AAL Project

Indoor and outdoor NITICSplus solution for dementia challenges

WP3: Pilots with primary and secondary users

D3.2: End-user classification and differentiation

Contractual Date of Delivery to the AAL CMU: M12

Actual Date of Delivery to the AAL CMU: M14

Participant(s): CITST[2], EXYS[1], UPB[3], IZRIIS[4], ASLO[5], WUT[6], DGW[7], BZN[8], ASH[9], SOFTIC[10]

Author(s): Oana Cramariuc[2], Jaouhar Ayadi[1], Angelo Consoli[1], Irina Mocanu[3], Neja Samar-Brencic[4], David Krivec[5], Jerzy Kolakowski[6], Katarzyna Broczek[7], Denes Perenyi[8], Zsuzsanna Nagymáté[9], Eszter Lena Matis[10]

Nature: R (P-prototype, R-report, O-other)

Dissemination: Public

Version: 4

Total number of pages: 26

Abstract:

The report describes activities carried out within Task 3.2 (Work Package 3). This task aims to prepare for the user involvement in the pilots. The outcome of this task is both a description of the target groups which will be selected for the field trials and a description of various use-case scenarios of these groups. We have defined and organized the end-users into different groups according to dementia specific needs and the support from the IONIS functionalities. The input given by the end-users in WP1 was taken as the basis of the categorization. Various selection and classification criteria are considered and justified. UML diagrams are constructed to illustrate use case scenarios of how different target groups interact with IONIS. Some of these scenarios will be considered for end-user evaluation in one or more of the end-user countries.

Keyword list: AAL, UML, use-cases, demographics

Executive Summary

The report describes activities carried out within Task 3.2 (Work Package 3). The outcome of this task is both a description of the target groups which will be selected for the field trials and a description of various use-case scenarios of these groups. We started by classifying the end-users into different groups according to dementia specific needs and the support from the IONIS functionalities. Next, dementia specific characteristics were presented and considered in the framework of the IONIS project. For example, for the purpose of the IONIS project the Mini-Mental State Examination (MMSE) was chosen as a primary tool for cognitive assessment and primary user selection. The following interpretation criteria are applied: MMSE score 28-30 points - normal cognitive performance; 24-27 points – mild cognitive impairment (MCI); 19-23 points – mild dementia; 11-18 points – moderate dementia; 10 or less points – severe dementia. The inclusion criteria for the IONIS project are: MCI or mild dementia. People with normal cognitive functions as well as those in more advanced stages of dementia are excluded. Similarly, people with severe sensory impairment (blindness of severe hearing loss) or significant motor disorders causing inability to write and complete MMSE were no qualified for participation in the project.

Technology specific criteria are also considered in connection which category of users would need most specific functionalities of the IONIS system. The input given by the end-users in WP1 was taken as the basis of the categorization. Various selection and classification criteria are considered and justified. UML diagrams are constructed to illustrate use case scenarios of how different target groups interact with IONIS. Some of these scenarios will be considered for end-user evaluation in one or more of the end-user countries.

Country specific demographics are also considered. For example, we can consider that internet access reflects to some extend the interest and knowledge about ICT technologies. Some statistics show that, once the elderly are confident enough to use technology, they start using the internet actively, just like younger generations. There are significant differences among the end-user countries regarding elderly use of the internet. Percentages vary from 10% of elderly accessing the internet once a week in Romania to 35% in Hungary. We think that it is safe to assume that the share of people with dementia that use internet is approximately the same, at least in early stages of dementia.

Table of contents

List of figures

List of tables

Abbreviations

AAL	Active and Assisted Living
ADL	Activities of Daily Living
CMU	Central Management Unit
DoW	Description of Work
EC	European Commission
EU	European Union
GA	General Assembly
GDS	Geriatric Depression Scale
IADL	Instrumental Activities of Daily Living
JP	Joint Programme
ICT	Information and Communication Technologies
IONIS	Indoor and outdoor NITICSplus solution for dementia challenges
MMSE	Mini Mental State Examination
PC	Project Coordinator
PDF	Portable Document Format
PwD	Person with Dementia
WP	Work Package
REM	Rapid eye movement sleep

1 Introduction

WP3 aims to test, optimize and validate the IONIS platform with primary and secondary users who will use the platform while performing their daily life activities (both indoor and outdoor). The goal is to have a considerable number of users test the platform for extended periods of time. Both the technological solution and the associated services developed within IONIS will be tested, optimized and validated. This WP will provide feedback to WP2 to perform the needed adjustments and tune-up the system, gather end-user feedback and validate the platform. Field trials in real-life settings will be conducted in different countries with help of the end-user organizations. Within WP3.2 which aims at “End-user groups classification and differentiation” we have defined and organized the end-users into different groups according to dementia specific criteria and the support from the IONIS functionalities. The input given by the end-users in WP1 was taken as the basis of the categorization. Various selection and classification criteria are considered and justified. UML diagrams are constructed to illustrate use case scenarios of how different target groups interact with IONIS.

The IONIS development strategy puts at its core both primary and secondary users. Consequently, there are mainly two types of end-user actors that interact with the system and benefit directly from it. Both primary end-users and secondary end-users benefit directly from the IONIS technology, but primary end-users are the ‘final’ beneficiaries. Secondary end-users mediate the influence of the system on several dimensions of assistance. For instance, a primary end-user may be assisted by a secondary end-user in performing certain daily activities or in support of certain executive physiological or cognitive functions.

2 Primary user classification criteria

Primary end-users can be classified according to a varying number of guiding principles or criteria, ranging in complexity from demographic separators (or categorical identifiers) to health statuses (including cognitive decline) or more elaborate criteria. However, two important selection criteria should be considered starting from the primary end-users targeted in IONIS and from the specific technologies that IONIS will provide to them:

(1) Primary IONIS end-users are people, not necessarily elderly, with mild dementia who are still capable of performing many of the regular indoor and outdoor activities despite declining memory and other cognitive functions. IONIS also targets users with Mild Cognitive Impairment (MCI) whose cognitive changes are serious enough to be noticed by the individuals experiencing them or by other people. Users with MCI have an increased risk of eventually developing Alzheimer's or another type of dementia.

(2) Primary end-users are the beneficiaries of the specific technologies that IONIS provides (see Table 1). Obvious criteria arise from the support offered by the IONIS modules to the limitations or needs of the end-users. These modules were described in WP2 and exploited when preparing the multinational survey in WP1.

Table 1. Basic groups of activities together and corresponding specific activities along with the IONIS modules/functionalities addressing them.

Groups	Generic/ broad category of activity	Dementia specificity	Modules/functionalities addressing the problem
Health-related	Health crisis	Higher incidence of falls [1]*	Fall detection
	Health monitoring	diseases which increase the risk for dementia or need monitoring (diabetes, cardio-vascular, obesity)	Monitoring of blood pressure, glucose level, heart rate, weight
	Health related activities	Sleep quality [2,3]** Taking medication Wandering	Sleep monitoring Reminders Detection of wandering and alert to caregiver
Daily activities indoor	Appointments and events (anniversaries)	Forgetting about events, appointments and activities	Calendar with reminders

	Reading, watching TV, working on computer, etc	Finding activity specific objects	Object localization and tracking
Daily activities outdoor	Shopping, exercising, visiting friends, going to the doctor, etc	Wandering	Localization, geofencing and alert to caregiver

* In [1] the authors observed that dementia participants experienced nearly 8 times more incident falls.
** Sleep quality and duration have been shown to also influence the risk of developing dementia.

2.1 Dementia specific criteria

Cognitive changes associated with the process of ageing are a continuum starting with minimal unnoticeable memory decline and in some individuals developing into various stages of dementia. Subjective memory decline affects to some extend the majority of older adults, but about 10% of people age 65 years and over are affected with mild cognitive impairment (MCI) and another 10% fulfil the criteria of dementia. Causes underlying cognitive impairment might be multiple and complex, including the most common: Alzheimer's disease (AD), vascular changes in the brain leading to vascular dementia (VD) and mixed cases (AD+VD). Dementia is a progressive disease, but the time of progression varies among individuals.

Cognitive decline remains often unnoticed and under-diagnosed because an individual cognitive reserve and partially preserved long-term memory allows to perform simple daily tasks and compensates for deficiencies for quite a long time. People with mild dementia might function relatively well in a well-known environment, and they might get lost and disorientated in the face of new tasks or unknown places.

At first, changes aren't especially noticeable but as dementia progress, person needs more and more help completing once simple daily tasks.

At the beginning, person with mild dementia needs more and more encouragement and guidance, to achieve common daily tasks, like brushing teeth, running errands, etc. Because of that it's important that they preserve and consolidate preserved cognitive pathways. In mild dementia we can also observe some behavioural changes. This usually means that some personal characteristics are even more expressed, like shyness, chattiness, etc. It is also common for this stage for person with dementia to be aware of the changes, which can lead to personal distress, depression, etc. Person with mild dementia needs fairly tolerant environment.

Person with moderate dementia already need 24/7 surveillance. They also need a lot of help – they can still achieve a lot, but they pause a lot in the middle of action and don't know how to proceed. They have less awareness of their own changes however they do notice numerous changes in their environment that they cannot explain. Person with mild dementia needs a lot of understanding and support.

In this last stage of dementia, persons with dementia need care and comfort. Persons with advanced dementia usually don't move around much, their body functions are shutting down, communication is limited and they are slowly retiring into they own world. In advanced stage of dementia, the most important part of communication is non-verbal communication.

