Learning from Long-Term Care practices for the European Care Strategy

The meanings of care and quality of care in Portugal

National report

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List of Acronyms

ADLs	Activities of Daily Living
CACI	Occupational Centre for Persons with Disabilities
CNIS	Confederation of IPSS
ECCID	Home-based Teams of Continuous Care
EGA	Hospital Discharge Teams
ERPI	Residential Care Facilities for Older Persons
IADLs	Instrumental Activities of Daily Living
IPSS	Private Institution of Social Solidarity
INE	National Statistics Office
LTC	Long-Term Care
RAI	Autonomous Residences for Persons with Disabilities
RNCCI	National Network of Continuous Integrated Care
RRP	Recovery and Resilience Plan
SAD	Homecare for Older Persons
SCM	Holy House of Mercy
SNS	National Health Service
UC	Convalescence Unit
ULDM	Long Duration and Maintenance Unit
UMDR	Medium Duration and Rehabilitation Unit

Executive summary

The expression “Long-Term Care” (LTC) is still today an expression that has no straightforward translation into Portuguese apart from the strict language translation – *Cuidados de Longa Duração*. Traditionally LTC in Portugal has developed from social assistance and therefore the concept in use more commonly is “social care”. But even this, that would translate as ‘*Cuidados sociais*’, is used mostly in the scientific literature. In legal and policy documents the term in use is ‘*Respostas Sociais*’, that translates as Social Responses. In 2006, it was created a new system, the National Network of Integrated Continuous Care (*RNCCI – Rede Nacional de Cuidados Continuados Integrados*), bringing together the Ministry of Health and the Ministry of Labour, Solidarity and Social Security, to create a new type of service under the National Health System (*SNS – Serviço Nacional de Saúde*) that would focus on securing continuous, long-duration and focused on rehabilitation and reablement care, as well as on palliative care.

Care is primarily understood as the other side of the coin against needs. The two notions end up being rather circular as they imply each other. In that sense, understandings of care are tied to how the system is organised in terms of programmes and services that provide care.

Despite the references to the term quality to discuss care services, interviewed stakeholders struggle with offering a clearly outlined definition of what quality of care means. Even if probed to be more explicit about the meaning of quality of care, it was not possible to get such a definition. Explanations remain fuzzy and at a very abstract level.

In Portugal, the data and regulatory infrastructures related to LTC provisions reflect the system fragmentation that separates social care from the RNCCI. Regarding the most pressing problems in provision of care, views collected in interviews and the literature offer a high level of consensus around some main ideas: low coverage rates and long waiting lists signal a need for fast expansion of the system; underfunding of the care system is preventing good quality of care; shortages of workers and of qualifications have a strong impact in quantity and quality of care.

The system draws on a one-size-fits-all approach, with national regulations applying to the entire country in the same manner. This includes issues of funding, types of services and regulations on licensing and operations.

The ongoing political debate is vague, mostly reacting to the occasional news in the media but showing no signals of any systematic holistic discussion taking place soon about LTC. Negotiations between the state and care providers is almost exclusively focused on funding issues.

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Introduction

This report is part of the European research project **LeTs-Care: Learning from Long-Term Care practices for the European care strategy**, a collaborative research project that engages and supports policy makers and other stakeholders in addressing the challenges posed by long-term care (LTC) across the European Union countries.

LeTs-Care brings together a consortium of seven European academic institutions, a unique European Network of Cities and Regions, and several social economy organisations operating in Austria, Denmark, Italy, Lithuania, the Netherlands, Portugal, and Spain. The project is coordinated by Ca' Foscari University of Venice, and in Portugal the research is conducted by University of Porto. The project started in April 2024 and will run until December 2027. It is funded by the European Union under Horizon Europe as stipulated in Contract 10113270.

Long-term care (LTC) systems across EU countries are facing important challenges and are trying to strike a balance between ensuring affordable, accessible and good quality care; high quality of work in the care sector and financial sustainability. According to the European Union's "care strategy", we should invest in practices that promote integrated and person-centred care to address these challenges.

However, to date, there is little systematic knowledge of the specific LTC challenges and of the meanings of, for instance, quality of care and quality of work in care across national and local contexts. In addition, we know that "good practices" are difficult to transfer or to extend because their outcomes are highly dependent on the context.

Furthermore, while "good practices" in care provision are frequently promoted across Europe, experience shows that their transferability is limited. What works effectively in one context may not yield the same results elsewhere, because outcomes are strongly shaped by local governance models, policy environments, available resources, and community networks. This complexity calls for a comparative, context-sensitive approach to the study of LTC systems — an approach that LeTs-Care aims to provide.

LeTs Care has three aims:

1. To provide a new, in-depth, reflexive understanding of LTC challenges across national and local contexts, for and with stakeholders and policy makers.
2. To understand how "integrative" and "innovative" practices work in context and to highlight the possibilities and limitations to their transfer.
3. To develop a new model for policy learning with and for stakeholders.

To achieve the first aim, the LeTs-Care team set out to understand the meanings of five structuring concepts within long-term care systems: *needs; care and quality of care; work and quality of work; sustainability;* and *inequalities*. Methodologically, LeTs-Care adopted a mixed-methods approach, combining the analysis of secondary data (including a review of national literature, both academic and grey literature, as well as policy documents) with the collection and analysis of primary data obtained through interviews with *stakeholders* and *policy makers* at national and subnational levels.

For each of the five key concepts, every national research team produced a dedicated report focusing on a contextualised understanding of its meaning within the respective long-term care system. The present document is one of these reports, forming part of the series of five national reports developed by the Portuguese research team within the framework of LeTs-Care. Specifically, this report focuses on the concept of long-term care needs in Portugal, examining how it is understood, articulated, and addressed within the national policy and care landscape. Equivalent

reports were produced by all research teams in the other participating countries. Building on the insights generated through these national analyses, the research consortium developed a comparative report that examines the five key concepts across the different national contexts, identifying convergences, contrasts, and shared challenges within European long-term care systems.

1. Definitions and History

The expression “Long-Term Care” (LTC) is still today an expression that has no straightforward translation into Portuguese apart from the strict language translation – *Cuidados de Longa Duração*. It is an expression that is used by some scholars who end up translating LTC into Portuguese but mostly because of their own exposure to the international literature. There is little use of the term long-term care in legislation and official documents, and when it is used, it does not relate to any unified understanding of what it entails, but rather as a qualifier of the type of care policies that are needed. The emphasis of the expression is on the duration of the care as opposed to acute short-term care, and primarily in the context of healthcare.

Traditionally LTC in Portugal has developed from social assistance and therefore the concept in use more commonly is “social care”. But even this, that would translate as ‘*Cuidados sociais*’, is used mostly in the scientific literature. In legal and policy documents the term in use is ‘*Respostas Sociais*’, that translates as Social Responses. Social Responses has an official definition that concerns the set of collective arrangements to provide social support to those who need it. Social Responses is a conceptual umbrella that covers all types of programmes and services that State sponsored parties organise to tackle people’s needs for support. The expression does not cover exclusively services that fall under LTC for older persons but rather all types of social care services. Services and programmes are then organised into a typology defined according to the population group they target. This system operates under the Ministry of Labour, Solidarity and Social Security.

In 2006, it was created a new system, the National Network of Integrated Continuous Care (*RNCCI – Rede Nacional de Cuidados Continuados Integrados*), bringing together the Ministry of Health and the Ministry of Labour, Solidarity and Social Security, to create a new type of service under the National Health System (*SNS – Serviço Nacional de Saúde*) that would focus on securing continuous, long-duration and focused on rehabilitation and reablement care, as well as on palliative care. From then onwards, a version of the term long-term care was introduced in the policy and practice vocabulary. This term is Continuous Care (*Cuidados Continuados*). In the decree of 2006 that creates the RNCCI, in the preamble, it reads that ‘(…) there are shortcomings in long-term and palliative care, due to the increase in the prevalence of people with disabling chronic illnesses. New health and social needs are thus emerging, requiring new and diversified responses to meet the expected increase in demand from older persons with functional dependence, patients with multiple chronic pathologies and people with incurable diseases in an advanced stage and at the end of life.’ (Decree-Law n.º101/2006).

The term care by itself (*Cuidados*) is a term that is more clearly associated with healthcare. In fact, in all the interviews, when asking interviewees about what is at stake when we talk about long-term care, the term ‘care’ immediately takes people to healthcare. It was necessary to specify we were also interested in discussing the *Social Responses*, the social care component, to have interviewees moving into that direction.

LTC as a policy field in Portugal is quite fragmented. One level of fragmentation concerns the split between healthcare and social care in public provision of care. Another level of fragmentation concerns the social actors involved in provisions of LTC and the distribution of roles across them. The organisation of this first section of the report is inspired by this fragmentation of LTC to offer a comprehensive overview about understandings of care and quality of care across the system.

1.1. Care and quality of care within the social care system

Social care in Portugal has developed as social assistance. Historically, it was not a field for public provision or state intervention. Across centuries, and as part of a society very much marked by the charitable tradition of Christianity and by dispositions of the Catholic Church, social care was secured by religious organisations that offered services to the most vulnerable and deprived of resources to meet their needs by themselves. Social assistance and charity for the poor walked hand in hand. The foundational approach was therefore strange to any notion of individual rights and did not rest in any collective agreement about the socialisation of mechanisms to tackle individual needs. Throughout the dictatorship period that marked the 20th century up to 1974, social care provisions were not part of state provision responsibilities and remained strongly dependent of non-profit organisations, most of them of a religious nature. It was only in the 1980s that a system of public provision of social care was created in the country. However, it was created not as a fully public provision system but rather as a mixed system that retains as care providers the institutions that had traditionally been securing care provision, and that defines state's responsibilities in the funding and in the regulation of care provision.

These words of context are critical to understand meanings of care and quality of care within the social care system in Portugal. In the next paragraphs we discuss the two separately.

1.1.1. What is care?

Care is primarily understood as the other side of the coin against needs. The two notions end up being rather circular as they imply each other. In that sense, understandings of care are tied to how the system is organised in terms of programmes and services that provide care. One could say that motives, processes and objectives merge to define what is care. Care is therefore about types of services and within services it is about satisfying types of needs.

