

National report on digital health and data literacy | Portugal





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1. Introduction

Despite the steady rise in literacy rates over the past 50 years, there are still 773 million illiterate adults around the world, most of whom are women. These numbers, published by the UNESCO Institute for Statistics (UIS), are a stark reminder of the work ahead to meet the Sustainable Development Goals (SDGs), especially Target 4.6, to ensure that all youth and most adults achieve general literacy and numeracy by 2030. While middle- and low-income countries are struggling with these general literacy aspects, the European countries have a large percentage of their adult population classified above the target levels of literacy proficiency (e.g. International Assessment of Adult Competencies Level 1). However, in Europe, more than 90% of EU professional roles require at least a basic level of digital knowledge and skills, just as they require basic literacy and numeracy skills [1]. Yet, around 42% of Europeans lack basic digital skills, including 37% of those in the workforce [2]. Thus, digital literacy has become an important aspect in the continuous education of the EU work force, and not only.

The COVID-19 pandemic has accelerated the growth and usage of the digital technologies in the health domain, on one side bringing significant advances in health and wellbeing promotion through self-monitoring and faster/easier provision of digital health services, but on the other side exacerbating health inequalities and negatively impacting on health literacy, in particular in the case of digitally illiterate adults. Health literacy [3] is a complex construct, covering three broad elements: (1) knowledge of health, healthcare and health systems; (2) processing and using information in various formats in relation to health and healthcare; and (3) ability to maintain health through self-management and working in partnership with health providers.

Digital and Health come hand in hand with Data, as the current digital transformation of the healthcare systems in Europe (and worldwide) is aiming at delivering person-centric data driven prevention and healthcare through new models, where medical experts are collaborating with health informaticians, data analysts, health data scientists and clinical information officers. Digital, Health and Data are becoming even more important in prevention and social and community care. Citizen-centred self-management of health and healthy lifestyles provide an adequate pathway to the expanding health care sector, thus supporting its sustainability. Citizens' enhanced digital and data skills enable them to take advantage of the further development of artificial intelligence for prevention and environmental measures. Thus, citizens are now urged to understand data concepts, data handling (e.g. collection, monitoring, transfer, storage), and security and privacy aspects related to their personal and health data.

Digital, health and data literacy represent a basic combination of elements needed by the European citizens in order to better track, manage and improve their health and well-being through the use of digital tools.





Because of the rapid digitalization of the healthcare system in Europe, citizens need to be proficient with their eHealth literacy skills and be sufficiently knowledgeable on the collection and sharing of digital data, as well as data privacy regulations. Digital and data literacy of citizens is also important to assess what is happening with their data and which data protection measures they can take.

TRIO aims to empower citizens through the development of a modular approach of the trio of literacies (digital, health and data), creating and designing a manual, a toolkit and a Green Paper, along with a platform that will ensure customization of content to different needs.

The Manual on digital, health and data literacy, the first deliverable of the modular approach, will start by making a definition of the average levels of digital, health and data literacy of the three age groups in the partner countries; define the criteria and necessary skills for each group and level; and understand the existing gaps.

This will allow to direct the learners in a bottom-up approach to look at the world with different eyes towards being in charge of their own health and well-being.

Awareness will be given to contexts beyond the well-researched theoretical practices or general population approaches, to explore instead the personal perspectives of citizens, including them in the outputs, as well as the ones of policy makers.

Definitions:

- Digital literacy: refers to the skills required to achieve digital competence, the confident and critical use of information and communication technology (ICT) for work, leisure, learning and communication [4].
- Health literacy: empowers people to make positive choices. It implies the achievement
 of a level of knowledge, personal skills and confidence to take action to improve
 personal and community health by changing personal lifestyles and living conditions
 [5].
- Data literacy: is the ability to read, write and communicate data in context, with an understanding of the data sources and constructs, analytical methods and techniques applied [6].

The TRIO project will focus on the overlapping areas, in particular the digital health data literacy (figure 1).





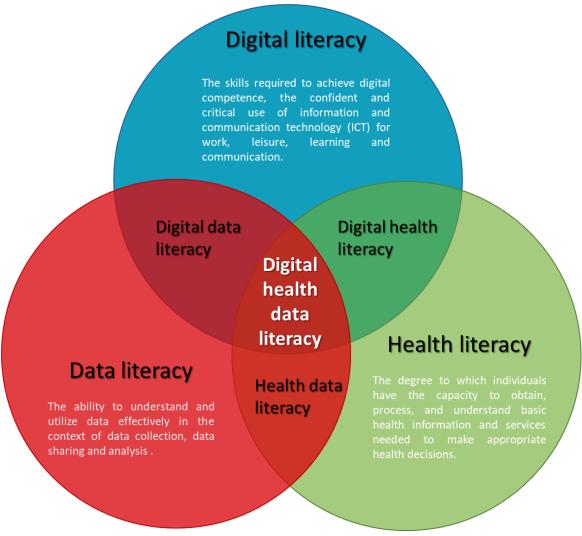


Figure 1. Venn diagram of the TRIO of literacies

1.1 Aim of the TRIO Manual and this national report

This national report will be the basis for the TRIO Manual that will be released in March 2023. Target groups of the TRIO Manual are:

- Citizens of different ages and levels of education (18-35, 36-50 and 51+) by providing an integrated approach of the competences and skills on health, digital and data, empowering them to navigate in the eHealth world.
- Formal and informal educators by providing them with organised content to share with the citizens.
- Policy makers who will benefit from them to support improved person-centred health pathways.





The manual will act as a stand-alone output, but its contents will also be integrated in the TRIO educational platform with 3 main purposes:

- As preparatory material it will sensitise the learners to digital health and data sharing practices and impacts.
- As a publication disseminated at EU, national and local level, it will be a tool for eHealth-related stakeholders, and general public.
- With its underlying data collection, it will serve to refine the educational features.

1.2 Methodology

In order to achieve the above-mentioned aims, the following methods will be applied:

- Desk research in each country concerning status (including quantitative data), main challenges and existing approaches to digital, health and data sharing literacy, bestpractice examples as well as training settings and contents
- Interviews in each partner country with stakeholders, experts and representatives of the target group for the training. For the interview questions cfr. Annex 9.





2. Overview of the national health system in Portugal

2.1 Portuguese healthcare regulations and financing

The National Health Service in Portugal (SNS – Serviço Nacional de Saúde) is the set of institutions and services, under the Ministry of Health, whose mission is to guarantee access to health care for all citizens, within the limits of the human, technical and financial resources available. Portugal's SNS is a universal tax-financed health system, covering all residents [7].

Healthcare in Portugal is provided by three systems: the National Health Service, run by the State, the special social health insurance schemes for certain professions (or health subsystems) and the private system. Each of these systems has different forms of access and costs [8]. Since the 1st of June 2022, the exemption of user charges in the National Health Service has come into effect, except for emergency services in hospitals without through the SNS24 line or in primary health care. The SNS aims to provide free healthcare, taking into account the economic and social conditions of citizens.

By 2020, private hospitals and public hospitals accounted for 53.1% and 45.6% of all hospitals respectively, while the proportion of hospitals in public-private partnerships was 1.2% [9].

App SNS 24 is a mobile application that allows citizens to access a wide range of digital health information and services, such as a vaccination bulletin, prescriptions (treatment guides), examinations (a guide to provision and results), usual medication consultation, requests for renewal of usual medication, teleconsultation, the EU COVID Digital Certificate, access to the Telemonit SNS 24 application where users can access their clinical monitoring plan, a QR Code - Electronic Kiosk, pathologies (allergies and rare diseases), clinical referrals, access to the SNS 24 portal, access to the MySNS application, medical certificates of multipurpose disability, among others [10].

2.2 Accessing the Portuguese medical system

The Portuguese SNS covers a broad benefits package, including GP visits and outpatient specialist care, as well as other services prescribed by doctors such as pharmaceutical products. Nevertheless, public coverage was notably lower than the EU average in 2019 (OECD 2020).

Although the SNS guarantees universal coverage for all citizens, barriers to access persist for some population groups, particularly for people on low incomes. People with lower incomes have unmet medical needs due to cost, distance or waiting time. Most of these unmet needs among people in the lowest income quintile were for financial reasons.

Regarding dental care, the situation is even more serious as public coverage of dental care is very low since dental care is mainly provided privately. To tackle this, plans are underway to





roll out a pilot project to integrate dentists into some municipal primary care centres by 2023 (OMD 2020).

The SNS covered the costs of COVID-19-related care and some voluntary health insurance. During the pandemic, it fully covered the costs of a coronavirus test if prescribed by an SNS doctor and adopted several coverage decisions regarding COVID-19-related treatments provided by the private sector.

However, the healthcare sector has been under unprecedented pressure, resulting mainly from the gap between increasing demand and decreasing capacity, accentuated by the COVID-19 pandemic. Waiting times for elective surgery have worsened over the past decade, with the number of elective surgery appointments decreasing by 21% in 2020 compared to 2019.

Additionally, medicine shortages are a growing issue in Portugal. In 2019, the Ministry of Health defined a new set of regulations that strengthen the public service obligation of the various players in the supply chain (manufacturers, wholesalers, and pharmacists).

Market authorisation holder must now monitor their stock positions continually, and communicate possible shortages in advance – both to other stakeholders and to the Portuguese regulatory authority, INFARMED. These measures are in line with the EU's pharmaceutical strategy for Europe, adopted in 2020, which aims to foster access to medicines (European Commission, 2020).

Portugal's Recovery and Resilience Plan was adopted in June 2021 (European Commission, 2021), holding as one of its objectives to strengthen the responsiveness of Portugal's National Health Service to demographic and epidemiological change, and support the digital transition of SNS. Other important priorities are strengthening the central role of primary health care services within the SNS, increasing the scale of long-term care and mental health services, and increasing efficiency by completing the reform of the governance model of public hospitals (OECD 2020).