The process of diagnosing dementia in clinical setting includes: cognitive assessment, brain imaging, and laboratory testing. However, for the purpose of research outside strictly medical or neuropsychological domains, screening test for cognitive performance might be used to assess the mental status of studied participants. For the purpose of the IONIS project the Mini-Mental State Examination (MMSE) was chosen as a primary tool for cognitive assessment. It is a 30-item screening test that is widely accessible, translated to many languages, validated in various settings and relatively easy to perform after appropriate training. The following interpretation criteria were applied: MMSE score 28-30 points - normal cognitive performance; 24-27 points – mild cognitive impairment (MCI); 19-23 points – mild dementia; 11-18 points – moderate dementia; 10 or less points – severe dementia. The inclusion criteria for the IONIS project were: MCI or mild dementia. People with normal cognitive functions as well as those in more advanced stages of dementia were excluded. Similarly, people with severe sensory impairment (blindness of severe hearing loss) or significant motor disorders causing inability to write and complete MMSE were no qualified for participation in the project.

2.2 Technology specific criteria

2.2.1 Health related end-user group

The end-users in this group are characterized by various health conditions. Of particular interests are users with health conditions which are known to increase the risk for developing dementia. Such health conditions are for example cardiovascular diseases and diabetes. During the "Multinational survey" in T1.2 the respondents (121 primary (elderly) and 103 secondary (caregivers)) were asked several questions concerning

their health problems and impairments. Almost 80% of the respondents suffer from cardiovascular diseases and 94% of them take prescription medications every day (see Figure 1).

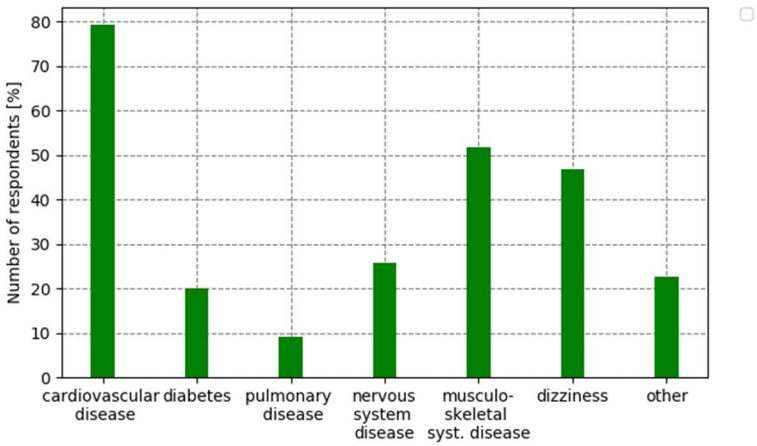


Figure 1. Health problems reported in the multinational survey.

Most of the respondents use a blood pressure meter, a thermometer and a personal scale on a regular basis while 40% measure regularly their glucose blood levels, although only half of them suffer from diabetes. Consequently, IONIS will address this category of user both as pilot users and as end-users of the IONIS commercial platform. The interaction with the IONIS platform of the users in this category is illustrated through two scenarios and the UML diagram in Figure 2.

Scenarios

Mark is a senior living at home. He suffers for cardiovascular condition (high blood pressure, heart disease). If not monitored and kept under control, his cardiovascular condition can lead to a stroke and subsequent vascular dementia. For this purpose, Mark has to measure regularly his blood pressure and maintain a healthy and active life style. Catherine, his nurse, has inputted in the IONIS system's calendar a rule planning Mark's daily physical exercises.

Scenario 1: The system reminds Mark every morning at 9 o'clock to measure his blood pressure and to perform a planned set of exercise. After the completion of the exercises, the system requests Mark to measure his blood oxygen level with the oxymeter integrated in the IONIS platform. Catherine can access a report giving the results (in tabular and graphical form) of Mark's health and activity parameters.

Scenario 2: same as Scenario 1, but now Mark forgets to measure his blood oxygen level. So the system sends a vocal (TTS) alert three times (with a gap of five minutes one from the other) to Mark, but receives no acknowledgement from him back. So the system sends an alert on the Web dashboard to Catherine, in order for her to intervene.

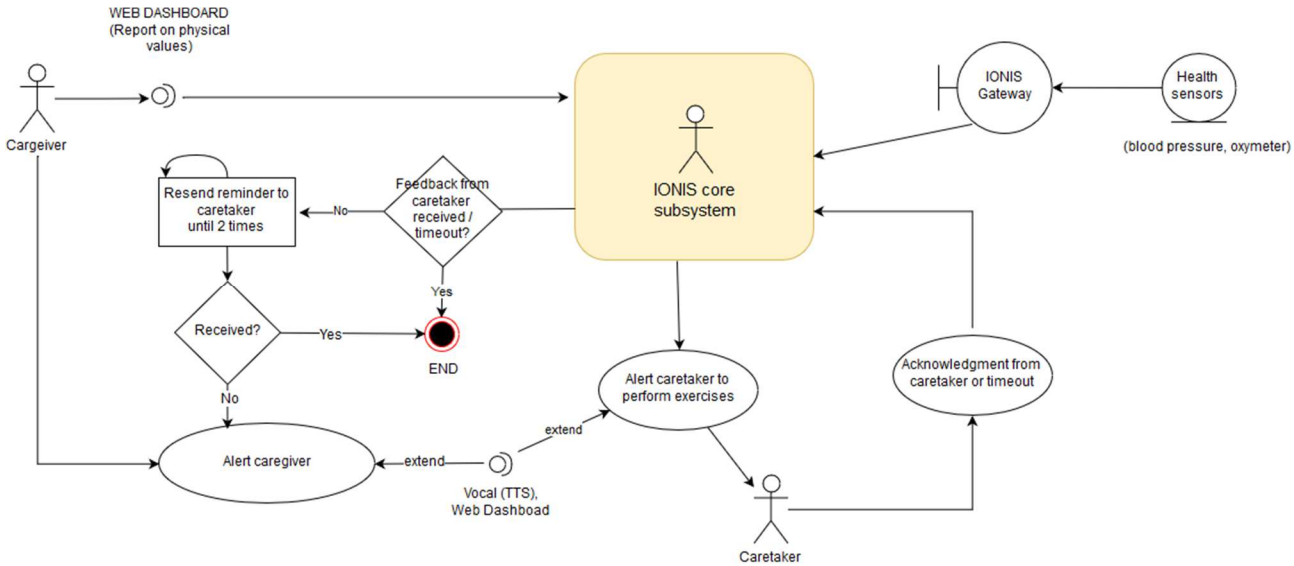


Figure 2. UML diagram of the interaction between the IONIS end-users and the IONIS platform.

2.2.2 Fall risk group of end-users

This group is relatively closely connected to the end-user group exhibiting various health problems as several health conditions can increase the risk of falls (see Table 1). Also people suffering from dementia are known to experience a significant (up to 8 times) higher number of falls [1]. More than 40% of the respondents in T1.2 have problems with balance and walking indoors (Figure 3) and have thus an increased risk of falling. The number slightly increases when persons leave their homes. While, the number of falls reported by the interviewed elderly in T1.2 is relatively small it is by no means negligible considering that falls can even lead to permanent bed immobilization especially in people suffering from dementia.

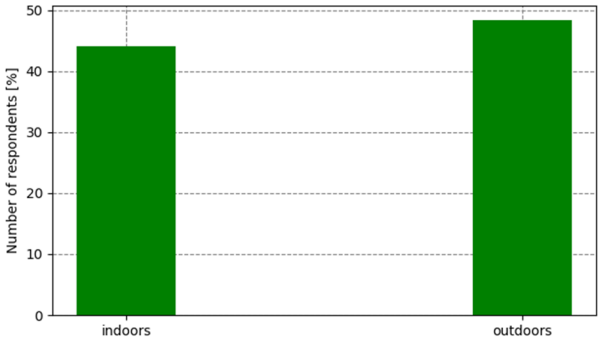


Figure 3. Disorder in balance and walking of the respondents in T1.2.

Thus, while all persons suffering from dementia are prone to falls, the category of users who would mostly benefit from the fall detection functionality in IONIS comprises users who report problems with balance and walking and/or users who have already experienced falls either indoor or outdoor. The interaction of the users (primary user and caregiver) with the IONIS platform in the event of a fall is shown in Figure 4 as UML diagram. The indoor and outdoor scenarios are similar but the devices used for fall detection might be different, i.e. WUT tags for indoor and a smartwatch for outdoor.

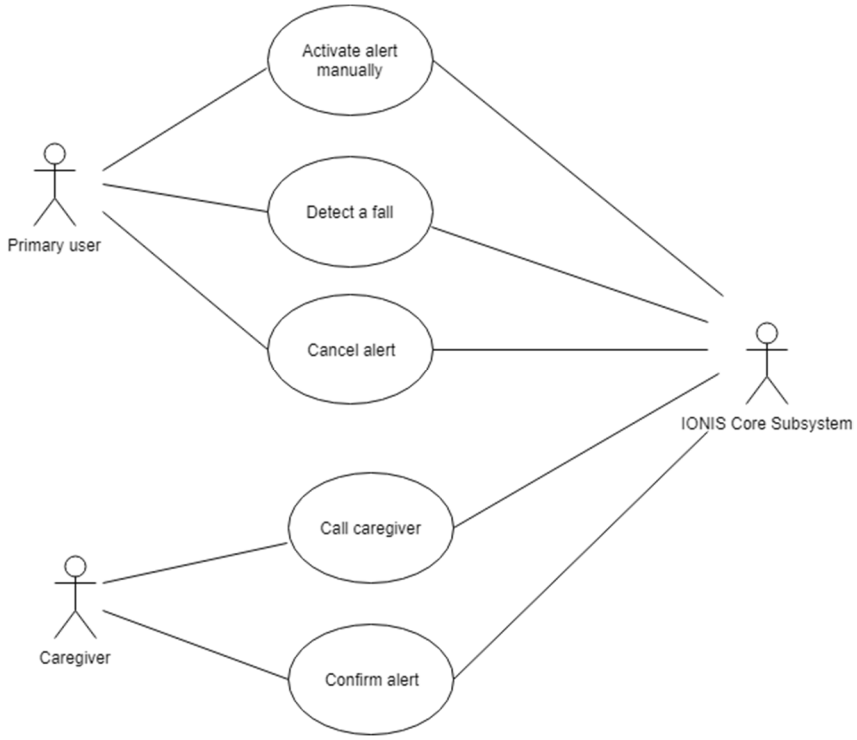


Figure 4. UML diagram showing the interaction of the users with the IONIS platform in the case of a fall.

