PORTUGAL
Country case study on the integrated delivery of long-term care
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Abstract
This report describes the current state of the delivery of health and social long-term care services in Portugal. The country has advanced the policy framework to achieve integrated services delivery. However, fragmentation in the governance, funding and delivery renders the long-term care system inequitable and inefficient. The main policy pointers to further advance integration include consolidating pathways and care transitions, promoting joint training and multi-profile teams and addressing the shortage of human resources, migration and working conditions. Further, promoting self-management and engaging family members and other unpaid caregivers in the care plans while addressing the growing needs of unpaid caregivers is of key importance. Lastly, the country could work towards establishing learning loops to improve workforce competencies and quality while strengthening the underpinning of health information for eliciting needs, managing services and informing policies.

Keywords
LONG-TERM CARE
HEALTH SERVICES FOR THE AGED
CAREGIVERS
INTEGRATED DELIVERY SYSTEMS
WOMEN’S HEALTH SERVICES
PORTUGAL
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Abbreviations

EU European Union
GDP gross domestic product
IHME Institute for Health Metrics and Evaluation
OECD Organisation for Economic and Co-operation and Development
Acknowledgements

This report is part of a series developed by the WHO Regional Office for Europe to assess the integrated delivery of services for long-term care across health and social sectors. The series is developed as part of an inter-programmatic initiative to accelerate progress towards integrating services to deliver long-term care services with a perspective of equity, gender and human rights. The collaborative includes the Health Service Delivery programme of the Division of Health Systems and Public Health, the Ageing and Health programme of the Division of Noncommunicable Diseases and Promoting Health through the Life-course and the Gender and Human Rights programme of the Division of Policy and Governance for Health, all at the WHO Regional Office for Europe.

Input was provided by representatives of Portugal's Ministry of Health and Ministry of Labour, Solidarity and Social Security; the National Network for Long-term Integrated Care (Rede Nacional de Cuidados Continuados Integrados); the National Confederation of Solidarity Institutions (umbrella association for providers), the National Network of Palliative Care, the union of the independent charitable misericórdias (umbrella organization for non-profit providers), Integrated Mental Health Care, the University of Porto and regional and local care coordination teams. There were also site visits to the following institutions: Hospital Fernando de Fonseca (Amadora), Local Coordination Team Oeiras (Lisbon), Regional Coordination Team Alentejo, Residencias Montepio (Montijo), Hospital de São João de Deus (Montemor-o-Novo) and Integrated Continuing Care Team Evora (Alentejo).

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Editors
Hector Pardo-Hernandez, WHO Regional Office for Europe
Juan Tello, WHO Regional Office for Europe

Contributors
The following individuals contributed to this document, in alphabetical order:
Erica Barbazza, WHO Regional Office for Europe
Stefania Ilinca, European Centre for Social Welfare Policy and Research
Kai Leichsenring, European Centre for Social Welfare Policy and Research
Ricardo Rodriguez, European Centre for Social Welfare Policy and Research

Series editors
Juan Tello, WHO Regional Office for Europe
Manfred Huber, WHO Regional Office for Europe
Isabel Yordi, WHO Regional Office for Europe

Publication productions
Erica Barbazza, design
David Breuer, text editing
Jakob Heichelmann, layout
Introduction

The European population is ageing rapidly (1). Low fertility rates and higher life expectancy are the leading causes fostering this shift (1). In the WHO European Region, births per woman have remained at around 1.7 between 2000 and 2019, below replacement level fertility (2). Average life expectancy has increased from 73.0 years at birth in 2000 to 77.1 years in 2015 (2). In the same period, life expectancy at age 65 years has increased from 16.4 to 18.4 years (2), and the percentage of the population 65 years or older has increased from 13.3% to 15.5%. In European Union (EU) countries, the proportion of the population older than 80 years is 5.6%, which is expected to increase to 14.6% by 2100 (3).

As the proportion and total number of older people increases, their needs and care should be considered. In 2017, cardiovascular diseases, cancer and nervous system disorders were the leading causes of death and disability-adjusted life-years among people 70 years or older, whereas musculoskeletal disorders, sense organ diseases and cardiovascular diseases were the leading causes of years lived with disability (4). The re-emergence and persistence of communicable diseases is an added challenge. In the WHO European Region alone, an estimated 72 000 people die every year from seasonal influenza (2). In EU counties in 2014, almost 50% of people 65 years or older reported long-term restrictions in daily activities, whereas more than two thirds reported physical or sensory functional limitations (3).

As a result of these changing scenarios, health systems have been compelled to adapt to meet the needs of older people (5). Meeting these needs is not limited to addressing the symptoms or disability associated with disease. It encompasses promoting the development and maintenance of the functional ability that allows well-being in older age, a process known as healthy ageing, and which enables people to live a fulfilling life in accordance with their values (6).

As part of the response to addressing the needs of older people, the 2016 Global Strategy and Action Plan on Ageing and Health calls for every country to implement a sustainable and equitable system of long-term care (1). Long-term care refers to “the activities undertaken by others to ensure that people with, or at risk of, a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity” (1).

Long-term care covers a wide range of health and social services that can be delivered in various settings, including the beneficiary’s home, hospice and day-care facilities (7). Fragmentation of services is not limited to the delivery of services; it also can be seen during needs assessment, when accessing benefits and packages, in data collection and in the diversity of quality improvement efforts (8). Fragmentation of services has been linked to dual administrative procedures, hindrances in access to care and longer waiting times (8) and has been identified as a barrier to reducing hospitalization for ambulatory care sensitive conditions (9).
In the European Region, the Strategy and Action Plan for Healthy Ageing in Europe 2012–2020 provides policy directions for ensuring healthy ageing (10). The WHO European Framework for Action on Integrated Health Services Delivery aims to streamline efforts for strengthening people-centred health systems and to promote integrated care models of primary, hospital and social services that are effectively managed and delivered by a coordinated array of providers (11). These efforts are in accordance with the recommendations of WHO’s 13th General Programme of Work for integrated services delivery based on a primary health care approach (12).

Addressing the needs of older people is underpinned by a strong gender component that goes beyond biological factors and their differential effect on ageing (13). The multiple facets of gender, understood as the social norms, roles and relationships of and between women and men, influence the provision of long-term care services (13). Older women report lower self-perceived health status and higher rates of unmet health needs (3) and are traditionally responsible for providing unpaid, informal care to older relatives at home (14). Men are affected by higher rates of risky behaviour and lower overall and healthy life expectancy (3). The Regional Office’s strategies on health and well-being for women (15) and men (16) highlight the importance of incorporating gender as determinant of men’s and women’s health to design policies that are responsive to their specific needs and contribute to achieving gender equality.

Promoting the availability and quality of long-term care services that are integrated, people-centred and properly managed is a right step for ensuring healthy lives and well-being in old age, in accordance with the United Nations Sustainable Development Goals (17).
Background

Social protection in old age in Portugal has traditionally revolved around the direct provision of old-age pensions and universal health care through a national health system. In contrast, the development of social services for older people has historically lagged far behind, and their provision has been outsourced to non-profit organizations (18). The roots of this underdevelopment lie in a deeply entrenched familism, since families are expected to ensure the welfare of older individuals and provide most forms of needed support. In addition, Portugal has a century-long tradition of non-profit social service providers, established as foundations with a religious and charitable character (misericórdias), catering to the needs of older individuals whose families cannot provide the necessary support (18).

The first attempts to formalize and strengthen social service provision in the light of population ageing and soaring demand were carried out in the 1980s. Although they fell short of creating a well-structured, publicly operated long-term care system, the reforms considerably extended the role of the public sector in funding social support services and regulating system standards, while the responsibilities for service provision remained with non-profit, private institutions. Decree-Law 119/83 defined and established activity standards for a new category of social service providers, the social solidarity private institutions (instituições particulares de solidariedade social) (19). Under this arrangement, the non-profit care provision sector has experienced rapid and sustained growth.

Further policy developments continued in the 1990s, with a focus on extending service provision for older people and their families. The Programme for Integrated Support for Older People (Programa de Apoio Integrado a Idosos) in 1994, the Programme for Older People in Nursing Homes (Programa Idosos em Lar) in 1997 and the Programme for Long-term Care (Programa de Cuidados Continuados) from 1995 to 1999 signalled an effort towards developing new types of care provision for older people in the home and in institutions and the improvement of quality standards for existing services (20). It is also noteworthy that, already in these early programmatic documents, the language of long-term care is present (19) and the goal of promoting coordination between different service providers and types is stated explicitly (20). In fact, subsequent programmes and policy initiatives mostly extend and strengthen the goals and the care provision infrastructure established in the 1990s.

The most prominent measure taken to date to address long-term care is the establishment in 2006 of the National Network for Long-term Integrated Care (Rede Nacional de Cuidados Continuados Integrados) (21). The National Network for Long-term Integrated Care was formed through a partnership of the Ministry of Health and the Ministry of Labour, Solidarity and Social Security and provides health, rehabilitation and nursing care services for residents unable to care for
themselves (22). The National Network for Long-term Integrated Care works in parallel to the Network of Social Services (Rede de Serviços e Equipamentos Sociais), affiliated with the Ministry of Labour, Solidarity and Social Security, to provide social services to older people with low resources or facing social exclusion (19).

Although establishing these structures has been a step in the right direction, long-term care services delivery faces several challenges (23). Previous work highlights how the persistent fragmentation of governance and funding arrangements remains the main obstacle to advancing the integration of services (19,21,24). There are persistently high rates of institutionalization, regional inequalities, overlapping mechanisms for needs assessment, limited accessibility, long waiting lists and a high proportion of hospital readmissions without ambulatory contact (19,21,23-25). In addition, there is very limited interoperability between information systems and a lack of a clear contractual model that unifies health and social services provision (21,23–26).

This report sets out to develop an actionable overview on the state of long-term care in Portugal from a services delivery perspective. As countries face accelerated population ageing and increasing prevalence of chronic conditions, the development and use of sector-spanning frameworks is of increasing importance. Recent European and global policies for advancing healthy ageing and system strengthening have called attention to this, with emphasis on integrated care and people-centred systems as a precursor to the integrated delivery of health and social services (1,6,10).
Methods

This assessment was completed following the principles of systems thinking (28), people-centredness and integrated care (11, 29), life-course approach (30), healthy ageing (6), human rights (31) and a gender perspective (32). The methods of this report have been published in greater detailed elsewhere (23). The conceptual framework underpinning this toolkit is the European Framework for Action on Integrated Health Services Delivery (11). This policy framework calls for designing models of care based on the health and social needs and the alignment of the system enablers accordingly. Based on this, the assessment is developed along four domains: health and social needs, performance, services delivery and system enablers (11, 33). These domains and their respective features are illustrated in Fig. 1 and listed in Table 1.

**Fig. 1. Framework for assessing integrated delivery of health and social services for long-term care**

The assessment was structured in the following four domains.

- **Health and social needs.** This domain explores the main demographic and epidemiological trends at the country level, with an emphasis on people 65 years or older. The main determinants of health and lifestyle risk factors affecting people’s health are listed, together with the underlying health needs of older people. The latter includes self-assessed outcomes and measures of disability and daily life limitations. The specific profile and needs of caregivers are investigated, together with measures to ensure older people’s rights, dignity protection and support from the community.

- **Performance.** This domain encompasses an appraisal of long-term care
services coverage. It also compiles information on quality of long-term care using waiting times, hospital length of stay, hospitalization rates for ambulatory care sensitive conditions, safety incidents prevention and reporting, among other performance measures.

