THE Tuscany Health Ecosystem
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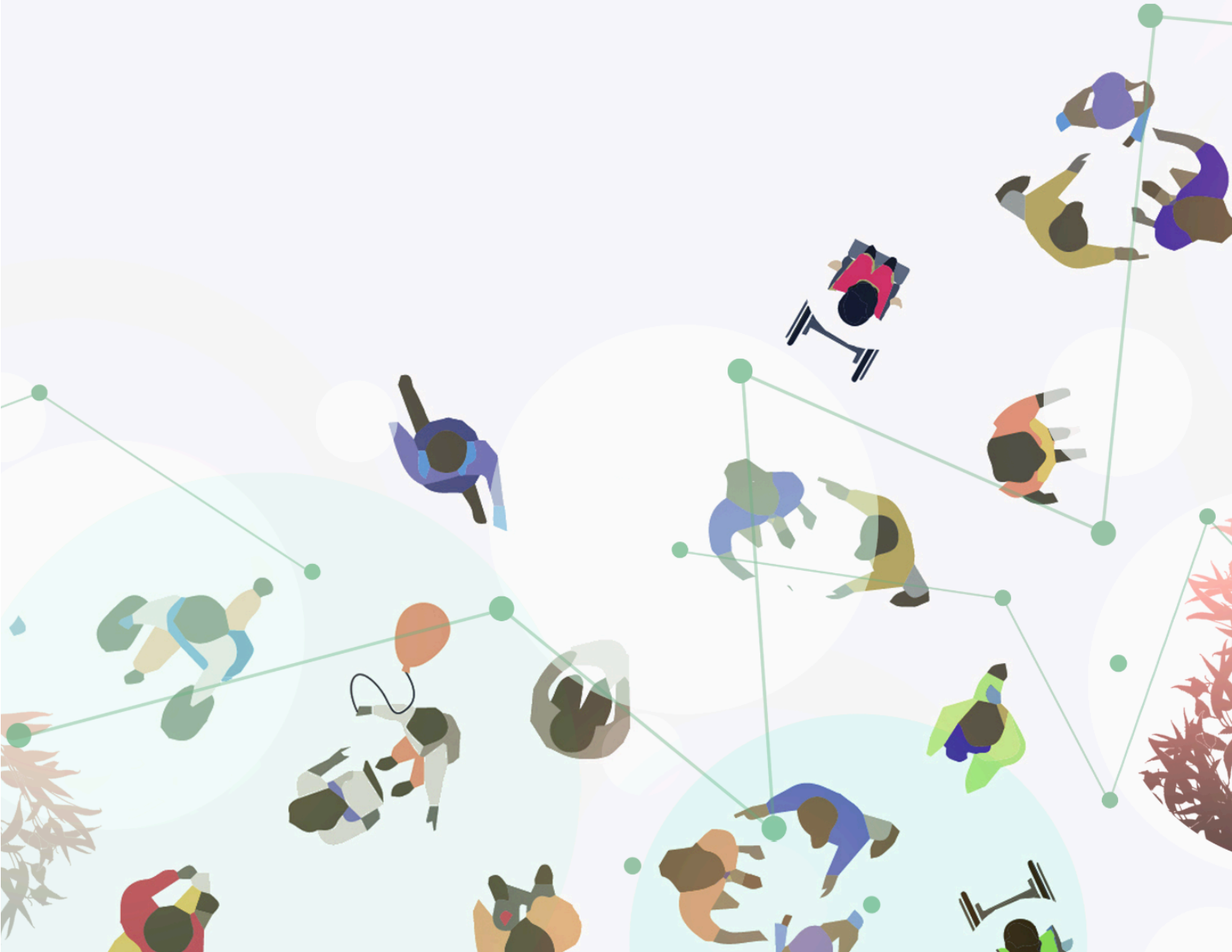
Health Community LAB

Comprehensive care

A consensus document for integrated, person-centred care pathways

REPORT



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This document seeks to use language that is inclusive and respectful of gender differences. However, where a fully neutral formulation was not stylistically appropriate, the masculine form has been used, following traditional Italian linguistic conventions.

Executive Summary

The ***Health Community Lab (HCL)* – Comprehensive care** project aimed to define and validate a shared model of **comprehensive care** for people with **severe acquired brain injuries (ABI)** and **spinal cord injuries**, two complex conditions that require an integrated and multidimensional approach. In a context where disability has a profound impact on individual and family life, the project sought to move beyond an exclusively clinical view of rehabilitation, adopting a **person-centred** and **capability-oriented** perspective that recognises the person, family and caregivers as active protagonists in the care pathway and their own life project.

Through the **HCL** methodology and the application of **the Delphi method**, the project involved **stakeholders**, healthcare professionals, researchers, associations and institutional representatives in a participatory process of co-creation and consensus building. The process was divided into three main phases: preliminary analysis through qualitative interviews, construction of a 73-item questionnaire for the first Delphi round, and final validation of the consensus document. This process resulted in **17 shared statements,** 16 of which were fully confirmed by the experts, representing the fundamental principles of comprehensive care.