The Portuguese social care system is organised into two branches, different in access rules and contents, but not mutually exclusive. One branch includes cash-for-care benefits. The other concerns in-kind care provision. Table 1 below summarises the main programmes and services in place to secure care to those in need of LTC with a focus on the adult population. Specific benefits and services targeting childcare were not included since they fall outside the scope of this report.

Table 1. Care services and cash-benefits as officially defined in applicable legal documents, in Portugal

BENEFIT / SERVICE	CASH / IN-KIND	CONTENTS/AMOUNTS (1)	ELEGIBLE PERSONS
Dependency allowance (***Complemento por Dependência***)	**Cash** Secured under the contributory system for those who are entitled to a statutory pension. Secured under the social assistance system for those who are not entitled to a statutory pension.	Amounts of cash are defined according to level of dependency: 1st level for those who require support in ADL and/or IADL; 2nd level for those who are bed-ridden and/or have dementia. Values also vary depending on funding system 1st level/contributory system = 127,63 €/month 1st level/social assistance system = 114,86 €/month 2nd level/contributory system = 229,73 € 2nd level/social assistance system = 216,96 €	Persons over 65 years of age who require support in aspects of daily life due to some limitation caused by chronic or degenerative illness or by declines in functional capacity
Social Inclusion Benefit (***Prestação Social de Inclusão***)	**Cash** Includes 3 components that are cumulative: base; complement to address poverty; supplement to compensate for specific needs.	The cash benefit addresses all needs of persons with disabilities including those related to care and support needs. The fundamental principle is the recognition that needs of persons with disabilities incur in higher costs that need to be compensated. Maximum value = 316,33 €/month Amount of the complement = 550,67€/month Amount of the supplement = pending regulatory decision	Persons with a certified disability of 60% or more and for whom the onset of disability took place before the age of 55.
Informal carer's allowance (***Subsídio de apoio ao cuidador informal principal***)	**Cash**	Means-tested benefit to compensate the main informal carer of a dependent person for the loss of income that becoming an informal carer may entail. Value computed as the difference between the individual income harmonised according to a defined algorithm that considers household income and household composition and expenses, and a reference value (max. value). Maximum value = 574,75€/month	Persons who have been granted the status of primary informal carer as stipulated in applicable legislation. Old-age pensioners are not eligible.

Table 1. Care services and cash-benefits as officially defined in applicable legal documents, in Portugal (cont.)

BENEFIT / SERVICE	CASH / IN-KIND	CONTENTS/AMOUNTS [1]	ELEGIBLE PERSONS
Home-care service (***Serviço de Apoio Domiciliário***)	**In-kind** **Home-based**	Support with ADLs and IADLs. The detailed menu of care includes personal hygiene and comfort; house hygiene (but only related to tasks of care provision, not general cleaning); food delivery and administration; laundry service; support with leisure activities and stimulation; teleassistance. A service must include at least four of the types of care listed above to be licensed to operate.	Persons over the statutory age of retirement and based on evaluation of needs and resources.
Day centre (***Centro de Dia***)	**In kind** **Semi-institutional**	These centres offer board care and activities for the occupation of time but are provided during the day only and on weekdays. The person goes back to his/her usual residence at the end of the day and on weekends. Transportation services can be provided.	Persons over the age of 65 that can stay in their own accommodation if they have the care provided in the day centre.
Old-age homes (***ERPI – Estrutura Residencial para Pessoas Idosas***)	**In-kind** **Institutional care**	This is the classic institutional care facility that provides board and residential care. The menu of care services includes activities of stimulation, occupation of time, promotion of autonomy and participation in society. Care also includes healthcare, although it is not defined what type of healthcare.	Persons over the statutory age of retirement and based on evaluation of needs and resources.
Personal assistance (***Assistente Pessoal***)	**In-kind** **Personal assistance**	Dedicated person that assists the person with disabilities in performing autonomously ADLs and IADLs.	Persons with disabilities. No age criteria.
Home-care (**SAD - *Serviço de Apoio Domiciliário***)	**In-kind** **Home-based**	Support with ADLs and IADLs. The detailed menu of care includes personal hygiene and comfort; house hygiene (but only related to tasks of care provision, not general cleaning); food delivery and administration; laundry service; support with leisure activities and stimulation; teleassistance. A service must include at least four of the types of care listed to be licensed to operate. It is like the one offered to older persons.	Persons with disabilities that can stay at their home with the support of this service.

Table 1. Care services and cash-benefits as officially defined in applicable legal documents, in Portugal (cont.)

BENEFIT / SERVICE	CASH / IN-KIND	CONTENTS/AMOUNTS	ELEGIBLE PERSONS
Day centre for persons with disabilities (**CACI – *Centro de Apoio e Capacitação para a Inclusão***)	**In-kind** **Semi-institutional**	These centres offer board care and activities for the occupation of time but are provided during the day only and on weekdays. The person goes back to his/her usual residence at the end of the day. Transportation services can be provided. Care is targeting also promotion of training and autonomy.	Persons with disabilities over 16 years of age.
Autonomy residences (***RAI – Residence for Autonomy and Inclusion***)	**In-kind** **Semi-institutional**	These are residences where residents (up to 5) live in an autonomous manner with some minimal support of care staff.	Persons with disabilities over 18 years of age.
Residential care (***Lares Residenciais***)	**In-kind** **Institutional care**	This is the classic institutional care facility for persons with disabilities that provides board and residential care. The menu of care services includes activities of stimulation, occupation of time, promotion of autonomy and participation in society. Care also includes healthcare, although it is not defined what type of healthcare.	Persons with disabilities over the age of 18.

Source: Segurança Social Direta, platform of the Social security services, available at https://www.seg-social.pt/inicio, last accessed on the 31st of January 2025.

All cash benefits are centrally managed by the Social Security services. Applications follow rules that apply the same way to the entire country. If eligible, the person gets the cash benefit directly from the Social Security services. There is no specific definition of care tied to these benefits but rather of needs. How one decides to tackle those needs, translated into care provision, is up to the person needing care or providing care. The cash benefits can be accumulated with the use of social care services. This is a peculiar characteristic of Portugal where you don not have a choice between cash-for-care of in-kind provision. They are cumulative.

In-kind provision has a more complex institutional configuration since establishments are managed by non-profits, under regulations established by the central state and within agreement contracts that are signed between the two parties. Those contracts regulate aspects of funding, namely amounts paid by the Ministry of Labour, Solidarity and Social Security, per user, to care providers, and rules concerning determination of co-payments by users of services. Funding is not tied to any menu of types of care but rather to the broad typology of services described in table 1. In other words, it is irrelevant for the purpose of public funding what specific type of care is being delivered to the person. Services are funded at a fixed rate per user. Table 8 under section 4 offers detailed information on the financials of social care services.

Direct public provision is extremely marginal. Over recent years, private commercial provision has been expanding but non-profits still represent the lion share in the system.

This aspect of how care is understood by the regulator was something interviewed stakeholders directly engaged in provision were very critical about. Insufficient funding is explained by a lack of recognition of the amount and complexity of the care that is provided in social care facilities.

These things are all wrapped up in each other. The change in the profile of users with new problems of dementia, dependency, forces institutions to change their human resource ratios. In particular, those human resources that deal directly with the user. And these are qualified resources - they have to be - which cost a lot of money. This will change the difference between the real cost and the technical cost.

[…]

The technical cost comes from the social response ordinance. And the real cost is much higher. And there could be a temptation to conclude that there's bad management because the real cost is higher than the technical cost. And these are nuances, I don't know if I'm making myself clear.

[…]

Just to tell you that, for example, the Day Centre, the Social Security contribution was only 27% of the cost. And nowadays the Day Centres, it would be worth studying the Day Centres, the Day Centres are a response in which the user only doesn't sleep. (...) He's picked up, but that can even be a separate contribution. They have breakfast, hygiene, assisted bathing, snacks, lunch, recreational activities for cognitive stimulation, all that, laundry and sometimes even dinner. He just doesn't sleep. And with a co-payment of 27%, which is how much Social Security co-pays.

Interviewee code: ORN_2410

1.1.2. What is quality of care?

The topic of quality of care in the social care sector has historically been a contentious one and a source of occasional tensions between the regulator and service providers. In its current configuration, the social care system does not operate with a unifying concept of quality of care and does not have in place any mandatory and standardised system of quality evaluation. Understandings of quality of care vary considerably across stakeholders depending on the institutional roles they take.

Starting with the official definitions, extrapolated from protocols of supervision of services by the regulator, quality of care is primarily focused on compliance with regulations that are used to license providers and that are routinely verified to keep the license active. This inspection work is carried out by inspectors from the Social Security services. It involves occasional visits and verification of spaces and administrative documentation. It does not involve any systematic collection of information on outcomes of care provision and does not involve consultation with the service users in a formal manner. Back in 2007, there were some attempts to introduce a quality system in social care but it did not work and was never fully implemented (see details in section 4).

This is a feature that generates views among stakeholders that one could consider paradoxical. On the one hand, service providers are critical about what they see as a very narrow understanding of what quality of care entails that does not go beyond bureaucracies. On the other hand, they are defensive about the intervention of the regulator on issues of quality control since they see quality of care as something that is very specific of each care setting.

A very instrumental evaluation. It doesn't measure what each user perceives, it doesn't measure the result. So, as I was saying, it's instrumental. It doesn't even measure the process, most of the time. It measures the inputs. What resources have I put in there? Is it compliant or not? Is it clean or not clean? Is the bed made or not? Do you have X hours of this or not? (...) But there's another issue when we talk about evaluation, which is bureaucracy. Which then leads to almost nothing. The amount of documents that have to be produced, the matrices that have to be filled in, the irritability it creates in the providers. The direct providers. When there are other ways of measuring results.

Interviewee code: DPL_1309

And that it really is necessary to define criteria, but in a very light way, it seems wrong to say light, in a light, practical way. I don't want them to invent another quality management system, but what I do want is for them to define the criteria to be monitored and then for each home to organise itself in terms of how it does this monitoring, without the imposition of maps, and little maps, and reports, and a hell of a lot of paper that nobody can stand to govern their lives like that. Now, this definition of the criteria to be monitored, and this isn't difficult. There's a lot of work done on this, in which we look, for example, at the risk of falls, the number of visits to the emergency room, and so on. There are a series of indices that are easy to define so that each household can then monitor these criteria in their own way. This is not difficult to do and to implement in practice, on the ground, in the life of the homes. And I think the vast majority don't do it. Whether it's social or for profit, it doesn't matter. I don't think the vast majority do.