- **Services delivery.** This domain exhaustively explores the existing services available to older people and their caregivers and the procedures in place for completing needs assessment, for diseases and transition management and the available care pathways. Policies for fostering patient engagement are also covered. The profile of service providers, whether they are public, private for-profit or not-for-profit and the different settings in which services are provided are also compiled. There is consideration of the quality assurance efforts within settings and the initiatives to ensure information exchange among providers.

- **System enablers.** This domain includes those health system facilitators that intersect with health services delivery, including governance, financing of and allocation of resources for long-term care, the planning, production and update of dedicated workforce and the availability of information technology.

**Table 1. Overview of the components of the assessment framework**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Subdomain</th>
<th>Feature</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health and social needs (*)</strong></td>
<td>Demographics</td>
<td>Population structure and dynamics</td>
</tr>
<tr>
<td></td>
<td>Determinants and risk factors</td>
<td>Socioeconomic status of older people</td>
</tr>
<tr>
<td></td>
<td>Health and well-being</td>
<td>Lifestyle and risk factors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Health and social needs of older people</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disability and well-being of older people</td>
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<tr>
<td></td>
<td>Socialization and behaviours</td>
<td>Social inclusions and networks</td>
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<tr>
<td></td>
<td></td>
<td>Gender behaviours when seeking care</td>
</tr>
<tr>
<td></td>
<td>Rights</td>
<td>Rights of older people</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rights and needs of caregivers</td>
</tr>
<tr>
<td><strong>Performance</strong></td>
<td>Coverage</td>
<td>Long-term care services coverage</td>
</tr>
<tr>
<td></td>
<td>System outcomes</td>
<td>Quality of care for older people</td>
</tr>
<tr>
<td><strong>Services delivery</strong></td>
<td>Types of services</td>
<td>Health services for older people</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social services for older people</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Services for caregivers</td>
</tr>
<tr>
<td></td>
<td>Patient engagement</td>
<td>Self-management support for older people</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shared decision-making with older people</td>
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<tr>
<td></td>
<td></td>
<td>Peer-to-peer support and social inclusion</td>
</tr>
<tr>
<td></td>
<td>Design of long-term care</td>
<td>Needs assessment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pathways and integrated services delivery</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disease management</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Management of transitions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Care/case coordination or management</td>
</tr>
<tr>
<td></td>
<td>Organization of providers and</td>
<td>Long-term care settings (public and private)</td>
</tr>
<tr>
<td></td>
<td>settings for long-term care</td>
<td>Long-term care providers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Out-of-hours services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cultural, social and gender patterns of caring</td>
</tr>
<tr>
<td></td>
<td>Management</td>
<td>Facility management</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Autonomy and decision making</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Quality management including quality improvement mechanisms</td>
</tr>
</tbody>
</table>
Data sources

This report was constructed applying mixed methods, relying on qualitative data, literature searches, observational facility visits, semistructured interviews and roundtable discussions with key informants. This design was adopted to consolidate a comprehensive view of long-term care in Portugal. The specific sources and process for data collection are described below.

Database data

Initial desk research was completed for existing, standardized indicators. Data were extracted from international databases: Eurostat (3), the Institute for Health Metrics and Evaluation (4) and the Organisation for Economic Co-operation and Development (OECD) (34) as well as Portugal’s National Institute of Statistics (35). These data have primarily informed an analysis of the current health context in the scope of depicting the health and well-being of older people in Portugal.

Scientific and grey literature

The literature search targeted scientific and grey literature on Portugal’s long-term care services using the topics listed in Table 1 as keywords. Searches for grey literature included the WHO database WHOLIS for Portugal-specific reporting such as the Health Systems in Transition series (26). Other grey literature included reporting from such organizations as the European Commission and the OECD. Searches for scientific literature were conducted using MEDLINE (PubMed) and Google Scholar on the topic of health and social services. Literature was reviewed in English and Portuguese.

Field evidence

A five-day country visit took place in 2018. The country visit included facility site visits and semistructured group interviews with care practitioners, coordinators
and managers. Group interviews included a hospital discharge management team, a local coordination team, a regional coordination team, care practitioners at a private and a non-profit residential institution with convalescence, medium and long-stay units as well as a nursing home care team (Fig. 2).

Open discussion forums with academic experts, policy-makers and representatives of the main care providers in Portugal were also organized and conducted during the country visit. Two discussions were held – one at the outset of the country visit and a second at the closing of the visit. Participants included representatives of the Ministry of Health; the Ministry of Labour, Solidarity and Social Security; the National Network for Long-term Integrated Care; the National Confederation of Solidarity Institutions (umbrella association for providers); the National Network of Palliative Care; the union of the independent charitable misericórdias; Integrated Mental Health Care; academics (University of Porto); and regional and local care coordination teams. More than 20 experts provided their input and insight. The second discussion served as a preliminary validation of the study’s findings (Fig. 2).

**Fig. 2. Field evidence components and informants**

<table>
<thead>
<tr>
<th>Semi-structured interviews</th>
<th>Site visits</th>
<th>Workshop</th>
</tr>
</thead>
<tbody>
<tr>
<td>Semi-structured interviews with:</td>
<td>Site visits to institutions delivering long-term care</td>
<td>Individual semi-structured interviews with:</td>
</tr>
<tr>
<td>• Hospital discharge management team</td>
<td>• Hospital Fernando de Fonseca (Amadora)</td>
<td>• Ministry of Health</td>
</tr>
<tr>
<td>• Local coordination team</td>
<td>• Local Coordination Team Oeiras (Lisbon)</td>
<td>• Ministry of Labour, Solidarity and Social Security</td>
</tr>
<tr>
<td>Regional coordination team</td>
<td>• Regional coordination team Alentejo</td>
<td>• National Network for Long-Term Integrated Care</td>
</tr>
<tr>
<td>• Care providers at a non-profit, residential institution</td>
<td>• Residencias Montepio (Montijo)</td>
<td>• National Confederation of Solidarity Institutions</td>
</tr>
<tr>
<td>• Care providers at a private, residential institution</td>
<td>• Hospital de São João de Deus (Montemor-o-Novo)</td>
<td>• National Network of Palliative Care</td>
</tr>
<tr>
<td>• Nursing home care team</td>
<td>• Integrated Continuous Care Team Evora (Alentejo)</td>
<td>• Union of the independent charitable Misericórdias</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Academics (University of Porto)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Regional and local coordination teams</td>
</tr>
</tbody>
</table>
Health and social needs of older people

About this section
The demographic and epidemiological data presented in this section provide a snapshot of the main characteristics of the older population and their needs. Data are disaggregated by sex when available. Data were mostly obtained through initial desk research; country experts filled in information gaps and validated the findings.

Demographics: the population is decreasing and ageing rapidly
Portugal accounts for about 2% of the total EU population, with about 10.3 million people in 2017, more than a quarter of a million less than in 2011 (Table 2) (35). The population is expected to decline to 9.9 million by 2030 and to 9.1 million by 2050 (27).

Table 2. Main demographic indicators

<table>
<thead>
<tr>
<th>Measure</th>
<th>Total</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population**</td>
<td>10 283 800</td>
<td>2018</td>
</tr>
<tr>
<td>Women (%)</td>
<td>5 423 800 (52.7)</td>
<td></td>
</tr>
<tr>
<td>Men (%)</td>
<td>4 860 000 (47.3)</td>
<td></td>
</tr>
<tr>
<td>Population 65 years or older** (% of total population)</td>
<td>2 228 750 (21.7)</td>
<td>2018</td>
</tr>
<tr>
<td>Women (% of population 65 years or older)</td>
<td>1 298 413 (58.3)</td>
<td></td>
</tr>
<tr>
<td>Men (% of population 65 years or older)</td>
<td>930 337 (41.7)</td>
<td></td>
</tr>
<tr>
<td>Population 85 years or older** (% of total population)</td>
<td>303 907 (3.0)</td>
<td>2018</td>
</tr>
<tr>
<td>Women (% of population 85 years or older)</td>
<td>206 024 (67.8)</td>
<td></td>
</tr>
<tr>
<td>Men (% of population 85 years or older)</td>
<td>97 883 (32.2)</td>
<td></td>
</tr>
<tr>
<td>Net migration**</td>
<td>5 058</td>
<td>2017</td>
</tr>
<tr>
<td>Fertility rate (births per woman)**</td>
<td>1.38</td>
<td>2017</td>
</tr>
<tr>
<td>Median age**</td>
<td>41.3</td>
<td>2015</td>
</tr>
<tr>
<td>Life expectancy at birth**</td>
<td>81.6</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>84.6</td>
<td>2017</td>
</tr>
<tr>
<td>Men</td>
<td>78.4</td>
<td></td>
</tr>
<tr>
<td>Life expectancy at age 65 years**</td>
<td>20.1</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>21.8</td>
<td>2017</td>
</tr>
<tr>
<td>Men</td>
<td>18.0</td>
<td></td>
</tr>
</tbody>
</table>

Sources: **Base de dados Portugal Contemporâneo (Contemporary Portugal database) (35); **Population statistics at regional level (3); **Profiles of ageing 2019 (36); **European core health indicators (37).
The steady pace of population decline (0.32% for 2015 and 0.31% for 2016) can be traced back to two main contributing factors. First, the negative natural balance (higher death rate than birth rate) accounts for most of the decline. Second, net migration was negative for most of the past 10 years, although it has turned positive since 2017 (Table 2) (3,35). The declining fertility rates in conjunction with significant gains in life expectancy have led to particularly accelerated population ageing.

**Life expectancy and share of older people in the population are increasing**

Life expectancy at birth is among the highest in the world: 84.6 years for women and 78.4 for men in 2017 (Table 2) (3). The 6.2 years difference between men and women exceeds the EU average of 5.4. In 2018, more than 2.2 million people (21.7% of the total population) were 65 years or older (3), of which 1.3 million were women (58% of people older than 65 years) (Table 2). The proportion of people 65 years of older is expected to increase to 27.0% by 2030 and to 34.8% by 2050 (36). The total population 85 years or older is slightly more than 300 000, about 3% of the total population (Table 2); this population segment is expected to grow to 410 000 by 2030 and to 657 000 by 2050 (36). The median age was 41.3 years in 2015 and is expected to increase to 45.5 years by 2030 and 47.4 years by 2050 (36).

There are noticeable differences in the geographical distribution of older population. Similar to other EU countries, most older people live in coastal, more densely populated areas, where they nonetheless represent a smaller proportion of the population (Fig. 3). In contrast, interior regions in which rural communities predominate currently report 30% to 45% of their population being older than 65 years (35).

**Fig. 3. People 65 years or older as a percentage of the total population by locality, 2016**

Panel A (population proportion)

<table>
<thead>
<tr>
<th>Proportion - %</th>
<th>Square</th>
</tr>
</thead>
<tbody>
<tr>
<td>27.9 - 45.5</td>
<td>No Data</td>
</tr>
<tr>
<td>24.1 - 27.9</td>
<td></td>
</tr>
<tr>
<td>20.7 - 24.1</td>
<td></td>
</tr>
<tr>
<td>17.1 - 20.7</td>
<td></td>
</tr>
<tr>
<td>7.8 - 17.1</td>
<td></td>
</tr>
</tbody>
</table>

Panel B (number of individuals)

<table>
<thead>
<tr>
<th>Proportion - %</th>
<th>Square</th>
</tr>
</thead>
<tbody>
<tr>
<td>27.9 - 45.5</td>
<td>No Data</td>
</tr>
<tr>
<td>24.1 - 27.9</td>
<td></td>
</tr>
<tr>
<td>20.7 - 24.1</td>
<td></td>
</tr>
<tr>
<td>17.1 - 20.7</td>
<td></td>
</tr>
<tr>
<td>7.8 - 17.1</td>
<td></td>
</tr>
</tbody>
</table>

Source: Base de dados Portugal Contemporâneo (Contemporary Portugal database) (35).
Smaller households and larger old age dependency ratios pose a challenge for ensuring the welfare of older people

The profile of families is rapidly changing because of many factors, including the budgetary restrictions resulting from the 2008 financial crisis (38) and migration (35). The average household size is currently 2.5, a slight decrease from 2.7 in the year 2008 (3). According to 2011 data, most people 65 years or older live either as a couple (35%) or alone (27%) or with children, extended family or non-relatives (38%) (36).