2.2.3 End-users requiring sleep monitoring

Sleep quality and duration have been shown to also influence the risk of developing dementia [2,3]. In addition, it has been recognized that people suffering from dementia have specific sleep patterns which can help in monitoring disease progression and optimization of their medication. For example, in most cases, patients with dementia experience progressively less REM sleep throughout the night, as well as an increase in nighttime

awakenings [4]. Longer sleep latency, increased sleep fragmentation, and a decrease in both sleep efficiency and total sleep time is also reported in dementia patients. The most common sleep disorder symptoms in patients with dementia are increased daytime sleepiness, night-time wandering, confusion, and agitation (also known as sundowning).

The results of T1.2 reveal that than half of the respondents complain about sleep problems and that one third of them often take sleeping pills (Figure 5).

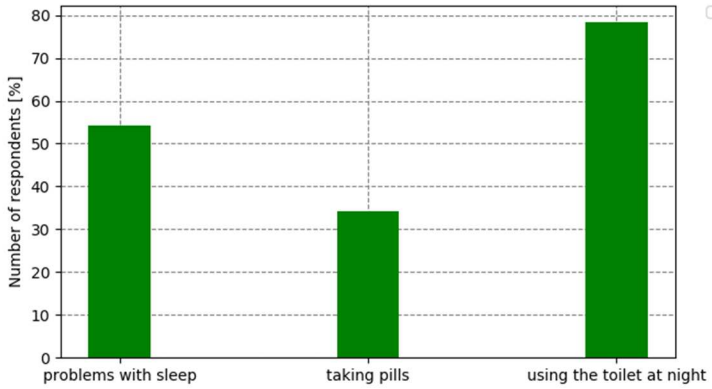


Figure 5. Figures reflecting sleeping problems of the respondents in T1.2.

Thus, all target users of the IONIS platform classify for testing and piloting the sleep monitoring functionality. This functionality will call a caregiver in situations when sleep problems associated with people with dementia are detected. The IONIS platform monitors the parameters that are acquired by a sleep sensor and compares them with parameters from normal periods (from the past). In case of detection of the modification of the sleep parameters, a notification is sent to the caregiver. The caregiver will contact the elderly person under his care to discuss about both sleep problems and daily activities. If the problem persists in the next period (for example, a few days - one week) another notification is sent to the caregiver in order to inform the doctor.

The interaction of the IONIS platform with the end-users is depicted as UML diagram in Figure 6.

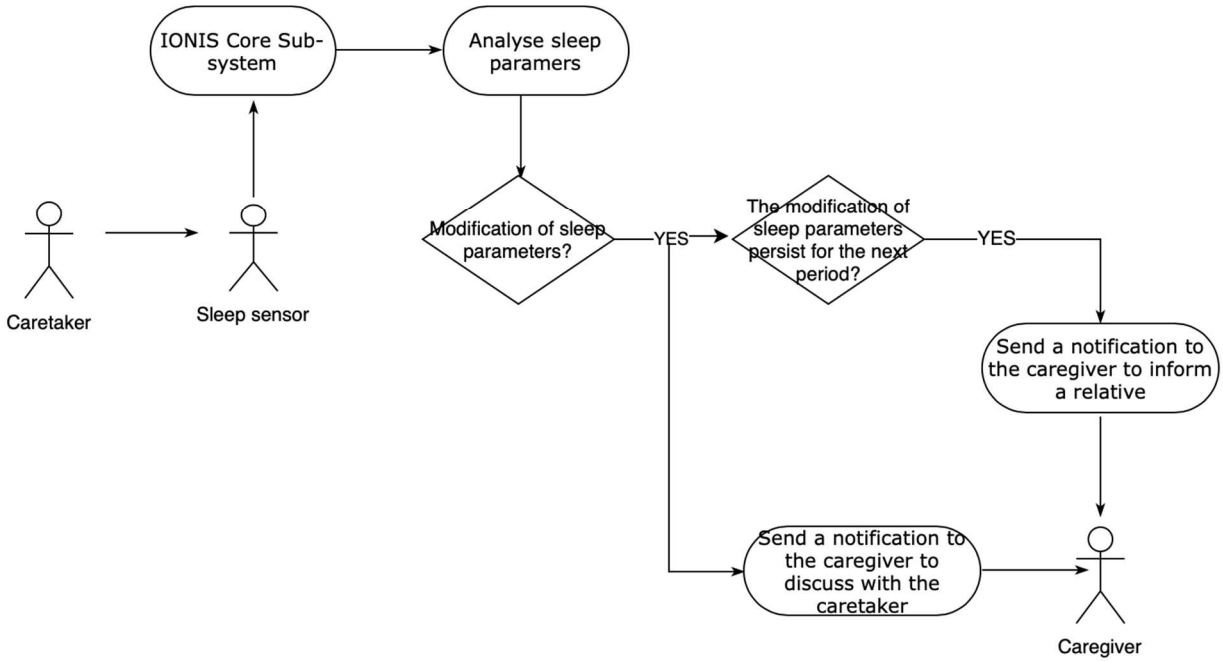


Figure 6. UML diagram showing the interaction of the end-users with the IONIS sleep monitoring and alerting functionality.

2.2.4 Memory and cognitive support group

Elderly users in this category will benefit from several of the IONIS functionalities in order to compensate for their loss in memory and other cognitive functions which can lead to frustration over not finding personal items, forgetting of scheduled medication or important events/appointments, disorientation and wandering in outdoor

environments, abnormal mobility patterns indoors, etc. While all IONIS primary users can exhibit such characteristics, some might be predominant over others. In the following we will present possible scenarios and use cases for object localization, indoor localization of users and mobility patterns extraction, outdoor localization and geofencing, remainders and alerts, home monitoring and alerting.

2.2.4.1 Object localization

People with cognitive impairment often have problems with localizing their items (e.g. keys, phones and glasses - Figure 8). These problems are encountered by almost 80% of Respondents that took part in the multinational survey carried out within T1.2 (Figure 7).

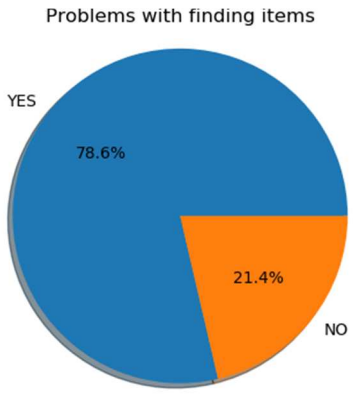


Figure 7. Percentage of Respondents having problems with finding items.

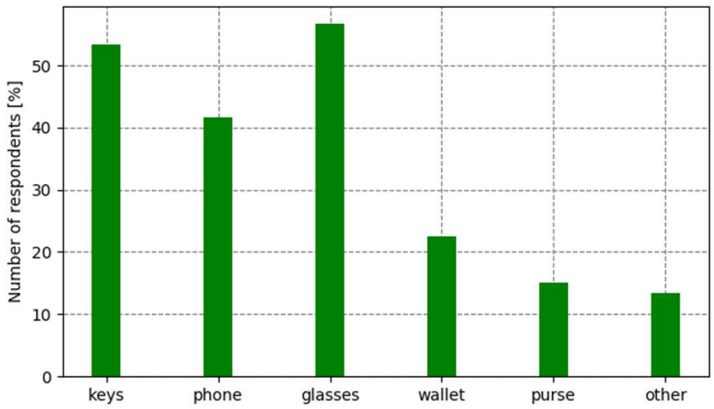


Figure 8. Typically searched for items.

The vast majority of Respondents considers item search support functionality as useful (Figure 9) and accepts attaching another device to commonly misplaced objects.

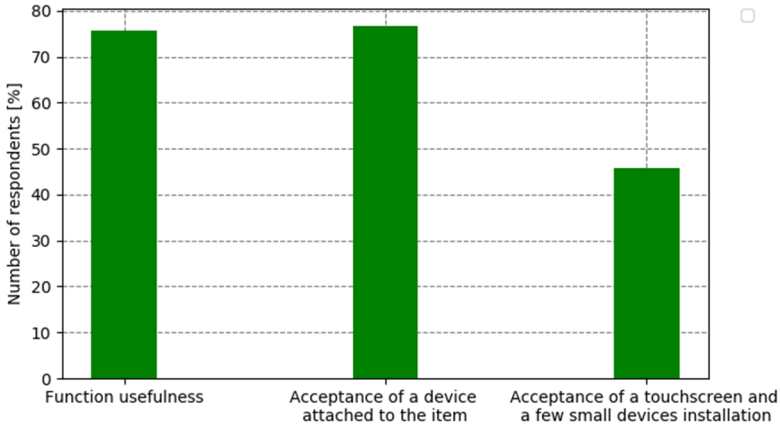


Figure 9. Usefulness of finding items functionality and acceptance of devices supporting localization.

