ESPN Thematic Report on Challenges in long-term care

Portugal

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Summary

For the last decade in Portugal, health and social policies have tried to respond to the increasing care needs of an ageing and/or dependent population by developing a long-term care (LTC) system based on the provision of community-based and institutional services.

The National Network for Integrated Continuous Care (RNCCI) is the main body responsible for the provision of formal LTC, integrating objectives and cooperation mechanisms as between different levels of the health and social services. The expansion of RNCCI provision has translated into an increase in the number of places available, although there are still some significant imbalances between institutional and homecare services, as well as important regional asymmetries. Informal care continues to play an important role in the provision of assistance to family members because of ill health or old age. Both carers and dependent persons are entitled to different types of cash and in-kind benefits, which are mostly subject to income-related conditions rather than being related to the degree of dependency or its impacts on families and potential carers.

The association of LTC with informal care provided mainly by family members – and mainly by women – still seems entrenched in the Portuguese society. State provision of community care services in Portugal has been characterised as scarce, and overall access rates to units of the RNCCI are low in all regions of the country. Affordability also remains an issue, as Portugal is the OECD country with the highest share of out-of-pocket funding for LTC, and publicly funded LTC is limited to the poorest parts of the population – even if standing at 8.97% of GDP in 2015 (according to Eurostat).

Minimum standards are in place within accreditation procedures for providers of LTC, allowing for the assessment of the quality of services. However, healthcare assistants are usually poorly educated and poorly trained. Even if job opportunities in the field exist, and probably provide relatively stable contracts, status and remuneration are far from being attractive.

The majority of informal carers are also usually poorly educated and poorly trained. Even if a few measures are already in place to support them in providing good-quality unpaid care, only the approval of a formal status for informal carers (currently under study) will trigger profound changes at this level. This process is also crucial in the sense that it may provide more stable grounds for discussing financial sustainability, notably because the work performed by informal carers can be estimated as representing over 2% of the GDP – within a context where Portugal is expected to face the highest increase in healthcare costs in the EU, including LTC costs.

In this respect, it should be borne in mind that Portugal still lacks a comprehensive long-term strategy for addressing the health-related costs of ageing. The last few years have witnessed efforts to improve the coordination and integration of different existing LTC schemes and actors. However, concrete decisive steps towards technological innovation and towards an analysis of the best way to increase the value for money in LTC still seem to be lacking.

Strengthening the existing provision of LTC might benefit from positively responding to some policy recommendations. These include: the need to adequately concretise on-going reforms in the area of informal care; overcoming the restricted scope of the existing eligibility criteria in order to widen access and affordability to formal LTC; valuing the dependency condition and its impacts on both dependent people and their family carers; adjusting existing benefits and supports (e.g. amounts, entitlement, fiscal benefits, social security contributions, work flexibility) to the actual needs arising from caring responsibilities; ensuring that home-based care services actually represent an alternative to institutional care; and developing systematic monitoring and evaluation of public policies in this area taking into consideration regional and gender impacts.

1 Description of the main features of the country's long-term care system

For the last decade, in Portugal, health and social **policies** have tried to respond to the increasing care needs of an ageing and/or dependent population by developing a long-term care (LTC) system based on the provision of community-based and institutional services.

Since 2006, LTC has formed one of the branches of the National Network for Integrated Continuous Care (RNCCI). The RNCCI – created in 2006 and implemented after 2007 – provides convalescent care, post-acute rehabilitation services, medium- and long-term care, home care and palliative care. The network was set up jointly by the Ministries of Health and Social Solidarity.[1]

LTC is provided in response to dependency associated with (among other things) the ageing process. It is aimed at providing humanised, qualified and comprehensive care at the point when it is needed, and reflecting the diversity of ways in which ageing is experienced, by the creation of proximity services throughout the territory. These principles are emphasised in the RNCCI legislation,[2] as is the promotion of more equity in accessing care. The programme is aimed at responding to increasing social and demographic challenges: for example, the ageing of the Portuguese population; the heterogeneous nature of the social situation of the elderly; the prevalence of chronic disabling illnesses; and the decreasing availability of 'traditional' family carers. Both the health and the social security systems are necessarily involved in responding to such challenges.

Since 2016, new developments have occurred in the area of mental health and palliative care responses. In June 2016 the strategic plan for the development of palliative care 2017-2018 (CNCP, 2016) was launched, following the designation of the National Commission for Palliative Care (CNCP) as responsible for implementing the National Network of Palliative Care (RNCP). In February 2017 the government announced the first 25 pilot projects within the framework of the network. These were expected to create 366 places, deemed to represent about 20% of those needed.[3]

The provision of LTC is therefore embodied in the **organisational model** of the RNCCI. This model – based on unified objectives and methods – introduced an important reform in the provision of LTC services by the national health system and the social security system, aimed at promoting high-quality practices (Mendes, 2014). Thus, the axial strategies defined for the implementation of RNCCI result from strong coordination between the different levels of health services, and between these and local/regional social services. Non-profit organisations and the private sector are also important partners in the programme.