The old age dependency ratio in 2017, defined as people 65 years and older who are economically inactive divided by the number of people 15–64 years old, is 32.5, higher than the EU average of 29.9 (37). The old age dependency ratio increased from 25.7 in 2005 and 27.5 in 2010.

Noncommunicable conditions are the leading causes of mortality and morbidity

In 2017, the top five leading causes of death for people 70 years or older included ischaemic heart disease, Alzheimer’s disease, ischaemic stroke, lower respiratory infection and chronic obstructive pulmonary disease (Table 3) (4). The top causes of lost disability-adjusted life-years are ischaemic heart disease, Alzheimer’s disease, type 2 diabetes, ischaemic stroke and chronic obstructive pulmonary disease (4). Leading risk factors associated with the number of years lived with disease and disability are metabolic and behavioural, specifically high fasting plasma glucose, high systolic blood pressure, high body mass index, smoking and alcohol use (4). Table 3 provides information disaggregated by sex.

Table 3. Causes of death and disability, 2017

<table>
<thead>
<tr>
<th>Measure of death or disability</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
</table>
| Top causes of death among people 70 years or older | Alzheimer’s disease  
Ischaemic heart disease  
Ischaemic stroke  
Lower respiratory infection  
Intracerebral haemorrhage | Ischaemic heart disease  
Alzheimer’s disease  
Lower respiratory infection  
Ischaemic stroke  
Chronic obstructive pulmonary disease |
| Top determinants of disability-adjusted life-years among people 70 years or older | Alzheimer’s disease  
Ischaemic heart disease  
Type 2 diabetes  
Ischaemic stroke  
Chronic obstructive pulmonary disease | Ischemic heart disease  
Type 2 diabetes  
Ischaemic stroke  
Alzheimer’s disease  
Chronic obstructive pulmonary disease |
| Top determinants of the number of years lived with disability among people 70 years or older | Type 2 diabetes  
Low back pain  
Age-related hearing loss  
Alzheimer disease  
Chronic obstructive pulmonary disease | Type 2 diabetes  
Age-related hearing loss  
Low back pain  
Alzheimer disease  
Chronic obstructive pulmonary disease |
| Top risk factors associated with disability among people 70 years or older | High fasting plasma glucose  
High systolic blood pressure  
High body mass index  
High LDL cholesterol  
Impaired kidney function | High fasting plasma glucose  
Smoking  
Alcohol use  
High systolic blood pressure  
High body mass index |

Source: Institute for Health Metrics and Evaluation (website) (4).
Alcohol consumption is higher and high blood pressure more prevalent among older people than in the rest of the EU, but the prevalence of daily smoking is lower. Women present higher rates of obesity but lower rates of daily smoking (Table 4).

Table 4. Selected measures of lifestyle risk factors and determinants of health

<table>
<thead>
<tr>
<th>Risk factor or determinant</th>
<th>Portugal (%)</th>
<th>EU 28 (%)</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>People 65 years or older reporting hazardous alcohol consumptiona</td>
<td>4.8</td>
<td>3.6</td>
<td>2014</td>
</tr>
<tr>
<td>People 65 years or older reporting high blood pressure in the past 12 monthsa</td>
<td>55.3</td>
<td>49.2</td>
<td></td>
</tr>
<tr>
<td>Obese population 65 years or older, measured (%)b</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>21.1</td>
<td>20.7</td>
<td>2014</td>
</tr>
<tr>
<td>Men</td>
<td>17.3</td>
<td>18.8</td>
<td></td>
</tr>
<tr>
<td>Daily smokers by age – 65–69 yearsc</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>1.9</td>
<td>11.0d</td>
<td>2015</td>
</tr>
<tr>
<td>Men</td>
<td>13.0</td>
<td>16.0d</td>
<td></td>
</tr>
<tr>
<td>Daily smokers by age – 70–74 yearsc</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>1.5</td>
<td>7.8d</td>
<td>2015</td>
</tr>
<tr>
<td>Men</td>
<td>6.2</td>
<td>11.0d</td>
<td></td>
</tr>
<tr>
<td>Daily smokers by age – 75–79 yearsc</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>1.0</td>
<td>5.5d</td>
<td>2015</td>
</tr>
<tr>
<td>Men</td>
<td>6.1</td>
<td>8.4d</td>
<td></td>
</tr>
<tr>
<td>Daily smokers by age – 80 years or olderc</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>0.6</td>
<td>3.3d</td>
<td>2015</td>
</tr>
<tr>
<td>Men</td>
<td>2.5</td>
<td>5.6d</td>
<td></td>
</tr>
<tr>
<td>Risk of poverty or social exclusion for people 65 years or olderb</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>15.4</td>
<td>17.3</td>
<td>2015</td>
</tr>
<tr>
<td>Men</td>
<td>13.9</td>
<td>12.8</td>
<td></td>
</tr>
</tbody>
</table>

Sources: aEuropean core health indicators (37); bPopulation statistics at regional level (3); cInstitute for Health Metrics and Evaluation [website] (4). dWestern Europe only.

Poverty rates are higher compared with the EU, especially among women

The prevalence of poverty or social exclusion for the entire population is 20.4% versus 19.9% in the EU. The prevalence of poverty or social exclusion among older people is lower, 14.6%, but still higher than the EU average of 15.2% (3). Women are more affected than men, a pattern also seen in the EU (Table 4) (3).

The income inequality (ratio between the total income received by the 20% of the country’s population with the highest income and the total income received by the 20% of the country’s population with the lowest income) for older people in 2017 was 5.4 versus 4.1 for the EU (37). This percentage is lower than that for people younger than 65 years (5.9%).

Key points

One in five residents are 65 years or older, a number expected to increase to one in four in the next decade. Although life expectancy has increased, especially among women, older people self-report worse health status than in the rest of the EU. There are also high rates of restriction in daily activities.
Health status and needs of older people: few self-rate their health as being good or very good

According to 2017 data, women are expected to live 57.0 years in healthy life versus 60.1 years for men (3). Life expectancy at age 65 years is 21.7 years for women and 18.0 years for men (Table 2). Healthy life expectancy at age 65 years is 6.4 years for women and 7.7 years for men (37).

Despite increasing life expectancy, older people report low self-perceived health status by several standards, especially compared with the EU (3,37). The proportion of people 65 years or older assessing their health to be good or very good in 2017 was 14% versus almost 40% in the EU (37). The healthy life expectancy in good self-rated health of people 65 years or older in 2016 was 11.9 years for women and 12.0 years for men (37) (Table 5).

Table 5. Self-rated measures of perceived health among older people

<table>
<thead>
<tr>
<th>Measure</th>
<th>Portugal</th>
<th>EU 28</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>People 65 years or older who assess their health as very good or good (%)a</td>
<td>14.3</td>
<td>39.6</td>
<td>2017</td>
</tr>
<tr>
<td>Life expectancy (years) in good self-rated health from age 65 yearsa</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>11.9</td>
<td>16.6</td>
<td>2016</td>
</tr>
<tr>
<td>Men</td>
<td>12.0</td>
<td>15.0</td>
<td></td>
</tr>
<tr>
<td>People 65 years or older reporting any longstanding health problem (%)b</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>74.1</td>
<td>63.2</td>
<td>2017</td>
</tr>
<tr>
<td>Men</td>
<td>70.4</td>
<td>60.3</td>
<td></td>
</tr>
<tr>
<td>People 65 years or older reporting severe or very severe body pain (%)b</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>34.2</td>
<td>19.0</td>
<td>2014</td>
</tr>
<tr>
<td>Men</td>
<td>16.4</td>
<td>10.2</td>
<td></td>
</tr>
<tr>
<td>People 65 years or older reporting severe physical and sensory functional limitations (%)b</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeing, women</td>
<td>12.8</td>
<td>6.8</td>
<td>2014</td>
</tr>
<tr>
<td>Seeing, men</td>
<td>6.4</td>
<td>4.0</td>
<td></td>
</tr>
<tr>
<td>Hearing, women</td>
<td>16.2</td>
<td>12.0</td>
<td></td>
</tr>
<tr>
<td>Hearing, men</td>
<td>16.6</td>
<td>12.4</td>
<td></td>
</tr>
<tr>
<td>Walking, women</td>
<td>30.1</td>
<td>25.3</td>
<td></td>
</tr>
<tr>
<td>Walking, men</td>
<td>14.0</td>
<td>15.7</td>
<td></td>
</tr>
<tr>
<td>Overall, women</td>
<td>43.5</td>
<td>32.1</td>
<td></td>
</tr>
<tr>
<td>Overall, men</td>
<td>28.5</td>
<td>24.3</td>
<td></td>
</tr>
</tbody>
</table>

Sources: aEuropean core health indicators (37); bPopulation statistics at regional level (3).

The proportion of people 65 years or older reporting long-term restrictions in daily activities is 63% versus 49% in the EU (37). Currently, it is estimated that there are almost 900,000 people of all ages with health-related living limitations (39). Women are at further disadvantage for all available measures disaggregated by sex (Table 5).

As of 2012, the total estimated number of people with dementia was 182,526, 1.7% of the total population, slightly higher than the EU average of 1.55%. Among

---

1. Cross-population comparability of self-reported data should be interpreted with caution.
people 60 years and older, the prevalence of dementia in 2018 was about 7.5%, slightly higher than rest of the EU (40). About 66% of the people with dementia were women (41). The proportions of women and men 65 years or older reporting depression in the previous 12 months for 2014 were 25.1% and 10.2%, respectively, both higher than the EU averages of 11.1% for women and 5.8% for men (3).

Data on oral health are scarce, but 12.1% of older people reported in 2014 unmet needs for dental care services because of financial barriers, waiting times or travelling distances. This number is higher than the 2.8% average for the EU (37). Regarding social services, 12.6% of older women and 12.8% of older men reported overall poor social support in 2014, lower than the respective 18.3% and 18.0% EU averages for the same year (3).

**Long-term care services rely heavily on unpaid caregivers, but their needs are not fully met**

Similar to other countries in southern Europe, Portugal relies on the support lent by families and other unpaid caregivers to provide long-term care for older people. Although the government has established mechanisms to ensure a basket of long-term care services in recent decades, care for older people continues to be understood as a responsibility of families (19). Families are required by law to care for their older relatives or to financially contribute to it.

Knowledge of the characteristics and needs of family members and other unpaid caregivers is limited. According to the 2016 European Quality of Life Survey, about 13% of the population (17% of women versus 9% of men) provide unpaid care for a relative, neighbour or friend at least once a week. This number is about half that for the EU (42). According to this survey, caregivers represent 8% of all people 35–64 years old, 10% of those 65 years or older and 3.6% of people 18–64 years old. The 2014 Portuguese National Health Survey estimated that 1.1 million residents older than 15 years provided unpaid care to another person. Of these, about 61% were women (daughters, mothers or wives) (43). A total of 42.6% of unpaid caregivers provided care for 10 hours or more per week (44). Unpaid caregivers are disproportionately affected by anxiety and depression (26).