2.3 Personal medical data

The Electronic Health Record (EHR) gathers essential information from each citizen to improve healthcare delivery. Built by clinical data collected electronically for each citizen and produced by entities that provide health care, it allows the registration and sharing of clinical information between the user, health professionals and entities providing health services, according to the requirements of the National Commission for Data Protection (Authorization No. 940/2013). It consists of the SNS 24 Personal Area, Professional Area and Institutional Area [11].

In the SNS 24 Personal Area, each citizen has access to his/her data including consultations, medication, surgeries, exams, the COVID-19 digital certificate, health records and the ability





to define/change who can access their information (type of entities and health professionals duly accredited) [12].

2.4 The digitalisation of the Portuguese healthcare system

Digitalization in health care is a priority for the European Union and, in this regard, Portugal is at the forefront in some areas, e.g. with an average monthly value of 98% of electronic prescriptions issued in the health system and different digital services aimed at citizens, with the SNS 24 being a relevant example.

COVID-19 was an accelerator of digital healthcare innovation in 2020. It helped break down regulatory, financial, and behavioural barriers which allowed virtual care to be widely integrated into our healthcare system and improved responsiveness to patient needs.

Beyond that, the pandemic led to a surge in telemedicine, with the government had expanded the regulations and payments for teleconsultations for physicians and psychotherapists during the pandemic to enable them to substitute for face-to-face consultations [13].

However, according to the Study on digital services in the health sector in Portugal (Deloitte 2021), there is still a lot to be done, with data interoperability, process dematerialization, artificial intelligence, remote patient monitoring and telemedicine identified as the priority areas in need of investment towards the digital transformation of the health sector in Portugal.

According to the same study, for this transformation to be possible, the challenges to address are:

- Digital literacy of citizens,
- Digital skills of health professionals
- Privacy, ownership and security of personal data.

It is thus clear that the TRIO project is of utmost importance to the Portuguese challenges.





3. Overview of digital, health and data literacy in Portugal

3.1 Statistics on digital, health and data literacy

Digital literacy

Portugal ranks 15th of the 27 EU Member States in the 2022 edition of the Digital Economy and Society Index (DESI), climbing one step up from the previous year's ranking [14].

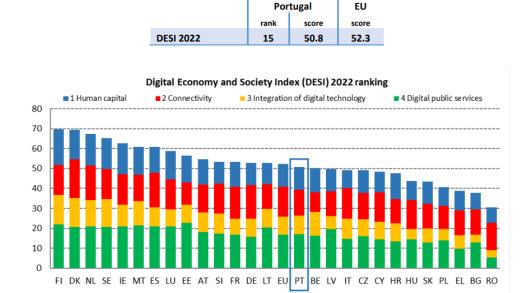


Figure 2. Digital Competences (European Commission 2022).

Portugal's digital transformation strategy and action plan have set digital inclusion, training of the public, and digital transformation of businesses and public administration as its national priorities.

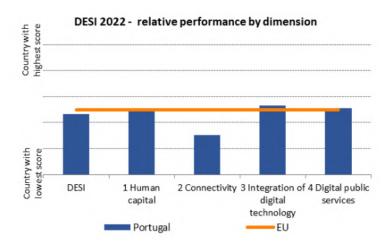


Figure 3. Relative performance by dimension (European Commission 2022).



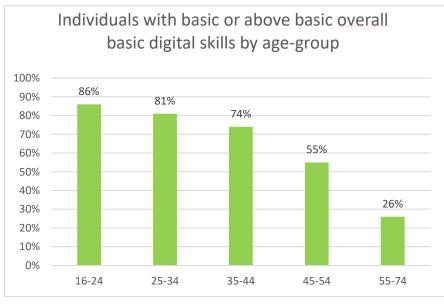


The digital skills deficit in Portugal hinders the adoption of e-government solutions by users, and over-reliance on advanced e-government may leave too many people behind.

Given that the ability to use ICT tools is strongly correlated with digital skills, the reinforcement of the population's competencies in this area is a primordial condition for their access to the different digital tools available.

In this direction, the programme *EU SOU Digital* aims to empower adults with digital skills, with the vision of helping to reduce inequities in access in Portugal. Increasing the population's level of digital skills has been set as a priority by the current Government, which intends to implement measures targeted at specific groups and the population in general through the National Digital Skills Initiative INCoDe.2030 [15].

Also, the Digital School Programme was created to promote digital skills in schools and the Digital Academy Portugal platform to promote the digital skills of the active population, a self-assessment tool of digital skills, with individual training plans and access to training (European Commission 2022).



When analysing digital skills by age, we can see that there is a decreasing trend as age goes up.

Among the youngest, the percentage is 86%, while only 25% of the population over 55 holds basic digital skills.

Graph 1. Individuals with basic or above basic overall digital skills by age group in 2021 [16].

Concerning gender, there is practically no difference in digital skills. As can be seen in the figure below, in the different types of digital skills, women show lower percentages, but with a minor difference (see figure 4).





Portugal

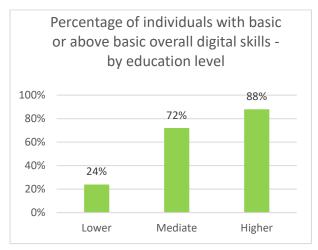
				FOIL	1 Bu
	Portugal			EU	
	Women Men		Women Mer		
	value	rank	value	valu	e
1 Use of internet					
1.1 Internet users	75%	22	78%	85%	879
% individuals, 2020	/5%	22	1070	83%	0/7
1.2 People who have never used the internet % individuals, 2020	20%	24	17%	10%	89
1.3 Online banking	-25.25				
% internet users, 2020	56%	22	65%	65%	679
1.4 Doing an online course					
% internet users, 2020	18%	10	18%	15%	159
1.5 Online consultations or voting	150/	-	100	110/	120
% internet users, 2019	15%	7	16%	11%	129
1.6 e-Government users	54%	22	60%	64%	649
% internet users submitting forms, 2020	34%	22	00%	0476	047
1 Use of internet	54	21		60	
Score (0-100)				00	
2 Internet user skills					
2.1 At least basic digital skills					
% individuals, 2019	49%	19	54%	54%	589
2.2 Above basic digital skills					
% individuals, 2019	30%	16	34%	29%	339
2.3 At least basic software skills	F30/	10	F 70/	FC0/	co
% individuals, 2019	53%	19	57%	56%	609
2 Internet user skills		10			
Score (0-100)	51	19		53	
3 Specialist skills and employment					
3.1 STEM graduates					
	15	6	26.4	14	28
Per 1000 individuals aged 20-29, 2019					
3.2 ICT specialists	1.8%	12	6.2%	1.7%	6.59
% total employment, 2020					
3.3 Unadjusted gender pay gap	14%	6		19%	
% difference in pay, 2019					
3 Specialist skills and employment	54	7		47	
Score (0-100)					
A Comment of the Comm					
Women in Digital Index	52.9	15		53.2	
Score (0-100)	32.3	13		33.2	

Figure 4. Digital competencies by gender in Portugal [17].

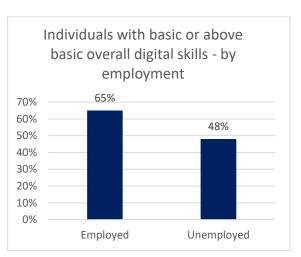
In the graphs below we present an analysis of digital skills according to different criteria.



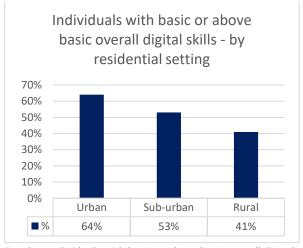




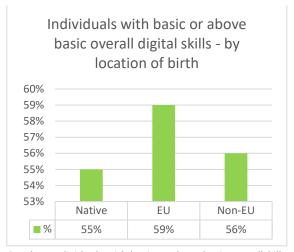
Graph 2. Individuals with basic or above basic overall digital education level in 2021 [18].



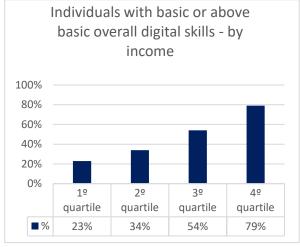
Graph 3. Individuals with basic or above basic overall digital skills by employment in 2021 [19].



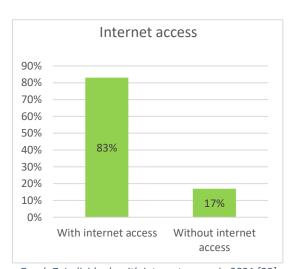
Graph 4. Individuals with basic or above basic overall digital in Residential settings in 2021 [20].



Graph 5. Individuals with basic or above basic overallskills digital skills by location of birth in 2021 [21].



Graph 6. Individuals with basic or above basic overall digital skills by income in 2019 [22].



Graph 7. Individuals with internet access in 2021 [23].





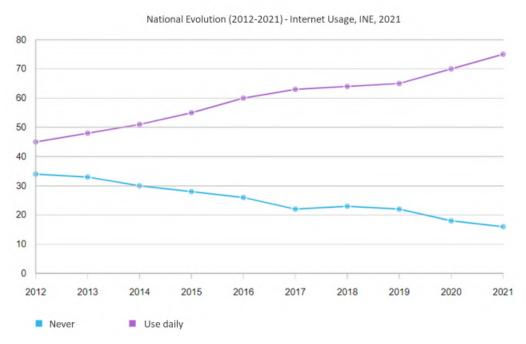


Figure 5. Evolution of individuals who have never used /use daily internet access (%) [24].