The RNCCI has a specific **financing model** based on the types of services provided, which may include funding from both the Ministry of Health and the Ministry for Solidarity, Employment and Social Security, as well as from users themselves through user fees.

The RNCCI comprises both public and private not-for-profit units (funded by the state). It provides four main types of health and social support care services which should provide

[1] For additional analysis of LTC in Portugal and, more specifically on the RNCCI, please refer to Baptista et al., 2018.

[2] For further details on the legislative framework, see Decree-law nº 101/2006, of 6th June and Dispatch nº 19040/2006, of 19th June, available at: http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Decreto-Lei_101_2006-1.pdf and http://www.arslvt.min-saude.pt/uploads/document/file/1362/upload-pdf-legislacao-11-2006-Despacho_n_19040_2006_de_3_Agosto.pdf (accessed 21/02/2017).

[3] For additional details on these developments, please refer to Baptista et al., 2018.

a continuum of formal care, taking place in different types of units: institutional care services (convalescence, medium-term care, LTC and palliative care units); hospital services (intra-hospital palliative care support teams and specialised patient discharge teams); and home care services (integrated continued care teams and community teams for palliative support care). Patients must be referred by a hospital or health centre, after which an assessment is made by the local coordination teams (ECL) of the RNCCI and/or by the hospital discharge management teams. The assessment is made according to a set of criteria that includes the degree of dependency and/or the presence of a serious illness or injury. In parallel, there are also private for-profit services providing LTC operating independently.

The assessment of the implementation of the 2016-2019 development plan for the RNCCI shows a positive quantitative evolution overall. However, some imbalances regarding the provision of **institutional vs home care services** are also identified. The 2016 monitoring report of the RNCCI, published in April 2017 (ACSS, 2017), registered an increase in the number of beds available of 8.1% compared with 2015, rising to 8.3% when considering the 10 beds for paediatric use introduced during 2016. This increase compares with the reduced number of places available (-4.9% between 2015 and 2016) within the home-based health and social care teams – the so-called ECCI[4] teams – providing support to dependent or convalescent people whose situation does not require institutional care. Significant regional asymmetries were also identified in the provision of the latter services. Table 1, in the Annex, depicts the number of units and number of places in services provided or supported by the social security system in mainland Portugal.

No payment is required for convalescent units or for palliative care. The national health system (and other subsystems) ensures funding. Users should pay the costs related to social support. However, these costs may be co-paid by the social security system if the value of the movable assets of the user's household is lower than 240 times the social support index (*indexante de apoios sociais* – IAS), i.e. EUR 102,936 in 2018.[5] The exact amount of the co-payment depends on the household's income. There is no legal obligation for family members to contribute towards the costs if the dependent person is unable to pay.

Still according to the monitoring report of the RNCCI, the different types of care within institutional services showed high usage rates: 97% for LTC, 94% for medium-term care, 90% for rehabilitation care and 91% for palliative care. Conversely, the usage rate for home-based care services stood at 68.4%, ranging from 60% in the Algarve to 73% in the Alentejo region (ACSS, 2017).

Apart from care which is made available through the existing formal network, as briefly described above, it is important to mention the role of **informal care** within LTC provision in Portugal.

According to the latest edition of the national health survey, in 2014 about 1.1 million people aged 15 years or more (12.5% of the total population) provided assistance or informal care to people in need because of ill health or old age. Over 85% of these provided informal care mainly to family members. More than half (57.4%) provided care for less than 10 hours per week. Women represented 61% of informal carers in total and 64.3% of those providing care for 10 hours per week or more (INE/INSA, 2016).

According to the results of the latest study on the accessibility and quality of continuing care, issued by the Health Regulatory Authority (ERS) in December 2015, Portugal had the highest rate of informal home care in Europe, as well as the lowest rate of non-home-based care and one of the lowest coverage rates of formal care (ERS, 2015).

[4] The integrated continued care teams (ECCI) are based on and operate under the responsibility of the local health centres (ACES).

[5] In 2018 the amount for the social support index is set at EUR 428.90.

As in other EU countries, the profile of the typical carer in Portugal is a woman aged between 45 and 75 years old. According to a national study, most carers have low educational achievement, and fewer than half are employed, although the large majority are of working age (Teixeira et al., 2017).

In recent years there has been growing concern at the need to develop support measures for informal carers, given their crucial role as one of the 'sustainability factors' of social and health systems (Teixeira et al., 2017: 5).

In 2016, the Association of Carers Portugal (*Associação Cuidadores Portugal*) estimated that the value of the work performed by informal carers reached almost EUR 4 billion annually[6] (Teixeira et al., 2017).

In this context, recent steps have been taken aimed at approving a formal status for informal carers and thus addressing some of the challenges[7] which have been identified but continue to affect the provision of this particular type of LTC care.

Statistical information on indicators regarding the performance of daily activities provides some useful insights for **evaluating the needs** for LTC among the Portuguese population.