The widespread nature of the problems related to finding items and the common willingness to accept technical solutions helping to solve them, were the main reasons for including the item search support functionality in the IONIS platform. The typical scenarios illustrating the system usage are presented below.

Scenario 1: Kate is a senior with mild dementia living alone in her flat. She regularly meets her friends at a senior club every Thursday at noon. Kate likes watching TV and spends her mornings in front of a TV set. One day, the TV program was so interesting that Kate totally forgot about the meeting. Suddenly her phone rang. One of her friends, Jane, reminded her about the planned meeting. Kate switched of the TV and hurriedly started to prepare to go out. She wanted to close the doors but realized that she could not find her keys. She desperately started to look for them, but with no result. Suddenly she recalled the system installed recently in the flat by her daughter. She came to the screen hanging on the wall. After touching it the screen came alive

and showed photos of different items. In the central part of the screen she saw a photo of her keys and touched it. The message telling "Kitchen" appeared on the screen immediately. At the same moment she heard a weak beeping sound coming from her kitchen. She went there and noticed pulses of red light from under one of her dishcloths. When she took up the keys, the sound and light suddenly vanished. Having found the keys in a short time, Kate could leave and come to the club meeting on time.

Scenario 2: During his last visit to a doctor John was diagnosed with mild cognitive impairment. John lives alone in his house and is daily visited by his son David who brings him fresh newspapers. One day, after David had left, John decided to read the newspaper. Then he realized that he cannot find his glasses. Fortunately he remembered that David recently installed, as he calls it : "a magical solution for finding items" at home. John came up to the small tablet mounted on the room's wall. He gently touched the screen and several icons appeared on it. He touched the icon representing glasses. The tablet immediately displayed the word: "bedroom". John went there and found his glasses on his bedside cabinet.

Implementation of the functionality supporting searching for the objects requires attaching small tags to the items. The UML diagram describing interaction between IONIS solution, user and objects is shown in Figure 10.

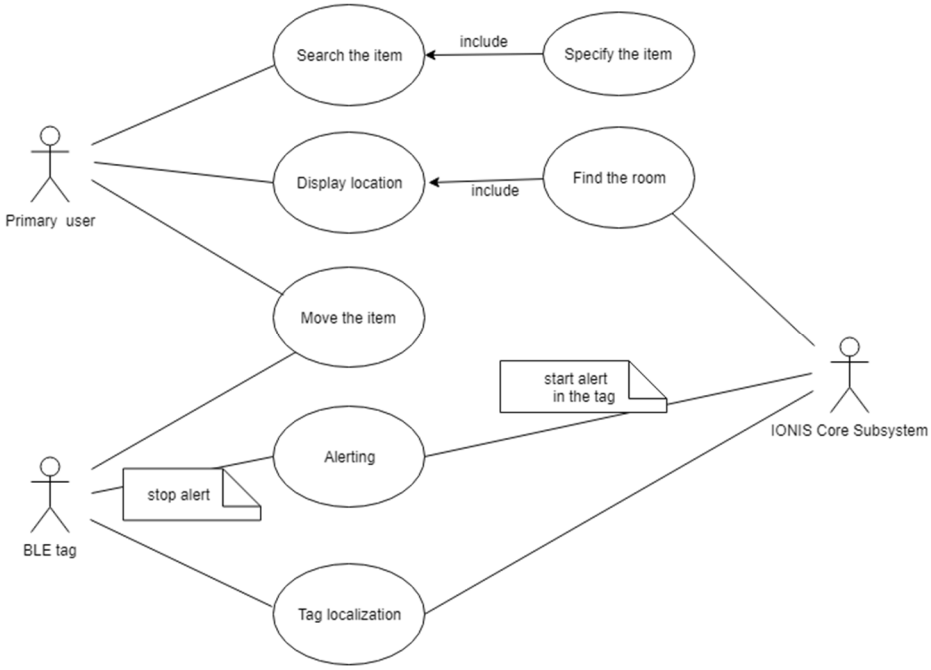


Figure 10. Use case - localization of items.

2.2.4.2 Indoor localization and mobility patterns

Changes in the mobility pattern may be important clues to acute changes in the health status of an older adult. Sudden increase in activity may indicate hyperactivity due to somatic causes: pain, diarrhea, necessity to use the bathroom more frequently for example due to urinary tract infection. In such cases quick response from the caregiver may facilitate early diagnosis and adequate treatment of the acute state underlying change in the mobility pattern. On the other hand, decrease of usual mobility may indicate sleepiness or unusual fatigue. These states might be symptoms of somatic disorders or exacerbation of diseases, for example heart failure (the most common cause of hospitalization of older adults), diabetes, arthritis etc. Therefore, quick reaction of a caregiver after being alarmed by the system would facilitate analysis of the situation and prompt reaction e.g. medical consultation. This could prevent, to certain extend, hospitalization due to exacerbation of chronic disease.

Of course, changes in activity: hyperactivity (wandering) or hypoactivity (apathy) may indicate progression of dementia or behavioral changes accompanying dementia - this would be possible after prolonged observation.

Scenarios

Tom is a senior living at home. He suffers from Alzheimer's disease. He's condition became worse in the past few months, he gets disoriented more often and starts wandering in the house without purpose. Moreover he left the house open a few times in the last week. The IONIS system's wandering module help him, and his caregiver with notifications and messages regarding the indoor mobility and deviations from daily patterns.

Thus, the IONIS system's wandering module helps to monitor Tom's behaviour and sends notifications to him and messages to his son.

Scenario 1: Tom leaves the house and doesn't lock the door behind him. The system sends a notification to his phone immediately. He reads it, locks the door and goes for shopping.

Scenario 2: Tom starts wandering between the main door and a window. It is possible that he will leave the house in this state and get lost. The system sends a notification to Kate, who is Tom's daughter and Kate calls him. The call disrupts the wandering state and Tom continues his day.

Scenario 3: Tom falls asleep in front of his TV. Usually he doesn't spend more than 2 hours sitting there, so after 3 hours the system sends a message to his phone. He wakes up to the notification and answers that everything is OK.

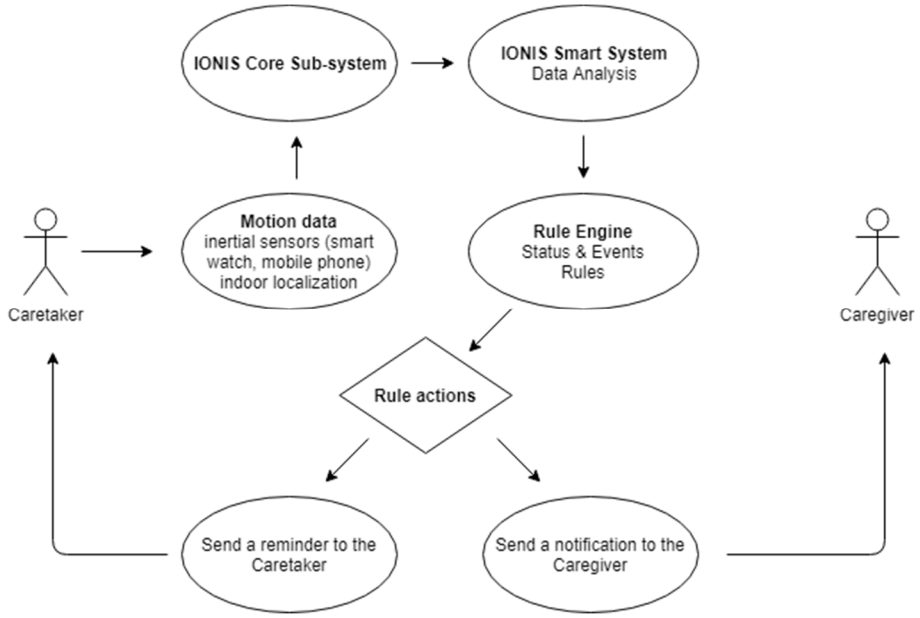


Figure 11. UML diagram showing the interaction of the end-users with the IONIS motion monitoring and alerting functionality.

2.2.4.3 Outdoor localization and geofencing

The IONIS system allows outdoor monitoring of the user in terms of the user's location. For this purpose the user has to wear a smart phone or a smatwatch. Both devices are capable to determine the location of the user by using the built in GPS and/or the build in localization services provided by the device operation system. The outdoor monitoring functionality is localizing the user and is also detecting when the users leaves the virtual bounds of his/her daily activity area. 2. The bonding area is either created by the IONIS system automatically from the mobility patterns of the user or by the caregiver manually. If the border of the bonding area is crossed a warning message is sent to the caregiver by using the devices built in communication network (3G, 4G).

A scenario for outdoor localization and geofencing is described below for the case of Frank who is suffering from mild dementia and is sometimes getting confused when leaving his home. This is happening especially in new surroundings.

Scenario: Frank is leaving every day his home to purchase the morning newspaper. Once or twice per week he goes to the local supermarket. His regular trips include also the nearby pharmacy and the park where he is meeting with some friends for a game of chess. These locations are stored in the IONIS system and are forming the bonding area which the system has constructed over a month period. One morning when Frank is not able to find his preferred newspaper at the regular kiosk and thus he is going in search of the newspaper to further vending points. Once Frank is crossing the bonding area defined in the IONIS system, a warning message is send to Franks designated caregiver. The caregiver is then able to follow Frank's location on a map such as to make sure that Frank is not getting confused and lost.

The interaction of the users with the IONIS platform for the localization and geofencing functionality is exemplified in the UML diagram in Figure 12.

