Portugal

Observatory of Technology Assessment (OAT), Ana Paula Gil, FCSH Nova University of Lisbon
António Brandão Moniz, FCT Nova University of Lisbon, José de São José, University of Algarve
With the collaboration of CICS.NOVA collaborators: Bettina-Johanna Krings (KIT), Bárbara Bäckström (Open University)

Introduction

This report was produced by the Observatory of Technology Assessment (OAT) of the research centre CICS.NOVA at Nova University of Lisbon, from June to September 2019. The Observatory is an associate member of European Parliamentary Technology Assessment (EPTA) since 2018. The EPTA partners advise parliaments on the possible social, economic and environmental impact of new sciences and technologies. That is also the case for OAT in Portugal. In this summary of the national report, we first present some facts and figures about Portuguese demography and its relation to the institutional organisation of long-term care system. Second, the following chapters provides the "Implications for elderly, staff and working places" with regard to information technologies (IT) applied in the care work, or as mentioned in this report, to "welfare technologies". There we analyse the digital effects on organisation of work in long-term care system, the education problems and further training of care staff.

The final chapters are about the challenges and risks of the use of technology in care work (covering the topics of integrity, ethical and economical challenges and risks), the societal debates, regulations and best practices, and, finally, the future perspectives and reflections. The fragilities of the social and economic structures in Portugal affect the labour market in this sector of health services, as well the innovation capacities and the organisational settings that need a strong modernisation process considering integration of family care structures and institutional ones. The report was developed within a very short timeframe, and it was not possible to include all the aspects that the topic deserves, namely a more complete literature review and a complete data collection and further analysis. This should be taken into consideration. Thus, the report is a first attempt to collect information on care work and the use of ICT in the sector, which needs a systematic and further research work.

Elderly population

Facts and Figures

The current population of Portugal is 10,219,798 and the population density in Portugal is 112 per Km^2 (289 people per mi^2), corresponding the total land area of 91,590 Km^2 (35,363 sq. miles). The majority of the Portuguese population (65.9 %) is urban (6,743,854 people in 2019) and the median age is 44.3 years (United Nations Population Division, 2019).

Changes in the composition by age groups of the resident population in Portugal reveal the ageing of the population in recent years, as has indeed been the case in most developed countries. As a result of the falling birth rate and increased longevity in recent years, in Portugal there has been a fall in the young population (0 to 14) and the working age population (15 to 64), alongside an increase in the elderly population (65 and older). In 2015, 2.1 million people, almost 20% of the Portuguese population, were 65 and older. The proportion of elderly people in the population has been growing and this trend is expected to continue. According to national projections, in 2030, the elderly is expected to represent approximately 26% of the population, increasing to 29% in 2060. The number of people aged over 80 will more than double between 2015 and 2060 and is expected to rise from 614 000 to 1 421 000 people.

The number of elderly people has long exceeded the number of young people in Portugal, and the ageing index [1] reached 140 elderly for each 100 young people in 2015 (please, see Table 1). In turn, the old-age dependency ratio, which lets us gauge the ratio of elderly people compared to the number of people of working age, has been continuously rising in recent decades, with 31 elderly people for each 100 people of working age in 2015 (please, see Table 1).

Table 1. Elderly population in Portugal, 2010-15 and forecast 2030-60

	2010	2015	2030	2060
Resident population (in millions)	10.6	10.3	9.9	8.6
0-14	1.6	1.5	1.1	1.0
15-64	7.0	6.7	6.0	4.5
65 and over	2.0	2.1	2.7	3.0
Dependency ratio (65+/15-64)	28.6	31.3	45.5	67.0
Longevity index (80+/65+)	25.9	29.3	30.5	46.7
Ageing ratio (65+/0-14)	125.0	140.0	242.6	306.5
Life expectancy at 65	18.84	19.19		
H	16.94	17.32		
M	20.27	20.67		
Fertility rate	1.4	1.3	1.3	1.6
Net migration	3,815	-10,481	15,312	19,493

Source: INE, 2017

According to the National Strategy for a Healthy and Active Ageing (Estratégia Nacional para o Envelhecimento Ativo e Saudável ENEAS 2017-2025), is also noteworthy the increase in the population aged 80 and over. In 1971, this population represented 1.43% of the resident population in Portugal, representing 5.84% in 2015. (PORDATA, 2015).