According to the latest Census (2011), almost half of the elderly population has great difficulty in performing, or is unable to perform, at least one out of six daily activities. Additionally, 16% of those aged between 15 and 64 also present long-term health problems and difficulties in performing basic activities.

The 2014 national health survey (INS) found that about 458,000 of the 2.1 million people aged 65 or older reported difficulty in performing at least one activity of personal care; among those, 35% reported that they needed help (or more help than they had) in order to perform such activities. Nearly 1 million people aged 65 or older reported having at least one difficulty in performing at least one household activity without help; among these, 28% reported that they needed help, or more help than they had, in order to perform such activities (INE/INSA, 2016).

The 2014 INS also recorded that around 20% of the population aged between 15 and 64 had limited physical mobility (long-term) – for example, walking or climbing stairs.

In Portugal, both carers and dependent persons are entitled to different types of publicly funded **cash and in-kind benefits**. However, there is a significant difference depending on whether the dependent relative is a child or an elderly person. There are considerable rights allocated to those caring for children, which is not the case for the care of dependent elders. Additionally, it is important to highlight that **entitlement** to cash benefits for dependent persons is not exclusively based on their level of dependency, but is partly based on their economic vulnerability.

Cash benefits for dependent persons include the following.

- The dependency supplement (c*omplemento por dependência*) may be granted to a person requiring the permanent assistance of a third person to perform the essential activities of daily living. This benefit may be attributed to: i) recipients of an invalidity pension; ii) recipients of an old-age or survivor's pension under the general social security scheme; iii) to pensioners under the non-contributory scheme; and to iv) non-pensioners with reduced mobility caused by predefined chronic illnesses. The amount of the benefit varies according to the level of dependency recognised by the social security services. The monthly amount varies between EUR 103.51 and EUR 186.31101.68,[8] respectively, for: a) persons who are unable to perform autonomously tasks relating to feeding or to mobility

[6] This amount was calculated on the basis of the minimum monthly salary.

[7] These are discussed in Section 2.

[8] These amounts relate to benefits granted under the general social security scheme.

or to looking after personal hygiene, and who are receiving pensions of EUR 600 or less per month; and b) persons who, in addition to meeting the above criteria for the first degree of dependency, are bedbound or have been diagnosed with severe dementia.

- The attendance allowance (s*ubsídio por assistência de terceira pessoa*) is granted to disabled children and young people who need permanent care from a third party. However, the beneficiary is the person caring for the disabled child/youngster. The latter must: i) be in a state of dependency owing to their disability and must need permanent care from the other person for at least six hours a day; ii) live under the care of the beneficiary, from whom they must be descended; iii) not be engaged in any occupation that requires pay-related social security contributions or contributions to another similar entity; and iv) receive the child benefit plus a disability supplement, or a monthly life annuity. Living under the care of the beneficiary implies living in the same household and implies that the disabled person's monthly income is lower than EUR 207.01 (amount of the social pension) or lower than EUR 414.02 (twice the amount of the social pension) if the disabled person is married. Currently, the attendance allowance amount stands at EUR 108.68 per month. In 2017, 13,264 people received this benefit.

Cash benefits for carers – aimed at replacing the loss of income arising from the need to provide care to a child in the household – include the following.

- The benefit for care for disabled or chronically ill children (s*ubsídio para assistência a filho com deficiência ou doença crónica)* is granted when a parent is prevented from working owing to the need to take care of a child (biological, adopted or stepchild), as long as they live in the same household; the payment level represents 65% of the reference wage of the six months preceding the second month before the event, up to a maximum monthly rate of two times the IAS, i.e. EUR 857.80. The minimum amount of the benefit corresponds to EUR 11.44 per day (80% of 1/30 of the IAS). Both employees and the self-employed are entitled to the leave as long as they have been working and paid social security contributions for at least six months.
- The child assistance allowance (s*ubsídio para assistência a filho*) and the grandchild assistance allowance (a*ubsídio para assistência a neto*) consist of cash supports aimed at replacing income loss resulting from the enjoyment of the 'absence for the care of a child' and 'absence for the care of a grandchild'. There are two sub-types of allowance: regarding the birth of a grandchild, and for care reasons. In the former case, the allowance corresponds to 100% of the reference wage. In the latter, it corresponds to 65% of the reference wage. The minimum amount of the benefit corresponds to EUR 11.44 per day (80% of 1/30 of the IAS). The leave period is relevant for the social security contributions record. For that purpose it is assumed that income is the same as the reference wage. However, the amounts received as benefit are not considered in the calculation of personal income tax (ISS, 2017).
- The special education allowance (s*ubsídio por frequência de estabelecimento de ensino especial*) is granted to the caregiver to meet the expenses of the child's attendance at private education institutions, whether for special or regular education. The amount of the allowance varies according to: the monthly fees paid to the institution; household income; the number of household members; and the cost of housing. In 2017, 14,008 people received this benefit.
- The disability supplement (b*onificação por deficiência*) is a supplement to the disabled children's child allowance. It is designed to compensate the families of disabled children and young people up to the age of 24 for the additional costs resulting from disability. In cases in which the carer has made social security contributions, contributions are required for the first 12 of the last 14 months

(this condition does not apply to pensioners). In cases in which the carer does not make social security contributions or contributions to any other social insurance scheme, a situation of financial need must be shown. The monthly amount of the benefit varies from EUR 62.37 for children up to the age of 14, to EUR 90.84 for children between 14 and 18, and EUR 121.60 for young people aged between 18 and 24. Lone-parent families are entitled to receive an additional 35%. In February 2018, 86,116 people received this benefit.