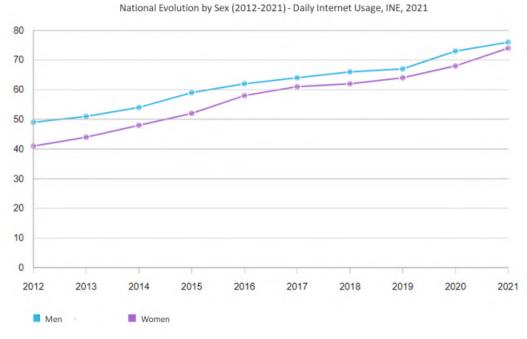


Figure 6. Evolution of men and women aged 16 to 74 using the Internet daily (%) [24].

According to the data obtained, we can conclude:

The education level has a large influence on digital ability levels. Of the population
with a low level of education, only 24% have basic or above basic overall digital skills,
increasing to 72% in the population with a medium level of education and 88% in the





population with a high level of education. This is also positively correlated with age, as the older population is part of the group with a lower level of education (see Graph 2).

- Employment also has a large influence on digital ability levels. Of people employed,
 65% have basic or above basic overall digital skills while of the unemployed only 48% (see Graph 3).
- Concerning the residential setting, 64% of people living in cities have basic or above basic overall digital skills, decreasing to 53% of people living in sub-urban and to 41% for those living in rural areas (see Graph 4).
- The place of birth has less impact. Of native people, 55% have basic or above basic overall digital skills while those from Non-EU origin represent 56% and the EU natives 59% (see Graph 5).
- Income has a large influence on digital ability levels. Analysing the data from the 1st, 2nd, 3rd and 4th quartiles of 2019, 23%, 34%, 54% and 79%, respectively, have basic or above basic overall digital skills (see Graph 6).
- Regarding internet access, 83% of the population has internet access at home and 17% has no access. Of the 55-74 population, internet access drops to 60%. Income has a large influence on digital ability levels (see Graph 7).
- However, according to the national evolution of internet use, it can be seen that, since 2019, there is a steady decrease in people who have never used the internet and an increase in people who use the internet daily (see Figure 4).
- Regarding the national evolution of internet use by gender, it can be seen that there
 has been a constant growth in use by both men and women. Although men use the
 internet more daily, the difference is not significant, having decreased from 2020 to
 2021 (see Figure 5).

Health literacy

Based on the Health Literacy Survey (HLS19-Q12), released in 2021 and consisting of a short questionnaire on the determinants of health literacy, plus the HLS19-Q12 questionnaire and health literacy-specific packages on digital health literacy, navigational health literacy, and vaccination health literacy, the results suggest that 7 out of 10 people in Portugal (mainland) have high health literacy levels and the questionnaires support the results of other studies concerning the main socioeconomic determinants of general health literacy. Furthermore, the results suggest that "navigation in the health system" tasks are the most challenging ones regarding specific health literacies [25].





These results are quite distant from the ones obtained in 2016 for the Portuguese reality, namely in the NOVA University of Lisbon study to translate and validate the HLS-EU for Portugal and to diagnose the health literacy level of the Portuguese population. This instrument can be compared with other European countries, to better direct and align health literacy strategies and interventions to be developed not only at a national level but also at a European level [26].

Also, the Calouste Gulbenkian Foundation, together with the Centre for Research and Studies in Sociology of the University Institute of Lisbon, produced the synthesis report on health literacy in Portugal. The Health Literacy Survey in Portugal (ILS-PT) was developed and applied by a team from the Centre for Research and Studies in Sociology of the University Institute of Lisbon, in collaboration with the HLS-EU Consortium, using the HLS-EU questions [27].

General Health Literacy

Regarding general health literacy, in the table below we present the difference in results between the studies, finding that the percentages of low levels of health literacy ("Problematic" and "Inadequate") are much higher than those indicated by the HLS-EU (Arriaga et al. 2022).

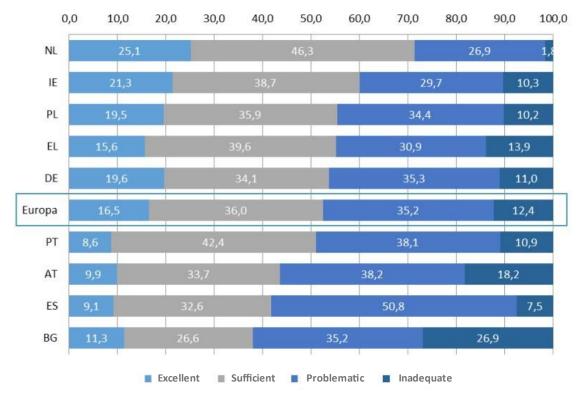
Levels	HLS-EU	HLS-EU-PT	ILS-PT
Excellent	5%	8.4%	8.6%
Sufficient	65%	30.1%	42.4%
Problematic	22%	44.4%	38.1%
Inadequate	8%	17%	10.9%
Low levels of health literacy	30%	61.4%	49%

Table 1. Comparison of studies on general health literacy [25], [26], [27].

According to the report prepared by the Calouste Gulbenkian Foundation, Portugal is characterised by 11% of the population having an "inadequate" level of literacy and about 38% of the population having a level of health literacy considered "problematic". Of the total Portuguese population, 50% have "excellent" or "sufficient" literacy, but the percentage at the "excellent" level (8.6%) is the lowest among all countries, followed by Spain and Greece, with 9.1 and 9.9%, respectively (see graphic 10).







Graph 8. General Health literacy in 2014 (%) [27].

Dimensions of General Health Literacy

The dimensions of health literacy were calculated by grouping together articles corresponding to health care, disease prevention and health promotion.

From the study conducted by the Calouste Gulbenkian Foundation, it was possible to obtain information on health by dimension, by age-group and by education level.

	Health Care	Disease Prevention	Health Promotion
Excellent	11.3%	12.5%	9.8
Sufficient	43.3%	42%	39.1%
Problematic (1)	35.3%	34.2%	34.5%
Inadequate (2)	10.1%	11.3%	16.5%
Low levels (1, 2)	45.4%	45.5%	51%

Table 2. Dimensions of General Health Literacy in 2014 (%) [27].

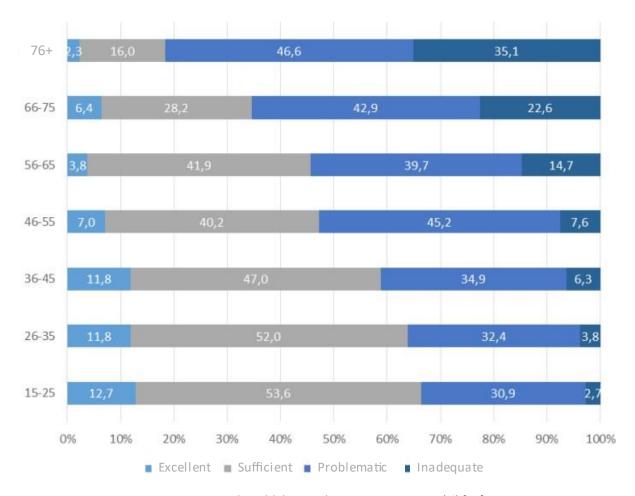
45.4% of respondents with limited healthcare literacy (10.1% and 35.3% are concentrated in the "inadequate" or "problematic" literacy levels, respectively). Regarding disease prevention, Portugal has 45.5% of respondents' literacy levels indicating limitations in the skills needed for disease prevention ("inadequate" or "problematic" levels).





Concerning health promotion, 48.9% of citizens have the highest levels of literacy and 51.1% have levels revealing limitations (problematic and inadequate).

In the graph below, we can see the distribution of general health literacy by age.

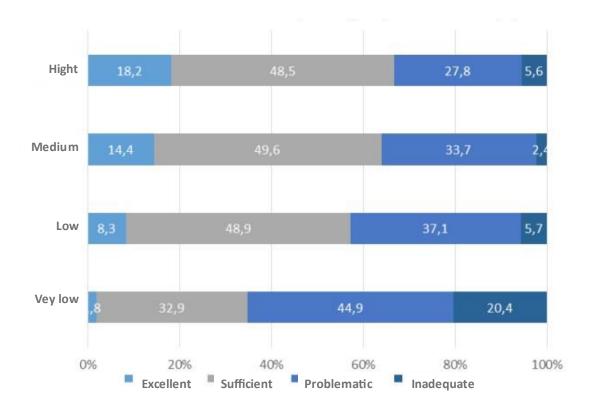


Graph 9. General Health literacy by age group in 2014 (%) [27].

In Portugal, it is among the older population that a higher proportion has low levels of health literacy, and more than 80% have levels revealing limitations (problematic and inadequate), a tendency that decreases progressively with younger age. It is the youngest who have the highest percentage of 'excellent' literacy levels.

In the graph below, we can see the distribution of general health literacy by education level.





Graph 10. General Health literacy by education level in 2014 (%) [27]

High levels of education tend to correspond to high levels of health literacy. In Portugal, more than 65% of respondents with higher education have excellent or sufficient literacy levels. In contrast, more than 65 per cent of respondents with very low education have problematic or even inadequate levels of health literacy.

Most vulnerable groups

A set of very vulnerable groups were also identified in the field of health literacy in Portuguese society, to which particular attention should be paid in terms of public policies to promote health literacy (Calouste Gulbenkian Foundation 2015).