Demographic projection suggests that the increase of people over 80 will reach 16% by 2060, when was 5% in 2013 (Eurostat, 2015). Public debate about the impact of longevity has been largely polarized on the issue of sustainability of social security systems [2]. Another debated topic is the status of the caregiver (July 2019) that was recently approved. It was defined a support

[1] Reflects the ratio of elderly people compared to the number of young people.

[2] On this issue, see the study of Amílcar Moreira on Financial and Social Sustainability of the Portuguese Pension System (Moreira, 2019)

allowance for caregivers and specific measures regarding the caregivers' contributory career. However, these measures, so far, have not been yet implemented in practice. According to the Survey of Health, Ageing and Retirement in Europe applied in 2015 (SHARE), 70% of informal care in Portugal is provided daily by women over 50 (OECD, 2017: 209).

Digital competence among elderly

The use of a computer and the internet has increased over time among the Portuguese population, including also the older population (Dias, 2012). Despite this general trend, clear disparities are found according to age and other factors. Starting by age, internet use decreases significantly with increasing age: in 2018, while in the age groups under 55 the proportion of internet users was always greater than 80%, in the age group 55-64, it was 55% and in the age group 65-74, it decreases significantly to 34%.

A study conducted by the Barometer of the Adoption of Telehealth and Artificial Intelligence in the Health System (*Barómetro da Adoção de Telessaúde e de Inteligência Artificial no Sistema da Saúde*) concluded that, in 2019, telehealth, as a component of the digital health care, is adopted by the majority of the institutions/organizations that provide health services. The most provided telehealth services are synchronic (in real time) medical appointments and screening appointments (BTIA, 2019).

The vast majority of the health professionals who have participated in this study agree that telehealth has an important role in remote monitoring of users with chronic diseases, in sharing clinical data that contributes to a higher level of user's compliance to prescribed therapies, and in decreasing the number of hospital readmissions. It is important to add that 47% of the respondents believe that telehealth improve the relationship between users and professionals. Finally, this study also identified the perspectives of the health professionals regarding the main obstacles to the implementation of telehealth: 1) reduced broadband internet coverage and internet access; 2) low level of users' literacy in telehealth; 3) low level of health professionals' motivation to use telehealth. The survey entitled Network Society in Portugal (*Inquérito Sociedade em Rede em Portugal*) shows that, in 2006, only 0,3% of the respondents used online medical/health services (Espanha et al., 2007).

The National Strategy for Active and Healthy Ageing (ENEAS) is a proposed strategy that meets the objectives included in the National Health Plan (Portugal. Ministry of Health. General Directorate of Health, 2015) and aims to promote health and well-being of older persons and to recognize the benefits and importance of active and healthy ageing throughout life cycle.

In the domain of e-health, the introduction of an integrated ICT system in the National Health Service (Serviço Nacional de Saúde – SNS) began to be noticed especially in the 90's with the launch of the Integrated System of Hospital Information, known by the acronym SONHO. One of the goals proposed by the National Health Plan for 2020 is to improve healthy life expectancy at age 65, that as we noted earlier there are still inequalities in healthy life years by socioeconomic and educational status at this age. In the domain of social care/long term care, Portugal also continued to implement the National Network for Continued Integrated Care (RNCCI), set up in 2006, under the joint responsibility of the Ministry of Health and the Ministry of Labour, Solidarity and Social Security, with a focus on the coordination and organisation of "long-term care", providing structured responses to people in a state of dependency, at different levels of functionality in all life stages.