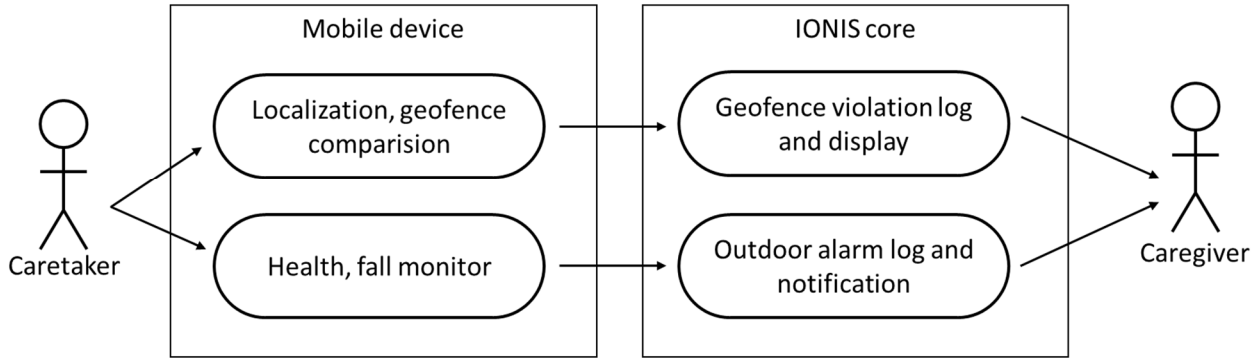


Figure 12. UML diagram for outdoor localization and geo-fencing.

2.2.4.4 Reminders and alerts

The IONIS system provides a personalized calendar capable to manage several use cases by responding to events with rules and alerts triggered by events and rules. The system expects that following the alert the user performs an action and he/she feedbacks the system with an acknowledgement. The Rules can be:

- Simple rule: managing a single event (timed, generated by a health sensor or home sensor), triggering an alert.
- Combined rule: managing a combination of events (for instance, an event coming from a health sensor and one from a Home sensor), triggering an alert.
- Prioritized rule: triggering an alert if an event happens AFTER another event or if an action was performed prior to it (for instance “measure your blood pressure before taking the medication”).

Mary is a retreating senior with mild dementia and diabetes. She must take medications (pills) once a day at a precise time in the morning. Louis, his caregiver, has inserted in the personalized calendar a reminder for Mary to take her medication. Mary receives the reminder on his tablet every day. To acknowledge the reminder and to confirm that she indeed took the pill, Mary has to push a button in the IONIS Web interface displayed on her tablet.

Moreover, Mary has to measure her glucose levels, in the evening before going to bed, with the glucose meter provided by the IONIS system: if the level of glucose in the blood is too high, another reminder to take an extra pill is sent by the system to Mary.

Scenario 1: Mary takes the pill and pushes the acknowledgment button on the Web interface. All went well.

Scenario 2: Mary doesn’t acknowledge his medicating action, so the IONIS system re-sends after 10 minutes an alert to her. This time Mary feedbacks correctly.

Scenario 3: Mary measures her glucose level before going to bed, and the level is out of the established range. So the system sends to Mary an alert to take an extra pill. Mary takes it and acknowledges the system back.

Scenario 4: Mary fails to measure her glucose level before going to bed. The system alerts her three time (with a time gap of 10 minutes from one alert to the other), but receives no reply. Therefore, the system asks Louis via SMS to intervene.

The interaction of the users with the IONIS platform for the above presented scenarios is exemplified in the UML diagram in Figure 13.

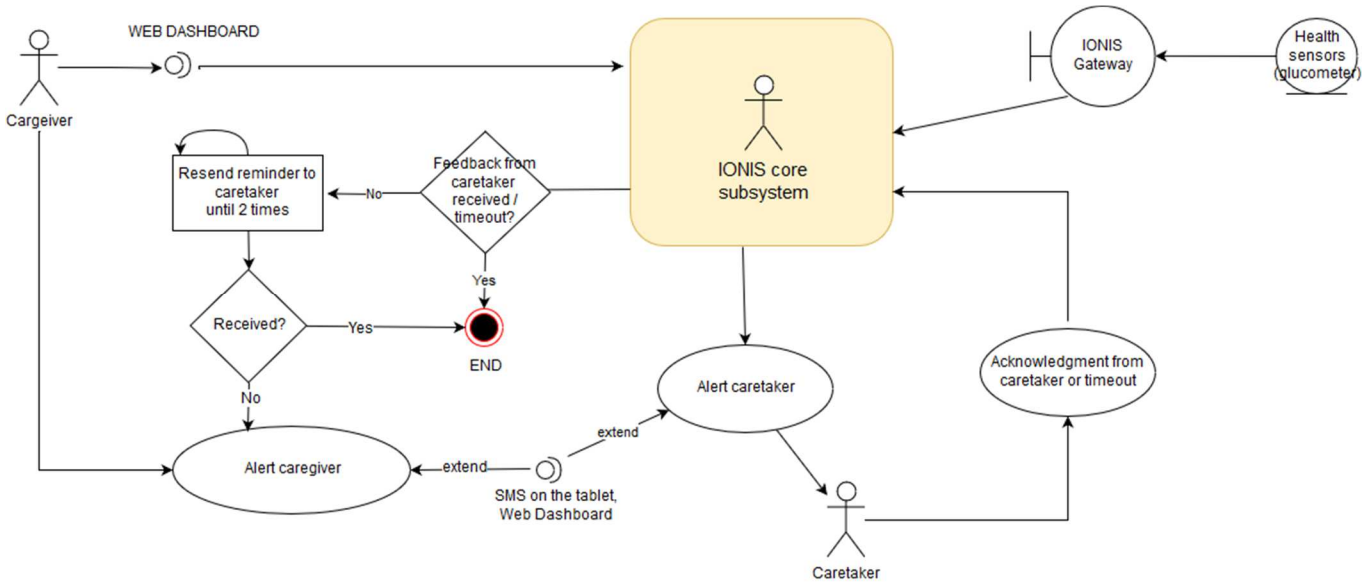


Figure 13. UML diagram for the reminder and alerts use-case.

2.2.4.5 Home monitoring and alerting

John has dementia (Alzheimer's disease), but not other relevant diseases, and he is living at home alone. His major problem in his daily life is that he forgets frequently common domestic activities like closing the bath faucet, switching off the stove, closing the windows.

Scenario 1: John washes his face and hands before going to sleep, but when he finishes he forgets to close the sink faucet. After a while the bathroom floor starts to get wet. The IONIS flood sensor detects the flood and sends an SMS, via the IONIS system, to John's caregiver's (Sylvie) smartphone. Sylvie calls John by phone and tells him to close the faucet. Moreover she sends to John's home an attendant who can evaluate the situation and in the described case make the floor dry again.

Scenario 2: John prepares lunch, but forgets to switch the stove off. The IONIS system sends and SMS to John in order to instruct him to switch the stove off. John performs the action correctly.

The interaction of the users with the IONIS platform for the above presented scenarios is exemplified in the UML diagram in Figure 14.

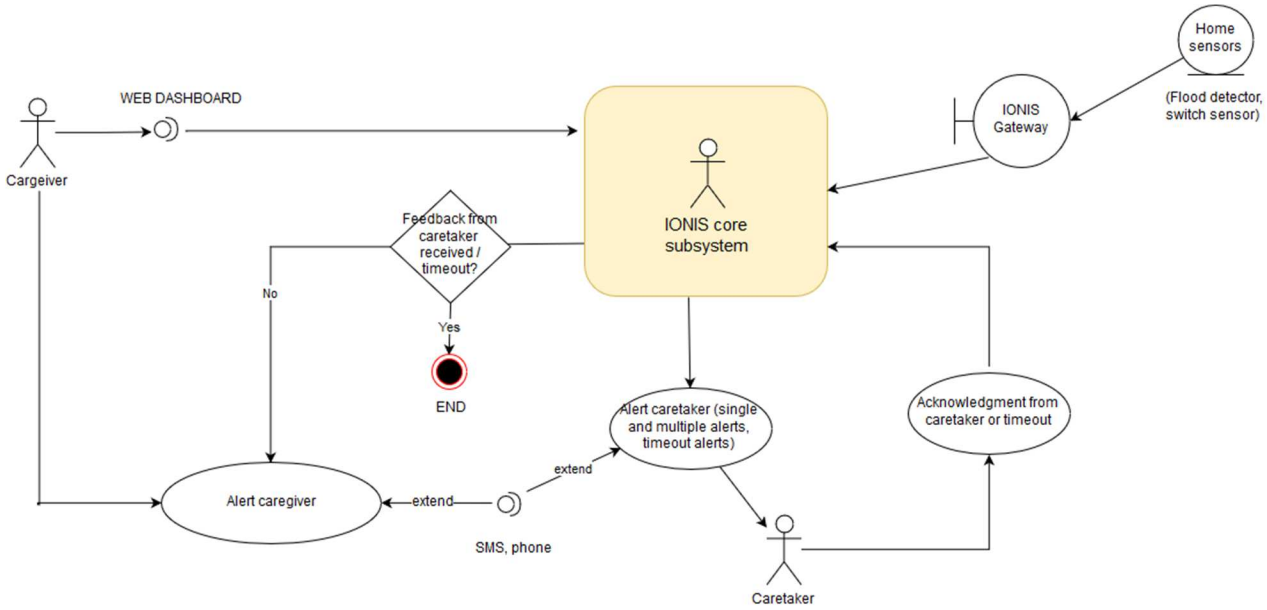


Figure 14. UML diagram for the home monitoring and alerts use-case.