The results highlight the importance of **multidisciplinary teams**, **continuity of care** between hospitals, non-profit associations, the community and the home, **psychological support** for patients and caregivers, **therapeutic education**, appropriate use of **telemedicine**, and the promotion of **peer support** and **personalisation of the rehabilitation project**. The consensus process made it possible to integrate scientific evidence, professional experience and people's experiences, building a realistic and shared operational framework.

The project represents a significant step towards defining **common standards of comprehensive care** that can be transferred to other chronic disabilities. The results provide a concrete basis for the development of personalised **Diagnostic-Therapeutic Care Pathways (PDTA)** and for the development of **regional policies** capable of ensuring equity, quality and continuity of care. The participatory and co-creative approach tested in HCL – Comprehensive care is thus confirmed as an innovative model for healthcare in Tuscany, based on collaboration between institutions, professionals and communities.

Key Messages

1. **Focus on the individual and caregivers**
   The project focuses on people with brain or spinal cord injuries, together with their families and caregivers, as active protagonists in their care pathway and life project, promoting empowerment, participation and overall well-being.
2. **Integrated and multidisciplinary approach**
   'Comprehensive care' is understood as a continuous process that combines clinical, rehabilitative, psychological and social aspects, thanks to a multidisciplinary team capable of ensuring continuity between the hospital, non-profit associations, the local area and the home.
3. **Co-creation and consensus as a method**
   Through the *Health Community Lab* model and the Delphi method, the project involved professionals, researchers, associations and citizens in a participatory process that led to the shared definition of 17 consensus statements on good care practices.
4. **Towards a transferable and sustainable model of comprehensive care**
   The results obtained provide a concrete basis for developing personalised and coordinated pathways (PDTA) and for disseminating a comprehensive care approach that can also be applied to other chronic disabilities, promoting equity, quality and innovation in healthcare systems. It also opens up opportunities for advanced training courses for all types of professionals and highlights the need for collaboration between hospital and healthcare services and local social services.

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1. Introduction

The *Health Community Lab Comprehensive care* project was created with the aim of developing a shared model of comprehensive care for integrated, person-centred pathways. Its case studies focus on people with severe acquired brain injuries (ABI) and spinal cord injuries, two conditions with a high clinical, psychological and social impact. These conditions not only compromise motor and cognitive function, but also radically transform the daily life of the person and their family, generating complex needs that require an integrated, continuous and personalised approach.

The Tuscany Health Ecosystem and the Health Community Lab

The *Tuscany Health Ecosystem* (*THE*) is a research project promoted **by the Region of Tuscany 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 and 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.

In line with the international trend towards *person-centred care*, the project aimed to move beyond an exclusively clinical view of rehabilitation and embrace a holistic perspective that values relational, social and participatory dimensions. This approach is based on two main theoretical references. The first is the complex process that led to the replacement of the biomedical model of disability (which conceptualises disability as the distance between a 'normal' level of functioning and that actually recorded by the person) with a biopsychosocial and rights-based model (which sees disability as the result of the interaction between a

person with certain characteristics and their life context). This process has seen two key milestones: the launch of *the International Classification of Functioning, Disability and Health (ICF)* by the World Health Organisation in 2001 (a 'vocabulary' to describe a person's functioning in line with a bio-psycho-social approach) and the UN Convention on the Rights of Persons with Disabilities (which serves as a legal framework). The second reference is Amartya Sen's *Capability Approach*, which considers well-being as intrinsically linked to the possibility of choice and the tangible, concrete opportunity to build a life that one has reason to value (Sen 1999).

Within this conceptual framework, HCL *Comprehensive care* has been structured as a process of co-creation and participatory research, inspired by the HCL method. The project involved healthcare professionals, researchers, institutional representatives and patient and caregiver associations in a three-stage process: preliminary exploration, consensus building using the Delphi method and final validation of the shared document.

Through qualitative analysis of interviews, consultation with experts and subsequent synthesis of the results, it was possible to identify the essential elements of truly comprehensive care. These include: the need for multidisciplinary teams with integrated skills; continuity of care throughout the entire care pathway, from hospital to home; the active involvement of the family and caregiver; the importance of psychological support and motivation; the personalisation of the rehabilitation project; the essential collaboration of associations and the appropriate use of technology and telemedicine to ensure access and monitoring over time.

The application of the Delphi method (Dalkey and Helmer, 1963) led to the definition of 17 consensus statements, 16 of which were fully confirmed by the panel of experts, outlining the key principles of comprehensive care for brain and spinal cord injuries. The results obtained represent an important step forward in the construction of a common language and a shared operational framework between disciplines and levels of intervention.

The added value of the project lies in its ability to combine scientific evidence with the concrete experience of individuals and professionals, generating transferable knowledge and guidelines useful for clinical practice, health planning and welfare policies.