The number of users of home-based care services increased considerably, from 49473 users in 2000 to 104551 in 2014. Daycare centres began to develop in an experimental way in the mid-1970s, with the aim of helping an individual to remain in his/her own socio-familial context for as long as possible and offering an alternative to institutional care (Carta Social, 2000). Between 1986 and 1995, the number of day care centres increased steadily (+55% from the previous period of 1975–85) (Joël et al., 2010) and the number of day centers rose in the beginning of 1990s as did the number of users: in 1987 there were 11370 users and in 2014 there were 64705.

In collaboration with the 24-hour health line and the General Directorate of Health, an elderly health monitoring system has been developed based on a dedicated telephone line and back office support system (Linha24). The University of Coimbra, together with the other members of the consortium "Ageing@Coimbra" supports a holistic ecosystem of stakeholders and it implements innovative practices to manage cognitive ageing, dementia, vision impairment, human kinetics and mobility.

Implications for elderly, staff and working places

Portugal has a mixed long-term care, composed of a social network of services, including care centres, home-based services and nursing homes ('residential structures for older people'), and the National Network for Integrated Continuous Care[3]. In this case the human resources are not allocated according to patients' needs as in other European countries, but by the number of weekly hours of care a patient is entitled to receive from each professional category (Lopes, Mateus and Hernández-Quevedoc, 2018: 213). Due to demographic changes, the number of people with chronic diseases has increased and the lack of long-term and palliative care is now more visible. Portugal now has new social and health needs which demand new and diverse solutions.

Whenever the residential structure accommodates elderly people in situations involving considerable dependency (dementia, cardiovascular diseases), the ratios of nursing staff, direct and care assistants are as follows: *a*) One nurse, for every 20 residents; *b*) One care assistant, for every 5 residents; *c*) One ancillary staff member for every 15 residents. The home-based care services have to be available every day of the week, also guaranteeing, whenever necessary, the support on Saturdays, Sundays and holidays (Portaria n.º 38/2013). The human resources (professional staff, manager and care workers) must have "a) an appropriate training for their work; b) communication competencies and friendly relationship that allow to adopt an attitude of listening and observation to respond the users' needs; c) be able to provide information for the assessment of the care program and services; d) to have training that allow adequate intervention in situations of dependence due to ageing and/ or disabilily" [4].

Although training is recognised as an necessary requirement for quality care practices, the care system is not focused on people, care workers job is underestimated, they don't receive adequate trainings and salary, and this has negative impact on their physical and mental health, job satisfaction, work environment and quality of service provided (Gil, 2018, 2019).

As far as profession or employment of family carers staff is concerned, there are also no specific data available. In Portugal there is no formal system for supporting family carers staff,

[3] D.R. Decree-Law 101/2006. D.R. I Serie A, 6th of July – Creation of the Portuguese National Network for Long-term Integrated Care (Rede Nacional de Cuidados Continuados Integrados) (in Portuguese) 2006: 3856–65. http://www.acss.min-saude.pt/wp-content/uploads/2016/10/Decreto-Lei101 2006-1.pdf.

[4] http://www.seg-social.pt/documents/10152/1197978/Port_38_2013

nevertheless some facilities, like day centres and home support systems constitute indirect measures that help family carers staff. When a family carer needs complementary help, it is usually another family member who fills in permanently or temporarily for the family carer in caring for the elderly.

As a conclusion, we consider that the carer staff level the education and training should strengthen the professionals' digital literacy through specific training programs. It should also sensitize practitioners to the advantages of e-care use (in terms of care and e-health in general).

The Adults Digital Literacy Project (LIDIA), aims to identify situations where adults are hindered from exercising their full citizenship, due to their lack of digital technologies knowledge. Initiated in March 2015, this is a project that involves a multidisciplinary team from the Institute of Education at the University of Lisbon. At senior level the implications must be: a) the focus on strengthening digital literacy; b) the focus on strengthening health literacy; c)the promotion access to affordable digital equipment and services.

