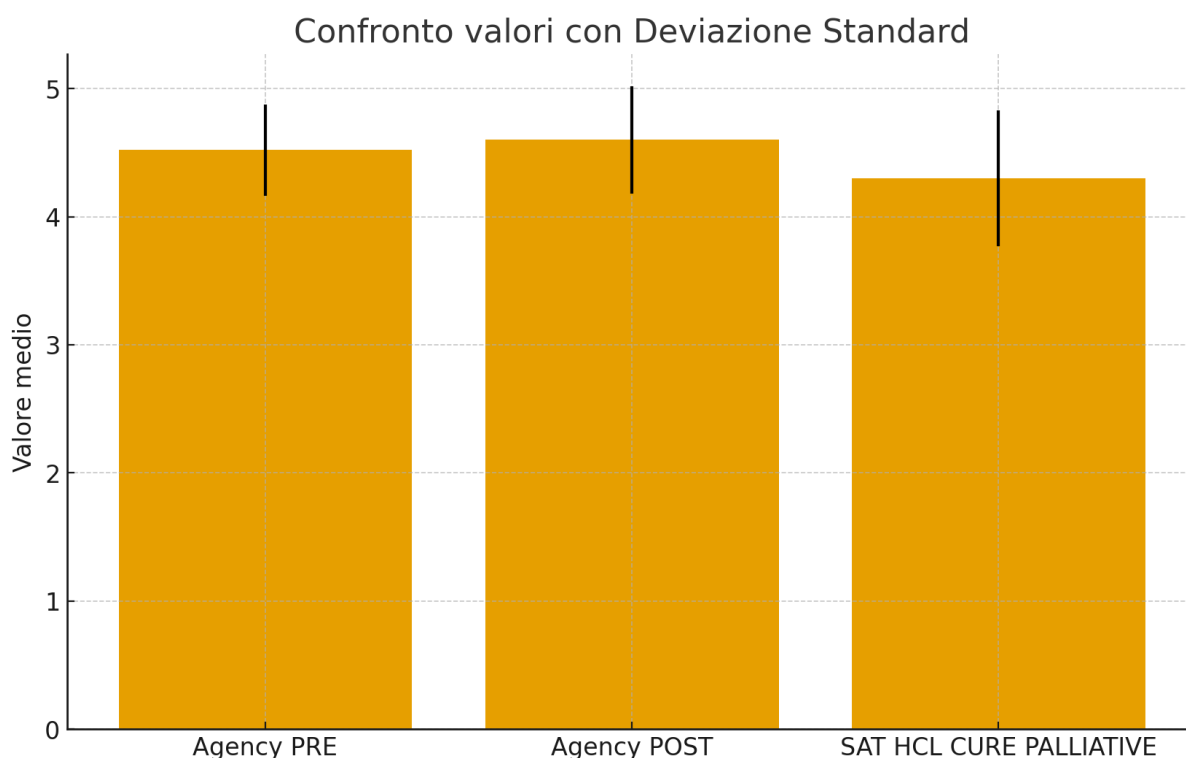


Figure 8 - Graph of the average values of PRE and POST co-creation activity agency and participant satisfaction (SAT).

In the section of the questionnaire concerning the elements judged to have an impact on well-being in PC, participants rated all the *items* proposed with high scores, showing cross-sectional agreement on these scores (Table 4). This result shows that an approach that takes into account multiple areas of health is necessary, favouring an integrated vision and confirming the initial point of view of HCL. Aspects of physical wellbeing, such as pain control, were considered equally important to psychological and existential aspects. The co-creation process therefore promoted an alignment of the psycho-physical and spiritual spheres with regard to the importance of caring for those who are facing a transition phase, such as potential *hospice* residents. Furthermore, in the context of developing a new social and health service, all participants identified the relationship and communication with healthcare professionals as a fundamental aspect in promoting the wellbeing and proper functioning of such a facility.

Intervention	Media PRE	POST media
Pain and physical symptom control	3.87	3.86
Psychological support for the patient	3.77	3.86
Psychological support for family members	3.77	3.80
Spiritual support for patients	3.82	3.83
Spiritual support for family members	3.67	3.80
Empathetic communication with the healthcare team	3.74	3.83
Welcoming, non-medicalised care environment	3.54	3.71
Opportunity for patients to process the meaning of their experience	3.82	3.83
Integration of meditation and mindfulness practices	3.54	3.71
Continuity of care between home, hospital and hospice	3.77	3.89

Table 3 - Average scores for palliative care impact factors assessed before and after the HCL implementation phase activities.

7. Conclusions

Ensuring early and comprehensive care in palliative care is now one of the most urgent challenges for healthcare systems, in a context of an ageing population, where the response to end-of-life needs is often fragmented and uneven. The current model of care is, in fact, characterised by late activation and a predominantly medical-hospital approach.

The aim of this HCL was to understand whether and how the early and comprehensive approach to PC, also developed by the CdG project, could be configured as a scalable, transferable model applicable in different territorial contexts.

The research conducted as part of the HCL confirmed this hypothesis, highlighting some key elements for its effective implementation. Among these, the need for specific training for doctors and social and healthcare professionals called upon to communicate diagnoses of potentially incurable diseases emerged as a priority. In fact, it has been found essential to complement clinical skills with transversal skills that promote empathetic, conscious and person-centred communication, even before treatment begins.

In response to these needs, the CdG has been identified as a scalable and innovative pilot model in the field of PC. It integrates timely care, from the moment of diagnosis, with a care pathway focused on the humanisation of care. This comprehensive approach, which attaches equal value to mind, body, relationships and spirituality, contributes to a significant improvement in the QoL of patients and their families.