Apart from cash benefits, there is a set of **services** (made available or supported by the social security system) for dependent people and their families. Users are expected to co-pay for these services, subject to a means-test (ISS, 2014a; ISS, 2014b). These services may directly target people with a disability, their families/caregivers, or both.

The first group of services targeting people with a disability include: conviviality centres/day centres, home support services, residential homes and the centres of occupational activities.

The second group – targeting both dependent persons and their families – includes the centres for welcoming, follow-up and social rehabilitation (c*entro de atendimento, acompanhamento e reabilitação social*), and early-intervention services.

Finally, the third group – targeting families – includes self-help groups, and centres for vacations and leisure (c*entro de férias e lazer*).

Transportation services ensuring access to healthcare and rehabilitation services may also be made available, although with some territorial restrictions.

Some municipalities and/or entities or projects also provide specific services at the local level. This is the case, for instance, in projects in several municipalities to support the carers of patients with conditions such as Alzheimer's and sequels from cerebrovascular accidents.

2 Analysis of the main long-term care challenges in the country and the way in which they are tackled

2.1 Assessment of the challenges in LTC

A central challenge regarding LTC provision in Portugal undoubtedly remains its association with informal care, which is expected to be provided mainly by family members and mainly by women. Despite significant changes over the years, the traditional idea of a welfare state supported to a great extent by a welfare society and especially by 'welfare women' (Santos, 1993; Portugal, 2008; Pego, 2013; Simões et al., 2017) still seems entrenched in Portuguese society, even if apparently more on the part of the state than individuals and families. As a consequence, **challenges persist in terms of access and adequacy**.

As emphasised by a recent study, "state provision of community care services in Portugal has been characterised as scarce, including long-term care, day centres and social services for the chronically ill, older people and other groups with special needs, such as people with mental and physical disabilities. There is a traditional reliance on the family as the first line of care in Portugal, particularly in rural areas." (Simões et al., 2017: 129)

According to the International Labour Office, Portugal has a very **high deficit in legal LTC coverage**. This originates in the low number of formal LTC workers, estimated to be 0.4 per 100 people aged 65+, which compares with 17.1 in Norway (the highest in the survey). As emphasised by the study, "the absence of formal LTC workers results in the exclusion of large parts of the older population from quality services. (…) In Portugal more than 90 per cent of the population is excluded." (Scheil-Adlung, 2015: xii)

According to the study by the ERS, in cases where continuing care included the admission of the recipient as an inpatient, low access was estimated to affect 93% of the population, ranging between 81% in the case of palliative care and 95% in the case of convalescent care.[9]

This is not surprising as, according to the aforementioned 2016 monitoring report of the RNCCI, only 8,400 beds out of the 14,640 established as a target had been created by the end of 2016 (ACSS, 2017).

An **analysis by region** demonstrates that low access is more evident in the North, Lisbon and Tagus Valley and, especially, Algarve regions. In the latter case, access is characterised as low across nearly all services (Table 2, in Annex).

Waiting time between referral to the RNCCI and actual admission to care ranges from 39 days (for palliative care and rehabilitation care) to 87 days (for medium-term care units), 166 days (for integrated continued care teams) and 219 days (for LTC). Again, there are considerable variations between regions. However, regarding 2015, LTC services registered a waiting time increase across all regions (ACSS, 2017).

Another challenge regards the **affordability** of services. Within OECD countries, Portugal has the highest share of out-of-pocket funding for LTC (45%) (ERS, 2015); and the ILO identifies Portugal as an example of an upper-middle-income country with very limited, non-universal LTC coverage, based on a means-tested approach that limits publicly funded LTC to the poorest parts of the population (Scheil-Adlung, 2015).

Focusing on care provision to people with dementia, a recent paper concluded that "besides the differences arising from the different economic resources of every family, there are different levels of responsiveness both from the health sector (hospitals, health centres) and from social responses – equipment and services (…) with prices almost always inaccessible for most people and families who need them." (Reis & Alvarez, 2017: 98)

LTC in Portugal also faces **quality challenges**. Contrary to other fields where studies allowing for assessment are still largely absent, different studies have been produced regarding the health sector – either focusing on the health system as a whole, including LTC (e.g. INE-INSA, 2016; Simões et al., 2017; OPSS, 2015, 2016, 2017) or specifically on LTC (e.g. ERS, 2015; ACSS, 2015, 2016, 2017).