Interviewee code: DRN_1209

Outside the official LTC system there are service providers and care arrangements that remain unknown but that are most likely quite sizable. Most of these are illegal non-certified institutional care facilities, paid by users and their families. There are anecdotal reports about the low quality of the services provided in these places and occasionally there are news about inspections leading to shutting down facilities. Interviewed stakeholders also associated these places to low quality of care.

Now the situation in clandestine homes for the elderly is even worse, because they are usually set up in small houses, which don't have much of a structure of their own suitable for caring for the elderly, they don't have enough staff or sufficient qualifications to look after the elderly, they don't have suitable equipment with articulated beds and so on.

Interviewee code: DRN_1209

But we don't talk about it, we only talk about illegal homes, basically we talk about the consequences, but we don't talk about anything to prevent things from happening. Even in Portugal there are almost as many illegal homes as legal homes

Interviewee code: MPN_0310

Despite the references to the term quality to discuss care services, interviewed stakeholders struggle with offering a clearly outlined definition of what quality of care means. Even if probed to be more explicit about the meaning of quality of care, it was not possible to get such a definition. Explanations remain fuzzy and at a very abstract level.

And quality is a very abstract concept, it's like emergency. My emergency is my emergency, my quality is my quality, and standardising quality is very complicated, it's complicated.

Interviewee code: DTN_1111

Quality care is all about the quality of care and the existence of evidence that it is quality.

Interviewee code: DPN_0212

There are also no dispositions about quality of care that takes place in home settings as part of private arrangements. More specifically, there is a care market of in-house carers, that often combine care provision with household chores. The phenomenon has been growing in recent years and in big urban centres it is involving growing numbers of migrants (Gil, 2020; Santini et al, 2023). The topic however did not come up much during the interviews and it is not found in any official report or any regulatory document.

1.2. Care and quality of care within the healthcare system

In 2006 it was launched the Integrated Network of Integrated Continuous Care (*Rede Nacional de Cuidados Continuados Integrados*). It is organised as an intermediate level of care between acute healthcare and social care. Persons are referred to a service depending on their clinical condition and their prospects of rehabilitation.

1.2.1. What is care?

The system includes several types of units that involve different combinations of healthcare and social care. Funding is shared by the Ministry of Health and the Ministry of Labour, Solidarity and Social Security. The component of healthcare does not involve costs for the user. The component of social care has co-payments and is means-tested. Providers include public health units, non-profits and private commercial entities. These services are part of a structure that splits into three branches: the general services, which are of a broader scope in terms of healthcare conditions; the mental healthcare care branch; and the paediatric services, focused on LTC for children and young people. When it was set up, the RNCCI included palliative care, which has since been autonomised into its own network (National Palliative Care Network), although the RNCCI maintains some palliative interventions. Table 2 below summarises the main care services that fall under the umbrella of the general services of the RNCCI. The paediatric branch is not included due to its small size but also because it falls a bit out of the scope of this report. The LTC network for mental healthcare is also not included given its very recent creation and the still ongoing regulatory process (ACSS, s/d).

Table 2. Typology of services within the general services branch of the RNCCI

SERVICE	LENGTH OF STAY	CARE SERVICES TO BE PROVIDED
Convalescence units	Up to 30 days	- Intensive functional rehabilitation; - Permanent medical care; - Permanent nursing care; - Complementary diagnostic, laboratory and radiological examinations; - Prescription and administration of medication; - Physiotherapy care; - Psychosocial support; - Hygiene, comfort and nutrition; - Socialising and leisure time.
Medium and long duration units	30 to 90 days	- Functional rehabilitation; - Daily medical care; - Permanent nursing care; - Physiotherapy and occupational therapy care; - Prescription and administration of medication; - Psychosocial support; - Hygiene, comfort and nutrition; - Socialising and leisure time.
Long duration and maintenance units	Over 90 days	- Maintenance functional rehabilitation; - Maintenance and stimulation activities; - Ongoing nursing care; - Regular medical care; - Prescription and administration of medication; - Psychosocial support; - Periodic physiological check-ups; -Physiotherapy and occupational therapy care; - Socio-cultural entertainment; - Hygiene, comfort and nutrition.
Integrated Continued Home Care Teams	-	- Nursing and medical care (preventive, curative, rehabilitative); - Physiotherapy care; - Psychosocial and occupational therapy support, involving family members and informal carers; - Health education and training for patients, family members and informal carers; - Support in meeting basic needs; - Support in performing activities of daily living; - Support in instrumental activities of daily living; - Appropriate use of drugs.

Source: *Unidade de Gestão e Acompanhamento da Rede Nacional de Cuidados Continuados Integrados* (2024). *Guia Prático Rede Nacional de Cuidados Continuados Integrados (N37 – v4.24). Instituto da Segurança Social, I.P. Available at https://www.seg-social.pt, last accessed on the 31st of January 2025*

The distinctive feature of care within the RNCCI is the integration of healthcare and social care. This is a feature that stems from an official understanding of LTC as integrated care and as rehabilitative care. At the date of creation of the RNCCI this was considered as an almost revolutionary step of the LTC system (Santana et al, 2014). Currently views are not so positive, as it could be heard from the stakeholders' interviews. Aspects that are seen as less positive concern the dominance of the biomedical perspectives and professionals in defining care, as part of a tense relationship between the health and the social care components, where the first tend to take the lead.

And the point is that there was also a policy of damage, wasn't there? Therefore, the accumulation, which favoured betting on other types of care, both at the level of health care in hospital care to the detriment of primary health care, and at the level of social security, residential responses and with this SAD service, which could and should be much better.

Interviewee code: DPN_0212

There are some studies done in Portugal about this, and some point to around 110,000, 120,000, 130,000, nobody knows for sure, but around 120,000, 130,000 people, a thousand Portuguese, are left to their own devices, in their homes, with their comorbidities and illnesses on their backs. But left to their own devices! Of course, what's going to happen? What door is open to them? Urgency. That's why we have this bias in the system, in which no one is followed up from an integrated point of view, and then seeks an answer to their pain, their breathing difficulties, their oedema, or whatever, in the emergency room. And this means that comorbidities then exist and prevail.(...) We live in a world dictated by illness and the medical response. The rest doesn't matter.

Interviewee code: MPL_0310

The models of hospital organisation that are starting to say that they need to discharge the elderly because they shouldn't be there, but they continue with their acute model, strictly, and that don't look at long-term health, continuity of care. That's why, when this European strategy comes along now, it reminds us that we need to look at long-term care.

Interviewee code: ORN_2410

1.2.2. What is quality of care?

Quality of care within the RNCCI is influenced by the quality assessment protocols that are standard in healthcare in general and therefore has clearer contours when compared to what is in place in the social care system. It still shows some traits of fragmentation since there are several norms and guidelines in place that are used for different reporting instances. But overall, one can say there is a regular and systematic protocol of evaluation of quality of the RNCCI activity. This translates into the publication of monthly, semester and annual reports by the central coordination of the system.

Regarding how quality of care is understood, there are different levels of analysis. In a stricter manner, reports specifically tackling quality of care phrased as such are based in the regular monitoring of two indicators: prevalence of falls and rate of bed sores in the services of the RNCCI. There are thresholds of reference that define what is acceptable and what is not for these two indicators.

To support the follow-up/monitoring of the implementation of the RNCCI, a Monitoring/Information System was developed - GestCareCCI ® - a computer platform in a web environment, which allows

the real-time management and monitoring of processes and their results. This system collects data on a broader range of indicators and is the base for the activity reports mention above. Although they can be understood, implicitly, as related to quality assessment, that is not explicitly stated in any report. Indicators available include physical autonomy on admission, during hospitalisation and on discharge from the unit; mortality; mortality in the first 10 days after admission; worsening of clinical condition, leading to hospital admission; evolution of autonomy levels; assessment of pain; waiting times for admission; discharges from the services by level of achievement of therapeutical goals.

1.3. Care and quality of care in the scientific literature

There seems to some circularity in the meanings of 'Needs' and 'Care' in the scientific literature, as each concept is defined by reference to the other. Integrated long-term care, for example, is defined as a response to the health and social needs associated with the phenomenon of population ageing (Petronilho et al, 2014). Figueiredo et al (2014) define caring as an 'individual act or the provision of support to others in their needs' (p. 273).

In some English-language texts, but authored by Portuguese scholars, there are references to the concept of LCT. For example, Cardoso et al (2015b) use the definition of LTC proposed by the WHO (2000), as a multidisciplinary approach that aims to improve the quality of life of individuals suffering from chronic illnesses and/or disabilities. The same authors in one other article (Cardoso et al, 2015a), in turn use the definition of LTC put forward by the OECD (2005), as a wide range of health and social services designed for people suffering from chronic illnesses and/or disabilities. Some authors choose to use the term services rather than care (especially those working on the incorporation of technologies in long-term care) (Marcelino et al, 2018).

It should be noted that the term 'long-term care' spelled-out as such is not common in the national literature. And in the few references where it is used, the definition of the concept is generally lacking (Costa & Mourão, 2015; Martins & Melo, 2016). Martins & Melo (2016) use the term long-term and palliative care, and they implicitly define long-term and palliative care as 'responses to the different contexts of dependence, both socially and in relation to the care associated with the different stages of the disease' (p104). Costa & Mourão (2015) also refer to long-term care but define the concept by listing the services that are part of it.

The terms 'integrated care', 'long-term care' and 'integrated long-term care', often used interchangeably, are mostly found in articles that address/analyse the RNCCI. For example, Pereira (2014) distinguishes between long-term care (for cases of very severe dependency), nursing homes, residential homes and home-care service. The literature somehow reinforces the observation that the term long-term care is used primarily in reference to the care provided within the scope of the RNCCI and not as a comprehensive overarching concept.