2.3 Country specific primary end-user groups

Primary end-user selection in the four participating countries will take into account the demographic differences. These are outlined in the following section starting with the prevalence of dementia in the four end-user countries and continuing with demographic data on the elderly population.

2.3.1 Dementia prevalence

With 19.94 million inhabitants, **Romania** is the seventh most populous member state. Bucharest- the capital is the sixth largest city in the EU. As of early 2014, the population of Romania was around 21,595,302, a slight decrease from the estimated 21,668,721 in 2013 and from the 2011 population estimates when the figure stood at 21,801,942. Romania's population is apparently decreasing at a rate of over 0.32% per year. In 2018, this yearly loss rate rose to .50%, indicating a more dramatic decline over the last year.

Alzheimer Europe estimates the number of people with dementia in Romania in 2012 as being 270,304. This represents 1.26% of the total population of 21,387,517. The number of people with dementia as a percentage of the population is somewhat lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Table 2. Dementia prevalence per age and gender in Romania.

Age group	Men with dementia	Women with dementia	Total
30 - 59	7,459	4,252	11,711
60 - 64	1,145	6,095	7,241
65 - 69	7,216	7,184	14,401
70 - 74	11,215	19,206	30,421
75 - 79	19,986	34,356	54,342
80 - 84	23,960	47,881	71,841
85 - 89	14,542	41,079	55,621
90 - 94	4,415	17,304	21,719
95+	546	2,463	3,009
Total	90,484	179,820	270,305

The population size (Main Statistical Office, 2017) in **Poland** is 38,422 thousands. The population structure is evidencing that people aged 65 years and more represent 17% of the population. The life expectancy at birth (Main Statistical Office, 2017) is: Males: 73.96 years; Females: 81.82 years. The life expectancy at the age of 65 (Main Statistical Office, 2017) is: Males: 15.9 years; Females: 20.3 years. Demographic changes between 2015 and 2050 are illustrated in **Error! Reference source not found.**.

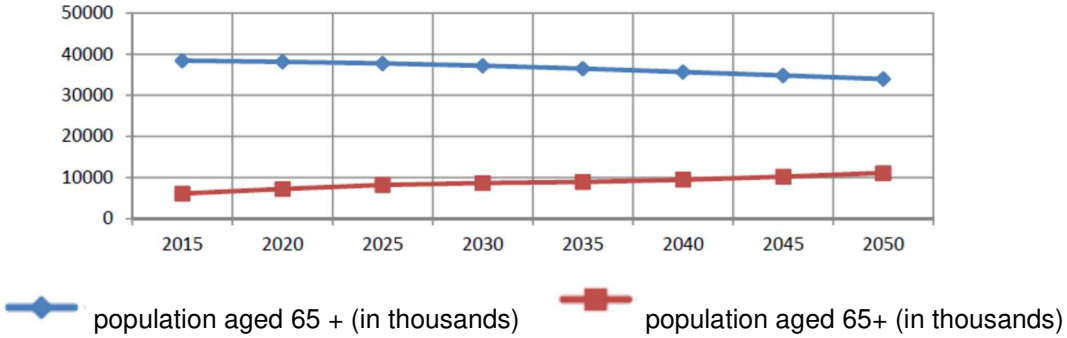


Figure 15. Demographic changes in Poland according to the Main Statistical Office.

According to results of the largest cross-sectional study of older adults in Poland – PolSenior, conducted between 2006 – 2011, the estimated percentage of people aged 65+ affected with dementia is 12% (720

thousands). Alzheimer's disease is responsible for over 50% of dementia cases therefore, it might affect 6-7% of people 65+ (360 – 470 thousands). These estimates are higher than those published on Alzheimer Europe website. The following table shows the estimates by the Alzheimer Europe (2014) of the number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Table 3. Dementia prevalence per age and gender in Poland.

Age group	Men with dementia	Women with dementia	Total
30 - 59	13,101	7,514	20,615
60 - 64	2,241	11,909	14,150
65 - 69	12,085	12,145	24,230
70 - 74	15,942	28,492	44,435
75 - 79	30,629	55,874	86,503
80 - 84	40,150	92,009	132,159
85 - 89	25,098	89,064	114,162
90 - 94	9,315	44,356	53,671
95+	1,808	9,358	11,167
Total	150,371	350,721	501,092

Slovenia is a small European country with a population of just over two million (2,040,057). Statistic for year 2017 for Slovenia shows that there are 407,333 people aged 65 years and over. There are 234,621 women 172,712 men. This is 19.7% of all Slovenian population. Statistic for year 2013 shows there are 22,711 women with dementia and 9,324 men with dementia living in Slovenia, aged 30 or more. Total sum of persons with dementia in Slovenia was 32,034 in 2013. One of the reasons the numbers keep rising might be the fact that the percentage of elderly residents is rising with each passing year. That said, the percentage of people who are older than 65 is 18.4%. Moreover, the number of people with dementia in Slovenia is just slightly higher than the EU average, which is 1.55% (Slovenia average is 1.57%). A study predicts that, still, only 50% of seniors in all disease phases have been diagnosed in Slovenia.

Most men with dementia are from the age group 80 – 84 years old, which are 2,398 men with dementia. Most women with dementia are from the age group 85 – 89 years old, which are 6,102 women with dementia. There are significantly more women than man living with dementia in Slovenia. The statistics is presented in **Error! Reference source not found.** and Table 4 [5].

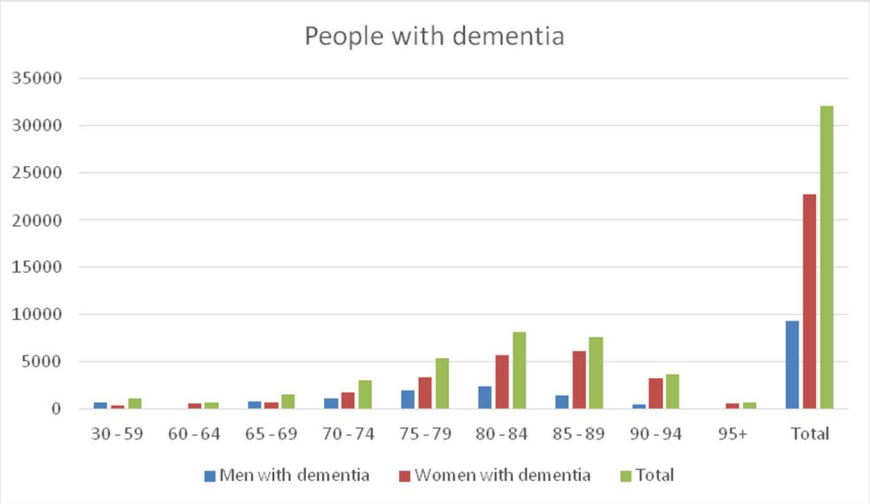


Figure 16. Dementia prevalence by age and gender in Slovenia.

Table 4. Dementia prevalence by age and gender in Slovenia.

Age group	Men with dementia	Women with dementia	Total
30 - 59	744	405	1,149
60 - 64	131	600	731
65 - 69	830	729	1,559
70 - 74	1,182	1,830	3,012
75 - 79	1,961	3,396	5,357
80 - 84	2,398	5,730	8,128
85 - 89	1,490	6,102	7,593
90 - 94	494	3,251	3,745
95+	94	668	762
Total	9,324	22,711	32,034

In **Hungary**, Alzheimer Europe estimated the number of people with dementia as being 148,927 in 2012. This represents 1.5% of the total population of 9,949,589. The number of people with dementia as a percentage of the population is comparable to the EU average of 1.55%. The number of women with dementia from this is 105.291 and the number of men is 43,636. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Table 5. Dementia prevalence by age and gender in Hungary.

Age group	Men with dementia	Women with dementia	Total
30 - 59	3,391	1,960	5,351
60 - 64	591	3,207	3,780
65 - 69	3,932	4,223	8,156
70 - 74	5,133	9,844	14,976
75 - 79	8,005	16,175	24,180
80 - 84	10,736	25,908	36,645
85 - 89	7,693	26,620	34,313
90 - 94	3,422	14,387	17,809
95+	750	2,966	3,716
Total	43,636	105,291	148,927

The following figures are illustrating the share of people with dementia in Hungary depending on age and gender.

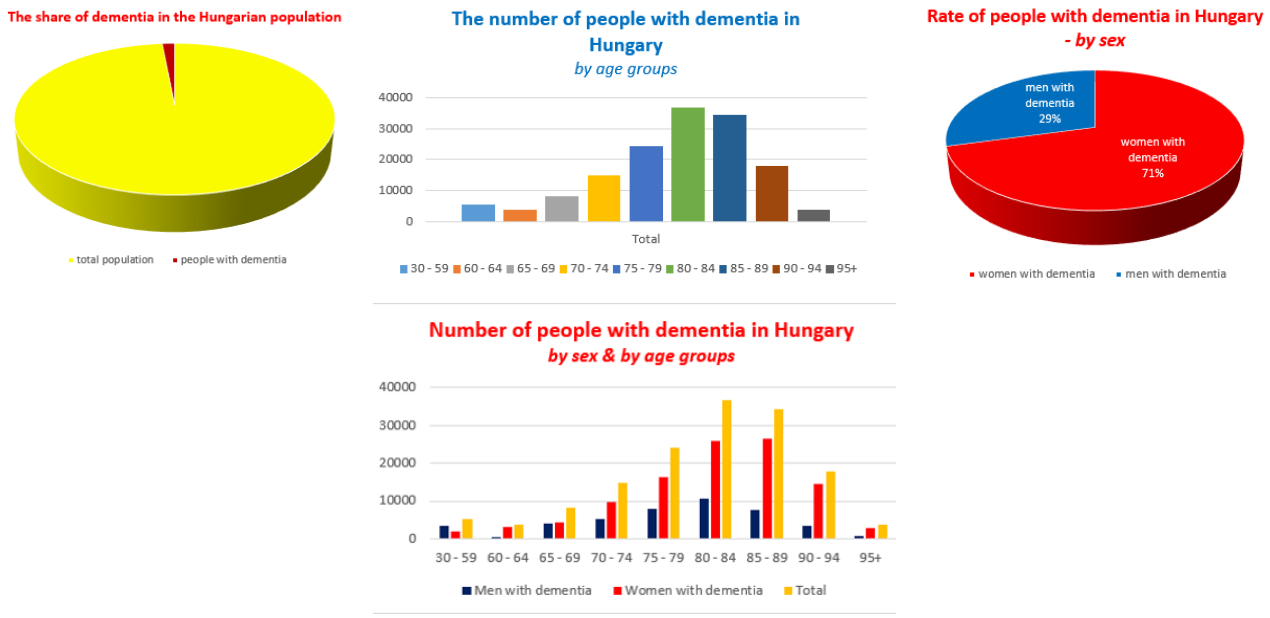


Figure 17. Distribution of dementia among Hungarian population according to 2012 estimates.