As emphasised by the ERS, Portugal has in place "accreditation procedures for providers of long-term care" (ERS, 2015: 79). These procedures define **minimum standards** for both equipment and supporting teams. The standards divide into general standards regarding structure, human resources and quality of care; and standards specific to each type of inpatient unit. Indicators regarding structure include the availability of beds and human resources and the existence of resting areas for relatives. There are also process and outcome indicators (see Section 3). The procedures also include an econometric model aiming at identifying changes in the length of stay as inpatient in long-term and palliative care units according to the users' characteristics, the type of unit and a set of quality indicators, . Finally, quality analysis includes inspections of a sample of providers and the evaluation of users' complaints (ERS, 2015: 80).

As regards **measures available to support family carers in providing good-quality unpaid care**, it should be mentioned that the Major Planning Options for 2018, in the section devoted to health, expresses the intention to expand and improve the RNCCI and other support services to dependent people, for which it establishes, among others, the

[9] The level of access was considered according to the targets for numbers of beds established at the launch of the RNCCI in 2007 and in 2015. Low access means that the number of available beds is lower than the targets both for 2007 and 2015; medium access means that the number of beds exceeds the target for 2015 but is lower than the original 2007 target; high access means that both the 2007 and 2015 targets have been exceeded.

need to "recognise and support informal carers supporting dependent people in their homes" (Portugal, 2017: 6764).

Training and empowerment of informal carers was included in the national programme for health, literacy and self-care launched by the Ministry of Health in March 2016. It should also be mentioned that the decree-law which established the RNCCI foresaw the possibility of creating posts destined to allow respite leave for informal carers.

Recently a working group was established for the elaboration of a report providing technical support for political decisions regarding measures aimed at informal carers. The report, dated September 2017 and publicly released in January 2018 (Teixeira et al., 2017), identifies a set of 47 experiences/projects supporting informal carers. Most of these experiences focus on (psycho)education, on the assumption that teaching, even if informal, is the trigger for skill acquisition and behavioural change.

The report emphasises the need to monitor and assess whether these initiatives are valuable in meeting the needs of informal carers; and the need to stimulate and replicate them if their effectiveness is confirmed. It further emphasises that "currently, in Portugal, there is a network of services (…) accompanying many users and their respective informal carers. This structure may be maximised without prejudice to other complementary solutions to be established according to specific needs." (Teixeira et al., 2017: 33)

As for **formal LTC workers**, studies have revealed that healthcare assistants are usually poorly educated, poorly trained and poorly paid women (Rodrigues, 2014; Pires, 2015; Gomes, 2017). Pires (2015) concluded that the main reasons for being an LTC worker were financial need, the absence of other job offers, and job stability (as demand for such jobs exceeds supply). In many cases, the job follows a period of unemployment.

Even if job opportunities in the field exist and probably provide relatively stable contracts, remuneration is far from being attractive. Precise information on the remuneration of LTC workers is not readily available. However, it is possible to use as a proxy workers providing human health and social support. According to the statistical bulletin of the Statistics and Planning Office of the Ministry of Solidarity, Labour and Social Security, issued in December 2017,[10] the basic monthly salary of these workers, in October 2016, was EUR 784.70, compared with EUR 968.60 for all workers (81%). At the same date their average monthly earnings were EUR 872.20, compared with EUR 1,154.20 (75.6%). For women, the latter figures were EUR 839.10 and EUR 993.30 (84.5%), respectively. The salary was set at the minimum wage in 27.6% of cases, compared with 23.3% for all workers.

As regards training, 21 training initiatives took place in 2016 (380 hours) involving 829 LTC professionals of different areas. However, it should be mentioned that, in most cases, participants were not the less-qualified LTC workers such as healthcare assistants but rather doctors, nurses, psychologists, social workers, pharmacists, etc.

The insufficient provision of formal care may lead to **employment challenges** as it may reduce the labour market participation of women. According to Eurostat, 7.4% of inactive females aged 15 to 64 in 2016 justified not seeking employment by reference to the need to look after children or incapacitated adults, compared with 0.8% of males. The same justification was provided by 5.2% of females for working part time.[11] The report by the working group for the creation of measures targeting informal carers emphasises that there are no definitive data for Portugal that can be extrapolated. However, based on previous studies (Alves, 2015; Eurocarers, 2017), it suggests that most informal carers in Portugal are poorly educated women aged 45 to 75, of whom only slightly more than half are employed (Teixeira et al., 2017).

[10] Available at: http://www.gep.msess.gov.pt/estatistica/remuneracoes/igdt_102016sint.pdf (accessed 14/02/2018).

[11] No reliable data for males.

Studies have identified several vulnerabilities among informal carers such as anxiety and depression (Simões et al., 2017), exhaustion, isolation, increased risk of poverty and difficulties remaining in the labour market (Teixeira et al., 2017). These risks have not been sufficiently tackled so far. Even if, as aforementioned, training and empowerment of informal carers is mentioned in the Ministry of Health's national programme for health, literacy and self-care, it remains simply an aspiration. Thus it is deemed that approving a formal status for informal carers (see below) would bring significant changes.