Ribeiro et al (2014) implicitly define what integrated long-term care is in terms of at least one of its dimensions, that of rehabilitation: 're-establishing the potential at the rehabilitation level in order to better capacitate people with physical and mental disabilities, enabling their reintegration into the family and society' (p.411). In the same line of thinking, Figueiredo et al (2014) point out that Continuous Care is aimed at groups of the population, including the older persons, who are in a situation of dependency, requiring specialised care for rehabilitation provided preferably at home, or if this is not possible, in long-term care units (inpatient care). Continuous care is therefore defined as care focused on rehabilitation and reablement, but also on the treatment of other clinical conditions in non-acute phases that were traditionally only treated in the hospital (Filipe et al, 2016).

Several authors analyse the creation of the RNCCI in the face of a shortage of adequate care responses to a new profile of needs, which resulted in pressure on hospital services: 'This has an impact on the efficiency of hospitals, namely in the increase in hospitalisation days, which compromises patient turnover and, consequently, the response to acute patients who really need hospital care.' (Martins & Melo, 2016, p.104). Cardoso et al (2016) refer to the creation of the RNCCI in 2006, following a growing awareness of the very limited involvement of the public sector in the long-term care sector, the need to increase the provision of long-term care services and the recognition that improving the coverage of long-term care could improve healthcare performance. The low supply of LTC care is seen as resulting in high costs for the health system as it leads to inadequate utilisation of acute care services (Unidade Missão RNCCI, 2010, as cited in Cardoso et al, 2015a).

Regarding the **concept of quality of care**, it is once again a field of the literature marked by implicit elements rather than by explicit and well delimited definitions. Figueiredo et al (2014), in stating that meeting needs in old age should 'always promote the autonomy, confidence, self-worth and Quality of Life (QoL) of the older persons' (p. 273), are implicitly defining some contours of quality of care. Gonçalves et al. (2016) in a qualitative study about care professionals implicitly referred to the notion that quality of care is person-centred care, that respects individual autonomy. Szczygiel and Almeida (2017) offer another implicit understanding of quality of care, this time regarding care in nursing homes: 'The role of the institution in this process is strategic to create a warm, hospitable environment, providing respect to a person's past and choices. Integration should also involve interventions enhancing the individual's empowerment as it conveys a sense of personal control' (pp. 588-589). Although some authors implicitly define quality care as that which promotes and respects autonomy and quality of life, the indicators for measuring the quality of care (as described in the section on resources, infrastructure and regulation) are still fundamentally linked to health gains. The Order of Nurses (2014), a national regulatory body that regulates the profession, defines quality of care as a 'better response to the objectives set out in the individual intervention plans, meaning a higher quality of life for the dependent person and fewer days in hospital, with better indicators and health gains' (p.32). A counterfactual approach is also used by some authors that identify the factors that put at risk the provision of care of good quality. Gonçalves et al (2016) for example discuss how care work involves bureaucracy suggesting that the quality of care would be improved if there was less bureaucracy.

Quality of care more specifically focused on social care is also addressed in the literature in rather implicit manners, again mirroring quality assessment protocols in place in the sector. Veloso et al (2018) implicitly understand quality care in nursing homes as care that meets the needs described in Ordinance No. 67/2012 that defines which needs nursing homes must tackle: adequate food for the needs of users, personal hygiene care, care with clothing and garments, cleanliness of spaces, sociocultural activities, support in users' activities of daily living, nursing care, as well as access to healthcare, and medication.

Several articles (Alves et al, 2015; Calha & Chambel, 2016) state more or less explicitly that one of the most important factors in ensuring quality of care is the human resources factor. For example, Calha & Chambel (2016) implicitly state that quality of care is related to the quality of humanised assistance, since this is critical in the act of caring. These authors associate quality of care to organisational policies in terms of management, performance of the technical staff, qualifications of care workers and opportunities of training the policy of the institution, the management, the technical staff, the level of qualification of the employees or the development of internal training (p.197). Pinheira and Beringuilho (2018) discuss how the profile of workers (preparation and ability to respond to needs) has an impact on the quality of care provide. Guerra et al (2019) highlight the negative impacts of high absenteeism and turnover of workers on the quality of care provided.

Alves et al (2015) look at how organisational strategies can positively shape and influence levels of employee commitment. This commitment is understood as boosting positive behaviour and productivity, promoting a better level of quality-of-service provision. In line with this, Araújo et al (2016) address the 'organisational climate' of social care residential facilities and a fundamental element with impact on the quality of work. This views, however, are mostly implicit and result from the interpretation of the authors of this report rather than from any explicit outlining of the concept of quality of care.

In a study about how stakeholders understand the concept of quality of care, Lopes and Dias (2018) already highlighted the main conclusion we put forward in this report. They stated that "quality remains (…) a fuzzy concept that is sometimes presented as a management issue, other times as a characteristic of the performance of professionals and still other times as the satisfaction felt by users, all in all a three-folded approach aligned with the classical model of Donabedian on the categories from where to extract data to measure quality: structure, processes and outcomes" (p.144). The authors further continue concluding that "one can safely say that quality of care is a topic that has remained absent from the regulatory framework of LCT in Portugal, and to a large extent this can be a side-effect of the chosen model of provision based on the quasi-monopoly of provision by the non-profit sector." (p.144), in a way linking meanings to institutional configurations of the system.

2. Boundaries, Differentiation and Interrelations

In the following subsections we summarise findings about the main issues that describe the mosaic of care and quality of care in the Portuguese LTC system.

2.1. Formal, informal and other care

The first, and most likely the one that is clearer in both the literature and in policies and discourses of stakeholders is the differentiation associated to who and where care is provided.

Research articles typically focus on either formal care provisions or informal care provisions, but rarely on both. When they address both, they tackle the topic of training of carers (Almeida et al., 2022). This signals a clear cut between the two that comes with different approaches to the concept of care. Formal care is addressed as care to meet health needs (Carneiro et al, 2014; Baldissera & Camarinha-Matos, 2016) and/or care to meet needs of support with ADLs and IADLs (Barbosa et al, 2018). Informal care is primarily approached focusing on the nature of the relationship between carers and cared after and on impacts of caring for carers (Barbosa & Matos, 2014; Santos et al., 2021; Tavares & Freitas, 2020.)

The articulation between formal and informal care is understood as weak (Santana et al, 2007 cit Barbosa & Matos, 2014), despite the existing legislation that targets the promotion of integration (Barbosa & Matos, 2014). The formal organisation of the care system advocates articulation/involvement with informal care. The RNCCI has a care model that promotes the integration of informal carers in the patient's rehabilitation process through daily meetings, identifying expectations and involving them in activities relating to food, medication, hygiene, physiotherapy and entertainment activities (Figueiredo et al, 2014). The vision is that family carers have access to relevant knowledge to ensure continuity of care after leaving long-term care facilities (which helps to

reduce carer stress) (Figueiredo et al, 2014). However, there are some obstacles to the implementation of this participation model: a) illiteracy of Informal Carers, b) the advanced age of informal carers c) the difficulty they experience with care that requires more physical effort (Figueiredo et al, 2014).

One important element of differentiation is the one opposing acute care/hospital care (Santana et al, 2014; Martins & Melo, 2016) to long-term care. They are understood as differing in several dimensions: the former are aimed at treating/curing and are administered in hospitals or health centres; the latter are aimed at convalescence, rehabilitation and regaining autonomy.

We have specialised hospital responses and we know that in the overwhelming majority of situations the hospital response is one of quality, technical, scientific, modern and everything else. And then we have long-term care. And then there's nothing else. And all this is limited by time, isn't it? When a citizen goes to hospital, it's to be treated for that specific need that has been identified. If they need to ask for some rehabilitation, some maintenance, they are referred to long-term care.

Interviewee Code: DPL_1309

2.2. What is the best care?

National results from a European study indicate ‘a preference for the patient to be under the responsibility of the family (50%), under the responsibility of a care service (21%), at home with a carer (6%) and in an institution (11%) – this represents a dominant choice of more than 80% for home care. In the same line of reasoning, Broeiro-Gonçalves (2017) , quote Gomes et al. (2013) where it states that ‘the majority of older people aged 75 and over would prefer to be cared for and die at home, if they were allowed to choose” (p.40). Filipe et al. (2016) state that proximity care models, namely home care, reduce costs (allowing the sustainability of the NHS), increase user satisfaction and reduce healthcare-associated infections.

Data from the study by Szczygiel & Almeida (2017) suggest that older people living in the community have a higher quality of life, more satisfaction with life and experience less loneliness compared to those who live in institutions. Based on the results of the study, the authors suggest that keeping older people in a community setting is better than institutionalisation. ‘There are voices supporting the view that aging should be lived and experienced at home as it is a place where a person has spent a large part of their life, replete with memories and own history’ (p.588). The ‘Aging in place’ concept aims to provide conditions for growing old at home in a safe, autonomous and comfortable way (McCunn & Gifford 2014 and Song & Chen 2015, as cited in Szczygiel & Almeida, 2017), while preserving the social network.

Integration of care is also associated to better care. It is argued that the existence of a network of health care, social care and professional service providers, working in conjunction through an effective management and intermediation service, can result in improving the quality of life of people with special needs (older persons and persons with disabilities) and at the same time support their carers (Cruz-Cunha et al., 2015),

3. Resources, Infrastructure, Regulation

In Portugal, the data and regulatory infrastructures related to LTC provisions reflect the system fragmentation that separates social care from the RNCCI.

This section offers data on provisions and on the financials of care provision.

Regarding the most pressing problems in provision of care, views collected in interviews and the literature offer a high level of consensus around some main ideas: low coverage rates and long waiting lists signal a need for fast expansion of the system; underfunding of the care system is preventing good quality of care; shortages of workers and of qualifications have a strong impact in quantity and quality of care.

3.1. Social care provision

The main source of data on social care provision is the *Carta Social* (could be translated as Social Charter). It is a web platform managed centrally by the services of the Institute of Social Security that offers up-to-date information about all the social care services that are licensed to operate, classified by target group of the population, by type of service and by territorial unit. The information available in the platform includes detailed information about each service provider, since it is a platform for the general population that also aims to facilitate location and contact of providers by those needing a service. The information open for public consultation also includes data on capacity and occupancy of each care service. The table below displays how the platform is organised and how any citizen can navigate to look for information on social care providers. The first three columns are the search filters that users can apply in sequential order as displayed in the table from left to right. The last column lists the information available for each care provider by fields. These are common to all care providers, irrespective of the filters.