2. Background

Spinal cord injuries and severe acquired brain injuries (sABI) are clinical conditions with a high impact not only in strictly health terms, but also in psychological, social and economic terms. The 2005 Consensus Conference defined sABI as brain damage of traumatic or other origin involving more or less prolonged coma, sensorimotor, cognitive and/or behavioural impairments and, in most cases, permanent disability (Biggeri et al. 2013). Spinal cord injury, on the other hand, is defined by the WHO (World Health Organisation) as damage to the spinal cord, spinal cone or cauda equina, of traumatic origin (falls, accidents, injuries, violence) or non-traumatic origin (infections, tumours, degenerative diseases, congenital conditions such as spina bifida). It can lead to partial or total loss of motor and sensory functions and deficits in the body's autonomic regulation, with consequences ranging from limb deficits to breathing disorders, cardiovascular regulation, bladder and bowel control, and sexual function (WHO 2013).

The impact of such events goes far beyond the clinical sphere, transforming the daily life of the person and their family, affecting their autonomy, plans, relationships and opportunities for social participation. In both conditions, the clinical pathway involves intensive medical and rehabilitative interventions in the acute and post-acute phases, which take place in hospital. This is followed by long-term care pathways, aimed not only at healthcare but also at supporting the person in regaining their roles in all areas of their daily life, including family, social, educational and professional. The consequences of these events also extend to the family and caregivers. Specifically, numerous studies have shown that when a family member takes on the role of primary caregiver, it can lead to a reduction in the capabilities and functioning of the caregivers themselves: loss or reduction of work and income, deterioration of physical and mental health, social isolation, weakening of support networks and difficulties in planning for the future. Alongside families, civil society associations play a crucial role, representing a response of agency and collective action, promoting guidance and access to services, protection of rights, mutual aid, relief, the construction of local networks, and advocacy and co-design initiatives useful for strengthening the capabilities and functioning of individuals and carers (Bonfanti and Biggeri 2012).

In light of these complexities, it is necessary to adopt theoretical and operational frameworks that go beyond a purely clinical view, in line with the international trend towards person-centred care, which places the patient's perspective at the centre of care. Specifically, this approach, as promoted by the WHO, sees the person, family and caregivers as active protagonists in the care pathway, highlighting the importance of information and empowerment and recognising the patient's rights and responsibilities, in order to co-design personalised interventions that can respond to individual needs and preferences (Santana et al. 2017).

Several theoretical frameworks have contributed to the evolution of healthcare systems in this direction, promoting a person-centred view of disability. The International Classification of Functioning, Disability and Health (ICF), developed by the WHO, takes a holistic and multidimensional approach to describing health conditions. The ICF provides a universal language that integrates biological, psychological and social aspects, allowing not only impairments and functional limitations to be described, but also barriers and facilitators that influence participation. In this way, it improves the ability of services to respond to the needs of the individual (van der Veen et al. 2022).

At the same time, the Capability Approach developed by Indian economist and philosopher Amartya Sen as a theoretical framework for human well-being and development (Sen 1999) has been introduced into the healthcare sector.

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 and abilities and substantial freedoms that a person has to do and be what they 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.

From this perspective, well-being is interpreted as the set of real freedoms that people have to lead a life that they consider valuable. Applied to disabilities, this approach shifts the focus from clinical or functional characteristics alone to equality in opportunities for choice, understood as concrete possibilities for realising one's life plans (Bonfanti and Biggeri 2012). Therefore, disability can be interpreted as a limited set of capabilities in relation to one's goals and values but, at the same time, as a space for creative adaptation and the development of new potential (Biggeri and Bellanca 2011). For this to happen, it is essential to also take into account the so-called conversion factors: with equal resources, individuals achieve different levels of well-being based on their personal characteristics and their family, social, cultural and political-institutional context. This makes support networks and local resources fundamental in the care pathway (Biggeri et al. 2013). The research also highlights the decisive role of civil society associations in supporting individual and collective agency. In the case of sABI, Ass.C.A. provides ongoing support to individuals and families through individualised projects, mentoring, volunteer training, continuous monitoring of activities and liaison with local resources, helping to integrate health and social care throughout the process of comprehensive and proactive care (Biggeri et al. 2013). From a broader perspective, associations are recognised as active players, no longer passive recipients, capable of networking, facilitating access to services, promoting rights, peer support and co-design, including through tools such as local observatories and peer counselling. This organised participation strengthens the *capabilities* of individuals and

carers, reduces isolation and fragmentation, and makes orientation within the service system more effective (Biggeri and Bellanca 2011).

In the theoretical framework of reference, the capability approach shifts the focus from means to outcomes of value for the person: functional recovery and real opportunities for participation, deciding and planning one's own life. In this perspective, agency, understood as the ability to act in accordance with one's own goals (Biggeri & Ferrannini, 2014), becomes an essential dimension of care pathways. Since capabilities depend on personal, social and institutional conversion factors, co-creation processes are configured as empowerment devices, capable of rooting interventions in contexts and rebalancing decision-making power among the various actors. This framework provides the conceptual frame of reference for interpreting the methodological and organisational choices presented in the following sections.