Another challenge with which LTC is confronted regards **financial sustainability**. Simões et al. (2017) note that it is estimated that 110,000 people in Portugal are in a dependent condition at home, and that 80% of them receive some kind of informal care. They also recall that a study conducted by the Portuguese Association for Consumer Protection found that, without informal carers, around 80% of elderly and dependent people would be institutionalised. According to Teixeira et al. (2017), the association 'Cuidadores Portugal' estimated the value of the work performed by informal carers to be around EUR 4 billion per year. Eurostat estimates that, in 2016, GDP in Portugal stood at EUR 185.2 billion. This means that the work done by informal carers is equivalent to over 2% of the Portuguese GDP.

Population ageing is expected to increase pressure for higher spending on LTC. Although public spending (as a percentage of GDP) on LTC in Portugal was still below the European average in 2015, it has been increasing at a faster rate than total public spending on health (ERS, 2015).

As emphasised in the European Commission's latest country report on Portugal, the country is expected to have the highest increase in healthcare costs in the EU by 2060, and consequently: "more efforts for cost compression should be pursued including by integrating primary care, hospital services and continuous care." (EC, 2017: 56)

The last few years have witnessed efforts to improve the coordination and integration of different existing LTC schemes and actors. The definition of the improvement of the RNCCI as one of the priorities of the government's programme for the health sector, as well as moves to improve the status of informal carer currently underway, represent crucial stepping stones.

One of the recommendations issued by the working group for the creation of measures targeting informal carers is that EU funds may be used to promote technological innovation within the RNCCI and within homecare, namely through technologies of tele-assistance, thereby stimulating prevention and boosting communication between health and social care professionals (Teixeira et al., 2017).

As aforementioned, home-based care services exhibit comparatively low usage rates, which led the Portuguese Health Systems Observatory (OPSS) to consider that "low use of this proximity resource is probably connected to the actual difficulties of families in assuming the care for their relatives and also to the policy of non-investment in this area in respect of human and material resources." (OPSS, 2017: 30)

As noted in the latest country profile, "Portugal lacks a comprehensive long-term strategy to address the health-related costs of ageing." (EC, 2017: 24) Thus, further investigation is deemed necessary in order to better understand how cost-effectiveness can be enhanced in relation to LTC provision. Any considerations should, evidently, also take into account the reforms planned, especially as regards improving the status of informal carers.

2.2 Assessment of reforms

Planned reforms are expected to change the face of LTC very significantly. In January 2018 the report from the working group created to study ways of implementing a formal status for informal carers was delivered to the Parliament's Commission for Labour and Social Security. This report followed the presentation, in July 2016, of a set of parliamentary resolutions recommending measures to improve support for, and the

status of, informal carers; and the presentation, in October 2017, of the final report of Petition 191/XIII/2ª, which pleads for the approval of a formal status for informal carers of people with Alzheimer's disease and other types of dementia.

Reflecting on the proposals laid down in the petition, Reis and Alvarez (2017) concluded that they are "in general, relevant and ambitious". They added that implementing them "will mean the transition from almost non-existent recognition and support for the carer to the actual approval of a formal their status, meeting what is needed and similar to what is already in place in other European countries." (Reis & Alvarez, 2017: 100)

The working group report, now made public, summarises much of the discussion on the subject and identifies two overall aspects to take in consideration, i.e. that measures should take into account the willingness and availability of the person to become an informal carer and should be independent from the age of the person cared for. Based on these overall aspects it draws up a set of recommendations, as follows.

- Carers should have a support plan. Professionals from the health sector and from social care should be involved in the definition of such plan, which should include easy access to specialist consultations.
- Carers should have better access to information and capacity-building, through individual interventions and the establishment of self-help groups. A permanent helpline, technologies for tele-assistance and respite services should be created and/or developed.
- Consideration should be given to using social benefits to reduce the risk of poverty for carers, and/or financial support compensating them for the loss of earnings resulting from taking on caring duties, for example part-time employment .
- Giving carers the option of taking emergency leave should be considered.
- Carers should be given incentives to engage in programmes of professional (re)qualification; and consideration should be given to ways of supporting them to remain in or re-enter the labour market and/or self-employment.
- Social partners should be involved in the debate on how to reconcile caring duties and professional life in ways that avoid negative impacts and discrimination, especially in terms of gender.
- The social value should be recognised of companies that promote good work practices and support for informal carers.
- Data should be gathered regarding the effect of informal caring on the carers themselves and on the persons cared for; and the benefits of informal care for the health and social systems should be analysed.