- Individuals aged 66 and over
- With low levels of education
- With an income of up to 500€
- Suffering from long-term diseases
- With a self-perception of "poor" health
- Who attended primary health services 6 times or more over the past year
- Who feel limited due to suffering from a chronic disease

Access to health information

The results revealed the preponderance of direct contact with health professionals (doctors or pharmacists) to be the privileged way to obtain health information. Interpersonal contact, first with specialists and second with friends and family, continues to be the main way of





obtaining health information. Other means are also used, such as TV and reading medicine leaflets or package leaflets. The use of networks (e.g. patient associations) is on average much less frequent, as is the reading of articles or books. The search for information on the internet emerges as the medium that, on average, is used the least frequently, but the internet is the means of searching for information that is most closely related to age and education (Calouste Gulbenkian Foundation 2015).

Concerning how people receive health information from different sources, the study highlighted the following important points:

- The high average levels of confidence of the population in the information provided by health professionals.
- In the relationship between education and reflexivity it is found that among respondents with high levels of education, reflexive and critical attitudes tend to be more frequent, decreasing uncritical reliance on non-expert sources.
- The existence of ambivalent attitudes towards the way health information is handled among respondents with high levels of health literacy, who may either question it, or receive it without the necessary care in assessing the credibility of the various sources.

Study findings:

- Portugal, in comparison with the 8 countries of the project, occupies an intermediate
 position in the General Health Literacy Index, with values slightly lower than the
 average of these countries;
- The younger the respondents, the higher the level of health literacy;
- The higher the level of education, the higher the level of health literacy;
- Health literacy, despite its specificity, cannot be dissociated from general literacy;
- There is a positive correlation between health literacy and daily literacy practices (such as reading from various materials or using information and communication technologies);
- ICTs emerge as a strong alternative to disseminate health information and to promote and develop health and health literacy skills, especially for the youngest and most educated.

On a quite different note, the study based on the Health Literacy Survey (HLS19-Q12) of 2021 reports that most participants presented high levels of HL: 65% "adequate" and 5% "excellent" levels, with only 7.5% of participants presenting "inadequate", and 22% "problematic" levels of health literacy. The results suggest that 7 out of 10 people have high levels of health literacy, representing very significant increase compared with previous studies.

In what concerns the different dimensions of health literacy - health promotion, disease prevention, and health care - participants presented higher levels in health promotion (71.6%





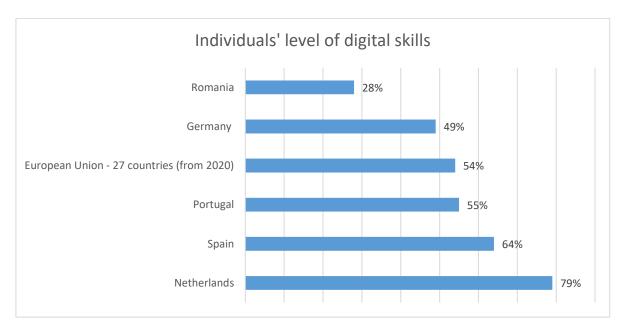
and 8.9% sufficient and excellent, respectively), while disease-prevention dimension was the most challenging task (with 18.4% and 21.3% problematic and inadequate, respectively).

The competence of "understanding information" was associated with the highest levels of health literacy (75%) but, "appraising health-related information" was considered the most challenging aspect for many participants, with 34.1% presenting problematic and inadequate levels of literacy.

Regarding specific health literacies, the data revealed poorer levels of navigational health literacy.

Data literacy

According to Eurostat, the number of Portuguese with basic or advanced information and data literacy is 55%, in line with the EU levels.

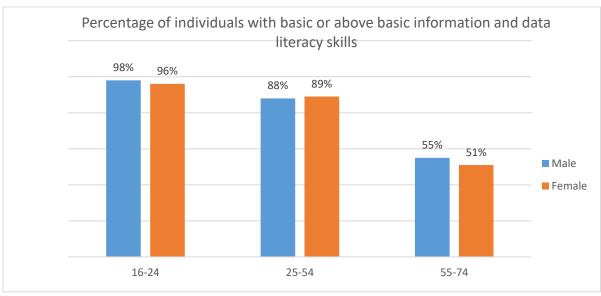


Graph 11. Individual's level of digital skills 2021 [28].

Data literacy skills are largely influenced by age, but not significantly by gender.



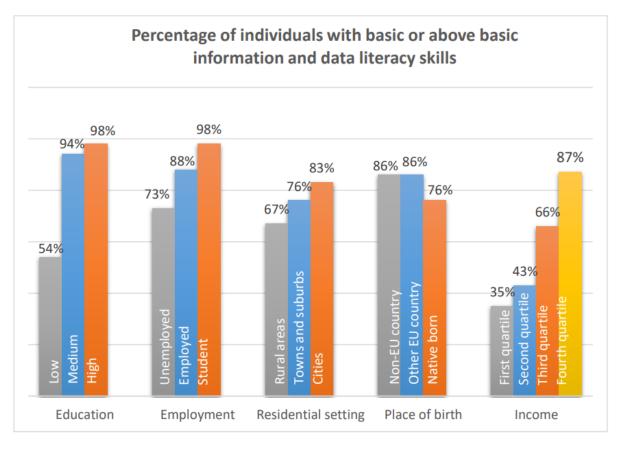




Graph 12. Individual's level of digital skills by age in 2021 [28].

There is some imbalance when comparing data literacy figures with various socioeconomic factors. Individuals with low education, low income, people who are unemployed and people living in rural areas tend to have lower information and data literacy rates (see Graph 13).

The difference between medium versus high education and working people versus students is statistically irrelevant.



Graph 13. Information and data literacy per socio-economic factor in 2019 [29].





Statistics for digital data use per age group show a significantly larger gap than information and data literacy in general. In general, people aged 55+ have significant difficulties in understanding data security (see Table 3).

	Digita	I data security by the perc	entage of individuals (2	2021)
Age	Individuals that know cookies can be used to trace the movement of people on the internet	Individuals that ever changed the settings in their internet browser to prevent or limit cookies on any of their devices	Individuals that checked that the website where they provided personal data was secure	Individuals that refused to allow the use of personal data for advertising purposes
16-24 years	85%	43%	67%	74%
25-34 years	85%	55%	64%	76%
35-44 years	79%	43%	58%	72%
45-54 Years	66%	30%	47%	59%
55-64 years	46%	16%	31%	38%
65-74 Years	27%	6%	16%	21%
Total	63%	30%	45%	55%

Table 3. Individuals that secure their data online by age group in 2021 [28].

The EU's General Data Protection Regulation (GDPR) aims to enhance individuals' control over their data, but its practical impact is still not fully understood by citizens. More effective, data-inclusive, open policies and data access systems to improve both customer relations and individual agencies are potential areas to explore.

On the European Mapcan, it is seen that in Portugal legislation exists that allows individuals to access their health-related data in an EHR. However, people still need more skills to be able to manage and access their data.





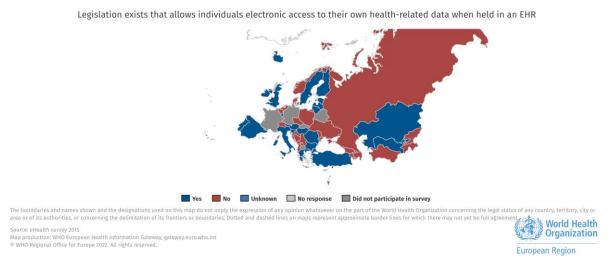


Figure 7. Existence of legislation in Europe for electronic access to people's health-related data held in an EHR in 2015 [30].

In a Eurostat (2020) report about Portugal, individuals revealed that in the 3 months before the report, they had difficulties managing and accessing personal data on the internet in the following aspects:

- a) reading privacy policy statements before providing personal data (38%);
- b) limited access to profile or content of social networking sites or shared online storage (52%);
- c) asking the administrator or provider of the sites or search engines to access the data they have about them to update or delete it (15%).

Related to the importance of information sharing as a barrier to Big Data supporting universal health coverage, Portugal has a moderately important barrier. Portugal has a data protection authority which concerns itself with the protection of public data [31].



Figure 8. The importance of information sharing as a barrier to Big Data supporting universal health coverage, 2015. [32].





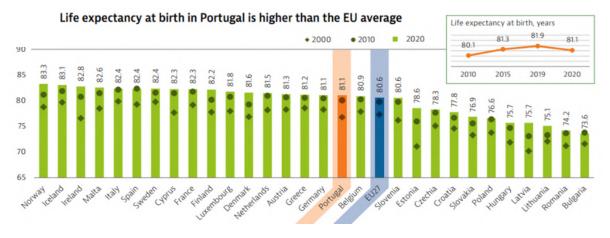
3.2 Statistics on societal and economic impacts

Health and wellbeing

Improving knowledge, skills and personal attitudes enables the population to go through the health system, make decisions, assess social determinants for their health, measure and understand risk factors and adopt preventive measures [33].

The life expectancy of individuals

Life expectancy at birth in Portugal was half a year higher than the EU average in 2020, although most western European countries have a higher life expectancy.



Graph 14. Life expectancy at birth [33].

Life expectancy in Portugal increased by more than five years between 2000 and 2019 (from 76.8 years to 81.9 years), but it fell temporarily by 0.8 years in 2020 because of deaths due to COVID-19. Gender inequalities in life expectancy are significant and persist. In 2020, women could expect to live over six years longer than men (84.1 years versus 78.0 years). The education level also influences healthy life expectancy.





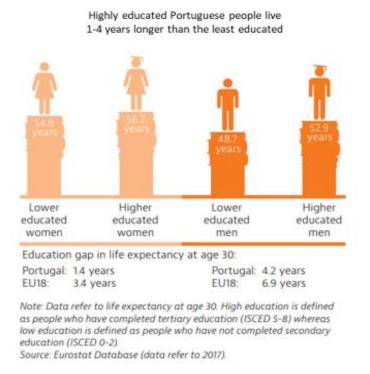


Figure 9. Life expectancy at birth by gender and education level in 2017 [33].