**Few data on individual and community empowerment**

The Portuguese National Health System Plan 2012–2020 aims to “promote a culture of citizenship for promoting literacy and empowering citizens so that they become more autonomous and responsible in relation to their health”, especially via education programmes on health promotion and disease prevention, including immunization, screening, use of services and risk factors (45). This Plan includes public health strategies aiming to reduce risk factors for noncommunicable diseases, including tobacco use, overweight and sedentary behaviour (7). No follow-up information on the implementation of these measures is available.

The National Programme for Health Education, Literacy and Self-care was launched in 2016. This Programme aims to foster patient involvement in the health system by disseminating health knowledge and by promoting informed decision-making (26).
In 2019, the Council of Ministers approved a motion to “establish a set of measures to support unpaid caregivers, regulating their rights and duties and of the people under their care” (46). The motion includes provisions to support full-time unpaid caregivers by such measures as cash benefits. Although no further details on the nature of this set of measures were provided and the scope of the benefits seems limited (47), this motion may become a stepping-stone for addressing the needs of unpaid caregivers.

### Key points

Political commitment to address the needs of unpaid caregivers is key to ensuring their well-being. Without their involvement, institutionalization rates for older people would be even higher. Information on the number of people providing unpaid care and their needs is very limited.

### Highlights

The steady pace of population decline and the accelerated rate of population ageing pose challenges for the system and for families to take care of older people and to ensure their well-being. Although life expectancy is increasing, this advantage has not been translated into healthy life years. Lifestyle risk factors could be improved: reducing obesity rates, alcohol consumption and smoking. Poverty rates are higher among women and, overall, higher than in the EU. The system relies heavily on unpaid caregivers to provide care for older people, but their needs are not systematically assessed. The available services for unpaid caregivers are insufficient, especially regarding legal protection, cash benefits and respite services. Women are overrepresented among unpaid caregivers, reported worse self-perceived health outcomes and are disproportionately affected by poverty.
Performance

About this section

Long-term care services coverage and system outcomes such as amenable hospitalizations, falls and ulcers and other preventable adverse events, waiting times and barriers to access are indicators of long-term care system performance. The data presented in this section were obtained from international databases and registries that allow Portugal’s system to be compared with those of other European countries.

Coverage of long-term care services is low

The Healthcare Access and Quality Index, a measure of health care access and quality, was 86 in the year 2016 (4). About 33 227 people 65 years or older were receiving long-term care services in an institution as of 2016, and 15 993 were receiving care at home (7). The rates of coverage and provision of services at home are both significantly lower than those of other Organisation for Economic Co-operation and Development countries (34).

There are encouraging indicators on amenable mortality and preventable hospitalizations

Amenable mortality is defined as avoidable deaths that could have been prevented by providing appropriate health care interventions (29). Avoidable mortality per 100 000 was 83.9 for women and 152.1 for men in 2014, both lower than the respective EU averages of 97.5 and 158 deaths (39). Avoidable hospitalizations caused by common chronic conditions (diabetes, hypertension, heart failure, chronic obstructive pulmonary disease and asthma) in 2015 were 5.7% of all hospitalizations and less than 600 discharges per 100 000 people (40). The former is similar to the EU average of 5.5%, and the latter is significantly lower.

Key points

Coverage of long-term care services is low and waiting times are long, especially for long-term support units. Although the system performs well on measures of amenable mortality and avoidable hospitalizations, waiting times are high and many residents report limitations in access to care for financial reasons.

The average length of inpatient stay for the total population for all causes was 7.9 days, similar to the EU average of 7.4 days, both for 2015 (3). Disaggregated by sex, the average length of stay was 7.1 days for women and 8.3 days for men (3). Hospital inpatient discharges were 8 per 100 population, half the EU average (7). The rates of day surgery for high-volume eligible surgical procedures are all above the EU averages. A total of 96.7% of cataract operations, 55.0% of inguinal hernia repair operations and 55.6% of tonsillectomies were performed as day surgery (40).
In 2013, about 12.3% of hospitalizations registered in mainland Portugal were attributable to ambulatory care sensitive conditions. Most of these occurred among older people, women being more affected than men (25). This rate is lower than the rate observed in Germany in 2012 (about 20%). Between 2000 and 2008, 4.1% of unplanned hospital admissions corresponded to readmissions. This number was also lower than that for other countries (48). Readmission rates were higher among older people (5.3% versus 2.6% for children) and men (4.5% versus 3.9% for women, P < 0.001) (48).

For 1000 older people, 54.3 had prescriptions for long-term benzodiazepines or related drugs in 2015. This number was 84.9 for long-acting benzodiazepines or related drugs (34). Both were higher than what is reported in other EU countries. Regarding patient satisfaction, perceived general practitioner quality was 6.8 of 10 in 2016, lower than the 7.3 EU average (40).

Between 2010 and 2012, 17.8 fatal falls per 100 000 older people were reported to the WHO Regional Office for Europe (49). This rate was among the lowest among countries providing data (49). The incidence of pressure ulcers within the National Network for Long-term Integrated Care was 5.1%, down from 7.3% in 2015 (50).

Waiting time for cataract surgery in 2017 was 122.7 days. Waiting times rates for an appointment with a specialist were 48.2 per 100 women and 43.2 per 100 men in 2015. Each of these indicators was higher than those of other EU countries (34). Waiting times for long-term care services provided as inpatient care in 2016 ranged from 39 in recovery units to 87 in rehabilitation units and 219 in long-term support units (50).

Breast cancer five-year age-standardized net survival between 2010 and 2014 was 87%, higher than the 83% EU average. Colon and rectal cancer five-year age-standardized net survival rates in the same period were 61% and 60%, respectively, both slightly higher than EU averages (40).

**Financial barriers to care are higher than in the rest of the EU**

Besides the barriers to dental care access presented above, further indicators illustrate financial barriers to care. The proportion of older people who reported unmet health care services for financial reasons was higher than the EU average (Table 6) (3).

Table 6. Self-reported unmet needs for specific health care services for financial reasons among people 65 years or older, 2014

<table>
<thead>
<tr>
<th>Type of care</th>
<th>Portugal (%)</th>
<th>EU 28 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical care, women</td>
<td>13.2</td>
<td>6.1</td>
</tr>
<tr>
<td>Medical care, men</td>
<td>8.0</td>
<td>4.7</td>
</tr>
<tr>
<td>Dental care, women</td>
<td>41.1</td>
<td>10.1</td>
</tr>
<tr>
<td>Dental care, men</td>
<td>28.1</td>
<td>8.3</td>
</tr>
<tr>
<td>Mental health care, women</td>
<td>34.7</td>
<td>2.0</td>
</tr>
<tr>
<td>Mental health care, men</td>
<td>22.5</td>
<td>1.2</td>
</tr>
<tr>
<td>Prescribed medicines, women</td>
<td>11.6</td>
<td>5.6</td>
</tr>
<tr>
<td>Prescribed medicines, men</td>
<td>7.3</td>
<td>4.5</td>
</tr>
</tbody>
</table>

Source: Population statistics at regional level (3).
**Highlights**

Coverage of long-term services is low. The system fares well in several performance outcomes, including amenable mortality, hospital length of stay and rates of day surgery. Population-level screening and cancer survival are also above the EU averages. Patient-reported outcomes need to be measured to assess satisfaction with long-term services. There are some data on health outcomes disaggregated by sex, but information on long-term care utilization, satisfaction with care and waiting times for women and men is lacking.
Delivery of services

About this section
An important requirement to assess the integrated delivery of long-term care is understanding the services available to older people, the organization of providers and settings, the needs assessment process and the care pathways. Obtaining this information exclusively via desk research may not provide the entire picture. In this section, data obtained from the published literature were complemented with information from semistructured interviews and discussion with key informants, including government representatives, managers, health practitioners and unpaid caregivers.

Health services available to older people are comprehensive

The basic health benefits package is defined yearly between the National Health Insurance Fund and the Ministry of Health and subsequently approved by the government (7). Coverage includes health services, medications and medical devices (26). Specific coverage is explained below.

Vaccination. Vaccination is free to all National Health Service users. For beneficiaries at risk and those 65 years or older, influenza vaccination is free of user charges and no prescription is needed (39). In 2014, the proportions of older people vaccinated against seasonal influenza were 48% for men and 46% for women. Both numbers are slightly higher than the EU averages for the same year but below the WHO recommended 75% coverage rate (Table 7) (37).

Dental care. The National Health Service does not cover dental care. Most dental care services are provided for pay in the private sector. Starting in 2008, school-aged children, pregnant women, older people receiving social benefits and other high-risk populations have access to dental care free of user charges via direct reimbursement of dental care expenses (7).

Diagnostic services. Diagnostic services are accessible via arrangements with the private sector: Laboratory tests, imaging and other diagnostic services are commonly conducted in the private sector (for-profit and not-for-profit entities) under contractual arrangements with the National Health Service (26).

Population-level screening. Breast cancer screening levels are higher than the EU averages (Table 7). Screening for colon and rectal cancer is significantly lower but still higher than the EU average (37).
Physiotherapy and renal dialysis. These services are generally provided by private institutions but subsidized via public funding.

Mental health care. Mental health ambulatory services are mainly provided in primary care, and inpatient and emergency care is provided in the hospital setting. The National Health Service, in conjunction with the social security and employment departments, provide rehabilitation services, while psychiatric hospitals provide residential care for those with no family or facing homelessness.

Medications. Outpatient prescription medications are subject to variable co-payments depending on the product’s therapeutic value. There is a mandatory electronic prescription system for medications covered by the National Health Service.

Medical devices. The public sector covers 47% of expenses for medical goods and devices, the rest generally being paid out of pocket. As of 2016, there were 8 magnetic resonance imaging scanners and 21 computed tomography devices per million population, both below the respective averages of 17 and 22 for the rest of the EU. The numbers of magnetic resonance imaging examinations and computed tomography examinations were 39 and 179 per 1000 population, respectively, versus 76 and 122 in the rest of the EU.

Rehabilitation. The National Network for Long-term Integrated Care covers rehabilitation care in units depending on the required length of stay. Rehabilitation coverage includes daily health care, physiotherapy and occupational therapy, prescription and administration of medications, psychosocial support, hygiene, nutrition and leisure activities.

Palliative care. Palliative care is provided under a specific national programme established by the Ministry of Health in 2017. The system aims to provide a wide range of service options both in hospitals and at home.

Table 7. Screening and vaccination rates among older people, 2014

<table>
<thead>
<tr>
<th>Measure</th>
<th>Portugal (%)</th>
<th>EU 28 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women 50–69 years old reporting a mammography in the past two years</td>
<td>84.2</td>
<td>68.7</td>
</tr>
<tr>
<td>People 50–74 years old reporting colorectal cancer screening in the past two years</td>
<td>36.2</td>
<td>31.3</td>
</tr>
<tr>
<td>Women</td>
<td>36.2</td>
<td>31.4</td>
</tr>
<tr>
<td>Men</td>
<td>3.5</td>
<td>31.3</td>
</tr>
<tr>
<td>People 65 years or older reporting influenza vaccination in the past 12 months</td>
<td>47.0</td>
<td>45.9</td>
</tr>
<tr>
<td>Women</td>
<td>46.0</td>
<td>44.5</td>
</tr>
<tr>
<td>Men</td>
<td>48.4</td>
<td>47.7</td>
</tr>
</tbody>
</table>

Source: European core health indicators.
Social services are provided under two separate structures

Social services are provided both under the National Network for Long-term Integrated Care and the Network of Social Services. However, no protocol for joint provision is in place. Social services provided by the National Network for Long-term Integrated Care are delivered at inpatient settings and at home through independent charitable organizations such as the *misericórdias*. These services include personal hygiene, nutrition, laundry services and accompanying people to health care visits (26). Services provided by the Network of Social Services include personal hygiene, nutrition, laundry services, home repairs, tele-assistance and accompanying people to health care visits and legal appointments (51). The Network of Social Services provides a dependence allowance in cash to pensioners based on health assessment. Its value, calculated as a percentage of the value of the social pension, varies according to the pension scheme and the severity of the dependence: moderate or severe.