These theoretical foundations gave rise to the rehabilitation model of the Life Project, which conceives of well-being as holistic and multidimensional. It is metaphorically represented as a 'mosaic' of dimensions of well-being that each person can compose in a unique way according to individual values and preferences (Biggeri et al. 2013), and has found concrete application in local experiences such as the Global and Proactive Care Protocol (PCGPA), launched by ASL 10 in Florence (now Azienda Usl Toscana Centro) for people with sABI in the post-hospital phase. The specificity of the model lies in its ability to create a continuum between clinical care and local resources, building truly comprehensive and personalised care pathways. Its effectiveness is based on collaboration between health services, local authorities and associations, which support the individual and their family in the various dimensions of well-being. In this way, the model shows how it is possible to translate innovative theoretical approaches into truly person-centred care pathways. To support this approach, the PCGPA evaluation adopted mixed methods, integrating quantitative and qualitative research. On the quantitative side, a survey was conducted with two separate questionnaires aimed at people with sABI and their families, administered to 105 individuals and 101 households under the care of the Neurological Care Clinic of the S. Giovanni di Dio Hospital, with CAPI collection and tools aligned with ISTAT sections to allow for external comparisons. The areas covered included quality of life and health (EQ-5D, EQ-VAS), direct and indirect costs, use of time, consumption, capability and a contingent valuation, as well as specific modules on PCGPA. The average duration of the interviews was approximately 150 minutes, and the interviewers underwent ad hoc training given the complexity of the target group. On the qualitative side, Structured Focus Group Discussions (Kitzinger, 1995) were conducted with individuals and caregivers connected to Ass.C.A. activities, and in-depth interviews were conducted with privileged observers to bring out dimensions that the questionnaires alone do not capture.

The results converge on the fact that integrated care focused on relationships and networks, rather than exclusively on services and medication, is associated with higher levels of multidimensional well-being for individuals and families. In estimates based on the questionnaires, PCGPA shows average improvements in perceived opportunities of between 23% and 47% in physical and mental health, work, relationships and quality of life. Structured discussions confirm a significant advantage of the PCGPA pathway over traditional rehabilitation, with differences of around 40% in physical health, around 50% in mental health and work, and up to 100% in interpersonal relationships, although caution is needed as the latter may be overestimated given the strong proactivity of the participants.

The evaluation design also includes a comparison with a control group of people followed in other standard programmes and a comparison with families in the general population using forms compatible with ISTAT questionnaires, in order to estimate more robustly the differences in outcomes in terms of autonomy and quality of life for the person and the caregiver. This phase is described as subsequent to the report mentioned here.

Throughout the programme, the decisive role of associations emerges, with Ass.C.A. acting as a link between the clinic, the local area and families, offering mentoring, support in life transitions, peer support, co-design and advocacy activities. This function strengthens capabilities, reduces isolation and fragmentation, and supports the caregiver's burden, with economic evidence also showing the value of informal care hours and the benefits for the family unit (Biggeri et al. 2013).

In line with this approach, in Tuscany, the Sant'Anna School of Advanced Studies (Pisa) has contributed mainly to the technological and organisational aspects of rehabilitation through the development of exoskeletons and wearable orthoses in collaboration with the Spinal Unit of the CTO of the Careggi University Hospital (CLIMB project), aimed at facilitating the recovery of walking in people with spinal cord injuries; clinical research on spinal neuromodulation (high-frequency epidural electrical stimulation) with evidence of reduced spasticity and improved motor control (Romeni 2025); and the design of regional tele-rehabilitation models (TABLET TOSCANA) to ensure continuity of care and monitoring at home.

3. Severe acquired brain injuries and spinal cord injuries

Severe acquired brain injuries (SABIs), mainly comprising traumatic brain injuries (TBIs) and other types of brain injuries, are one of the leading causes of disability and mortality in European countries, with a significant impact on health and social systems. According to the systematic review by Brazinova et al. (2015), conducted on 66 European studies, the incidence of TBI varies widely between countries, ranging from 47.3 to 694 cases per 100,000 inhabitants per year in national studies and 83.3 to 849 per 100,000 in regional studies, depending on the methodology and definitions used. The main causes identified are road accidents and falls, with a gradual reduction in the weight of traffic accidents and an increase in those related to advanced age, especially in high-income countries (Brazinova et al. 2021).

A cross-sectional analysis of Eurostat data from 24 European countries estimated an average rate of hospital discharges for TBI of 287.2 hospital discharges per 100,000 and 11.7 deaths per 100,000, with marked differences between countries, accounting for 37% of all trauma deaths. Applying these values to the European population (737 million inhabitants), it is estimated that in 2012 alone there were over 2 million hospitalisations and approximately 82,000 deaths related to head trauma (Majdan et al. 2016).

The differences between countries are marked, with higher mortality rates in higher-income regions and among males, where mortality is almost double that of females (Majdan et al. 2016).