2.3 Policy recommendations

Apart from the **recommendations** issued in the study by Teixeira et al. (2017) mentioned above – which we endorse – and as well as the approval of a formal status for informal carers currently underway, a few additional policy recommendations seem relevant:

- ensuring that formalising and improving the status of informal carers does not perpetuate the over-reliance on family members (especially women) for care provision;
- widening access and affordability to formal LTC in order to ensure that large segments of the population are no longer excluded;
- revising entitlement to benefits, especially cash benefits, ensuring a closer linkage to the level of dependency rather than focusing excessively on means-testing criteria;

- revising the amount of the cash benefits;
- granting tax benefits to those taking responsibility for caring for their relatives;
- allowing time spent on care to count towards the workers' social security contributions record, e.g. for pensions;
- assessing the constraints on the use of home-based care services that currently prevent them from representing a real alternative to institutional services;
- allowing greater flexibility in working schedules (e.g. starting and finishing times, establishment of a bank of hours, concentrated working schedule, incentives for tele-working) in order to facilitate the caring needs of jobholders (bearing in mind possible gender impacts);
- developing a process of systematic monitoring and evaluation of public policies in the field, including ex-ante assessments;
- ensuring that the above recommendations take into consideration existing regional imbalances.

3 Analysis of the indicators available in the country for measuring long-term care

Indicator in national language	Indicator in English	Precise definition	Source	Years available	Frequency	Web-site address	Comments
Número de camas contratadas em funcionamento, total, por região e por tipologia (convalescença; média duração e reabilitação; longa duração e manutenção; paliativos; pediátricas - UCIP nível 1)	Number of beds in total and by region and institutional care service (convalescent units; Medium-term care units; LTC units; palliative care units; paediatric UCIP)		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Evolução do nº de camas, total, por região e por tipologia	Evolution of the number of beds, total by region and type		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Nº de camas abertas, total, por região e por tipologia	Number of new beds, total by region and type		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Número de camas por 100 mil habitantes com 65 ou mais anos, total e	Number of beds per 100,000 inhabitants aged 65+, total		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continua	

Indicator in national language	Indicator in English	Precise definition	Source	Years available	Frequency	Web-site address	Comments
por tipologia	and by type					dos/	
N.º de acordos celebrados, total e por tipo de entidade prestadora	Number of agreements, total and by type of provider		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
% total de acordos celebrados, por tipo de entidade prestadora	Total % of agreements, by type of provider	Distribution of the agreements established between the RNCCI and providers, by type of provider	ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
N.º de camas contratadas, total e por tipo de entidade prestadora	Number of beds, total and by type of provider		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Autonomia na admissão	Autonomy at admission	Percentage of users with incapacity/ dependency at the moment of admission at the RNCCI	ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Motivos de referenciação, total e por tipologia	Motives for referral, total and by type		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continua	

Indicator in national language	Indicator in English	Precise definition	Source	Years available	Frequency	Web-site address	Comments
						dos/	
% de camas contratadas por acordos celebrados, total e por tipo de entidade prestadora	% of beds according to the type of provider		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Nº de acordos por tipologia, total e por região	Number of agreements, by type, total and by region		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Número de equipas de cuidados continuados integrados (ECCI)	Number of integrated continued care teams (ECCI)		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Variação (%) do número de ECCI	Variation (%) of the number of ECCI		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Número de lugares em ECCI, total e por região	Number of places in integrated continued care teams (ECCI)		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continua	

Indicator in national language	Indicator in English	Precise definition	Source	Years available	Frequency	Web-site address	Comments
						dos/	
Nº de ECCI, lugares e capacidade média das ECCI por região	Number of ECCI, places and mean capacity of the ECCI, by region		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Cobertura populacional de lugares na RNCCI por região - Camas, ECCI e total de lugares	Coverage rate of places in the RNCCI by region – beds, ECCI and total of places		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Tempo de referenciação a identificação de vaga, total e por tipologia	Number of days between referral and identification of a place, total and by type		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Tempo de avaliação das ECL - mediana	Median of the time for evaluation of the ECL	Median time taken by the ECL for assessing the cases	ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Tempo máximo de avaliação das ECL	Maximum time for evaluation of the ECL	Maximum time taken by the ECL for assessing the cases	ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continua	

Indicator in national language	Indicator in English	Precise definition	Source	Years available	Frequency	Web-site address	Comments
						dos/	
Tempo de avaliação das ECR – mediana, por tipologia	Median of the time for evaluation of the ECR, by type	Median time taken by the ECR for assessing the cases, by typology	ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Tempo máximo de avaliação das ECR, por tipologia	Maximum time for evaluation of the ECR, by type	Maximum time taken by the ECR for assessing the cases, by typology	ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Utentes referenciados, total e por tipologia	Number of referrals, total and by type		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Utentes que aguardavam vaga, total e por tipologia	Number of users waiting for a place, total and by type		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Número de utentes assistidos, total e por tipologia	Number of users, total and by type		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continua	