Approximately one-third of all deaths in Portugal in 2019 are due to behavioural risk factors. Being overweight and obese are growing public health issues among adults and young people. In 2018, 22 % of 15-year-olds were overweight or obese, which is higher than the EU average. Low physical activity is one factor contributing to increasing rates of overweight and obesity.

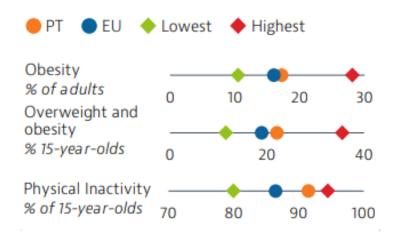
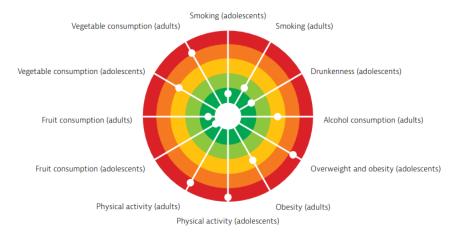


Figure 10. Risk factors in 2019 [33].







Note: The closer the dot is to the centre, the better the country performs compared to other EU countries. No country is in the white "target area" as there is room for progress in all countries in all areas.

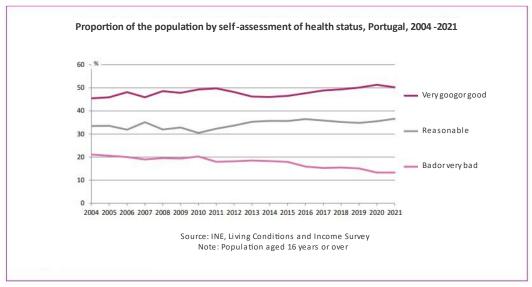
Sources: OECD calculations based on HBSC survey 2017-18 for adolescents indicators; and OECD Health Statistics, EU-SILC 2017, EHIS 2014 and 2019 for adults indicators

Figure 11. Portugal's performance in behavioural factors for health [33].

Lack of physical activity, overweight and obesity, and low vegetable consumption are public health issues of concern.

Self-perceived health

Regarding self-perceived health, 50.2% of the Portuguese population indicated having a "Very good or good" state of health in 2021, while in 2020 the percentage was 51.3%. In addition, the percentage of people who indicated having a reasonable state of health increased and the percentage who indicated having a "Bad or very bad" state of health decreased.

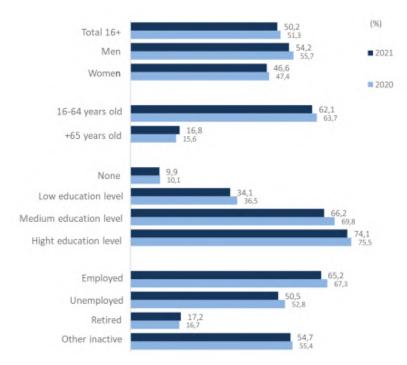


Graph 15. Self-assessment of health status [33].





In the graphic below we can observe the Portuguese population that indicated having a "Very good or good" health status by socio-demographic categories.



Graph 16. Population Self-assessment of health status in 2020-2021 [33].

The analysis by age group shows a decrease in the proportion of people with a positive evaluation in 2021, from 93.2% in the first 10 years of life to 11.3% after 80 years of age, and a strong increase in the intensity of variation from 40-49 years of age onwards. In the opposite direction, an increase in the proportion of people with reasonable health throughout the first 60 years, and a reduction in the more advanced age groups, is highlighted.

Presence of chronic conditions

In 2021, 43,9% of the population aged 16 and over reported having a chronic disease or long-term health problem, up 0,7 p.p. from 0.7% higher than in 2020 (43,2%) and 2.7% higher than in 2019 (41,2%).

This condition affected more women (47.0%) than men (40.4%), and especially the population aged 65 and over (71.4%, compared to 34.1% for the population under 65). On the other hand, this situation was considerably lower for the population who had completed secondary education or higher education (in both cases, around 31% in 2021), compared to the population with basic education (53.3%) and the population without any completed level of education (80.1%) (OECD 2020).





By employment status, it is clear that the prevalence of chronic morbidity is higher among the retired population (71.1%) than among the employed population (30.9%) or the unemployed population (40.6%).

Also, the proportion of people who reported having limitations was considerably lower for the population who had completed secondary or higher education (22.1% and 20.1%, respectively), and for the employed population (22.4%). In 2021, an increase was recorded in the existence of limitations in the performance of activities due to health problems compared to previous years.

In 2020, the number of medical consultations in hospital outpatient units decreased by 12.7% compared to 2019. Public hospitals held 62.2% of the total number of outpatient medical consultations in hospital settings.

The specialist departments with the highest number of consultations in general hospitals were Orthopaedics (8.6%), Ophthalmology (7.5%), Gynaecology-Obstetrics (7.3%), Paediatrics (5.0%), General Surgery (4.7%), Psychiatry (4.5%) and ENT (4.5%) (OECD 2020).

Physical and mental health

In Portugal, more than ¼ of the population reported experiencing the negative effect of the COVID-19 pandemic on their mental health.

By 2021, 26.6% of the population aged 16 and over reported experiencing the negative effect of the COVID-19 pandemic on their mental health.

This situation was mentioned more by women (30.2%) than men (22.4%) and in quite similar proportions in the population under 65 (26.8%) and in the older population (25.9%).

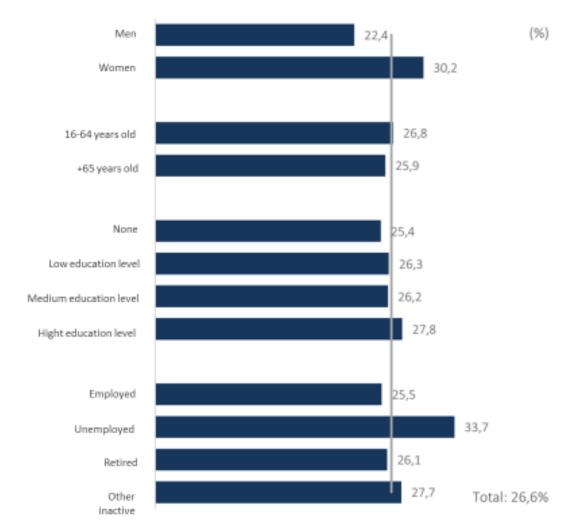
By level of education, although without very significant differences, the population with a completed higher education registered a proportion of 27.8%, higher than the national average, and the population without any completed level of education had a proportion of 25.4%.

By labour status, it is in the unemployed population that this indicator reached the highest value (33.7%), 7.1% above the average.

Regarding physical health, in the Portuguese population, there exists a lack of physical activity as well as overweight and obesity, situations that directly influence mental health [34].







Graph 17. Population with negative mental health effects due to the COVID-19 pandemic [33].

The DGS - General Directorate of Health has included the National Programme for Mental Health within the Priority Health Plans, with the intent to boost the monitoring of the mental health of the Portuguese population, the implementation of programmes to promote the well-being and mental health of the population and the prevention, treatment and rehabilitation of mental illnesses. It also aims at encouraging the articulation of specialised mental health care with primary health care, developing the National Network for Integrated Continued Mental Health Care and boosting the participation of users and carers in the rehabilitation and social integration of people suffering from serious mental problems [35].

Participation in society

Regarding participation in society, namely concerning the relationship that the population maintains with friends and family, we can observe the results in the table below.





FREQUENCY		Every day	Every week	Once a month	Several times a month	Not in the last 12 months	At least once a year
Total	Family and relatives	32,6	38,6	7,8	10,9	3,3	6,9
Total	Friends	36,7	33,3	8,2	10,8	5,6	5,4
Male	Family and relatives	31,2	38,6	8,3	11,7	3,2	7,1
IVIAIC	Friends	42,1	32,4	6,9	10	3,8	4,7
Female	Family and relatives	33,8	38,5	7,4	10,2	3,3	6,7
remaie	Friends	32	34,1	9,3	11,4	7,2	6
16-24 age group	Family and relatives	29,4	40,7	8,5	12	2,8	6,6
10 24 agc group	Friends	69,1	20,9	2,3	4,9	1,8	1
25-34 age-group	Family and relatives	33,3	39,9	9,1	10,2	2,3	5,2
23 34 age group	Friends	38,6	40	6,7	10	2,1	2,5
35-49 age-group	Family and relatives	31,5	41,5	7,4	10,7	2,9	6
	Friends	31,2	37,8	10,5	12,3	3	5,2
50-64 age-group	Family and relatives	31,5	37	8,8	11,7	3,5	7,7
	Friends	32,8	32,7	9	11,7	7,1	6,6
65-74 age-group	Family and relatives	36,3	35,7	6,6	9,5	3,7	8,1
os 74 age group	Friends	31,9	31,1	9,3	11,7	8,9	7,1
Low education	Family and relatives	32,2	38	8,5	10,2	4,2	6,8
level	Friends	71,9	17,4	2,2	4,8	2,3	1,4
Medium	Family and relatives	27,5	41,5	9,3	13,8	1,6	6,3
education level	Friends	69	22,2	2,3	4,5	1,6	0,4
Hight education	Family and relatives	22,9	51	4,9	14	0,4	6,9
level	Friends	55,2	33,5	3,3	7,1	0	0,9

Table 4. Participation in society (%) in 2015 [36].

From the data in the table above, it can be seen that the Portuguese population has a significant percentage of people who do not maintain regular social contact (daily - 28.9% or weekly - 30%).