The Network of Social Services home-help services exceeded 100,000 users in 2014 but still reach less than 5% of people 65 years and older. This is significantly below the rates in northern European countries, where coverage rates consistently exceed 15% (52). Day social centres have grown by more than 25% in the past 10 years, reaching more than 65,000 places in 2015, but the occupancy rate declined to 65% in 2015 (51).

Care for older people provided at residential homes, home-help services and day social centres are the main services available for older people, accounting for more than 60% of new instances of services provided by the Network of Social Services in 2017. Although service provision has grown steadily during the past decade, the coverage was 12.7% in 2017 (51).

Services available to unpaid caregivers are insufficient

Unpaid caregivers are not entitled to cash benefits or any other financial incentives besides 15 days of unpaid leave from work annually. A dependence allowance paid in cash is assigned to older people who have been assessed as being bedridden or dependent on the help of others and can be used to compensate unpaid caregivers. Other available resources include respite care provided via the long-term support units and training and counselling services (53). Support outside the public sector is limited to the network of unpaid caregivers of Portugal (Cuidadores Portugal), a non-profit organization embedded within the European network of unpaid caregivers called Eurocarers. This network fosters the development of new technologies with the support of municipalities, universities and research centres with the objective of facilitating social inclusion and meeting the needs of unpaid caregivers (26).

Beneficiaries feel engaged in health care decisions, but there are data on very few outcomes

As of 2015, the proportions of older people who reported having been involved in decisions about care or treatment by any doctor were 90.8% for men and 91.1% for women. Likewise, the proportions of older people who reported having spent enough time with any doctor during consultation were 91.1% for men and 88.2% for women (34). Patient choice is limited to the selection of services among those
available in a given geographical area. Referrals to other geographical areas or to the private sector are possible if the maximum allowed waiting time has been reached (26).

Care mix design: health and social services are not fully integrated

Entitlements for health and social services are assessed separately
Access to the National Network for Long-term Integrated Care is granted following a referral either from a multidisciplinary discharge management team after an acute episode or from a general practitioner. The referring party ascertains an individual’s needs and makes recommendations for the type of services, duration, intensity and setting. Subsequently, the local coordination teams, comprising health providers, social workers and representatives of the Ministry of Labour, Solidarity and Social Security, review and confirm referrals (19). Since there is no needs assessment linked to a “right to care”, referral is thus reactive (following an acute episode and/or sudden deterioration in health) and not proactive in anticipating and addressing needs, including those of informal caregivers, for which there is no separate assessment of needs.

The assessment performed by the National Network for Long-term Integrated Care is based on the National Functional Table, which has the WHO International Classification of Functioning, Disability and Health as its reference. Eligibility is determined based on care needs and dependence, regardless of the person’s age, in accordance with Law No. 101/2006. A criterion for accessing nursing care at home from the National Network for Long-term Integrated Care is whether users are “able to be cared for at home”. Although there is no explicit rule linking this to the presence of informal caregivers, this criterion benefits mostly older women living alone, experiencing housing deprivation or with greater care needs.

For the Network of Social Services, needs assessment is applied on discretionary basis without an standardized tool. Instead, dependence is ascertained using the Bio-psychosocial Assessment instrument (54). Older people or their relatives can directly request access to the Network of Social Services. It is, nevertheless, regulated by the availability of service providers, patronage and ability to pay out-of-pocket contributions (19).

Means testing: existing financial benefits are limited in amount and coverage
The main cash for care benefit is the dependence allowance, which is given to pensioners based on health assessment. Its value varies according to the pension scheme and the severity of the dependence and is calculated as a percentage of the value of the social pension (the minimum means-tested pension granted under the non-contributory scheme) (Table 8).
Since 2013, the dependence allowance is subject to a means test (the total pension income of the beneficiary cannot exceed €600 monthly) for moderate need. This has reduced the number of beneficiaries, from 231,285 in 2012 to 213,909 in 2016, despite the constant increase in the number of older people experiencing some form of dependence.

Integration of care is on the right track, but further measures are needed

The establishment of the National Network for Long-term Integrated Care is an important measure to integrate the delivery of long-term care services. The National Network for Long-term Integrated Care mix of providers is an asset and, potentially, a driver for integration. The large non-profit sector, well established as the primary provider of care, has an especially long history of seeking integration among stakeholders active in the sector.

At the local level, there appears to be a fair degree of collaboration and coordination, spurred by the initiatives of personnel in the local and regional coordination teams, social security centres, municipalities and providers. These informal links have the potential to achieve seamless transitions and satisfaction among users despite the absence of pathways between the National Network for Long-term Integrated Care and the Network of Social Services. These arrangements, however, are not systematic or fully recognized at the national level.

Other efforts for integrating health and social services in Portugal have followed these structural changes, though with a more limited scope and reach (24). Following the model of partnership between the Ministry of Health and Ministry of Labour, Solidarity and Social Security underpinning the National Network for Long-term Integrated Care, efforts have been made to build on the mandate of the National Network for Long-term Integrated Care. For example, the Action Plan for the Restructuring and Development of Mental Health Systems and the Long-term Integrated Mental Care Structure, rolled out in 2007 and 2010 respectively, aimed to create multidisciplinary structures for integrated long-term mental health care. In addition, an initiative for creating a joint system of supportive technical aids and funding was rolled out in 2009 (24).

To date, there is limited if any standard harmonization between the National Network for Long-term Integrated Care and the Network of Social Services in needs assessment and referral procedures. Since users often transition between the two networks, lack of coordination in managing user pathways is an important source of inefficiency.

### Table 8. Dependence cash allowance: monthly amounts

<table>
<thead>
<tr>
<th>Budgetary source</th>
<th>Moderate 2015</th>
<th>Moderate 2018</th>
<th>Severe 2015</th>
<th>Severe 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>General contributory scheme (euros)</td>
<td>100.77</td>
<td>103.51</td>
<td>39.6</td>
<td>2017</td>
</tr>
<tr>
<td>Non-contributory pension schemes (social assistance) (euros)</td>
<td>90.69</td>
<td>93.15</td>
<td>171.30</td>
<td>175.96</td>
</tr>
</tbody>
</table>

Source: Rede Nacional de Cuidados Continuados Integrados (RNCCI) (22). These amounts are doubled in July and December, similar to the rule for pensions and wages in most sectors.
Disease management: clinical guidelines are available, but adherence remains an issue

Clinical guidelines are mandatory and widely implemented. They are developed under the joint responsibility of the Ministry of Health and the Portuguese Medical Association, which encompasses all medical specialties. In general, clinical guideline compliance is higher in the hospital setting (58%) than in primary health care (32%) (25). There are also recommendations on procedures, and both the National Network for Long-term Integrated Care and the Network of Social Services have developed manuals to promote the standardization of practices in individualized care planning and medicine management (55). Clinical guidelines have also been adopted to promote sensible drug prescription (7).

No clinical guidelines are organized around pathways or conditions. There are, however, recommendations on procedures, and both the Network of Social Services and the National Network for Long-term Integrated Care have developed manuals that aim to standardize some practices in individualized care planning, medicine management, pressure ulcers, etc. (55).

Increasing adherence to clinical guidelines could be an opportunity for ensuring that care is up to date with the latest available evidence. Guideline development must adhere to internationally accepted standards – the AGREE II tool to assess the quality and reporting of clinical guidelines and the RIGHT statement – and overcome shortcomings in the inclusion of patient values and preferences (56).

Pathways: case management and transition coordination are provided up to the entitlement phase

The care provider who first interacts with the user and refers the case to the National Network for Long-term Integrated Care is responsible for carrying out the needs assessment. Often entry into the Network follows an acute episode. In this case, hospital-based care practitioners and multidisciplinary discharge management teams based in hospitals carry out the needs assessment.

Upon referral, the discharge management teams, the general practitioner or the primary health care centres make a recommendation for the care services needed, their duration and intensity and the setting in which care is to be provided. The referral and recommended care plan are then evaluated and must be confirmed by a local coordination team. Local coordination teams are set up as a multidisciplinary group, including doctors, nurses, social workers and representatives of the Ministry of Labour, Solidarity and Social Security. They are responsible for reviewing and confirming all referrals to the National Network for Long-term Integrated Care within their catchment area. The decision process is based on the users’ medical or hospital release file based on the WHO International Classification of Functioning, Disability and Health, on the detailed information included in the referral form to the National Network for Long-term Integrated Care and, when necessary, on additional information obtained by the local coordination teams directly from the user and the family and/or care practitioners involved with the specific case under assessment.

Once the local coordination team has confirmed referral, users are provided with information about potential providers and are allowed to choose three preferred providers, subject to availability. Subsequently, the case file and the proposed types of care are passed on to the regional coordination team. At this level, the proposed
types of care (National Network for Long-term Integrated Care response) are re-evaluated and, if confirmed, the user can be admitted to the National Network for Long-term Integrated Care. The regional coordinating teams also control the places available for care and ultimately decide on user admission. Referral to respite care follows a similar procedure.

**Organization of providers for long-term care follows a public-private care mix**

Long-term care in Portugal follows a model of public-private care mix with a limited role of the state in directly providing services. The government ensures public subsidies to non-profit and for-profit providers that jointly account for most of the long-term care delivery capacity (19). Primary health care is the cornerstone of the health system, provided by family health units and mobile units that reach out to isolated communities. Residents are required to register with a general practitioner, but 7.7% of the population do not have a general practitioner assigned (7). Primary health care providers act as gatekeepers, referring beneficiaries to specialist care. A prescription issued in primary health care is mandatory for medications covered by the National Health Service (7).

**Long-term care providers are organized under two main structures**

Long-term care services in Portugal are provided by the National Network for Long-term Integrated Care and the Network of Social Services (Fig. 4).

**Fig. 4. Organizational overview of actors involved in long-term care**

The oval shapes denote governing or coordinating entities. Rectangular shapes denote types of services or settings of service delivery. A dashed border denotes services not yet implemented. Arrows depict the alignment and hierarchy of accountability arrangements in terms of the assignment of mandate but do not capture the details of resourcing, reporting and feedback.

Source: adapted from Lopes et al. (21); Carta social: Rede de serviços e equipamentos 2017 [Carta social: services and equipment network – 2017 report] (51).
In 2006, the National Network for Long-term Integrated Care was jointly established by the Ministry of Health and the Ministry of Labour, Solidarity and Social Security to “provide adequate care, health and social support to all people who, regardless of age, are in a situation of dependence”. There was a special emphasis on integrating care, including convalescence care, recovery and reintegration of chronically ill people. The National Network for Long-term Integrated Care provides inpatient and community-based care. Inpatient care, intended for beneficiaries requiring care that cannot be provided at home, is delivered through: (1) recovery units, (2) rehabilitation units, and (3) long-term support units. The specific unit to be accessed is determined according to a length of stay of (1) up to 30 days, (2) 90 days or (3) more than 90 days. Long-term support units also provide respite care.