Challenges and risks (integrity, ethical and economical

As mentioned in the article of Hülsken-Giesler and Krings, the "reflections on the use of technologies in the context of care in a society of longer living cannot be limited to pragmatic aspects of technology development, use or assessment. Instead these issues demand a constitutive discussion over the basic questions of society's development and provoke debates on the societal way of dealing with age and vulnerability as well as the relationship between effectively and efficiency and care in a modern society" (Hülsken-Giesler and Krings, 2015: 4). In addition to these broad issues, other challenges and risks are identified: i) Digital divide between older people and younger people – the use of ICTs by older people, particularly internet, is low, and the same is found in relation to the use of e-health and telecare, ii) Negligence of a user-centred approach to technology design and service delivery by industry and service providers, iii) Resistance in accepting care-oriented ICTs by staff and older people, iv) Violation of ethical and deontological guidelines by care staff – the use of care-oriented ICTs should respect the preservation of users' privacy and the principle of informed consent for the collection of information and the principle of confidentiality of the collected information.

Societal debates, regulations, best practices

The debates, regulations and best practices have already been discussed in previous sections thus, we will not repeat in this section. One of the good practices is the Senior Census program of the Ministry of Internal Affairs. This program aims to identify the elderly population living alone and/or that are isolated. It aims also to detect new cases of situations of risk and social vulnerability. Another good practice is the consortium "Ageing@Coimbra" that supports a holistic ecosystem of stakeholders implementing innovative practices to manage cognitive ageing, dementia, vision impairment, human kinetics and mobility.

Several measures have been implemented which target the main challenges for long- term care. The main one was a joint project between the Ministry of Health and the Ministry of Labour and Social Solidarity called Programme of Integrated Support to the Elderly (Programa de Apoio Integrado a Idosos), that was developed during the last years of the decade of 1990, and which has

enabled the development of initiatives in both health and social areas oriented for home care and informal caregivers as part of a job creation policy [5].

Future perspectives and reflections

The introduction of new technologies in social care could be an asset not only in terms of the administrative and social process of users, the registration, monitoring and evaluation of care provided. However, there are already some practices of recording personal care (hygiene, food, nursing care) through the use of tablets in residential structures for the elderly in Portugal, a practice still very incipient in the Portuguese landscape.

Bibliography

BTIA (2019). *Barómetro da Adoção de Telessaúde e de Inteligência Artificial no Sistema da Saúde*, Relatório Final, Lisboa, Associação Portuguesa de Administradores Hospitalares.

Cardoso, G., Costa, A. F., Coelho, A. R. and Pereira, A. (2015). *A Sociedade em Rede em Portugal. Uma Década de Transição*, Coimbra, Edições Almedina.

Carneiro, R. and Rodrigues, N. (2007), A sociedade da informação e a desigualdade: um retrato português, in Coelho, J.D. (coord), *Sociedade da Informação: o percurso português,* Lisbon, Sílabo, pp. 293-318.

Coelho, A. R. (2017). Os seniores na sociedade em rede: dinâmicas de promoção da inclusão e da literacia digitais em Portugal, *CIES e-Working Paper* N.º 213/2017, Lisboa, CIES-IUL.

Costa, F.; Cruz, E.; Viana, J.; and Pereira, C. (2015), *Digital Literacy of Adults: Education needs for the full exercise of citizenship*, IEEE

Delgado, A. and Wall, K. (2014). *Famílias nos Censos 2011 - Diversidade e Mudança*, Lisboa, Imprensa de Ciências Sociais.

Dias, Isabel (2012). O uso das tecnologias digitais entre os seniores: motivações e interesses, *Sociologia – Problemas e Práticas* [Online], 68, consultado no dia 30 abril 2019. URL : http://journals.openedition.org/spp/686.

Direção Geral de Saúde (2017). *Estratégia Nacional para o Envelhecimento Ativo e saudável 2017-2025.* Proposta do Grupo de Trabalho Interministerial (Despacho n.º12427/2016), Lisboa: DGS

Espanha, R. (2013). *Informação e Saúde*, Lisboa, Fundação Francisco Manuel dos Santos.