The age distribution shows a bimodal pattern, with a first peak in young adults (15-35 years), largely related to road accidents, and a second peak in the elderly (over 65 years), mainly due to falls in the home. This trend is also confirmed by the latest data from the CENTER-TBI project (Sivco et al. 2023), which show that increased survival in old age and the higher frequency of comorbidity have changed the epidemiological profile, making sABI increasingly a condition linked to the ageing of the European population.

4. Methodology

HCLs are based on the concept and rules of *the Living Lab*[1] (Leminen et al., 2012), i.e. an innovation environment 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 community[2]. 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.

Following the HCL approach, the methodology is divided into three phases:

1. Preliminary *phase*: this begins with an assessment of the needs related to a specific health or well-being issue (*conceptualisation*), followed by a context analysis in which the key stakeholders[3] and key players to be involved in the subsequent phases are identified and data useful for the successful implementation phase is 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 the evaluation of 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 4.1 is dedicated to the design of the study, while sub-sections 4.1.1, 4.1.2 and 4.1.3 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.

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[1] 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.

[2] For further information on HCLs, see Biggeri et *al.* 2025a.

[3] 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 plurality of stakeholders** (Vargas et al., 2022), aimed at **the creative solution of shared problems** (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-programming 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.

4.1 Study design

HCL phase	**Prototype creation activities**	**Actors involved**			
		Public actors	Private actors	Research institutions	Civil society
Preliminary phase	Conception	x	x	x	
	Context analysis and planning	x	x	x	x

Implementation phase	Design	x	x	x	x
Evaluation phase	Distribution/ Dissemination		x	x	
	Evaluation			x	
	Maintenance	x		x	x

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

4.1.1. Preliminary phase

The preliminary analysis involved conducting and analysing eight qualitative interviews with two representatives of associations, healthcare professionals and clinical-organisational representatives from neurology departments and spinal units at the Careggi and San Giovanni di Dio University Hospitals (FI).

The eight interviews were transcribed verbatim and analysed qualitatively with the aim of highlighting the essential elements and functioning of individual care and treatment processes. The items identified were submitted to a group of experts, who systematically assessed their relevance, clarity and feasibility (calculating content validity indices at item level), providing guidance for linguistic and operational refinement.

Based on this process, a 73-item questionnaire was constructed, which constituted the first round of the Delphi method, used to converge towards an informed consensus on the essential requirements for comprehensive care for people with neuronal and spinal cord injuries.

4.1.2 Implementation phase

The Delphi method was applied in a structured and iterative manner to select and refine the elements considered essential for comprehensive care. The design involved consulting a panel of experts selected for their expertise, with the aim of gathering and summarising opinions on a complex issue and bringing them together to reach a shared consensus. The experts were invited to respond anonymously to structured questionnaires, and the responses were then analysed and returned to the panel as aggregated feedback, allowing each member to review their own assessments in light of others' judgements and reducing group pressure.

The Delphi method

The Delphi method is a structured technique for gathering and analysing the opinions of a group of experts, used to reach consensus on a complex issue. It is based on a series of **successive rounds of anonymous questionnaires** in which experts express their assessments. After each round, the responses are analysed and returned to the group in aggregate form, allowing participants to review their positions in light of the collective opinions. This iterative process continues until a convergence of opinions is achieved. The Delphi method is particularly useful when there is no reliable data or when it is necessary to predict future developments based on

specialist expertise.

4.1.3 Evaluation phase

The consensus document formed the basis of the second Delphi round, which was submitted to the same experts who took part in the first round of item evaluation, with the aim of assessing the clarity, accuracy and consistency of the information. The process made it possible to translate the outcome of the first evaluation into a set of coherent and verified statements, maintaining continuity between the two steps and preserving the focus on the personal and clinical-organisational relevance of the selected items.

Along with the consensus document, a set of questions was also proposed to assess the participants' sense of agency, administered at two distinct moments corresponding to the two phases of the Delphi model. The questionnaire aimed to detect changes in the participants' perception of agency and to assess their degree of satisfaction with the experience. Responses were collected anonymously using an identification code. The areas investigated concern:

- Responsibility and civic values within their community;
- The degree of commitment and active participation, including volunteering;
- Sense of connection and social relations with the community of reference.

4.2 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.

5. Evaluation

5.1 Results of the preliminary phase

Thematic analysis of the interview transcripts revealed six macro-conceptual areas within which the relevant topics were organised.

- Complexity of the process:

In describing what 'comprehensive care' really means, practitioners emphasise a responsibility that goes beyond individual services and accompanies the person through different and often concurrent needs, reducing organisational burdens and uncertainties.

> *'Proactive comprehensive care that is strictly healthcare-related. I look at what you need, whether it's an X-ray of your foot, an MRI scan of your head, a urologist for your prostate, or a gastroenterologist. You need to have tests done, whatever you need, I manage it directly, I make the requests and book the tests, thanks also to the nurses.'*
>
> (Doctor)

The injury, especially when it is sudden, not only interrupts clinical continuity but also breaks the routine of everyday life: from one moment to the next, automatic responses and certainties disappear, and the entire system of life needs to be reorganised.