Overall, the HCL process, especially the co-creation phase involving healthcare professionals, volunteers and institutional representatives, made it possible to gather experiences, identify needs and formulate proposals, giving rise to a collective reflection that led to the development of guidelines aimed at promoting the replicability of the model at regional and national level. The guidelines include the main operational recommendations for creating, transferring and/or implementing the early and comprehensive care approach, including: the creation of comprehensive care pathways aimed at supporting the psychological, physical and spiritual well-being of people with illness and their families; the use of communication and socialisation as key tools for managing end-of-life expectations and combating loneliness; the creation of recreational spaces accessible to patients, *carers*, operators and the surrounding community, which contribute to positively redefining the reality *of the hospice*, making it more accessible and inclusive.

The HCL methodology placed the research team, composed of university representatives and experts in the field, in a neutral support role, facilitating discussion among participants in *the co-creation workshops*. This approach promoted the dissemination and exchange of different perspectives, while ensuring substantial equality among participants, through the organisation of groups that were homogeneous in terms of role but heterogeneous in terms of background. This approach allowed every voice to be heard, making co-creative interaction truly effective in designing solutions that meet the needs of communities and territories.

7.1 Reflections and implications for the future

The HCL experience has given rise to a number of recommendations that are useful for the dissemination and implementation of an early and comprehensive approach to PC.

Firstly, the HCL highlighted the need to strengthen the training of doctors and social and healthcare professionals on this issue, so that they are able to provide early and

comprehensive support to patients from the earliest stages of the disease and, therefore, even before the formal activation of PC. Such training should include the development of interpersonal and communication skills that promote authentic and informed dialogue with patients.

A further aspect concerns the strengthening of coordination between social and healthcare services through the establishment of a dedicated professional figure to accompany the person with the disease and their family members, helping to reduce the fragmentation of interventions and related costs.

At the same time, in order to overcome the cultural resistance that still exists towards PC pathways, particularly in *hospices*, and to promote greater awareness of the issue, it is important to introduce *death education* programmes in schools and to strengthen the training of all social and health workers involved in this sector.

Within this framework of structural and cultural interventions, it is equally essential to ensure the continuity, sustainability and replicability of initiatives dedicated to promoting comprehensive care, such as the CdG project. To this end, it is necessary to promote their stable integration within the network of services promoted by the Health System, institutions and local authorities. To this end, a memorandum of understanding was recently signed between the Tuscany Region, the Azienda USL Toscana Centro, the Società della Salute di Prato and the *Tutto è Vita Foundation* (Tuscany Region, Resolution No. 1136 of 04.08.2025), with the aim of establishing a technical committee responsible for coordinating the actions of the signatories in support of the Foundation, defining permanent methods of collaboration between the actors involved, strengthening the integration between the CdG and the SSR, and gradually expanding the network through the accession of new interested institutional partners.

The Future of HCL

HCLs were created to activate shared and sustainable innovation processes, in which the community and stakeholders become protagonists. Their purpose is not to co-create temporary solutions, but to leave the responsibility and capacity to carry them forward over time in the hands of the community. Each HCL therefore aims to build autonomy and collective *agency*, encouraging the creation of local networks capable of sustaining and regenerating the change produced.

To ensure that these local experiences do not remain isolated initiatives but become structural policies and stable tools for innovation in the regional healthcare system, a further step is necessary: the creation of *the Health Community Hub* (HC HUB).

The HC HUB represents the evolutionary perspective of HCLs: a regional platform for coordination, learning and enhancement, capable of ensuring methodological consistency, disseminating and replicating innovations, and integrating results into healthcare system policies and services. Without such an institutional and political framework, HCLs would risk remaining episodic experiments, whereas their potential is to become permanent drivers of systemic innovation, serving the health and well-being of Tuscan communities.

7.2 The replicability of the model

With regard to the replicability of the early and comprehensive care model at national level, it is essential to promote the dissemination of guidelines with the aim of encouraging the implementation of similar experiences, albeit adaptable to local contexts, specific territorial needs and available resources.

With this in mind, in June 2025, a first edition of care pathways inspired by the CdG was implemented in Liguria, at the Abbey of Santa Maria di Castello in Genoa. The initiative was born from the idea of a group of oncologists working in the Liguria region, who had already participated in training courses organised by *the Tutto è Vita Foundation*. The trial was promoted by the Braccialetti Bianchi Association, which is mainly active at the San Martino Hospital in Genoa, with the aim of offering empathetic and spiritual support to sick people, including those at the end of their lives, their families and those who are grieving (<https://www.braccialettibianchi.com/>).

7.3 Critical issues and future developments for HCL

This HCL represented the first step in a broader process. Therefore, further steps will be necessary to complete the analysis and dissemination of the care model.

In this first phase, attention was focused on a specific group of participants, given the limited time available due to the timing and deadlines of the THE project. However, the participatory methodologies adopted during the project clearly highlighted the need for dialogue and

discussion between all those involved in the PC system. Therefore, for the subsequent stages of development, it will be essential to involve patients and family members who use the services in a structured manner, in order to enrich the reflections of professionals and volunteers.

Similarly, it will be necessary to include representatives from other associations operating in the PC sector, in order to integrate *best practices* and support the creation of collaborative networks in the region.

Finally, greater representation of specialists and young operators within the discussion groups will need to be ensured in order to incorporate new or less established perspectives. For this reason, it will be important to devote adequate time and attention to the participant recruitment phase, to be conducted through accurate mapping of local stakeholders.

Overall, the HCL experience retains significant potential for development: consolidating and disseminating the CdG project as a model of care requires inclusion, a plurality of perspectives and continuity in the dialogue between all the actors involved.

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