Espanha, R. and Ávila, P. (2016). Health Literacy Survey Portugal: a Contribution for the Knowledge on Health and Communications, *Procedia Computer Science* 100, 1033-1041.

Espanha, R., Cardoso, G. and Araújo, V. (2007). *Utentes e Saúde na Era da Informação: Internet, telemóveis e media*, Lisboa, CIES-ISCTE.

[5] D.R. Joint Dispatch no. 259/97, 21st of August – Creation of the Programme of Integrated Support to the Elderly (PAII) (in Portuguese) 1997. http://www.seg-social.pt/documents/10152/87923/DESP_CONJ_259_1997/4a846364-eab5-489f-aa6f-9b771ffe71a5.

Eurofound, (2017) *In-work poverty in the EU,* Luxembourg: Publications Office of the European Union.

Eurostat (2015) People in the EU: who are we and how do we live? – Statistics on an ageing society, Luxembourg: Publications Office of the European Union.

GEP (2000), *Carta Social,* Gabinete de Estratégia e Planeamento, Lisbon: Ministério da Solidariedade, Emprego e Segurança Social.

Gil, A.P. (2019) "Quality procedures and complaints: nursing homes in Portugal", The *Journal of Adult Protection*, https://doi.org/10.1108/JAP-09-2018-0018.

Gil, A. P. (2018), Care and mistreatment – two sides of the same coin? An exploratory study of three Portuguese care homes, International Journal of Care and Caring, vol 2, no. 4, pp. 551–73

Gil, H. T. (2014). *Os cidadãos mais idosos (65+ anos) do concelho de Castelo Branco na utilização das TIC, e-Saúde e e-Governo Local*, Relatório de Investigação de Pós-Doutoramento em Ciências Sociais na especialidade de Políticas Sociais, Lisboa, Instituto Superior de Ciências Sociais e Políticas.

Gilleard, C., Higgs, P. (2008). Internet use and the digital divide in the English longitudinal study of ageing, *European Journal of Ageing*, 5(3): 233. doi: 10.1007/s10433-008-0083-7.

Greenhalgh, T., Shaw, S., Wherton, J., Hughes, G., Lynch, J., A'Court, C., Hinder, S., Fahy, N., Byrne, E., Finlayson, A., Sorell, T., Procter, R., Stones, R. (2016). SCALS: a fourth-generation study of assisted living technologies in their organisational, social, political and policy context, *BMJ Open*, 15;6(2): e010208. doi: 10.1136/bmjopen-2015-010208.

Greenhalgh, T., Procter, R., Wherton, J., Sugarhood, P., Hinder, S., Rouncefield, M. (2015). What is quality in assisted living technology? The ARCHIE framework for effective telehealth and telecare services, *BMC Medicine*, 23; 13:91. doi: 10.1186/s12916-015- 0279-6.

Greenhalgh, T., Wherton, J., Sugarhood, P., Hinder, S., Procter, R., Stones. R. (2013). What matters to older people with assisted living needs? A phenomenological analysis of the use and non-use of telehealth and telecare, *Social Science & Medicine*, 93: 86-94. doi: 10.1016/j.socscimed.

Hülsken-Giesler, M. (2008), *Der Zugang zum Anderen. Zur theoretischen Rekonstruktion von Professionalisierungsstrategien pflegerischen Handelns im Spannungsfeld von Mimesis und Maschinenlogik*. Osnabrück

Hülsken-Giesler, M. and Krings, B.-J. (2015), Technik und Pflege in einer Gesellschaft des langen Lebens: Einführung in den Schwerpunkt, *TATuP – Zeitschrift für Technikfolgenabschätzung in Theorie und Praxis*, Nr. 2, Vol. 24, pp. 4-11.