2.4 Country specific demographics

IONIS is targeting primary users with mild cognitive impairment and initial stages of dementia as well as caregivers (in many cases spouses). Thus representative data on the elderly population is expected to be valid also for the IONIS users (primary and secondary). In this section, we are presenting demographic differences between the IONIS end-user countries. These are outlined in the following section which is using Eurostat statistics [6] to present in more detail the following aspects:

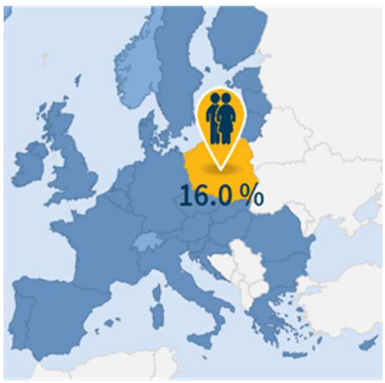
- The share of elderly (65 or over) in the total population
- The life expectancy after 65 years
- The years of being healthy over the age of 65
- The share of elderly who live alone
- The share of elderly who are still economically active
- The share of elderly who travel
- The share of elderly who use the internet at least once a week

2.4.1 The share of the elderly (65 or over) in the total population

The ageing population is one of the greatest social and economic challenges facing the EU countries. Projections foresee a growing number and share of elderly persons (aged 65 and over), with a particularly rapid increase in the number of very old persons (aged 85 and over). These demographic developments are likely to have a considerable impact on the number of people with dementia. As shown in Figure 18, the share of elderly (65+) in Romania is 17.4%, 16.0 % in Poland, 18.3% in Hungary and 18.4% in Slovenia. For the EU-28 member states, it is 19.2%.

Romania

Poland



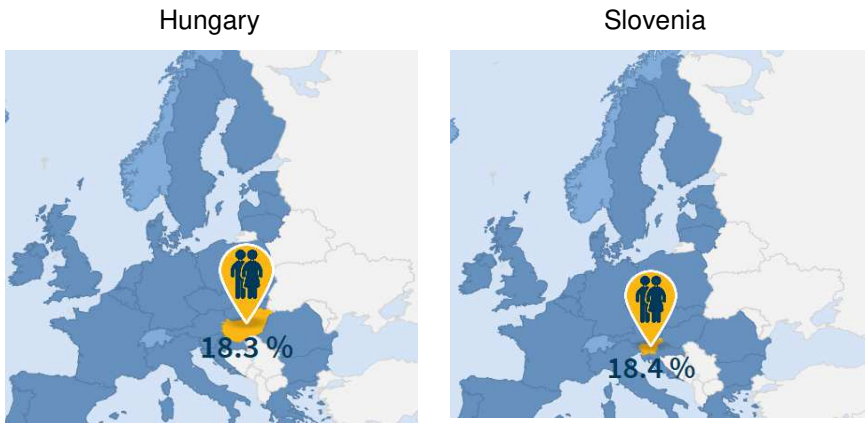


Figure 18. The share of elderly (65+) in the total population.

2.4.2 The years that men and women expect to live over 65 years old

While it is broadly positive that life expectancy continues to rise and each person has a good chance of living longer, these years also bring about an increase in physical and mental illness, thus an increase in dementia incidence. As shown in Figure 19, it is expected that in Romania men live approximately 14.5 years more after the age of 65 years while women exceed the age of 65 by approximately 18 years. For Poland the numbers are 15.7 for men and 20.1 for women, while the numbers for Hungary are 14.5 for men and 18.2 for women and for Slovenia the numbers are 17.6% for men and 21.4% for women. For the EU-28 the numbers are 21.2 for women, and 17.9 for men.

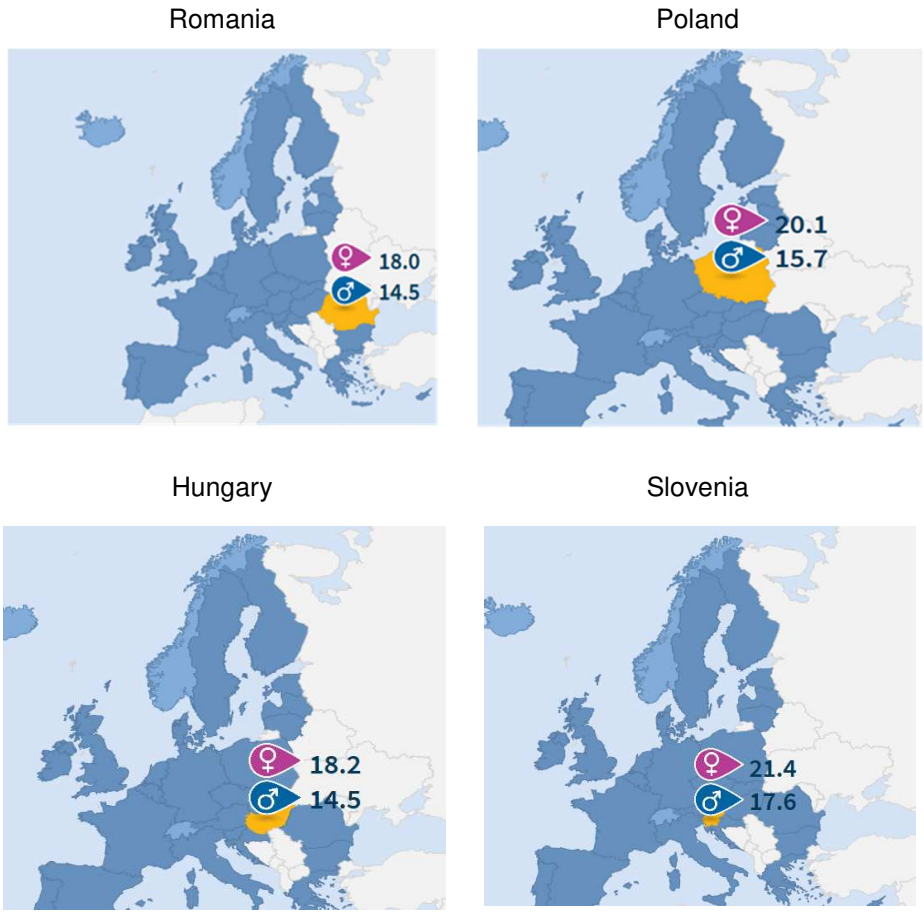


Figure 19. ***The years that men (♂) and women (♀) are expected to live over 65 years old.***

2.4.3 The healthy life years men and women can expect to live over 65 years old

Health is an important priority in Europe and also for Romania, Poland, Hungary and Slovenia as EU member states. The competence for the organization and delivery of healthcare services is largely held by the individual

EU Member States [7]. As shown in Figure 20, the expectation to live a healthy life over 65 years old is in Romania almost 6 years for women and about 6 years for men. In Poland it is 7.6 for men and 8.4 for women, in Hungary it is 5.9 for men and 5.9 for women and in Slovenia it is 8.2 for men and 7.6 for women. For the EU-28 member states as a whole, it is 9.4 years for men, and 9.4 years for women. Thus, Romania, Poland and Hungary face challenges as compared with the EU-28 as a whole.