The social care web platform also includes some additional materials that have potential interest for research and policy analysis. Every year there is access to the report of operations of the social care system in the previous civil year. There are also some ad-hoc reports focusing on specific topics that are published as a one-off (e.g. levels of satisfaction of users of services). The web platform also includes a dedicated section on legislation and another on concepts and terminology. Finally, the platform also offers a dashboard are where one can have access to data about capacity, occupancy and territorial distributions of social care services.

Table 3. Care services as classified in the social care web platform of *Carta Social*

TARGET GROUP OF THE POPULATION	TYPE OF SERVICE	TERRITORIAL LEVEL	INFORMATION AVAILABLE
Older persons	Community centre Day centre Night centre Residential care (nursing home) Home care	District (*Distrito*) Municipality (*Concelho*) Local council (*Freguesia*)	Name of provider Full address of provider E-mail of the provider Phone number of the provider Type of provider (legal status: private commercial; non-profit; public) Number of places in the service (capacity) Number of current users (occupancy) Date of last update of the information displayed
Persons with disabilities	Service centre Occupational day centre Institutional care Autonomous residence Home care Personal assistance Transportation service	District (*Distrito*) Municipality (*Concelho*) Local council (*Freguesia*)	
Dependent persons[(1)]	Integrated home care Continuous care home care teams Home care for dependence Paediatrics home care unit Convalescence unit Integrated paediatrics care unit Palliative care unit Long term and maintenance unit Medium duration and rehabilitation unit	District (*Distrito*) Municipality (*Concelho*) Local council (*Freguesia*)	
Persons with mental health problems	Home care mental healthcare team Occupational centre Autonomous residence Moderate support residence Maximum support residence Training of autonomy residence	District (*Distrito*) Municipality (*Concelho*) Local council (*Freguesia*)	

Source: Carta Social web platform, available at https://www.cartasocial.pt/inicio

(1) Services for dependent persons are the ones offered under the RNCCI. They are also listed in the social care platform since the RNCCI integrates social care and healthcare. The same information is available in the RNCCI web platform (see section 3.2.).

The table below lists the available indicators of social care provision to offer an overview of care resources in the country. Figures shown are the most recent data available. Data cover Portugal mainland only. The Autonomous regions of Madeira and Azores are not included in this platform. Although the general legislation applicable is common, the organisation of the Social Security services in the islands falls under the regional governments. No equivalent data source exists in any of the two archipelagos.

Table 4. Social care infrastructure in Portugal mainland (capacity and occupancy) by type of service[1]

INDICATOR	MOST RECENT FIGURE AVAILABLE
Number of home care services for older persons	2,739
Number of day centres for older persons	2,025
Number of residential care units (nursing homes)	2,622
Number of home care services for persons with disabilities	34
Number of institutional care units for persons with disabilities	299
Number of autonomous residences	82
Number of day centres for persons with disabilities	447
Number of personal assistance services	35
Capacity of home care services for older persons	115,323
Capacity of day centres for older persons	62,315
Capacity of residential care units (nursing homes)	105,638
Capacity of home care services for persons with disabilities	1,203
Capacity of institutional care units for persons with disabilities	7,052
Capacity of autonomous residences	444
Capacity of day centres for persons with disabilities	16,200
Capacity of personal assistance services	1,315
Occupancy of home care services for older persons (rate)	76,188 (66%)
Occupancy of day centres for older persons (rate)	35,595 (57%)
Occupancy of residential care units (nursing homes) (rate)	99,356 (94%)
Occupancy of home care services for persons with disabilities (rate)	816 (68%)
Occupancy of institutional care units for persons with disabilities (rate)	6,796 (96%)
Occupancy of autonomous residences (rate)	437 (98%)
Occupancy of day centres for persons with disabilities (rate)	15,157 (94%)
Occupancy of personal assistance services (rate)	722 (55%)
Coverage rate[2] of home care services for older persons	4,7% (16,0%)
Coverage rate of day centres for older persons	2,5% (8,7%)
Coverage rate of residential care units (nursing homes)	4,3% (14,7%)
Coverage rate[3] of home care services for persons with disabilities	0,4%

Table 4. Social care infrastructure in Portugal mainland (capacity and occupancy) by type of service(1) (cont.)

INDICATOR	MOST RECENT FIGURE AVAILABLE
Coverage rate of institutional care units for persons with disabilities	2,0%
Coverage rate of autonomous residences	0,1%
Coverage rate of day centres for persons with disabilities	4,7%
Coverage rate of personal assistance services	0,4%

Source: Carta Social, available at https://www.cartasocial.pt/inicio

(1) Services listed are the ones that have some relevance in terms of quantity. The ones included in table 3 but not in table 4 are very marginal in terms of implementation in the country. The table only includes indicators for social care services for older persons and for persons with disabilities. Services under the RNCCI are presented in section 3.2 below. Data is for 2023 for all indicators except the last on specific type of care service provided to older persons, which refer to 2022.

(2) Coverage rates of services for older persons are computed by the authors of the report as the ratio of the capacity of the service to the total number of persons aged 65+, per 100 persons and in brackets the ration is computed for persons aged 80+. For computation of ratios we have used the population estimates for 2023, as published by INE.

(3) Coverage rates of services for persons with disabilities are computed by the authors of the report as the ration of the capacity of the service to the total number of persons with disabilities, per 100 persons. We took as reference to compute ratios the number of persons with disability as defined in the national census of 2021. Definition of disability follows the Washington Group Short Set on Functioning (https://www.ine.pt).

Data on care provision is collected directly from providers that must fill in a form, every January, to update information on the web platform. The data collected from the care providers via the forms is more extensive than what is available for public/open consultation. The data however does exist, and it is reasonable to assume that it could be accessed by the research community upon request. The authors have not requested access.

3.2. National Network of Continuous Integrated Care provision

The RNCCI's responses take the form of healthcare and social support for people in situations of dependency, structured around three areas: i) the General Network (RG), which is its main pillar; ii) Integrated Continuous Mental Health Care (CCISM); iii) and Paediatric Integrated Continuous Care (CCIP). In each of these areas, the RNCCI distinguishes different types of care, provided by inpatient units, outpatient units and home teams (see table 5 for the full list of services).

Table 5. Branches and services of the RNCCI

BRANCH OF THE RNCCI	IN-PATIENT CARE	OUT-PATIENT CARE	HOMECARE
General network	1. Convalescence unit 2. Medium duration and rehabilitation unit 3. Long duration and maintenance unit	--------	1. Integrated Continuous Care Teams
Integrated Continuous Mental Health Care	1. Autonomous residence 2. Training of autonomy residence 3. Training of autonomy residence for children and youth 4. Maximum support residence 5. Moderate support residence	1. Occupational centre 2. Occupational centre for children and youth	1. Homecare teams 2. Homecare teams for children and youth
Paediatric Integrated Continuous Care	1. Integrated Paediatric Care Unit – level 1	1. Out-patient paediatric unit	--------

Source: ACSS (s/d). Monitorização da Rede Nacional de Cuidados Continuados (RNCCI) – 2023.

Data on the RNCCI can be retrieved by any interested party from the online platform that is named Transparency Portal of the National health System (*Portal Transparência do SNS*, available at https://www.sns.gov.pt/transparencia/). Data is kept up-to-date and can be accessed by interested citizens to facilitate information about availability of places in the services. Table 6 below lists a selection of available data entries regarding the RNCCI. The list is not exhaustive and reflects a selection carried out by the authors considering the scope of this report and the focus on LTC for adult persons. Data can also be retrieved from the activities reports that are published annually and that include some data that is not accessible in the web platform.

Table 6. List of data entries available for analysis of care provision under the RNCCI

INDICATOR	CONTENTS OF THE DATA COLLECTED FOR THE INDICATOR
Number of patients waiting placement, by region and type of unit [a)]	Waiting list for entry into the RNCCI, by region and typology. Daily tabulation. When presenting annual data, 31 December is taken as the reference.
Number of beds/places [a)]	Installed capacity of the network measured in number of beds/places contracted in the period under review, by region and type. Monthly calculation.
Number of admissions [a)]	Number of users admitted, by region and type. Monthly tabulation.
Number of discharges [a)]	Number of users discharged, by region and type. Monthly tabulation.
Occupancy rate [a)]	Occupancy rate in the period analysed, by region and type. Monthly calculation. Occupancy rate = Actual number of hospitalisation days in the unit / Possible number of hospitalisation days in the unit *100
Distribution of the destination of discharges from the Network [a)]	Number of users in each of the destination options after hospitalisation in the Network (home with support, home without support, social response or equipment, nursing home, other response, other network response), by region and type. Monthly tabulation.
Prevalence of falls [a)]	For the purposes of monitoring the quality of care in long-term care, the prevalence rate of falls in the RNCCI is calculated by region and type. Calculated every six months/year. Prevalence rate of falls = Number of users with falls/Total number of users
Incidence of bed sores [a)]	For the purposes of monitoring the quality of care in long-term care, the incidence rate of pressure ulcers in the RNCCI is calculated by region and type. Calculated every six months/year. Pressure ulcer incidence rate = Number of users who developed a pressure ulcer during hospitalisation/Total number of users
No. of users referred by hospitals and health centres to the Network [a)]	Number of users referred by hospitals and health centres to join the Network, by region and proposed typology. Refers to users referred and awaiting ECL approval. Calculated monthly.
N.º de acordos celebrados por natureza jurídica das entidades prestadoras [b)]	No. of agreements concluded by legal nature of the providers.
Main reasons for referral [b)]	Percentage distribution of the main reasons for referral among the patients referred (ADL dependency; Teaching the patient/family; Rehabilitation; Wound/pressure ulcer treatment; Post-surgical care; Cardiovascular disease; Management of the therapeutic regime; Carer's rest; Patients with nasogastric tube or percutaneous endoscopic gastrostomy; Palliative care, by proposed typology.

Table 6. List of data entries available for analysis of care provision under the RNCCI (cont.)