> *"Spinal cord injury is something that no one is prepared for. In the sense that it is a very sudden traumatic event, which from one moment to the next takes away what we... let me use this term... what we take for granted or what we took for granted before the event."*
>
> (Doctor)

- Multidisciplinary team

Working as a team in this context does not mean combining skills, but creating conditions so that rehabilitation is also an experience of motivation, pleasure and self-esteem, as well as technical exercise.

> *"In other words, when the patient leaves here, they should say, 'Wow, I worked for an hour, an hour and a half, and I even enjoyed myself,' tired, because there is a healthy tiredness, they have 'switched off' from the healthcare aspect."*
>
> (Doctor)

- Critical issues

Alongside the progress made, there remain organisational issues concerning the 'aftermath': the stated objective is not only to treat patients in hospital, but also to accompany them home, oversee the transition and prevent interruptions in the process.

'We should take the person and accompany them until they are discharged home, i.e. we shouldn't work to then send them to another hospital, that's our job.'

(Doctor)

The same awareness emerges when we recognise that disability affects language, relationships and intimacy: care involves rebuilding an overall balance and not just restoring functions.

"Spinal cord injury is something that the person is not prepared for... they lose what we... what we take for granted... I am referring not only to walking, but to the way of speaking, the way of making love... So a new balance has to be recreated."

(Doctor)

- Psychosocial aspects and reintegration

One of the most effective ways of accelerating adaptation and autonomy is peer exchange: those who have already been through the process quickly transfer practical knowledge that would otherwise take years of trial and error to acquire.

"Hundreds of patients come and go in this centre, so there is an exchange of peer advice where new people meet experienced people who immediately inform and instruct them on a whole range of practices, daily life, work, sexuality and body care, whatever. And so you find yourself, let's say, explaining what I may have learned in twenty years in two hours."

(Association)

Similarly, some testimonies offer a sincere and at the same time vibrant account: the journey should not eliminate obstacles, but aim to restore dignity and prospects in life.

"Dealing with these things is not easy, it has been a wonderful journey that I would not have been able to take if I had died, so I am happy to be here anyway and to have managed to build a dignified life, with its ups and downs, but just like you have, just like everyone else has."

(Association)

- Opportunities

If there is one trait that effective pathways have in common, it is their ability to adapt to individual circumstances: timeframes, priorities, resources and desires are not the same for everyone, and comprehensive care should be able to accommodate them.

"It's a journey, everyone has their own and everyone overcomes it, overcomes it in their own way."

(Association)

Among the main topics highlighted are: care throughout the entire treatment process (acute, rehabilitation and post-rehabilitation phases) with continuous follow-ups*;* a multidisciplinary approach with trans-specialist skills within the team and the presence of a reference figure within the group; structured coordination with the local area and general practitioners; therapeutic education for patients and families, accompanied by psychological support; personalisation of the rehabilitation programme; integration of physical and sporting activities and collaboration with associations; attention to the emotional-relational sphere and sexuality; equitable access to services in different geographical areas and the use of telemedicine and home care; peer support; rehabilitation aimed at returning to work; training in the use of aids for daily living; reference to the ICF classification; the use of advanced technologies and robotics and cognitive and motivational simulation laboratories.

5.2 Results of the implementation phase

Following the thematic analysis of the interviews and the subsequent preliminary selection, an initial questionnaire was constructed consisting of 73 items, organised into four categories: team, care pathway, services, and personalisation of care.

The questionnaire was administered to 24 experts in the field, who were asked to rate each item on a five-point scale ('not important', 'unimportant', 'neutral', 'quite important', 'very important') with reference to comprehensive care. The responses were analysed using an inclusion criterion based on achieving at least 75% agreement in positive ratings. The items that reached and/or exceeded this threshold were sorted and adapted to form a consensus document consisting of 17 elements.

5.3 Results of the evaluation phase

At the end of the two-month administration period, 14 responses were received, all from professionals who had also participated in the first round.

Of the 17 items proposed in the last round, 16 were confirmed as relevant to the topic and of fundamental importance in the concept of comprehensive care. The item that did not reach the 75% cut-off point was adapted according to the comments and suggestions provided during the completion of the form and was therefore included.

The consensus document was supplemented with comments and suggestions and finalised thanks to the validation of the participants.

The items that received the highest scores are shown below.