Young people are the ones who maintain more social contact with friends, while women have less contact. Concerning the level of education, the difference is not significant.

Concerning the older population, there is a percentage of 27.9% of people do not regularly maintain social contact with their family and relatives and 37% that do not have regular contact with friends, synonymous with the isolation and loneliness of this age group.

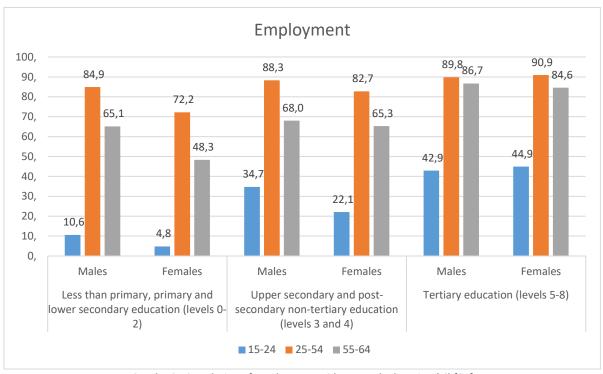
It can also be seen that, as age increases, the social relationship with family and relatives members decreases.





Employment

In the graph below, the relationship between employment, age and level of education are portrayed:



Graph 18. Correlation of employment with age and education (%) [37].

When we relate employment with age and education level, we find that the highest employability is in the 25-54 age group, reaching the highest percentage in the population with the highest levels of education, with no gender difference. In the population with a low or medium level of education, the gender difference is already more significant, with men having higher percentages of employability. The main factor is that, in different age groups, employability increases with the level of education.

Illiteracy and low literacy

According to data from the last Census carried out, the illiteracy levels in Portugal are as follows:

Illiteracy rate (%) by Place of residence and Sex - Decennial - INE, Population and Housing Census - Census 2021					
Place of residence	Total	Men	Women		
Portugal	3,08	2,10	3,96		
Continent	3,04	2,03	3,95		
Azores Autonomous Region	3,10	3,40	2,82		
Madeira Autonomous Region	4,51	3,68	5,24		

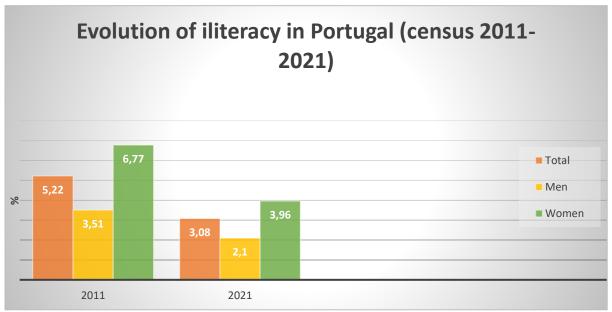
Table 5. Illiteracy rate (%) [38].





Portugal still has a total of 3.08% illiterate people, of which 2.10% are men and 3.96% are women, with only the Autonomous Region of the Azores having the opposite situation. In the Autonomous Region of Madeira, the levels of illiteracy are higher than in the other regions.

The evolution of illiteracy in Portugal from 2011 to the 2021 census shows a considerable decrease, especially in women (see Graph 19).



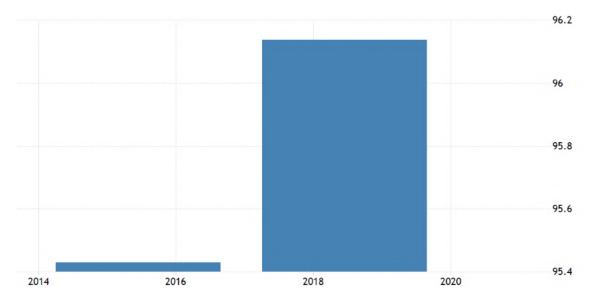
Graph 19. Evolution of adult illiteracy (%) [39].

According to the Trading Economic indicators, the adult literacy rate is the percentage of people aged 15 and above who can both read and write with an understanding of a short simple statement about their everyday life. Generally, literacy also encompasses numeracy, the ability to make simple arithmetic calculations [40].

The adult people's literacy rate, in Portugal, was at 96.14% in 2018, according to the World Bank collection of development indicators (see Graph 20).

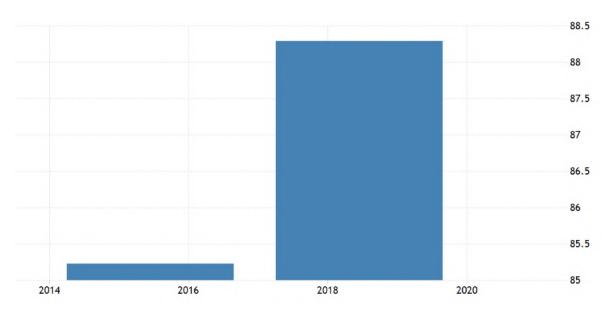






Graph 19. Total adult literacy rate (% of people ages 15 and over) [40].

The older people's literacy rate, in Portugal, was 88.3 % in 2018 (see Graph 21). Furthermore, considering gender, the female literacy rate was 85.07%, while the male literacy rate was 92.75%.

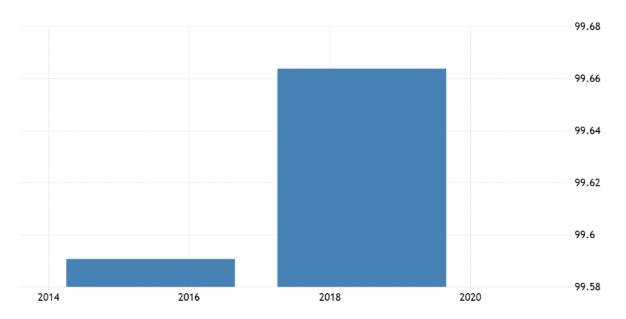


Graph 20. Total older people literacy rate (% of people ages 65 and over) [40].

The youth total literacy rate in Portugal was 99.66 % in 2018 (see Graph 22).







Graph 21. Total youth people literacy rate (% of people ages 15-24) [40].

		Low Education level		Medium Education level		gh on level
Age	16-64	65+	16-64	65+	16-64	65+
2019	70,9	29,1	94,1	5,9	90,5	9,5
2020	67,9	32,1	93,9	6,1	89,1	10,9
2021	65,8	34,2	93,5	6,5	88,9	11,1

Table 6. Educational level (%) [41].

According to the data in the table above (PORDATA), it can be seen that the percentage of the population aged 16-64 with the lowest level of education has been decreasing over the years. Regarding the population with medium and high levels of education, there has been a decrease, but not significant.

On the other hand, in the population, aged 65 years and over, the percentage of the population with the lowest level of education has increased together with the percentage with medium and high education levels. However, the highest percentage of the population aged over 65 years corresponds to the lowest level of education.

The minimum compulsory level of education is the middle level, where the highest percentage of the population aged 16-64 years is found, in contrast to the lowest level, where the lowest percentage is found.

Considering the increase in life expectancy and the consequent ageing of the Portuguese population, we can conclude that, as this is the age group with the lowest literacy levels, it is essential to adopt measures to improve their literacy.

In Portugal, educational attainment plays a decisive role in average health literacy levels. We found that the higher the level of education, the higher the levels of health literacy, with





individuals with the 1st cycle of basic education showing the lowest results in comparison to the groups of other levels of education [42].

The population with lower levels of education show difficulties in skills such as reading and calculation, related to the consultation and interpretation of the information provided, as well as making inferences and mental calculations, not being able to use written information related to health effects (Fundação Calouste Gulbenkian, 2015).

Although the levels of literacy in Portugal have improved in recent years, it is still below the European average, and the education of the population is a point to work on, but it is an action that will take time to produce effects [43].

Health mis- and disinformation

A study conducted by a researcher from the Institute of Public Health at the University of Porto found that 73% of the population has difficulty accessing, understanding and using health information [44]. There is also a need to teach health professionals how to communicate with patients to mitigate the problem.

Health literacy levels decrease with age and low education levels and, following low levels of digital literacy among older and less educated people, access to online health information is limited.

The ERS - Entidade Reguladora da Saúde (Health Regulatory Authority) makes the frequently asked questions on access to health information available on the website, - including access to services and data protection - and the relevant legislation currently in effect, with the intent to guide the user [45].

The DGS - General Directorate of Health provides a wide range of information on health in Portugal, namely the General Health Plan, Health Programmes, Primary Health Programmes and the Prevention of Violence in the Life Cycle.

In Portugal, with the digital renewal of public service in recent years, including the health sector, there are several reliable information sources (public and private) where the population can obtain information appropriate to their needs. In this way, the process of empowering people with digital skills to access the available information will allow them to make choices regarding health care and, in addition, will contribute to the elimination of health disparities.

Nevertheless, with the increasing use of the internet and social media, non-credible sources are increasingly consulted, leading to further misinformation. Portuguese seek diagnosis, help and advice through internet searches and self-help tools, considering them reliable sources of health information. The lack of criticism to question what we see, read and hear allows fake news to increasingly become a danger for health misinformation [44].







ec.europa.eu/eurostat

Figure 12.. Share of people seeking health information online [46].

According to the EU statistics office, in Portugal, the share of people seeking information online was lower than the European average.

Almost half of the Portuguese (49%) aged between 16 and 74 years searched online for health information related to injuries, illnesses, nutrition, health improvement or similar in 2020.

Despite the pandemic, the figures recorded by Portugal in 2020 are similar to previous years: in 2019 it was also 49% and in 2017 more Portuguese (51%) searched for health information on the Internet. Still, looking at the Eurostat data, in general, the trend of demand is increasing.