INDICATOR	CONTENTS OF THE DATA COLLECTED FOR THE INDICATOR
Main diagnoses in referral [b)]	Percentage distribution of the main diagnoses in the referral, among the users referred (Acute but ill-defined cerebral vascular disease; Femoral neck fracture; Chronic skin ulcer; Fracture of ncop or unspecified parts of the femur; Ncop cerebral degenerations; Heart failure; Ncop or ill-defined cerebral vascular disease; Pneumonia due to unspecified microorganism; Diabetes mellitus; Osteoarthritis and associated diseases), by proposed typology.
Median number of days from referral to vacancy, by region and typology [b)]	Median time (number of days) from referral to vacancy identification, by region and typology.
No. of transfer requests in the Network [b)]	Number of transfer requests in the Network, by type of origin and type requested.
No. of users assisted, by age group [b)]	Number of users assisted by age group (0-17; 18-49; 50-64; 65-79; 80 or more)
No. of users assisted, by gender group [b)]	Number of users assisted by gender (Female; Male)
No. of users assisted, by educational level [b)]	Number of users assisted by years of schooling, in groups (0 years/illiterate; 1 to 6 years; 7 to 12 years; 13 or more years; no record)
Marital status of assisted users (%)[b)]	Marital status of assisted users (Married; Divorced; Separated; Single; Unmarried; Widowed; Unknown) (%)
Number of assistances per assisted user (%)[b)]	Number of supports for assisted users (from 1 to 8 supports) (%)
Type of support for assisted users (%) [b)]	Types of support for assisted users (Food; Hygiene at home, Hygiene of clothes; Personal hygiene; Medicines; Technical aids; Pecuniary; Other types of support) (%)
Source of support for assisted users (%)[b)]	Source of support for assisted users (Family; Home support; Health technicians; Social service technicians; Housekeeper; Day centre, Neighbours; Other source of support) (%)
Functionality level on admission of assisted users (%)[b)]	Level of functionality of users on admission, assessed by applying the National Functionality Table (Absent functionality; Very low functionality; Low functionality; Average functionality; Total functionality), by typology (%). Patients who met the following criteria were included in the analysis: assessment records made up to the 4th day after admission and up to 7 days before the recorded discharge date; patients over 17 years of age; discharged in the year under analysis).
Evolution of functionality (%)[b)]	Evolution of functionality during hospitalisation, by region and type (Worsened; Maintained; Improved) (%). Excludes hospitalisations of less than 11 days and deaths.

Table 6. List of data entries available for analysis of care provision under the RNCCI (cont.)

INDICATOR	CONTENTS OF THE DATA COLLECTED FOR THE INDICATOR
Reason for discharge (%) [b)]	Percentage distribution of reasons for discharging patients, by region and type (objectives met; worsening; deterioration; need for other care; discharge on request) (% - Multiple answer)
Average time of stay of discharged patients [b)]	Average number of days of hospitalisation for discharged patients, by region and typology
Mortality rate (%) [b)]	Deaths of assisted users, by region and type

[a)] Indicators available in the online platform that is named Transparency Portal of the National Health System (*Portal Transparência do SNS*, available at https://www.sns.gov.pt/transparencia/).
[b)] Indicators available in Annual Monitoring Reports of the RNCCI (available at https://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/#tab_documentacao)

The RNCCI was only created in 2006, but it has experienced a significant relative growth over the years. Currently, and based on data retrieved for 2023, the total of units/homecare teams in the general branch was 686, 41 in the mental healthcare branch and 2 in the paediatric branch. Focusing specifically on the general branch, that accounted for 96,5% of the total provision within the RNCCI, there were 9557 beds in in-patient units (1242 in convalescence, 3208 in medium duration and 5107 in long duration) and 6024 users capacity in homecare teams (Source: *Tribunal de Contas, 2024. Auditoria à RNCCI*). Considering the size of the population over 65, these figures represent a total of 396 beds per 100,000 inhabitants aged 65+ (in-patient care) and a total of 249 places per 100,000 inhabitants aged 65+ in homecare services (population estimates retrieved from INE for year 2023).

4. Stakeholders, Governance

Across centuries and up to the last quarter of the 20th century, following the democratic revolution of 1974, Portugal did not have any national public system of care provision, neither regarding social care, nor healthcare. Care provision was secured by private providers, most of them charities (in social care) or organizations associated to professional corporations (in healthcare). It was only after 1974, more precisely in sequence of the Constitution of 1976, that a National Health System was established, following the Beveridge principles of universal coverage, tax-funding and free of charge for end-users. Simultaneously, a national Social Protection system was also implemented, but this one social insurance-based. Within the Social Protection system, non-contributory social assistance based sub-system would be created to regulate aspects of social care provision. This institutional design of the Portuguese welfare state would lead to a dual approach to LTC. Healthcare would become a national system resting on direct public provision and funding that secures the fulfilment of a universal right, while social care would become a mixed system of partial public funding with private non-profit provision, with no formal definition of the right to access social care and resting on a subsidiary approach to care responsibilities.

4.1. The care provision

4.1.1. Social care

In the mid-1980s (Decree-Law n.º 119/83), legislation was issued to formalise a specific type of entity within the non-profit sector: Private Institutions of Social Solidarity (*IPSS – Instituições Privadas de Solidariedade Social*). The legislation stipulates a series of conditions that institutions must meet to be awarded the status of IPSS. This classification became mandatory to have institutions eligible to sign contract agreements with the central State. The model put in place involves a collaboration between the central government and the IPSS organisations, whereby the first sets the rules, licenses facilities and pays for the services, and the second provides the services.

Social care is organised into a menu of services, grouped by target group and by type of service (see section 3.1. above). IPSS apply for a license and to get it they must fulfil a series of rules that are centrally defined by the state. Rules include aspects of size and layout the facilities, staff size and composition and contents of services. Once the license is issued, cooperation contracts are signed between the provider and the Social Security services. In these agreements it is stipulated the number of users that are eligible for funding by the Social Security and rules regarding co-payments by users. Social Security funds places in social care providers at a fixed rate, defined by legislation per user and per type of service. Co-payments by users are stipulated taking as a reference a ceiling for the total price of care provision and an algorithm to determine the individual income of the user. If just considering applicable legislation, co-payments are means-tested but they should not be considered to determine neither eligibility nor admission. These values are negotiated biannually. At the date of production of this report, the values in place concern the 2023-2024 agreement, that was recently revised to add a 3,5% increase in all values to account for inflation and rising costs. For each user in a residential care unit for older persons, the Social Security services will transfer, per month, a total of 573,53 euros, a value that can be increased upon certain conditions being met (total number of users in the facility, incidence of severely dependent and/or persons with dementia). Users and relatives will be responsible for a co-payment following a means-testing protocol. Co-payments can go as high as the difference between the amount paid by the Social Security Services and the reference value for the service (in this case, set at 1,400 euros per month). So, for each service, value is stipulated for the transfers per user, per service, and per month, from the central government to the care providers (homecare is 350.23 euros; day-centre is 165.17 euros; institutional care for persons with disabilities is 1,469.22 euros) (Source: Acordo de cooperação do setor social para o Biénio 2023-2024 e Adenda ao Acordo de Biénio de outubro de 2024).

The financials of care provision is the topic that gathers more consensus across interviewed stakeholders, that speak with one voice complaining about the insufficient funds transferred by the state that are seen as compromising not only the sustainability of care providers (see more on this topic in the report on meanings of sustainability), but also the quality of the care provided.

> *I hear a lot of comments from people who assure me, namely nurses and other health professionals who move from one unit to another, etc., and they say that in units A, B and C, the quality of patient care has dropped a lot. And it's gone down a lot at various levels, from the point of view of the lack of human resources, which means that the teams aren't complete and so patient care isn't as good as it should be, the quality of the food, the materials they use, nappies, etc., and so on. And I have, for example, [name of care provider], which even wrote a letter to the government saying: 'I'm going to lower the ratio of human resources, I'm going to reduce the quality of the services we provide to patients, because the money isn't enough, so please increase the prices you pay us so that this doesn't happen, otherwise we'll have to close down'.*
>
> **Interviewee Code: DRN_1009**

And I realise that, as much as the institutions would like to, they can't survive with negative balances. Who prioritises, not issues directly related to quality, but, let's say, the staff who have to deal with patients? This is a balancer, but I agree with you. Because only by monitoring quality can we come up with proposals for improvement that can change the sector. And we have seen, in recent times, some critical situations within long-term care, let's say, of bad, even mistreatment. But there aren't many. Despite everything... (...) There shouldn't be any. But it's this evaluation, I agree with you, that would have to be a... and you have to prioritise it as a necessity, but it also has to be accompanied by an increase in funding

Interviewee Code: ORN2_2410

An important aspect of governance of the social care sector concerns the representation level of care providers. IPSS are represented by a sectorial body that acts as their national representative – National Confederation of IPSS (*CNIS – Confederação Nacional de Instituições de Solidariedade Social*). This organisation sits at the negotiation table with the central government, represented by the Minister of Labour, Solidarity and Social Security, to negotiate all aspects of the relationship between the State and care providers, particularly the financial arrangements of that relationship. These negotiations typically take place every two years, but extraordinary settlements can also take place. They are always marked by some tensions between the two parties that push in opposite directions in issues concerning not only the matter of funding but also aspects of central regulation such as rules of admission and quality control.

Stakeholders have different views about this model of representation, namely in regards the quality of the representation work of CNIS. Some were very critical about it. Others were more defensive of CNIS and pointed fingers at the regulator.

We have a leader of the CNIS, with a miserabilist discourse, in which he thinks we all have to be poor and honourable. The honourable part I agree with, the poor part I don't. He even plays this role a lot in public speeches. And in meetings with the government, he doesn't make any demands. We have a representative of the Misericórdias who, for example, at a meeting with the government last month, the representative of the Confederation of Portuguese Cooperatives said exactly what I say, which is that salaries in this sector must be equal to those in the civil service. And the president of the Misericórdias doesn't think so. When the president of the Misericórdias tells the government this, the government rubs its hands in glee, because it realises that there is no unity between the representatives, and it realises that, after all, there is a representative of a very strong sector, such as the Misericórdias, who thinks that they also have to have miserable salaries and that they don't have to have salaries equal to the civil service.