- *The establishment of a multidisciplinary team ensures comprehensive care for people with acquired brain or spinal cord injuries, addressing clinical, rehabilitative, psychological and social aspects simultaneously. The coordinated presence of different professionals ensures stability and safety during the course of treatment and recovery. In this context, each member brings specific skills to the table, contributing and working towards common and shared goals, with well-defined roles.*

- *The presence of a professional dedicated to psychological health is always essential in the journey of a person with a brain or spinal cord injury. This figure plays a primary role both in the acute and post-acute phases, as well as throughout the rehabilitation process. The scope of this professional's intervention also covers the relational aspects of the caregiver(s) and the management of the motivation and needs of the person with the injury.*
- *The quality of care depends largely on the effectiveness of internal communication between professionals and the speed with which clinical information circulates. Well-organised communication allows the patient to perceive consistency and trust in the team, while reducing stress and preventing errors for the operators.*
- *It is crucial to include learning sessions related to the practical use of aids (technical, technological or environmental) intended for daily use in the rehabilitation process. In this way, the patient can try out and adapt each tool to their needs under the supervision of professionals, integrating it into their routines.*
- *The rehabilitation plan for people with brain or spinal cord injuries must be personalised. Rehabilitation should encourage personal adaptation to the new challenges and difficulties encountered by the individual, promoting the acquisition of new skills rather than simply recovering those that existed prior to the injury.*

6. Participation questionnaire results

The Participation Questionnaire for the process carried out within the Delphi sessions showed a slight increase in agency levels among participants in most items, albeit with some discrepancies. Unlike other HCLs, this process was carried out remotely and anonymously, in accordance with the Delphi methodology, which may have resulted in lower effectiveness in increasing the participant's perceived level of influence on the project context and the community to which they belong (Table 3). In particular, items related to the impact that participants can have on the community actually decreased after the Delphi phases, perhaps due to the specificity of the topic, which highlights the individual difficulties in civil and collective participation.

Item (summary)	PRE average	POST average
I feel responsible for my community	4.27	4.36
I believe I can make a difference in my community	4.14	4.18
I strive to be useful in my community	4.32	4.36
Every citizen has a responsibility towards their community	4.55	4.45
It is important to be informed about community issues	4.59	4.64
I believe it is important to do voluntary work	4.45	4.36
When I work with others, I help my community	4.45	4.27
It is important to help members of one's community	4.59	4.45
I am involved in voluntary work in my community	3.77	4.09

My social relationships are rewarding and supportive	4.04	3.92
I feel connected to a wider community	4.00	3.77
I use my strengths to help others	4.46	4.31

Table 2 - Results of the Participation Questionnaire, agency items.

The level of satisfaction showed a more consistent increase, particularly with regard to the possibility of exchanging information and points of view with various professionals and stakeholders on the topic of comprehensive care (Figure 1). On the other hand, the levels of satisfaction related to the acquisition of new knowledge and concepts were less significant, as this HCL was more focused on reaching a consensus between the parties rather than on exploring the topic in depth.

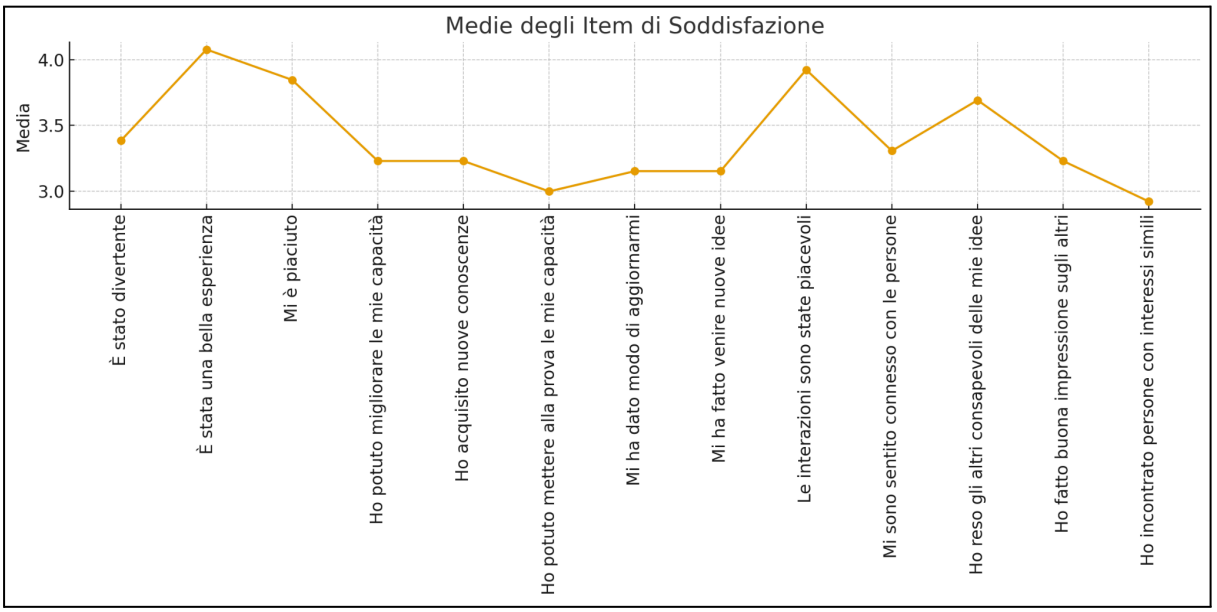

Figure 1 - Level of satisfaction assessed by participants in the implementation phase activities.