Evolution of seeking health information online						
TIME	2018	2019	2020	2021	2022	
All Individuals	44,59	49,41	48,98	53,33	49,46	
Individuals, 16 to 24 years old	57,07	67,13	65,33	63,73	61,03	
Individuals, 25 to 34 years old	66,29	76,36	67,04	77,23	64,92	
Individuals, 35 to 44 years old	61,96	68,19	64,68	71,77	65,00	
Individuals, 45 to 54 years old	44,56	50,35	52,85	56,54	56,16	
Individuals, 55 to 74 years old	22,16	23,16	26,36	30,28	28,09	
Individuals with no or low formal education	27,21	28,79	27,55	29,99	27,07	
Individuals with medium formal education	60,00	67,86	61,81	68,32	61,35	
Individuals with high formal education	68,01	74,34	73,78	76,01	70,05	

Table 7. Seeking health information online (%) [47].

By analysing the table above, it can be seen that the age group that least uses the Internet to search for health information is the 55-74-year-olds and the groups that use it the most are the 25-34 and 35-44-year-olds.

On the other hand, the Portuguese with the lowest levels of education are those who least use the Internet to search for health information and those who use it the most are those with the highest levels of education.

3.3 Intersectional analysis

In summary, it can be stated that digital literacy levels among Portuguese citizens are low for the needs of the current world. Portugal met the European target of 50% of basic digital proficiency. However, a disproportionate amount of digital illiterates are present among older people and people with lower education or income.

Older age, low education, and low-income background negatively influence digital, health and data literacy rates in Portugal. In older generations, the main problem is low digital proficiency. This problem is reinforced by the decreasing participation of older people in society. Moreover, people with a low education background are less likely to be employed and more likely to have a low income and a low social status. More focus should be put on health promotion and disease prevention, including nutrition and lifestyle.

Digital tools are a strong instrument to disseminate health information and to promote and develop health actions and health literacy promotion, especially for the youngest and most educated. They can also promote empowerment and more control over health prevention and promotion if the 3 literacies are reinforced throughout the whole society.

For older adults and people of all ages in an occasional or chronic situation of disease, digital tools can make a huge difference to ensure telecare, home care and more autonomy from hospitals and residential units. The three areas are directly related: low digital literacy makes for low health literacy - same for data sharing literacy.





4. Reported and identified gaps, needs and demands

4.1 Identified gaps

Desk research

General digital literacy levels:

- Increase the level of education of the population as a way to improve levels of digital capability
- Increase digital literacy levels as a way to improve access to digital tools and reduce inequalities

General health literacy levels:

- Review of communication channels used for health information (considering the socio-demographic factors)
- Assess patients' numeracy skills can be instrumental in improving appropriate medication use and preventing dosing errors
- Information to the population about the entities that provide reliable health information and about the type of information that may be unreliable
- More information on mental health and creating ways to eliminate stigma on these pathologies
- Promotion of telecare and home care

General data literacy:

- Improvement of data information, both in quantity and quality (accessible also to the population with low levels of education and digital skills)
- Information/awareness-raising campaigns on data protection
- Training on the use of SNS 24 (access and change the accessibility of personal information)

Health promotion:

- Accessing information and applying information on disease prevention
- Information on the importance of regular measurements of health indicators and ways of measuring/recording them
- Information/awareness-raising campaigns on health promotion
- Increase socialisation

Intersectional analysis:

- Reduce inequalities in income to facilitate digital access and thus eHealth
- Training on the use of the tools made available to the population, especially by public services (the tools exist but the skills to use them are lacking)





- Improved access to telemedicine
- Increase the information about data literacy with a simple language that is accessible to the general population

Interviews

- Extending access to broadband networks in more remote locations (a factor of exclusion that the CoVID-19 pandemic has highlighted)
- Clarify the benefit/cost of using digital tools
- The Personal Health Record (all the user's clinical data is gathered) should have the
 entire medical history (including the public and private health system), with an
 electronic health record that can be accessed anywhere, even in another country,
 taking into account the Directive on Cross Border Care (the goal of SNS24 is that, but
 it's not working yet).
- Streamlining health information in an accessible, simple, appealing way, for a better understanding, thus reducing inequalities in access
- Patients overvalue the role of the doctor-patient relationship as a facilitator of communication in the consultation
- Differentiation and analysis between what is urgent and what is not urgent. The response capacity of an emergency number, such as SNS 24, allows triage, which is essential for referral, either to the hospital or to health units
- Increased provision of primary health care and health promotion programmes

4.2 Identified needs and demands of target groups

Digital Literacy:

Older people, low level of education, unemployed, on low incomes, living in rural areas

- Increase digital competences
- Increase confidence in using digital tools
- Training tailored to needs
- Increase access to the internet and technologies

Health literacy:

Older people, low level of education, low income

- Simplify existing information about health
- Encourage preventive medicine by reducing risk behaviours
- Improve the communication skills of professionals





- Promote telecare and home care
- Increase the provision of primary health care and health promotion programmes
- Increase socialisation

Data literacy:

Older people | low level of education | low income

- Simplify existing information about data
- Training tailored to needs
- Information on citizens' rights

4.3 Suggested learning needs target groups

Older people | low level of education | low income | living in rural areas

- know how to search for information
- read health data
- save data digitally
- use the alert function of the mobile phone
- use an application to track health
- read information data with graphics
- access health data on the internet
- identify what is important to accept/not accept in an application.

In general:

- ability to access their health data
- ensure health data is protected
- decide with whom health data will be shared
- identify the veracity of health information on the internet
- identify why some health applications are safer than others
- distinguish which health service to go to in a given situation (emergency/nonemergency).





5. Examples of good practices and educational training offer

https://portugaldigital.gov.pt/

Available training in digital skills

https://portugaldigital.gov.pt/plano-de-acao-para-a-transicao-digital/

The Action Plan for Digital Transition reflects the strategy defined for the digital transition, materialised in the Portugal Digital Mission Structure. This includes three main pillars of action:

- Training and digital inclusion of people
- Digital transformation of the business structure
- Digitalisation of the State

https://repositorio.ul.pt/bitstream/10451/36790/1/Activities for Digital Inclusion FINAL.p df

LIDIA project – Adult Digital Literacy - Activities for Digital Inclusion of Adults

https://www.cases.pt/rutis-universidades-academias-seniores/

RUTIS (Associação Rede de Universidades da Terceira Idade) is a Private Institution of Social Solidarity (IPSS) and Public Utility supporting the community and senior citizens, on a national and international scope.

https://www.academia.edu/22897188/O Ensino das Tecnologias da Informa%C3%A7%C 3%A3o e Comunica%C3%A7%C3%A3o aos Cidad%C3%A3os Seniores em Portugal

Experiences of teaching information and communication technologies (ICT) to senior citizens that took place in the north of Portugal, namely in Private Social Security Institutions (IPSS), in a training course at the University of Aveiro and a Senior University.

https://www.splsportugal.pt/

An institution created in 2022 that aims to contribute, through a set of strategies, to literacy in individual, organisational and public health, for better health and well-being of people, in their life cycle, with arts, techniques and communication.

https://www.splsportugal.pt/ files/ugd/b5314a dc2df8f771cd45f396e45b961bdab1f6.pdf Health Literacy and Young People

https://www.dgs.pt/documentos-e-publicacoes/manual-de-boas-praticas-literacia-emsaude-capacitacao-dos-profissionais-de-saude-pdf.aspx

The Directorate-General for Health has developed the "Health Literacy Best Practices Manual - Empowerment of Health Professionals", which is intended to be a tool to contribute to the increase of health literacy levels of the Portuguese population.





https://www.dgs.pt/documentos-e-publicacoes/plano-de-acao-para-a-literacia-em-saude-2019-2021-pdf.aspx

ACTION PLAN FOR HEALTH LITERACY ACTION PLAN PORTUGAL

To increase the levels of Health Literacy, improve people's critical thinking skills in matters regarding their health and provide services and professionals with appropriate tools for this purpose, which poses a challenge to public health in Portugal.

https://vohcolab.org/

VOH.CoLAB is a non-profit private organization whose mission is to measure value in Health.

https://www.iniciativaeducacao.org/en

The goal of Iniciativa Educação is to help ensure young people achieve educational success, by supporting exemplary projects that have the potential to be replicated in both the educational system and in society at large. The promoters approved the beginning of the activities with three projects that aim to promote reading and literacy, enhance professional training, and disseminate knowledge and information about education.