Interviewee Code: DRN_1009

And when you're a partner, it means that partnership means negotiating, representing. And so it's up to CNIS, just as it's up to the Union of Misericórdias, mutual societies and co-operatives, to represent the sector and its members when it comes to negotiating and defining policies. But also to defend what is the DNA of the institutions, which is at the heart of their constitution. Because they are organisations that are born in the community, they are born from the bottom up, they emerge from the will of a group of men and women to organise themselves, etc. And they have two aspects, two values, two traits that are fundamental: identity and autonomy.

Interviewee Code: DTN_1111

Next to IPSS, there is another important stakeholder providing services: the Holy Houses of Mercy (*Santa Casa da Misericórdia - SCM*). There are several across the country. They have a special status since they follow some aspects of canonical law but operate following the legislation of IPSS. They are represented by another sectorial body that also sits at the table of negotiations with the central government – The Union of Holy Houses of Mercy (União das Misericórdias Portuguesas – UMP).

4.1.2. Healthcare

Long-term care was not part of the public health agenda for a long time and, apart from the care provided inside the family, and the care secured in the social care system, which does not have by nature any differentiated healthcare, there were no specific dispositions regarding the healthcare component of LTC. Applicable legislation on social care services includes, in the list of care provided in residential care facilities, helping residents with healthcare. What this entails is not defined and since it is not mandatory to include among the staff any healthcare staff, it has always been a underdeveloped aspect of social care provision.

In the early 2000s, the public debate started discussing the idea that hospitals were being pressured in their capacity to provide acute healthcare by the insufficiency of responses from the social care system in a context of ageing. It was argued that there was a high number of unnecessary hospital stays of old age patients that had clinical criteria to be discharged but lacked family support to go home, and given the lack of vacancies in the social care system had to stay in the hospital. Over the years there was a growing sense of urgency around the topic of bed-blocking, largely triggered by the publication of figures about the phenomenon by the national association of hospital administrators. The phenomenon was never studied in length, but there was consensus around the idea that it was necessary to reduce the length of stay in expensive acute care units and the need to ensure smoother transitions of care and simplify patient follow-up. This led to the creation of the National Network of Integrated Continuous Care (RNCCI), by Law 101/2006, under the Ministry of Health and the Ministry of Labour, Solidarity and Social Security. The RNCCI was designed to be a national coordination structure that would regulate the operations of specialised units that would provide rehabilitation and reablement care.

The model of provision itself was somehow inspired in how the social care system was organised. Care providers can be public providers (units inside existing public hospitals), non-profits and private commercial entities. The central government licenses operators and regulates aspects of provision, as well as aspects of funding. The model is a dual model: the healthcare component falls under provisions of the National Health Service and therefore is fully paid by the Ministry of Health in line with national dispositions about universal access to healthcare; the social care component follows the rules applicable to the social care sector, whereby the Social Security services pay a fixed rate per user and users and their families participate with co-payments, these defined following means-testing. Funding comes primarily from the revenues of legal gambling that are assigned to both the Ministry of Social Security and to the Ministry of Health.

The non-profit sector controls a significant portion of the existing capacity of the RNCCI (77,8% of all provision in 2023), but private commercial providers also have a role (15,5% of the total provision). It is important to note that pricelists for the healthcare component involve values that are more attractive from a business perspective than those regarding the social care system. This is probably one of the reasons why there was some vivid interest in the early years from potential providers. Subsequent problems of funding, largely associated to the lack of regular updating of pricelists has brought difficulties to providers, difficulties that interviewed stakeholders have described in length.

In the last three years, 307 long-term care beds have been closed. They went bankrupt. Units closed because they were insolvent... because they couldn't cope with the deficit from the existing underfunding. And there are many units at the moment, in fact there have been for a long time, but at the moment there are many units in these circumstances, on the verge of closing, because of underfunding (...) from 2015, with the entry of the new government, the minimum wage went up and up a lot, but then the prices of long-term care remained frozen. Then came the Covid crisis, the pandemic, the minimum wage continued to rise, costs increased and prices remained frozen. In a period of 13 years, so now I'm including 2024, in a period of 13 years, the prices of long-term care have been updated four times and with very low values. This caused a huge financial squeeze on long-term care centres, which led to the closure of several centres and others that are on the verge of closure. (...) It was the war in Ukraine. There was an energy crisis, energy prices skyrocketed. We're in the wholesale market, as is industry, and the government created a programme to support precisely those entities that had high energy consumption, and once again long-term care was left out. We haven't received a cent. And so this has been the story since 2015 […] Long-term care, I would say, has been persecuted by the government.

Interviewee Code: DRN_1009

Table 7. Pricelist, state funding and co-payments of services by users, by type of service of the general branch of the RNCCI (in euros)

TYPE OF SERVICE [3]	REFERENCE VALUE FOR TOTAL PRICE (Healthcare)	REFERENCE VALUE FOR TOTAL PRICE (Medication, materials and exams)	TRANSFER FROM THE STATE, PER USER, PER DAY	REFERENCE VALUE FOR TOTAL PRICE (Social care) [1]
Convalescence units	98,87	16,40	115,27	-
Medium stay units	64,30	13,20	77,5	22,85
Long stay units [2]	26,16	11,34	37,5	42,62

[1] Co-payments apply to the social care component, on a means-testing basis. The healthcare component has no costs for the user.
[2] In Long stay units an additional 1,40 euros, per day and per user is paid to cover costs with nappies.
[3] Home-based healthcare is not included in the price lists. This service is supposed to be secured by teams of professionals located at local health centres, meaning they have to accommodate the costs in their own budget.

One aspect that was signalled as dysfunctional by stakeholders in the global LTC system in the country stems from the funding model in place for the two components: healthcare and social care. In particular, the fact that the healthcare component involves no costs for users creates an incentive for families to keep their relatives in the long stay units rather than accepting placing them in the regular residential care facilities of the social care system. The quality of care they receive in the RNCCI is perceived as higher due to the differentiated healthcare component and cheaper. It is if there is an element of distortion that prevents the desired smooth transition along the care continuum.

The long-term care network is clogged up with social cases. These are people who have been discharged from hospital and are still there. Either because they have no family or because their family refuses to pick

up their relative. Anyway, a private home costs 1,500 euros, and in the worst case scenario, a person with a high income pays 500 euros to the long-term care network, in this case to the long-term care unit, to have their family member there. So it's a third of the cost, with a much higher quality of service than a nursing home.

Interviewee Code: DRN_1009

But long-term care centres were not designed to be institutional care. And these people who have no resources are also staying in long-term care centres, which cost 3000 euros a month. And because the state also allows families to refuse to take the elderly away when they are discharged from hospital, to refuse subsidised places in IPSSs. The state allows this. There is nothing to make the family responsible for finding a solution on the day of discharge. I can share with you […] that even families who can afford it try their best not to pay.

Interviewee Code: MPN_0310

One last aspect of governance that should be highlighted concerns the management of admissions. While in the social care sector providers retain a very high level of control of admissions, in the RNCCI admissions are managed by the state-controlled structure that was assembled to coordinate the system. There is a national coordination team, with a representative appointed by each of the two ministries. They supervise a body of regional and local teams that deal with aspects of referral and placement of eligible patients. Patients are referred at the hospital, by hospital discharge teams, and at the local health centre. Once referred, patients are registered in a national database. Regional and local teams of the RNCCI oversee locating an adequate available place in a unit and they are the ones sending the patient for admission in that unit, if the patient agrees. In this sense, providers are not directly involved in selection and admission of users, making this a more transparent and independent process.

4.2. The quality of care

Aspects of quality assessment reflect once more the dual nature of the LTC system in the country. Within the social care system, protocols are flexible and less ambitious. In the RNCCI, largely by influence of quality control mechanisms in place in the national health system, are more clearly defined and implemented.

4.2.1. Social care and quality

The most relevant instance of quality assessment in the social care system is the moment of licensing of the service provider. The legislation stipulates strict rules that need to be met to get the licence. These involve aspects of size and layout of facilities, contents of services and staff composition and ratios.

There is currently no national formal quality certification system in place for social care facilities, just some guidelines. Since 2005, service providers have access to a manual of good practices that offers guidelines about how social care facilities should be operating, focusing on aspects of daily life and of quality in service provision. Along the following years manuals were made available, Manual of Key Procedures (*Manual de Processos-Chave*), which offer detailed instructions, including templates, for the delivery of services in different social care services, along the lines of a

person-centred approach. In 2007, there was an attempt to set up a formal system of quality certification, by the initiative of the Social Security Services. It became known as the model of assessment of quality, and it established eight dimensions of analysis and within each a list of indicators that would be considered for awarding a final classification along a scale of 3 posts: A, B and C, with A corresponding to the highest level of quality. The original goal was to create a system that would guarantee a minimum level of quality (C) that would be mandatory for any IPSS wishing to sign an agreement of cooperation with the Social Security Services. At the same time, the goal was to introduce a system of differentiation among service-providers. Levels B and A would be voluntary and a system of dissemination of information concerning the level of quality each service provider would achieve would be created and made accessible to the public. Although the manuals and templates produced in 2007 are still available on the website of the Social Security Services, the project was never truly implemented, most likely because most care providers did not even reach the C level.

Quality of services is monitored by the regulator by means of inspection audits carried out by teams of auditors of the Inspectorate Service of the Institute for Social Security. According to the original piece of legislation that regulates the relationship between the State and the IPSS sector, published in 2015, a yearly plan of audits was planned to be made available to the public on the website of the Social Security Services, during the month of January, and the subsequent reports of the audits would be made available at the same place. The revision of this original piece of legislation, in 2019, introduced changes in article 39º, where auditing procedures are defined. Consequently, audits are no longer of public knowledge, and neither are audit reports available for consultation. This revision only clarified what had been the practice already up to then. Except for year 2016, one cannot find any lists of planned audits. And there is no access to any audit reports. This topic remains a sensitive one in the relationship between regulator and service providers, with representatives of sectoral bodies voicing concerns about what they consider a non-transparent, one-sided, and overly bureaucratic process of quality verification.