Until 2015, the National Network for Long-term Integrated Care provided late stage and end-of-life care to beneficiaries with terminal illness through palliative care units, now part of the national network of palliative care.

The community-based care under the National Network for Long-term Integrated Care is intended for individuals with temporary or prolonged loss of functionality who are frail, have limited mobility or severe functional limitations or suffer from severe, advanced or terminal disease but can be safely treated at home. Community-based care is organized as nursing care at home and as day care services. The former has not yet been implemented. Nursing care at home is provided by integrated care teams: a multidisciplinary team comprising physicians, nurses, therapists and social workers. Services target individuals who require health care at least once a day or at least three days a week for a duration longer than 1.5 hours each time, who have potential for rehabilitation or whose unpaid caregivers need support or training for providing care at home. Once implemented, day care services will provide care for those who can remain living at home but who cannot get the required health and social services there.

The Network of Social Services provides social services to vulnerable groups facing poverty, social exclusion or difficulties combining work and family life. Created several decades before the National Network for Long-term Integrated Care, the Network of Social Services focuses on addressing needs related to difficulties with instrumental and general activities of daily living. Services from the Network of Social Services are delivered through: (1) residential homes, (2) day social centres, (3) night social centres, (4) home-help services, (5) family accommodation and (6) assisted facilities. The former services are exceedingly rare, reflecting an underinvestment in more innovative care arrangements. Private investments in developing sheltered accommodation and assisted living facilities targeting older dependent individuals from high-income groups are also rare and have generally been met with resistance from older users. In addition, investment is needed in assisting devices for self-management and self-care, since the use of tele-assistance and telemedicine is extremely limited.

Provider capacity – inpatient and residential care has grown steadily during the last decade

Residential care provision capacity and coverage rates are below the European average. There is nevertheless a sustained pace of growth over the past 15 years, despite the economic downturn (52) (Fig. 5). Residential care capacity has grown within the National Network for Long-term Integrated Care from 1808 beds in 2007 to 8840 in 2015, the equivalent of a 364% increase over 9 years. Of the
total number of beds in the Network, 75.5% are located in institutions operated by non-profit providers, 20.5% are located in privately run institutions (for profit) and 3.8% are operated by public care providers.

Fig. 5. Number of residential care beds within the National Network for Long-term Integrated Care, 2007–2015

The considerable expansion of the National Network for Long-term Integrated Care can mostly be traced back to the rapid development of medium-stay (adding more than 1600 beds between 2007 and 2016) and long-stay units (adding more than 3700 beds) (Table 9). In comparison, the number of beds in convalescence units increased more slowly. Despite this increase in capacity, occupancy rates are high and waiting times are long. Demand for long-term stay beds far exceeds the available supply throughout the country, but the shortages are especially acute in larger urban areas (such as Lisbon). Since long-stay beds are also used to provide respite for overburdened family members and unpaid caregivers, it becomes apparent that the same capacity limitations that affect users who need long-term residential care also limit (or delay) access to respite care.


<table>
<thead>
<tr>
<th>Number of beds, individuals treated</th>
<th>2007</th>
<th>2011</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of beds</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Convalescence units</td>
<td>423</td>
<td>906</td>
<td>764</td>
</tr>
<tr>
<td>Medium-stay and rehabilitation units</td>
<td>646</td>
<td>1747</td>
<td>2306</td>
</tr>
<tr>
<td>Long-stay and maintenance units</td>
<td>684</td>
<td>2752</td>
<td>4411</td>
</tr>
<tr>
<td>Palliative care units</td>
<td>55</td>
<td>190</td>
<td>278</td>
</tr>
<tr>
<td><strong>Total National Network for Long-term Integrated Care</strong></td>
<td>1808</td>
<td>5595</td>
<td>7759</td>
</tr>
<tr>
<td><strong>Number of individuals treated</strong></td>
<td>5934</td>
<td>41852</td>
<td>46528</td>
</tr>
</tbody>
</table>

Between 2000 and 2014, residential care capacity in the Network of Social Services has increased by more than 60%, from 55,000 to almost 90,000 places (Table 10). The pace of growth has progressively increased over the same period, reaching a 26% increase in the number of available places between 2010 and 2014. The considerable increase in capacity has led to small but sustained reductions in the occupancy rate, from 97% in 2005 to 91.5% in 2014. Despite these significant gains, coverage rates for people 65 years or older have increased only modestly, from more than 3% in 2000 to 4.2% in 2014 (8.3% to 9.0% if only people 75 years or older are considered).

Table 10. Residential care capacity in the Network of Social Services, 2000–2014

<table>
<thead>
<tr>
<th>Measure</th>
<th>2000</th>
<th>2005</th>
<th>2010</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of places</td>
<td>55,523</td>
<td>60,884</td>
<td>71,261</td>
<td>89,666</td>
</tr>
<tr>
<td>Occupancy rate (%)</td>
<td>95.3</td>
<td>97.2</td>
<td>95.3</td>
<td>91.5</td>
</tr>
<tr>
<td>Capacity increase in previous five years (%)</td>
<td>–</td>
<td>9.0</td>
<td>17.0</td>
<td>25.8</td>
</tr>
</tbody>
</table>

Source: Carta social: Rede de serviços e equipamentos 2017 [Carta social: services and equipment network – 2017 report] (51), adapted from Lopes (19).

Services provision within the Network of Social Services relies mostly on non-profit entities, which is reflected in the rapid development of the sector from about 1500 providers in the 1980s to more than 5000 by 2015 (19). For the same year, the social solidarity private institutions list of entities operating in social security accounted for 27% of the total versus more than 60% for non-profit entities (51). Their unequal territorial distribution (Fig. 6) largely reflects the vast geographical inequalities in population size and structure but also in the degree of urbanism and economic development.

Fig. 6. Coverage rate of long-term care services within the Network of Social Services, by municipality

In addition to the highly variable provider mix between geographical regions and localities, the quantity and type of care provided are vary considerably. The areas most affected by insufficient capacity for long-term care services are those surrounding the large metropolitan areas of Lisbon and Porto and the southern region of Algarve (coverage rates lower than 13% for people 65 years or older). Conversely, in Portugal’s interior, where the population is significantly older than in coastal regions, most municipalities enjoy coverage rates of long-term care services from the Network of Social Services exceeding 20% (35).
Capacity – home-based care can either be support in daily activities or home nursing care

Home-based care is provided primarily under the Network of Social Services in the form of home-help services. These services are limited to support with daily activities and do not include health care support. Although semi-qualified or non-qualified workers generally provide home-help services, they can support older individuals to continue living in their communities longer and can at times compensate for the absence of an informal caregiver.

As demand for home-based support has steadily increased in recent decades, so has service capacity. The number of registered home-help providers increased from 1667 in 2000 to 2707 by 2015 (51). Decreasing utilization rates (from 93.7% in 2000 to 73.9% in 2014) might indicate that the progress of supply does not closely reflect changes in the structure of demand, and might lead to mismatches between the two, limiting user choice and the uptake of services by older individuals (19).

Home-based care offered by National Network for Long-term Integrated Care multidisciplinary home-care teams is better described as home nursing care. These services emphasize medical and nursing care components, in addition to rehabilitation, psychological support and help with activities of daily living. Since the Network was created, home nursing care capacity has increased considerably (Table 11). Capacity has declined during the past decade because of readjustments resulting from what was perceived as overestimated capacity by some home care teams.

Table 11. Trends in home nursing care capacity within the National Network for Long-term Integrated Care, 2008–2016

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of teams</td>
<td>72</td>
<td>96</td>
<td>214</td>
<td>253</td>
<td>243</td>
<td>267</td>
<td>274</td>
<td>286</td>
<td>279</td>
</tr>
<tr>
<td>Number of places</td>
<td>1660</td>
<td>5050</td>
<td>8063</td>
<td>7332</td>
<td>7183</td>
<td>7053</td>
<td>6766</td>
<td>6585</td>
<td>6264</td>
</tr>
</tbody>
</table>

Source: Lopes et al. (21).

The geographical distribution of home nursing capacity also indicates the regional disparities that characterize Portugal’s long-term care system in terms of both supply and demand for care. The regions with the highest capacity are in Lisbon (2015 places) and the North region (1623 places). At the other extreme, 564 treatment places are available in Alentejo. The average workload for a home-care team varies between regions, from 35 treatment places per team in Lisbon to 13 in the Centre region and 15 in Alentejo. The workload of home-care teams can indicate the stringency of capacity limitations, but it also reflects the characteristic challenges of home care work in each region. For instance, the average travel distance between home care users in the densely populated region of Lisbon represents only a fraction of the distances that home-care teams must cover in areas with low population density (such as the Centre region and Alentejo). As transport time increases, it limits the ability of home-care teams to visit more users in a working day. Occupancy rates for home-based nursing care are highest in Alentejo (70% in 2016) and lowest in the Centre region (52% in 2016), while the other regions vary within a small margin between 66% and 69% (50).
In 2016, the coverage rate of home nursing care treatment places provided under the National Network for Long-term Integrated Care was 3.2 per 1000 people 65 years and older, varying between 2.2 in the Centre region and 12.3 in Algarve (50). This accounts for only a marginal part of the home-based care provided within the Network of Social Services (about 5% of the number of available places nationwide). The current capacity falls short of that envisioned at the creation of the National Network for Long-term Integrated Care, with 279 home-care teams versus the forecast 363 teams (21).

**Capacity – community-based care: occupancy rates are falling**

Community-based care solutions for long-term care are significantly less developed than residential and home-based care provision, but they have a long tradition within the Network of Social Services in the form of day care social centres. About 2000 profit and non-profit day care services providers were operating in 2015 (51). Capacity in day-care centres has also increased over the same period, although more slowly than residential care and home-based care services. Capacity is increasing, but it is unclear whether the provision of day care in community-based centres is responding to existing care demand or to users’ preferences. Occupancy rates for day-care centres have traditionally fallen below those of nursing homes and even community-based care. Day-care centre occupancy rates have declined from 80.5% in 2000 to 70% in 2005 and 65% in 2015 (51). It is unclear whether this trend is linked to the quality of care provided, operational difficulties or the co-payments that users must pay out of pocket.

**Data capture and information exchange structures are state of the art**

Portugal’s health system relies on several information technology platforms for registering, collecting and analysing care processes. The most prominent and specialized one is the GestCare CCI online data management system, which enables timely information sharing between providers within the National Network for Long-term Integrated Care. The GestCare CCI platform supports detailed recording of the National Network for Long-term Integrated Care users’ characteristics, health status and care needs in a complex modular structure. This structure includes information relevant to social characteristics, such as social and financial situation, family and household characteristics as well as health care support, such as medical history, specific assessment of cognitive, functional and palliative health status and identification of main health risks.

In addition, the health data platform houses electronic medical records and unique patient identifiers. This platform processes electronic patient record data on health-related information, prescriptions and appointments and data related to long-term care. The health data platform has portals for beneficiaries, health care providers and agencies providing services (26).

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**Key points**

- The information technology structure is state of the art. The GestCare CCI platform within the National Network for Long-term Integrated Care and the electronic medical records are key system enablers.
- There is no corresponding information technology infrastructure within the Network of Social Services.
Electronic medical records were introduced in 2012. Coverage in primary and secondary facilities exceeds 75% and is lower than 25% in tertiary facilities (58). Laboratory and pharmacy information systems are also available (58).