Indicator in national language	Indicator in English	Precise definition	Source	Years available	Frequency	Web-site address	Comments
						dos/	
Taxa de ocupação por tipologia	Use rate by type		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Demora média, por tipologia	Mean number of days as inpatient/outpatient by type		ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Percentagem de pedidos de transferência efetivados	Percentage of transfer requests met	Percentage of transfer requests between different typologies concretised	ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Transferências para ECCI	Transfers into ECCI	Transfers from other care typologies into ECCI	ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continuados/	
Custo com a RNCCI	Cost with the RNCCI	Investment and operational costs with the RNCCI	ACSS-RNCCI monitoring reports	2006-…	Annual reports	http://www.acss.min-saude.pt/category/cuidados-de-saude/continua	

Indicator in national language	Indicator in English	Precise definition	Source	Years available	Frequency	Web-site address	Comments
						dos/	
Impactos entre trabalho e família, por sexo	Work-family impact index, by sex	Impacts felt between work and family, based on the differentiated frequency of these impacts and their direction (family on work, and work on family)	INUT research project	2015	One-off	http://www.cesis.org/admin/modulo_news/ficheiros_noticias/20170201143128-1inutbooken.pdf	
Recursos humanos (ETC) por 100.000 habitantes residentes em cada ARS	Human resources (FTE) per 100,000 inhabitants in each ARS	Number of doctors, nurses, other health professionals and social workers per 100,000 inhabitants by Health Regional Administration	ERS	2015	One-off	https://www.ers.pt/uploads/writer_file/document/1647/ERS_-_Estudo_Cuidados_Continuados_-_vers_o_final.pdf.	
Percentagem de Unidades de Convalescência (UC), Unidades de Cuidados Paliativos (UCP), Unidades de longa duração e manutenção (ULDM) e Unidades de	Percentage of Convalescence units (UC), Palliative care units (UCP), Long-term care units (ULDM) and Medium term care units (UMDR) with a number of medical hours		ERS	2015	One-off	https://www.ers.pt/uploads/writer_file/document/1647/ERS_-_Estudo_Cuidados_Continuados_-_vers_o_final.pdf.	

Indicator in national language	Indicator in English	Precise definition	Source	Years available	Frequency	Web-site address	Comments
média duração e reabilitação (UMDR) com número de horas médicas inferiores e iguais ou superiores às orientações	lower and equal or higher than recommended						
Percentagem de UC, UCP, ULDM e UMDR com número de horas de enfermagem inferiores e iguais ou superiores às orientações	Percentage of UC, UCP, ULDM and UMDR with a number of nursing hours lower and equal or higher than recommended		ERS	2015	One-off	https://www.ers.pt/uploads/writer_file/document/1647/ERS_-_Estudo_Cuidados_Continuados_-_vers_o_final.pdf.	
Avaliação de risco	Risk evaluation	Percentage of users evaluated in terms of risk of falling	ERS	2015	One-off	https://www.ers.pt/uploads/writer_file/document/1647/ERS_-_Estudo_Cuidados_Continuados_-_vers_o_final.pdf.	
Rácio de incapacidade e dependência, por tipologia e ARS	Incapacity and dependency ratio by type and ARS	Percentage of users with incapacity and dependency at the time of discharge compared with	ERS	2015	One-off	https://www.ers.pt/uploads/writer_file/document/1647/ERS_-_Estudo_Cuidados_Continuados_-	

Indicator in national language	Indicator in English	Precise definition	Source	Years available	Frequency	Web-site address	Comments
		the time of admission, by typology and Health Regional Administration				_vers_o_final.pdf.	
Ocorrência de quedas e incidência e prevalência de úlceras de pressão	Falls and incidence and prevalence of pressure ulcers		ERS	2015	One-off	https://www.ers.pt/uploads/writer_file/document/1647/ERS_-_Estudo_Cuidados_Continuados_-_vers_o_final.pdf.	
Motivo da alta dos utentes	Motive for discharge		ERS	2015	One-off	https://www.ers.pt/uploads/writer_file/document/1647/ERS_-_Estudo_Cuidados_Continuados_-_vers_o_final.pdf.	
Destino após alta,	Destination after discharge		ERS	2015	One-off	https://www.ers.pt/uploads/writer_file/document/1647/ERS_-_Estudo_Cuidados_Continuados_-_vers_o_final.pdf.	

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Annex

Table 1. Number of units and number of places in services provided or supported by social security in mainland Portugal (2014)

Type of service	Number of units	Number of places
Centres for welcoming, follow-up and social rehabilitation	30(e)	5,850(e)
Conviviality centres/day centres	2,048	64,705
Home support services (elderly)	2,650	104,551
Home support services (disabled)	35(e)	1,100(e)
Early intervention services	110(e)	9,500(e)
Residential homes	265	6,103
Centres of occupational activities	386	14,402

(e) Estimation on the basis of the graphs made available on-line. Concrete figures may be provided by the Ministry of Solidarity, Employment and Social Security only upon formal request and authorisation.

Table 2. Distribution of population by level of access to inpatient units, by region (%)

	Low	Medium	High	Total
North	99	1	0	100
Centre	74	12	15	100
Lisbon and Tagus Valley	99	1	0	100
Alentejo	70	18	11	100
Algarve	100	0	0	100
Total	93	4	3	100

Source: ERS, 2015: 68.