6. Suggested input for TRIO training and education

Navigating the internet

- Searching and accessing websites
- Information on the different training offers available
- Accessing, understanding and using health information
- Knowing which sites contain trustworthy information
- Information that helps younger people "teach" older people how to use the tools

Health promotion and disease prevention

- Information on health promotion and well-being and its relation to the prevention of certain pathologies
- Recording of control measurements (diabetes, blood pressure, weight, etc.)
- Information on payment/purchasing models for medical devices
- Information on existing tools
- How and where to find credible health information
- Identification of available services and devices

Telehealth

- Information on available tools
- Recording of control measurements in SNS24 (diabetes, blood pressure, weight, etc.)
- Tele-consultations and telecare

Health portal and data security

- Information on data terms (meaning and application)
- Usage of tutorials (e.g. SNS24 website and application)
- Accessing and changing health data
- Information about rights, duties and precautions concerning medical data
- Identification of available services and devices
- The benefits/costs of using tools





7. Relevant stakeholders and potential cooperation partners

Agency for Healthcare Research and Quality - Tools and up-to-date information about HL. https://www.ahrq.gov/health-literacy/index.html

Centres for Disease Control and Prevention - Information on HL research, application and evaluation. https://www.cdc.gov/healthliteracy/index.html

Health Literacy Online - A research-based guide to help and develop intuitive health websites and digital tools that can be easily accessed and understood by all users. https://health.gov/healthliteracyonline/

National Institutes of Health - Links to information designed to support public health and science communicators to disseminate health information. https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication

The Institute for Healthcare Advancement (IHA) - This institute is dedicated to empowering people to have better health. It organises conferences, and sponsors and runs the Health Literacy Solutions Center forum, among other activities. https://iha4health.org/

Plain Language Association International (PLAIN) - This association brings together professionals from all over the world and from different fields around plain language. https://plainlanguagenetwork.org/

Health Literacy Month Handbook: The Event Planning Guide for Health Literacy Advocates – Guide to boosting activities and communications, with ideas for initiatives and strategies for evaluating their results. https://healthliteracy.com/health-literacy-month-resources/

Portuguese Society for Health Literacy - It aims to promote, develop and improve the practice of Health Literacy in Portugal. https://www.splsportugal.pt/

Healthwords | Patrícia Rodrigues – It aims to disseminate scientific information (appropriate to the target audience), increase health literacy, promote healthy behaviours and choices, educate about health, improve the communication skills of health professionals and improve the health and well-being of the population. https://healthwords.pt/servicos/

Portuguese Protective Association of Diabetics - Courses and educational material for health professionals and people with diabetes, family members and carers. https://apdp.pt/

Make Code project - A digital literacy project to support schools run by the Youth Foundation. It uses learning tools based on computer games, motivating students to learn and thus facilitating the educational task of teachers and schools. https://portugal2020.pt/promover-a-literacia-digital-nas-escolas/

COMEDIG project - Digital and Media Literacy Skills in Portugal - Coimbra University. https://www.uc.pt/fpce/comedig/workplan





National School of Public Health - New University of Lisbon - Health Literacy, Health Promotion and Social Cohesion in Migrant Populations. https://www.ensp.unl.pt/projectos/literacia-em-saude-promocao-da-saude-e-coesao-social-em-populacoes-migrantes/

Health in Knowledge Project – Ciência Viva - National Agency for Scientific and Technological Culture - aims to disseminate the research carried out in the area of health, seeking to promote greater knowledge and involvement of society in this scientific area, thus contributing to the scientific culture in Portugal. https://www.oftalpro.pt/2021/01/13/mais-literacia-em-saude-com-o-projeto-a-saude-no-saber/

ISCTEC – University Institute of Lisbon - Iscte-Health - Development, capacity building, and health training. Interdisciplinary space for applied health research. Internationalization of Iscte_Health. https://www.iscte-iul.pt/conteudos/iscte-saude/2079/

Quotes of interviewees

[On the topic of equal access to health] "In addition, the existence of a differentiated health subsystem for civil servants has been widening the gap between those who can only access public SNS resources (with severe constraints on waiting times, for example) and those who can choose the clinicians and therapists they want." [36-50, high education].

[On the topic of the accuracy of the information on the internet] "I don't venture out, precisely because I feel difficulties of choosing the best." [36-50, low education].

[On the topic of the online learning platform] "Yes, because I think it is important to be up to date. For me, it would be easier using explanatory text and images." [18-35, medium education]; "No, because of age and not working with the internet" [>51, low education].

[On the topic of barriers to the use of digital health tools] "The lack of digital knowledge and skills." [Adults education].

[On the topic of eHealth tools missing] - "Clearly, there is a need for a Personal Health Record where all the clinical data of the user is aggregated. In terms of services, I think that within the SNS framework some steps have been taken in primary health care, but there is no record kept for the user of their hospital journey." [Senior Consultant on Innovation and Information/Communication Technologies].

[On the topic of where medical data is stored] - "I don't think so, I don't know. I never understood where our data is kept, some are in the DGS, others in the hospital, and others got lost. So I don't know where they are kept, who has them and who is in charge of them." [Clinical Research].





8. Resources

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9. Annex 1 - Interview questions

Lead questions for interviews with citizens

Introduction to the TRIO project:

Our healthcare system is being digitalised very rapidly, but not everyone has the digital skills, the health information skills, or the data skills to keep up with this change. The TRIO project aims to help people improve these three skillsets, so that the healthcare system will remain accessible for everyone. For this purpose we are developing several tools: a manual, a toolkit, a Green Paper, and an online learning platform for adult education. But first we need to investigate where exactly the gaps and needs are and how we can best personalise our tools to fit these needs? For this purpose we are interviewing people from different age groups and educational backgrounds, as well as professionals in healthcare and policymaking.

Use of data:

The interview will first be summarised and then sent back to you for revision. The summary will be used as an information source in our national report, but will not be transcribed literately. The answers you give are completely anonymous. We may ask you if we can include a quote in the report, but your name will not be mentioned. Instead we will group all interviewees by age and level of education, and any quotes will be referenced as such.

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Age:
Gender:
Country of birth:
Educational level (ISCED 2011 level 0-8): (partners search for the allocatio

Educational level (ISCED 2011 level 0-8): ... (partners search for the allocation of their national education programs into ISCED 2011)

Background in professional and/or voluntary work: ...

- Q1 Do you think that basic healthcare in your country is equally accessible for everyone? In the financial sense, as well as in terms of physical and mental capability.
- **Q2** Do you know how to search for health information on the internet? If so, how would you do that?
- Q3 How can you tell if the health information you find on the internet is accurate (and not incorrect or misleading?)?
- **Q4** How useful do you feel the internet is in helping you make decisions about your health?





- **Q5** Do you make use of any online medical portal [include country-specific example. If this does not exist in your country the question could be: Would you make use of an online medical portal if this was available to you?]? If yes, why? If no, why not?
- Q6 Do you know where your medical data is stored? If so, where?
- Q7 Do you know who has access to your medical data? If so, who?
- **Q8** Do you find your medical file to be easy to understand? For instance, do you have trouble reading medical documents, such as examination reports or blood tests? Do you understand medicine dosing instructions?
- **Q9** Do you know if and how you can access your medical file and make changes to its content and accessibility? For instance, if you want to delete part of your medical history or make sure other healthcare professionals cannot access it, do you know how to proceed?
- Q10 Do you use any digital tools to keep track of your doctor's appointments or medication schedule, like a phone calendar or alarm? If so, do you find them easy to use? If not, do you know where to find these and how to use them?
- Q11 Do you use any application to help you monitor your health, such as keeping track of your weight, blood pressure, or blood sugar levels? Is it something you use? If so, what does it do?
- **Qop1** Is it common for you to be asked to sign a document containing your personal information when you go for a medical examination? Can you read and understand the document? [optional question, for when applicable to your country]
- **Qop2** Are you able to tell the doctor about the medical history you have? Is it necessary to bring your previous exams? [optional question, for when applicable to your country]

The next few questions will focus on the TRIO project in particular

- Q12 Would you be interested in using an online learning platform and/or a manual to improve your digital health skills? If yes, why? If no, why not?
- Q13 If you would use an online learning platform, what form of information (e.g. explanation texts, images, videos, exercises, etc.) would be most helpful for you?
- Q14 What do you think would be a good way to encourage people, e.g. those with socioeconomic or health issues, or people of older age, to participate in a training for improving their digital health and data literacy?





Lead questions for interviews with experts

Introduction to the TRIO project:

Our healthcare system is being digitalised very rapidly, but not everyone has the digital skills, the health information skills, or the data skills to keep up with this change. The TRIO project aims to help people improve these three skillsets, so that the healthcare system will remain accessible for everyone. For this purpose we are developing several tools: a manual, a toolkit, a Green Paper, and an online learning platform for adult education. But first we need to investigate where exactly the gaps and needs are and how we can best personalise our tools to fit these needs? For this purpose we are interviewing people from different age groups and educational backgrounds, as well as professionals in healthcare and policymaking.

Use of data:

The interview will first be summarised and then sent back to you for revision. The summary will be used as an information source in our national report, but will not be transcribed literately. The answers you give are completely anonymous. We may ask you if we can include a quote in the report, but your name will not be mentioned. Instead we would reference you by your profession.

Get signed version of the permission form

Organisation: ...

Professional background: ...

- Q1 In your line of work, do you meet many people with poor digital-, health- or data literacy skills?
- **Q2** If so, are there socio-economic or demographic variables that you feel are linked to this?
- Q3 In your opinion, which benefits and which problems arise from the digitalisation of the healthcare system?
- **Q4** Do you yourself make use of online health tools, such as health portals, medical websites or online health support?
- Q5 In your opinion, what are the most important digital health tools for people? Examples: Medication reminders on cell phones? Yes or no. Posting medical monitoring information such as weight, blood pressure and sugar levels? Yes or no. Accessing pharmacy prescription? Yes or no.
- **Q6** Which online health tools are missing or not made properly available to everyone?





- Q7 What do you feel are the main barriers preventing people from using digital health tools?
- **Q8** How can we use policy to help a wider range of people access online health information?
- **Q9** Do you think that it is known to people where their medical data is stored? Do you know yourself where your medical data is stored?
- Q10 Do you think it is important for people to have insight into their own medical history by using an online platform? Do you think this is [for countries that already have this] / would be [for countries that don't] easy to use?

The next few questions will focus on the TRIO project in particular.

- **Q11** What information should the TRIO learning platform contain so that it is useful for people? And what form of information (e.g. explanation texts, images, videos, exercises, etc.) would be most helpful?
- What should an online learning platform contain so that it is more attractive to people with fewer opportunities (e.g. those with socio-economic or health issues, or people of older age)? How can we accommodate people who have less opportunities (for example due to financial or health issues) to use the e-learning platforms? What is needed for them?
- Q13 How could we motivate people with poor eHealth skills to participate in an online learning platform?
- **Q14** Do you have ideas or know about inspiring examples to improve access and understanding of digital health data?