Quality control is a subject that generates different views among stakeholders. If conceptually it remains fuzzy, technically positions oscillate between those who see the benefits of implementing independent quality control systems tying results to funding eligibility (Lopes, 2016), and those who see it as unduly intrusion of the regulator in aspects that concern providers and that must always be assessed in context.

After that, it also happened with this change to the ordinance that regulates nursing homes, in addition to the training aspect that I mentioned, the minister also added a new article saying that nursing homes had to have a person responsible for managing the quality of the establishments. With criteria to be defined later. That was in November last year, it's now September, almost a year later, and there has been no publication of these criteria. And that it really is necessary to define criteria, but in a very light way, it seems wrong to say light, in a light, practical way. I don't want them to invent another quality management system, but what I do want is for them to define the criteria to be monitored and then for each home to organise itself in terms of how it carries out this monitoring, without the imposition of maps, and little maps, and reports, and a hell of a lot of paper that nobody can stand to govern their lives like that. Now, this definition of the criteria to be monitored, and this isn't difficult. There's a lot of work done on this, in which we look, for example, at the risk of falls, the number of visits to the emergency room, and so on. There are a series of indicators that are easy to define so that each household can then monitor these criteria in their own way. This is not difficult to do and to implement in practice, on the ground, in the life of the homes.

Interviewee Code: DRN_1209

4.2.2. Healthcare and quality

Quality assessment is a topic that is more enshrined in regular healthcare provision and in hospital administration protocols, so not surprisingly it is more clearly defined in the RNCCI than in the social care sector. Quality is associated with the ability to provide safe, effective health care and social support that is appropriate to the clinical and social situation of users, capable of guaranteeing their dignity and comfort, as well as meeting their health and social support needs. This translates into three specific domains defined as critical to measure the quality of care provided to users. They are used in monitoring reports of activities of the RNCCI: falls, bed sores and functionality outcomes of patients.

Falls are related to safety and are used because they are considered a leading cause of death by trauma and a leading cause of hospitalisations and loss of healthy years of life, especially in old age. Bed sores are seen as directly related to the quality of personal care the patient receives. A differentiation is made between bed sores that existed prior to admission to the RNCCI and bed sores that develop after admission. Functionality outcomes are assessed to evaluate efficacy of care provided against targets defined at admission and at regular patient clinical evaluations. Considering that the primary goal of the RNCCI is rehabilitation of patients, this is a critical domain of quality evaluation. However, it was only in 2017, ten years after the creation of the RNCCI, that functional assessments were introduced as a criterion of referral and admission, as well as an aspect to include in regular assessments of the patient's evolution. Despite this disposition, still today there is difficulty in evaluating the progression of patients in terms of functionality given they only have one assessment (at entrance), or none. According to the recent audit carried out by the Court of Auditors, in the general branch of the RNCCI only 41% of patients, in 2023, had been evaluated for functional capacity at admission and at discharge. For the remainder the available data is insufficient to assess changes (Source: Report of the audit to the RNCCI by the Court of Auditors, 2024). The table below offers a summary of some data for indicators of quality of the general branch of the RNCCI for year 2023.

Table 8. Data on quality of the RNCCI, 2023

DIMENSION OF QUALITY	CONVALECENSE UNITS	MEDIUM STAY UNITS	LONG STAY UNITS	HOMECARE TEAMS
Number of falls	941	1944	1342	357
Prevalence users experiencing falls	7,5%	10,5%	7,2%	1,8%
Total number of bed sores	856	2112	2412	3303
Prevalence of users with bed sores	9,7%	16,3%	20,0%	19,0%
Prevalence of users developing bed sores during stay	2,1%	5,0%	5,9%	1,9%

Source: Report of the audit to the RNCCI by the Court of Auditors, published in 2024 and available at https://www.tcontas.pt/pt-pt/ProdutosTC/Relatorios/RelatoriosAuditoria/Documents/2024/rel016-2024-2s.pdf

In general, views about existing mechanisms of quality control are positive in terms of the criteria defined in the applicable regulations. There are some criticisms about the quality of the data keeping among care providers, which hurts the quality of the quality assessment. In principle, care providers

are mandated to register in a national platform (GestCareCCI ®), data on patients admitted, from the moment of admission, throughout the care provision and at discharge, be it for a different service within the RNCCI or to the final destination of the patient. This task is seen as cumbersome by some care providers, and as such not efficiently carried out by all.

The process needs to be more streamlined, much more streamlined in terms of bureaucracy and greater trust. For example, the instruments we have in the network from the point of view of the platform, I mean, look at it, change it, make it more agile.

[…]

If I have a system, a network platform, Gestcare, which has nomenclatures that I would say are strange, such as the individual intervention plan, who in Portugal works with individual intervention plans? As a nurse, I've always been trained in integrated plans, with diagnoses, intervention prescriptions, results, reassessment, reformulation, closing diagnoses, opening new ones, allocating new interventions, prescribing new interventions, or closing others. Dynamic. The PII? What is it? What's an intervention plan? That's of no use. If the network wants to take data, it can't. I'd like to tell the researcher... I think the network's latest report is from 2016. For the time being, anyone who knows anything about it, when they read it, immediately throws it in the bin

Interviewee Code: MPL_0310

5. Territorial Differentiation

The system draws on a one-size-fits-all approach, with national regulations applying to the entire country in the same manner. This includes issues of funding, types of services and regulations on licensing and operations. This lack of differentiation is seen by some interviewees as a source of difficulties for some regions due to either the characteristics of local populations (age structure, type of needs, types of communities) and to the characteristics of the territory (topographic characteristics, dispersion of villages with areas of low density, roads and general infrastructures).

Looking at the territory, it's clear that the south, and often the central part too, has a harder time because of, let's say, exactly that, the possibility of people moving to these areas. They have far fewer people and they also have much poorer support in the area of health in general, unlike the North. You see, a large part of the health Misericórdias, the large health response Misericórdias, are all in the north, all in the north and very good with great responses. […]. The South has fewer people, everything is more expensive, the distances are much greater, people are much more isolated, and this limits a standardised response at national level. So, what's different has to be treated differently, in a different way. That's obvious to me, what's different must be dealt with in a different way and this needs to raise awareness of these territorial differences, if you don't do that, it ends up creating a great deal of dissociation between populations.

Interviewee Code: ORN2_2410

Territorial considerations are mostly related to issues of coverage and some performance indicators. It is a topic that the reader can explore in more detail in the report on meanings of inequalities.

Regarding territorial differences, the classic urban/rural divides, high-density/low-density, central/hard-to-reach dichotomies are the ones most used in both the literature and by stakeholders.

Although we're in a small territory, we have a big dichotomy here, I think, which is the big cities in this small territory, the big urban centres, and then a whole dispersed, rural territory. I'm not saying which is better, which is worse, which has more... But it's certainly different. It's certainly different, with different needs and the requirement to respond differently. We don't have to have a single model for anything. We have to have a model based on principles, based on values, which can then diverge into responses with a common denominator, but a minimum denominator. The entire composition of the response must be very much geared towards specific needs.

Interviewee Code: DRN_1009

There is an implicit acknowledgement that there are territorial imbalances that need correction. For example, the calls for funding of new operations, under which non-profits can apply to funding to build new facilities, include in the evaluation criteria as a positive discrimination factor if the new facility is in an underserved territory.

6. Debates and Strategies

A rather pressing theme that was highlighted by almost all interviewees sometime along the interviews is the underfunding of LTC preventing expansion of coverage and higher quality of care provision. It is not the only topic though and when looking at the list of themes that have spontaneously emerged when asking the common opening question: what is the biggest challenge, the most pressing issue regarding LTC in Portugal? responses show the multidimensional character of debates currently ongoing in the country. Table 9 below shows the list of topics that were selected by interviewees when asked about the most important current challenge of LTC in Portugal.

Table 9. Topics identified by interviewed stakeholders as the most important challenge to LTC in Portugal

MOST IMPORTANT CHALLENGE TO LTC IN PORTUGAL	NUMBER OF INTERVIWEES
Financial sustainability of care services	4
Shortage of care	2
Integration of care	3
Person-centred care	2
Care workers qualifications	2
Bureaucratic complexity of care provision	1

It is worth noting that the combination of topics offers a good coverage of aspects that one would expect to include in a broader discussion about the system in a more holistic manner. Debates about the system though are rare and confined to expert-based discussions, typically promoted by some entities of the civil society that organise debates on contemporary issues. These are usually big foundations that actively promote debates about contemporary society, but with no specific role in LTC organisation. The political debate has been scarce and is usually confined to discussion of very particular aspects of funding. A broad debate about LTC and the future of LTC in Portugal is still to happen.

A National Plan for the Promotion of Healthy Ageing, which included provisions on LTC, was approved in late 2023. This came in response to the calls of the European Commission following the publication of the European Care Strategy and the need to nominate a national representative to sit in the commission of national coordinators. In the meantime, and following a change in government in early 2024, the plan was put on hold and the nominated coordinator dismissed. A new national coordinator was appointed, and news were issued stating that the national plan for healthy ageing would be revised soon as part of a broader strategy on longevity. The process is on pause at the time of submission of this report.

The ongoing political debate is vague, mostly reacting to the occasional news in the media but showing no signals of any systematic holistic discussion taking place soon about LTC. Negotiations between the state and care providers is almost exclusively focused on funding issues.

The topic of informal care has been gaining some traction in recent years namely after the approval of the Informal Care Act and the official recognition of informal carers as such. Some grass-root coalitions have been emerging and putting the topic of supporting informal carers in the public arena, with increasing visibility and influence. Although the Informal Care Act was legislated in 2019, it has already been revised to expand eligibility criteria to be recognised as an informal carer.

There are also discussions about shortages of care workers and some developments have taken place to attract more workers and improve their qualifications, namely with the creation of a qualifications centre uniquely focused on training professionals for and in the social care sector. Recently the centre was dismantled, and its director dismissed. It was one more change that happened because of the change in government.

This is an important aspect of political dynamics concerning LTC and old age in general: strategic plans do not seem to have the ability to survive political cycles and changes in government formation, which in a domain that requires long-term vision and structural reforms that are likely to have deferred impacts is a very significant shortfall.

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