INE (2013). Aprendizagem ao longo da vida – Inquérito à Educação e Formação de Adultos 2011, Lisboa, Instituto Nacional de Estatística.

INE (2018). Sociedade da Informação e do Conhecimento - Inquérito à utilização de tecnologias da informação e da comunicação pelas famílias, Destaque – Informação à Comunicação Social, Instituto Nacional de Estatística, file:///C:/Users/35196/Downloads/21IUTICF2018.pdf.

Joël, M.-E.; Dufour-Kippelen, S.; and Samitca, S. (2010), The Long-Term Care System for the Elderly in Portugal, *ENEPRI Research Report* No. 84/June 2010, 13 pp.

Krings, B.-J. (2014), Technische Assistenz- und Pflegesysteme in Zeiten des demografischen Wandels: Ein Beitrag aus sozialwissenschaftlicher Perspektive, *TATuP – Zeitschrift für Technikfolgenabschätzung in Theorie und Praxis*, Nr. 2, Vol. 23, pp. 81-87.

Lopes, H; Mateus C; and Hernández-Quevedo, C (2018), Ten Years after the Ten Creation of the Portuguese National Network for Long-Term Care in 2006: Achievements and Challenges, *Health Policy*, 122, pp. 210–216

Magnusson, L. and Hanson, E.J. (2003), Ethical issues arising from a research, technology and development project to support frail older people and their family carers at home, *Health and Social Care in the Community*, 11 (5), pp. 431–439

Martin JI, de Oliveira LM, and Duarte NS. (2013), An overview of in-home care for older people in Portugal: an empirical study about the customers, *Care Management Journal*,14(1): pp. 50-57.

Ministério da Saúde. Alto Comissariado da Saúde, and Coordenação Nacional para a Saúde Mental (2008), Plano Nacional de Saúde Mental. National Plan for Mental Health, Coordenação Nacional para a Saúde Mental, Lisbon: MS-ACS

Moreira, A. (cord.) (2019), *Financial and Social Sustainability of the Portuguese Pension System* [Sustentabilidade do Sistema de Pensões Português], Lisbon: Fundação Francisco Manuel dos Santos e os autores

OECD (2018), *Health at a glance 2017: OECD indicators*, Paris: OECD Publishing

OECD (2017), *Health at a glance 2017: OECD indicators*, Paris: OECD Publishing.

OECD (2016), *Long-term care data: Progress in data collection and proposed next steps*, DELSA/HEA/HD (2016)3, Paris: Directorate for Employment, Labour and Social Affairs Health Committee.

Pimentel, Lopes and Faria (2016). *Envelhecendo e Aprendendo: A Aprendizagem ao Longo da Vida no Processo de Envelhecimento Ativo*. Lisboa, Coisas de Ler Ed.

Ratzan and Parker, "What is Health Literacy?", in Nielsen-Bohlman's, 2000, available in http://www.nap.edu/openbook.php?record_id=10883&page=32.

Santana, Dias, Souza, and Rocha (2007), The Domiciliary Support Service in Portugal and the change of paradigm in care provision, *International Journal of Integrated Care*, Vol. 7, ISSN 1568-4156

Scheil-Adlung, X. (2015) *Long-term care (LTC) protection for older persons: A review of coverage deficits in 46 countries,* European Social Survey working paper no. 50, Geneva: International Labour Office.

Sousa, L. and Figueiredo, D. (2004), National Background Report for Portugal, Project "Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage" - EUROFAMCARE, Hamburg, 66 pp.

Selwyn, N. (2004). The information aged: a qualitative study of older adults' use of information and communications technology. *Journal of Aging Studies*, 18: 369-84.

UNECE (2015), Active ageing index home. United Nations Economic Commission for Europe & European Commission.

Vassli, L.T and Farshchian, B.A. (2017). Acceptance of Health-Related ICT among Elderly People Living in the Community: A Systematic Review of Qualitative Evidence, *International Journal of Human–Computer Interaction*. DOI: 10.1080/10447318.2017.1328024