**An around-the-clock call centre provides guidance to patients**

There is no established policy on out-of-hours care. The Saúde 24 call centre provides urgent and non-urgent guidance and counselling, health promotion and disease prevention (7, 25).

**Managing delivery of long-term care**

The Ministry of Health and the Ministry of Labour, Solidarity and Social Security are mainly responsible for managing long-term care delivery. Other stakeholders, such as municipalities and non-profit providers (such as the misericórdias and other charitable organizations linked to the Catholic Church), also play an important role.

The National Network for Long-term Integrated Care is managed at the local level by the local coordination teams, which report to the regional coordination teams, in turn under the regional health administrations. Besides confirming the referrals of users to National Network for Long-term Integrated Care services, the local coordination teams also coordinate service delivery within a given geographical area. Local coordination teams link with municipalities to address some needs (such as home reforms) and to report on existing supply and shifting demand to regional coordination teams. The regional coordination teams oversee larger geographical areas –corresponding to one or several districts– and have a greater say in accrediting providers and quality inspection and liaising with municipalities, district social security branches and the regional health administrations to lobby for services if demand increases. Management of service delivery by the National Network for Long-term Integrated Care has therefore several elements of a bottom-up management structure, especially for assessing needs in a given geographical area.

Delivery of services in the Network of Social Services is managed by the Institute of Social Security through its district centres and through the public misericórdia of Lisbon (Santa Casa da Misericórdia de Lisboa), which is the main provider in the City of Lisbon. Apart from the misericórdia of Lisbon, direct public provision is limited. Despite contracting service provision with providers (usually non-profit), the Institute of Social Security has limited ability to influence the referral of users to providers of the Network of Social Services, since need is not assessed and there is a single entry-point (see the previous section on pathways and referrals). The exception to this is the 10% of capacity that each subsidized provider must use at the discretion of the Institute of Social Security, generally for urgent cases or more deprived users. The Institute of Social Security seeks to ensure that access criteria are clearly defined and benefit those with greater financial need.

Municipalities may lobby for the provision of services but in practice have very limited means to affect the provision of care directly. However, the role of municipalities in signalling users to the Network of Social Services and in carrying
out adaptations in older people’s homes should not be underestimated. Much of the actual coordination of care taking place in delivering long-term care happens through informal contacts, working relations and agreement on procedures involving municipalities, providers, local coordination teams and other local social security organizations (such as local social assistance offices). The underlying character of these collaborations is very informal.

Private providers (both for-profit and non-profit) may increase their capacity if they receive ministerial authorization. The National Network for Long-term Integrated Care does not manage privately provided care (care paid entirely out of pocket by users); it is licensed by a different body within the Ministry of Health. Providers must ensure that existing capacity contracted to the National Network for Long-term Integrated Care and common areas and services (such as laundry) are not affected by expanding capacity (such as by reducing the personnel allocated to the National Network for Long-term Integrated Care within a given unit). Misericórdias and non-profit providers have also developed pilot initiatives of new forms of care aimed at filling gaps in care provision in specific areas or target groups (such as training informal caregivers).

Quality standards and quality assurance differ between the two structures providing long-term care services

Performance monitoring and quality assurance again differs very much between the National Network for Long-term Integrated Care and the Network of Social Services. The former has a well-established system of compulsory quality reporting at the provider level, emphasizing clinical outcomes. Quality reporting is linked to the referral and data gathering system of the National Network for Long-term Integrated Care (the GestCare), which collects information on all the users that are referred to the Network and enables follow-up across providers. Regional coordination teams carry out regular inspections with providers and collect information on user satisfaction (55). Regional coordination teams monitor the licensing process based on established minimum standards for providers, including staff ratios for residential facilities. Although detailed information on outcomes is published regularly for the National Network for Long-term Integrated Care, no public information on quality indicators at the provider level is available to users.

Regional coordination teams carry out licensing for the Network of Social Services. Providers receiving public funding to deliver services in the Network of Social Services must comply with a set of regulations regarding their operation (such as operating hours) and satisfy minimum standards established by the Ministry of Labour, Solidarity and Social Security. Since 2007 (Decree-Law No. 64/2007), these minimum standards have been an essential condition for awarding public funding and comprise three levels of quality: minimum, voluntary and good practices.

The system of licensing and regulation is still relatively recent. Some assessments of Portugal’s long-term care system have questioned its effectiveness in improving quality. There is concern regarding the limited scope for user choice and the dominant position of the non-profit sector (19).
Highlights

Services available to older people are comprehensive, but out-of-pocket expenditure is a barrier for comprehensive coverage of some services. Long-term care services are provided under two independent structures. This arrangement and the lack of common entitlements and patient pathways hamper integration of care. Capacity has grown but, in some instances, is still insufficient to meet demand. Quality standards and quality assurance activities are not harmonized throughout the long-term care system. Information on long-term care-related services utilization, including use of benefits available to unpaid caregivers and data related to clinical pathways, is not disaggregated by sex.
System enablers

About this section
Integrated services delivery is fostered by implementing measures that enhance governance, funding, adequate staffing and information technology platforms. This section describes these system enablers. The data was collected from published evidence, databases and from consultation with stakeholders.

Joint coordination for governing long-term care
The National Network for Long-term Integrated Care is governed by the National Coordination Commission, a joint coordinating body led by a representative of the Ministry of Health and composed of three representatives each from the Ministry of Health and the Ministry of Labour, Solidarity and Social Security, one of them being the national coordinator from the Ministry of Health. This coordination body is responsible for strategically developing and managing the full scope of activities concerning the National Network for Long-term Integrated Care, from defining quality criteria and technical requirements for each type of service to developing priorities for increasing the supply of services. Governance of the Network of Social Services falls entirely within the remits of the Ministry of Labour, Solidarity and Social Security.

Expenditure on long-term care is below the EU averages
Health expenditure in 2017 was €2066 per capita and 9.0% of GDP, both below EU averages (40). Public expenditure on health is 6.1% of GDP, and 12.6% of government spending is dedicated to health versus 8.0% and 15.0% in the EU, respectively (7). The public system is funded mostly via general taxation. Government sources accounted for 66.8% of total expenditure on health in 2015, the remaining corresponding to private insurance and out-of-pocket payments. Private voluntary health insurance uptake was 20.2% and 5.5% of total health expenditure, both also in 2015 (7). Out-of-pocket expenditure represented 27.7% of expenditure on health, higher than the EU average of 15.9% (7). Out-of-pocket payments are required for primary care and specialist consultations, hospital care, home care, emergency care and pharmaceuticals.

Inpatient care in 2015 accounted for 17.6% of expenditure versus 39.4% for outpatient and rehabilitative care. The 15.5% expenditure on pharmaceuticals was in accordance with the EU averages for 2015 (7). In 2016, €308 was spent on retail pharmaceuticals per capita versus €417 average for the EU. Of this, 45% was paid out of pocket, higher than the 34% EU average (40). Generics are strongly promoted, with policies aiming to make generics account for 60% of the National Health Service market.
Public expenditure on long-term care in 2016 was 0.5% of the total public expenditure, less than half of the EU average of 1.3% (59). Long-term care accounted for 3% of overall health expenditure, below the 13% EU average (40). Virtually 100% of expenditure was devoted to in-kind benefits, higher than the 84.4% EU average (7). Public expenditure on long-term care is funded through general taxation for the National Network for Long-term Integrated Care and the Network of Social Services. In addition, a percentage of the revenue from lottery games is also earmarked to the National Network for Long-term Integrated Care (26).

Provider payment mechanisms are mostly fee for services

General practitioners are paid based on capitation services calculated based on the population they serve and pay for performance (7). General practitioners also receive a performance-related bonus based on measures such as patient follow-up, cost-effective use of medicines and others. Physicians working in health centres and in hospitals are salaried; those working in outpatient private practices are paid fees for services (7). Nurses are salaried both in public and private settings (7).

The workforces differ substantially between the two structures providing long-term care services

The Ministry of Health regulates personnel supply through quotas for medical schools and medical specialties (7). With 365 physicians per 100 000 inhabitants in 2015, Portugal was one of the countries with the highest concentration of physicians licensed to practice, surpassed only by Austria and Greece (7). Portugal has 62 general practitioners per 100 000 population, lower than the EU average of 78 (7). The number of nursing professionals per 100 000 population in 2015 was 650, less than half the rates in Belgium, Germany, Ireland and Norway. This trend is likely to be reversed in the future, because the number of nurses in Portugal is increasing more rapidly than the number of physicians, especially because changes in perception relative to the roles and the definition of tasks for different care professions (26).

### Table 12. Selected system enablers: health expenditure and workforce

<table>
<thead>
<tr>
<th>Measure</th>
<th>Portugal</th>
<th>EU 28</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expenditure on health (euros per capita, adjusted for purchasing power)</td>
<td>2066</td>
<td>2773</td>
<td>2017</td>
</tr>
<tr>
<td>Expenditure on health (% of GDP)</td>
<td>9.0</td>
<td>9.6</td>
<td>2017</td>
</tr>
<tr>
<td>Expenditure on health as a proportion of total government expenditure (%)</td>
<td>12.6</td>
<td>15.0</td>
<td>2015</td>
</tr>
<tr>
<td>Out of pocket (% of total expenditure on health)</td>
<td>27.7</td>
<td>15.9</td>
<td>2014</td>
</tr>
<tr>
<td>Public expenditure on long-term care (% of GDP)</td>
<td>0.5</td>
<td>1.3</td>
<td>2016</td>
</tr>
<tr>
<td>Expenditure in long-term care as a proportion of total health expenditure (%)</td>
<td>3.0</td>
<td>13.0</td>
<td>2016</td>
</tr>
<tr>
<td>Number of physicians (per 100 000 people)</td>
<td>365</td>
<td>344</td>
<td>2015</td>
</tr>
<tr>
<td>Number of general practitioners (per 100 000 population)</td>
<td>62</td>
<td>78</td>
<td>2015</td>
</tr>
<tr>
<td>Number of nurses (per 100 000 people)</td>
<td>630</td>
<td>864</td>
<td>2014</td>
</tr>
</tbody>
</table>

Sources: *Health at a glance: Europe 2018: state of health in the EU cycle (40); Joint report on health care and long-term care systems & fiscal sustainability. Country documents – 2019 update (7); Sousa-Pinto et al. (48); Simões et al. (26).
Following the rapid development of the National Network for Long-term Integrated Care, the long-term care workforce in Portugal has continued to increase, with marked gains in the number of both home-based care and institution-based care practitioners since 2012. The more pronounced increase in the workforce (Table 13) in the inpatient setting largely reflects the nature of the National Network for Long-term Integrated Care, although in relative terms the changes in the home-based and inpatient sector are entirely comparable (both registering an increase of about 50% before 2012 and 2017). Despite this increase, Portugal compares unfavourably with most of the analysed countries, according to OECD health statistics for 2015. The density of nurses and personal caregivers active in the formal long-term care workforce is only 1.5 per 1000 people versus 8 per 1000 people in Spain, 10 per 1000 people in Germany and 24 per 1000 people in Sweden.