7. Conclusions

The path we have taken has demonstrated how a participatory and gradual approach can transform an initially diverse set of voices gathered in interviews, the practical skills of services and the perspectives of associations into a coherent set of shared guidelines for the comprehensive management of spinal cord injuries and sABI. The double iteration of the Delphi method made it possible to move from a wide range of proposals to 17 consensus statements, 16 of which were fully confirmed and one reformulated based on the comments received, ensuring continuity between the phases and anchoring decisions not only to the literature but also to the reality experienced by individuals, families and professionals.

7.1 Strengths

One of the strengths was the fact that the items were constructed on the basis of interviews: this choice rooted the entire process in concrete problems, in the everyday language of the services and in the experiences of those who deal with the complexity of the process on a daily basis. The iteration with aggregated and anonymous feedback acted as a refinement engine: experts were able to review their positions without role pressure, reducing the risk of conformism and improving the quality of the argument. The variety of the panel - Spinal Unit, hospital sABI pathway, associations - broadened the vision of 'comprehensive care' beyond disciplinary boundaries, and the adoption of an explicit cut-off point (≥75% agreement) made clear the transition from the initial 73 items to the final 17 statements, clearly marking the distinction between what is considered essential and what remains in the background.

7.2 Limitations

The decrease in participants between the first and second rounds could introduce a non-response bias, with the risk that some sensitivities are not adequately represented. Keeping two different clinical conditions, spinal cord injury and sABI, together allowed common principles to emerge, but also sometimes obscured specificities (such as in care profiles, follow-up times, or rehabilitation trajectories). Furthermore, in sABI pathways, the perspective of caregivers emerged at times more than that of patients, offering an important organisational insight that must, however, be balanced with the direct experiences of those who have lived through the injury. Finally, by their very nature, consensus statements tend to present themselves as guiding principles rather than operational procedures: this implies the need for a subsequent phase to translate them into responsibilities, sequences of action and measurable indicators, and careful reflection on their transferability to contexts other than those in which the research was conducted.

In conclusion, what emerges strongly is that “comprehensive care” is not just an organisational label, but rather a coordinated set of choices, roles and relational practices that must run through the entire continuum of care. The combination of qualitative listening and the Delphi method provided a solid consensus on 17 statements: the decisive step will be to translate these into concrete actions, accompanied by measurement and learning in the field. Only in this way can the framework we have built truly support person-centred pathways that combine clinical effectiveness, well-being and participation.

7.3 Implications for the future

The consensus document is a useful tool to be disseminated and used as a starting point. It can be:

- disseminated beyond the group of authors and participants: a 'technical' version aimed at the clinical and organisational community (spinal units, sABI pathways, health management), accompanied by an executive summary for decision-makers and administrators, and accessible materials for associations, patients and carers;
- initiate an informed dialogue which, starting from the shared statements, is capable of influencing the political agenda and guiding allocation choices, programming priorities and governance tools in line with a comprehensive approach.

With this in mind, the consensus can be translated into clear and practicable *policy* recommendations, such as:

- the formalisation of Diagnostic Therapeutic Care Pathways (PDTA - standardised and coordinated care plan) that make explicit the critical transitions between acute, post-acute and community care;
- the establishment (or strengthening) of a reference figure with clearly defined responsibilities;
- the systematic inclusion of therapeutic education, training in the use of aids, and psychological support;
- the appropriate use of telemedicine and proactive follow-ups.

Another aspect to consider is the generalisability of the principles. Although they arose from discussions on spinal cord injuries and sABI, they describe a model of comprehensive care that includes multidisciplinarity, continuity, personalisation and the involvement of the family and community, which can be adapted to other conditions of disability, such as neurological and neuromuscular conditions or the results of complex pathologies. In order to extend this model, contextualisation work will be necessary: it will be necessary to identify the 'core' elements that remain constant and specify, for each area, the clinical and organisational modules that vary (teams, key moments, specialist skills, tools and settings). In this way, consensus can become a basis from which to develop vertical operating standards, while maintaining a common structure that facilitates scalability and comparison between different areas. This is defined as a matrix approach that triggers actions whenever they are aligned with the redefined life project. In this perspective, civil society associations play a structural role of support and networking for the generalisability of the model, connecting hospitals, community services and homes, supporting the empowerment of individuals and carers through guidance, peer support, education and advocacy, and participating in the co-creation and validation of pathways as consensus actors. This relational infrastructure is already indicated in the consensus document among the key principles of comprehensive care, where continuity of care explicitly includes links with non-profit associations and community participation mechanisms, elements that facilitate the adaptation of the model to different contexts and pathologies.

To ensure quality and consistency over time, it will be useful to reconnect with the network of stakeholders who contributed to the project, with the possibility of periodic meetings dedicated to monitoring implementation, analysing critical issues and good practices, updating principles based on experience, and defining annual micro-priorities.

A sign of the usefulness of this HCL was already evident in November 2025, when the research results were presented to the Medical Director of the Toscana Centro Local Health Authority and to the General Director of the same authority in support of the activities of the ASS.C.A association. The evidence regarding the value of a global perspective on patients with severe brain injuries made it possible to coordinate future interventions supporting this approach with the regional healthcare facilities.

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.

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