Table 13. Residential care capacity in the Network of Social Services, 2012–2017

<table>
<thead>
<tr>
<th>Year</th>
<th>Capacity at home</th>
<th></th>
<th>Capacity in institutions</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>Nurses</td>
<td>Personal caregivers</td>
<td>Total</td>
</tr>
<tr>
<td>2012</td>
<td>1949</td>
<td>895</td>
<td>1054</td>
<td>8923</td>
</tr>
<tr>
<td>2013</td>
<td>2134</td>
<td>937</td>
<td>1197</td>
<td>10298</td>
</tr>
<tr>
<td>2014</td>
<td>2314</td>
<td>992</td>
<td>1327</td>
<td>12362</td>
</tr>
<tr>
<td>2015</td>
<td>2942</td>
<td>1197</td>
<td>1745</td>
<td>13080</td>
</tr>
<tr>
<td>2016</td>
<td>3098</td>
<td>1390</td>
<td>1708</td>
<td>12671</td>
</tr>
<tr>
<td>2017</td>
<td>2952</td>
<td>1290</td>
<td>1662</td>
<td>13502</td>
</tr>
</tbody>
</table>

Sources: OECD statistics [online database] (34).

Nevertheless, it is important to highlight the dual workforce currently operating in Portugal’s long-term care system. The workforce in the National Network for Long-term Integrated Care includes highly qualified practitioners working in multidisciplinary environments and offered multiple training opportunities (Box 1). On the other hand, the Network of Social Services workforce primarily comprises care workers with few or no qualifications and whose opportunities for continuing professional improvement and training are very limited. The difference in background and skills between the practitioners in the National Network for Long-term Integrated Care and those who work in the Network of Social Services often renders collaboration difficult and limits opportunities for joint working and planning. To respond to this situation, local initiatives for joint training between the National Network for Long-term Integrated Care and Network of Social Services for teams providing home-based care are already taking shape.
Interoperability among information technology platforms remains a challenge

While the solid information technology infrastructure in place is conducive to efficiency and integration, linkage of individual records and interoperability among the different platforms remains a challenge. Plans to ensure the interoperability of data from the health and social sectors are currently being discussed and developed. Interoperability of platforms would facilitate the use of this data for conducting an array of research projects such as measuring and monitoring utilization trends, outcome-related performance and patient values and preferences.

GestCare is not the only data management platform currently operating in the care system. The Ministry of Health, through the central administration of the health system, has also established several information technology platforms intended to support registering, collecting and analysing care processes and the activities of health units. Further, the central administration of the health system also operates and manages the national database of hospital admission (26). Although the development of a strong information technology infrastructure is certainly conducive to efficiency and integration and has strengthened Portugal’s health and long-term care systems, its limits are now beginning to show. In building dedicated data management platforms for different parts of the health care and long-term care system, the country has in effect created parallel structures and is now facing the challenge of ensuring linkage of records and interoperability.

Currently, the GestCare platform is interoperable with the National Registry of Users, from which it can import data such as patient’s name, date of birth, fiscal number and address. Plans to ensure interoperability with other information systems currently operating in the health and social sectors are being discussed and developed. These refer primarily to improving interoperability and information exchange between GestCare and the information systems used in hospitals and primary health care and with the platform of Social Security Direct that is being
developed by Instituto de Informática I.P. in conjunction with Shared Services of the Ministry of Health. Although this is a complex and lengthy process, there is good reason to expect that the stated goal of linking the various information and technology platforms currently coexisting into a comprehensive and system-wide data management platform will be achieved in the near future.

**Highlights**

The current governance structure does not foster integration of care between the two structures providing long-term care services. Long-term care expenditure is low and does not reflect the needs of an increasingly older population. Efforts should be invested in promoting multidisciplinary work among personnel delivering services. The information technology structure is adequate, but interoperability among providers and platforms is needed.
Policy pointers

The following are suggestions to address needs, coordinate providers and align system components towards the integrated delivery of health and social care. A full discussion expanding on these suggestions and on the implications of their implementation for the long-term care system has been published elsewhere (23).

Increasing patient engagement and promoting healthy lifestyles

The Portuguese National Health Plan 2012–2020 (45) and the National Programme for Health Education, Literacy and Self-care (26) are two initiatives that have potential to foster patient engagement and the promotion of healthy lifestyles. These programmes should include activities for reducing alcohol consumption, increasing physical activity and informing people about vaccination, screening programmes and other preventive activities currently available.

Regarding addressing the needs of older people, the recently developed Rights of Older People Index can serve as guidance for ensuring access and affordability of care, legal protection of older people’s rights and social inclusion, among others (57). Measuring the implementation of these programmes and ensuring coverage of underserved geographical areas is of interest.

Addressing the specific care needs of women and unpaid caregivers

Women report worse health status than both men and other European women. These include shorter life expectancy in good self-perceived health, higher rates of physical and sensory disabilities, severe body pain and other limitations. Women also present higher rates of poverty and barriers to care for financial reasons and are disproportionately responsible for caring for older individuals as unpaid caregivers. The needs of women should be addressed from a system perspective, building on the primary care setting as a starting-point to identify needs and care options. In addition, it would be important to monitor long-term access, utilization and satisfaction of quality care among women and men to identify, for instance, potential biases in service provision.

The recent motion from the Council of Ministers approving measures to support unpaid caregivers is a step in the right direction for acknowledging the system’s reliance on family members for taking care of older people. It will be important that this motion results in efforts to facilitate training (upskilling), promote policies to reconcile employment and care, provide cash benefits or pension entitlements such as recognizing the time spent caring full time and consider co-residence when calculating income to access social assistance (8). The specific implications of this motion and the measures that will result should be discussed and agreed on with representatives from all stakeholders.
Organizing providers with a focus on primary health care
to address geographical inequalities

Procedures to ensure that all residents are registered with a general practitioner are crucial for strengthening primary care provision. Coverage needs to be expanded in underserved geographical areas, including not only the availability of physicians but also out-of-hours care and call centres. Strengthening primary care provision will facilitate interaction with beneficiaries and the implementation of health literacy and health promotion programmes. It will also prevent unnecessary hospitalizations and reduce waiting times.

Integrating services provided by the two main actors delivering long-term care

The National Network for Long-term Integrated Care and the Network of Social Services should decisively integrate the services they provide. Under the current dual system, the Network for Long-Term Integrated Care offers mostly public services provided by highly qualified practitioners. The Network of Social Services offers services based on the beneficiary ability to pay that are delivered by underqualified personnel. Provision of care is organized around the type of provider instead of service types or user needs. This type of organization goes against the principles of people-centred care and curbs the integration of care, resulting in disparities in access, coverage and quality of services.

The very strong information technology structure can serve as a starting-point to implement joint needs assessment, standard care pathways and other measures to pursue coordination and the integration of long-term services provision. The role of discharge managers and general practitioners as gatekeepers could be extended to the Network of Social Services, which has no standard procedure for referrals. Attention should be given to eliminating overlapping services, including care provided under the National Network for Long-term Integrated Care’s long-term support units and integrated care teams and the home-help services available via the Network of Social Services. The roles of community-based care provided at home and in the day care facilities that are to be introduced should be contrasted with the services available via home-help services and assisted facilities. This rearrangement is an opportunity for ensuring provision and capacity-building that is attuned to the growing demand for long-term care and that strives to keep older people at home to reduce high institutionalization rates.

These measures are in accordance with the recently developed ICOPE recommendations for achieving integrated health care and social care services for older people (60,61). The ICOPE recommendations include a scorecard that enables the level of implementation of integrated care for older people to be measured across services and systems. This scorecard can serve as a blueprint and guidance to design care pathways and strengthen governance (61).

Standardizing and refocusing quality assurance procedures towards outcomes

Integrating and rearranging the services currently provided under the National Network for Long-term Integrated Care and the Network of Social Services also provide an opportunity for designing and implementing minimum standards of quality across the spectrum of services, both for the health and the social services.
Service provision would benefit from integrating quality assurance processes and indicators across both networks with greater emphasis on outcomes and processes. Measures to improve quality management can be implemented at the system level, the organizational level, the health care professional level and the user level (62). These include strengthening the legal framework of services provision, measuring performance indicators and creating new roles to address the needs of beneficiaries related to long-term care.

Evidence-based clinical guidelines that are developed in accordance with internationally accepted quality standards could inform quality assurance benchmarks and standards (56). Further measures include strengthening the legal framework of services provision, audits and performance reviews, health impact or health assessments and performance evaluation of health practitioners (63) at the National Network for Long-term Integrated Care and the Network of Social Services level.

The National Network for Long-term Integrated Care currently collects data related to referrals, transitions, waiting times, user satisfaction and clinical indicators, which could be expanded to the Network of Social Services, where no such information is collected. Standards for facility licensing and regulation of services currently under the oversight of the local and regional coordination teams for the National Network for Long-term Integrated Care and by the Institute of Social Security for the Network of Social Services could be consolidated and subject to a similar set of standards across providers.

Management could be integrated by building on existing protocols at the local level. Local and regional coordination teams are responsible for the daily management of operations, certification and inspection of National Network for Long-term Integrated Care providers. These efforts could also be expanded to support management for social services carried out by the Institute of Social Security, non-profit providers and municipalities.

The proposed system overhaul will require coordination of governance mechanisms by public stewards and collaboration between ministries and their corresponding agendas (64). A starting-point would be assessing the impact of the National Coordinating Commission on the establishment, roll-out and overall strategic guidance of the National Network for Long-term Integrated Care.

**Harmonizing working conditions and ensuring continued professional development**

Collaboration between sectors and the establishment of multidisciplinary teams as required for the proposed integration of services will require harmonizing the working conditions and salaries of workers providing long-term care. Professionals providing social services report dissatisfaction because of low salaries, limited opportunities to progress professionally, high workload and levels of stress and job instability (8,21). Personnel in the National Network for Long-term Integrated Care have better working conditions and are eligible for continuing education programmes. Unless these disparities are addressed, joint working and planning will remain challenging. Besides increasing funding for salaries, feasible measures include ad hoc training sessions of varied length and intensity that promote the acquisition of new clinical skills, multidisciplinary collaboration and leadership and management enhancements (63).
Increasing funding and aligning the payment of providers

Current expenditure on health and especially on long-term care remains below EU averages (7,48). Additional efforts to increase the funding of long-term care without increasing out-of-pocket expenditure are required at the national level. This calls for collaboration in allocating budgets, setting priorities and expanding services among the Ministry of Health, the Ministry of Labour, Solidarity and Social Security and the Ministry of Finance. The former has a final say on many budgetary decisions, particularly as they relate to services with a high degree of public provision (7,21).

Under the current funding scheme, the system is in effect paying for services and not for outcomes, which may create gaps and unmet needs along the continuum of care. Further, the coexistence of universal and means-tested services is likely to hinder the efficient allocation of services and constitute a barrier to accessing services. Currently, the social component of care requires a contribution regulated by law when subsidies are involved, usually for non-profit providers, and depends on the person’s income, assets, dependence level and monthly expenditure. Measures of cost containment can include the implementation of fee-for-service and pay-for-performance schemes. Integration of care at the long-term care level and at the primary and hospital levels can result in much-needed cost compression (65).

Improving interoperability among the various information technology platforms

Several of the proposed measures to spur integration of care require the interoperability of the information technology infrastructure available in Portugal. This includes the GestCare CCI online data management system of the National Network for Long-term Integrated Care, the National Health Service’s electronic patient records and electronic medication prescribing and the individual electronic national health system card. These resources are undoubtedly one of the main strengths of the long-term care system. Ensuring interoperability will facilitate joint needs assessment, the creation of integrated entry points into the system and case management of multimorbid beneficiaries. These resources could also support management and quality assurance measures across settings.
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World Health Organization
Regional Office for Europe
UN City, Marmorvej 51, DK-2100 Copenhagen Ø, Denmark
Tel.: +45 45 33 70 00   Fax: +45 45 33 70 01
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Website: www.euro.who.int