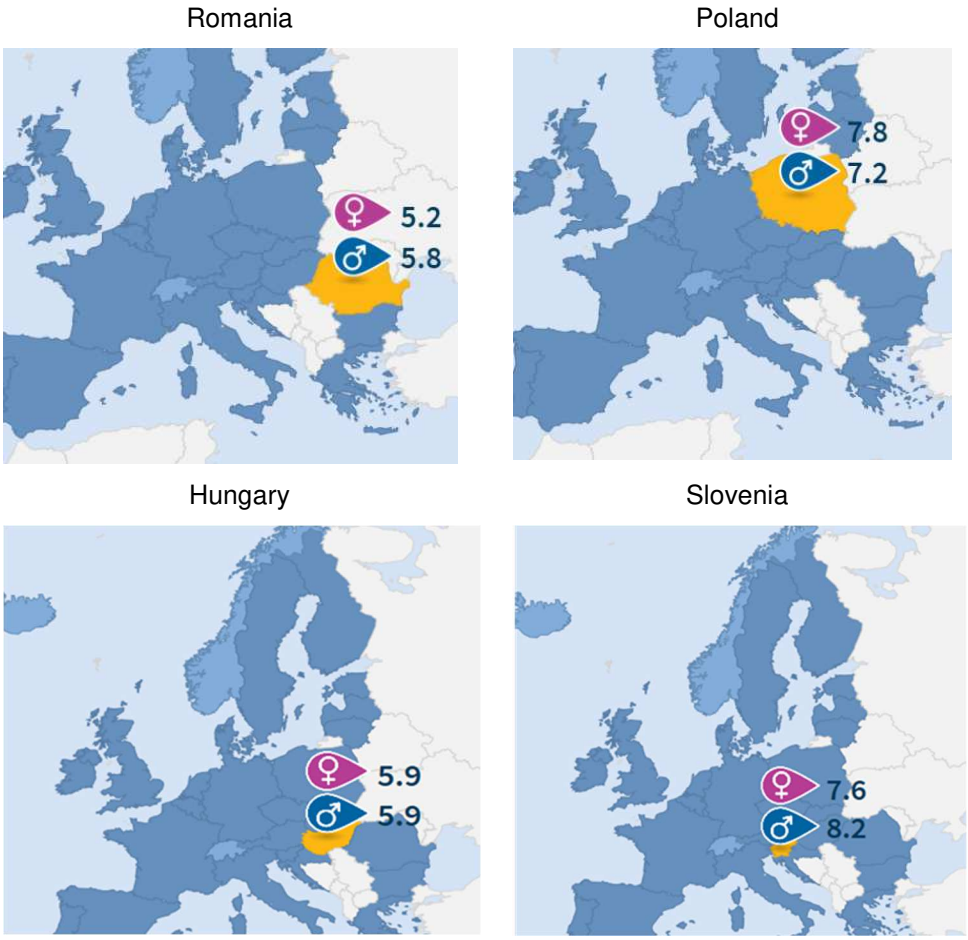


Figure 20. ***Healthy life years for men (♂) and women (♀) over 65 years.***

In **Romania** the health system is a decentralised and pluralistic social health insurance system based on a contractual relationship between the health insurance funds and service providers. Services and benefits provided by the State are funded through an obligatory health insurance and general taxation. The Ministry of Labour, Social and Family Solidarity is responsible for social support to people with dementia/dependent elderly people. Alzheimer's disease, vascular and Parkinson dementia are now recognised as handicaps. Access to services and support from the State is dependent on eligibility for the severe handicap category and not on age. There is a significant problem concerning adequacy and accessibility of services. First of all, there are very few services that are specifically designed for people with dementia. People with dementia can benefit from services designed either for handicapped people or elderly people but in a limited way (e.g. a person cannot attend a day care centre if cognitively impaired and he/she is not admitted into hospital due to a lack of personnel trained in dealing with dementia issues). There are few hospital wards able to provide specific care for people with dementia and a family member is required to provide care while his/her relative is hospitalised. Social assistance is very poorly represented.

In **Poland** there is no system of social support specifically designed for people with dementia and their caregivers. However, people who are ailing or need social support, because they live alone or are dependent, are entitled to receive paid (or partly paid) home help and support organised by local governments. NGOs are involved in various activities aimed at providing services for people with dementia and their caregivers. The Ministry of Health may (or may not) co-finance certain activities and tasks of NGOs, but it is up to NGOs to fight for a better quality of life for people with dementia in Poland. The private sector provides some services, e.g. nursing homes, but mostly they are not specially designed for people with dementia.

In **Slovenia**, nursing homes do not have dedicated dementia wards. However, the government provides daytime centres in nursing homes with different activities for patients with dementia. Also, supervised sections for dementia patients are available in nursing homes. For daily home support, the person with dementia or the carer must find a helper and pay for the related costs. Public social organisations or local communities can provide home support twice or 3 times a week. While these will pay part of the cost, a financial contribution will be requested from the caregiver. It is possible for an informal carer to become a 'Family Helper', but the governmental financial support is very low. Most families decide to look for help from another informal carer. This assistance is payable. The cost is around EUR 3 to 7 per hour and the price varies depending on how many hours the caregiver stays with the patient (PwD), the expertise of the caregiver and the needs of the PwD.

In **Hungary**, the Ministry of Social Welfare and Labour, the Ministry of Health, local governments in the country and the "Service of Charity of the Roman Catholic Church" are all responsible for social support to people with dementia/dependent elderly people. In Dementia Centres, social workers provide social and legal assistance to families caring for people with dementia. They are also responsible for diagnosing dementia. Unfortunately, there are only 84 such facilities in Hungary and waiting lists are long (from 2-4 months). General practitioners who first come into contact with people with memory problems tend to see this as a natural part of ageing, so many people with dementia do not get help from dementia centres in time. Private institutions are virtually inaccessible due to high costs. State, supported home-care is limited to the provision of meals (in many towns and villages) at a low cost. People with dementia and their family carers are not entitled to home care benefits because dementia is not regarded as "disability" under existing Hungarian law. Financial resources are very limited at local government level. Therefore, applications made by carers of people with dementia are mostly refused because they are not disabled. Owing to the high cost of Alzheimer medications the majority of people with dementia cannot afford to buy them. Only 50% of the cost is covered by the Social Security. The Hungarian Alzheimer Society is lobbying to change this to 90% (or 70% minimum) as the cost of Alzheimer drugs is very high compared to the average income of Hungarian citizens. Dementia is not currently regarded as a health care priority in Hungary.

2.4.4 Internet access among elderly population

In the context of the IONIS users, we can consider that internet access reflects to some extend their interest and knowledge about ICT technologies. Some statistics show that, once the elderly are confident enough to use technology, they start using the internet actively, just like younger generations. We think it's safe to assume that the share of people with dementia that use internet is approximately the same, at least in early stages of dementia.

In relation to the regular use of the internet, there is a relatively large digital divide between northern and western EU Member States on one hand and southern and eastern EU Member States on the other. Luxembourg (88 %), Denmark (81 %), Sweden (80 %), the Netherlands (77 %), the United Kingdom (73 %), Finland (66 %) and Belgium (57 %) were the only EU Member States where more than half of the elderly population aged 65–74 used the internet in 2016 at least once a week. In Romania and Bulgaria, on the other hand, around 12 % of all senior citizens aged 65–74 went online at least once a week. Figure 10 & 11 shows the share of elderly people who use the internet at least once a week internet compared to the total elderly population (65 or over: 1.798.979) in Hungary in 2016. This rate means about 629,643 elderly people who use the internet at least once a week in the year 2016.

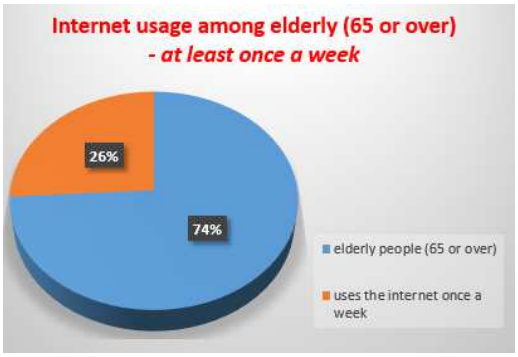


Figure 21. The share of the elderly (65 or over) who use the internet at least once a week (2016) in Hungary.

Figure 22 shows percentage of elderly people in Slovenia (aged 65 – 74 years) who use internet in comparison to the whole population in Slovenia in 2016. The share of elderly people (aged 65 and over) that use internet at least once a week in Slovenia is 28%, as seen in Figure 22. It seems that elderly people in Slovenia are most comfortable using internet at least once a week and reading news on the internet. However, elderly

people in Slovenia do not use as much internet for participating in social networks on purchasing items or internet banking.

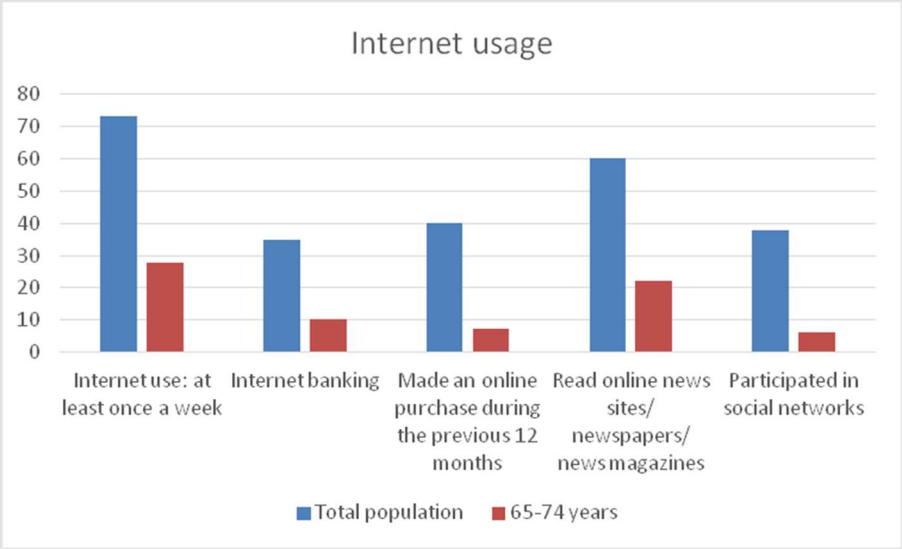


Figure 22. Internet usage in elderly people in Slovenia in 2016

The information for Romania, Poland, Hungary and Slovenia is given also in Figure 23. This should be compared to an EU-28 average of 45%. It can be easily seen that there are significant differences between the four end-user countries. Hungary is closes to the EU-28 average while Romania is significantly lacking behind. Only 10% of the elderly in Romania are accessing the internet at least once per week while the number in Hungary is almost four times higher. Extensive rural area and significant discrepancies between Romanian rural and urban regions might be one of the reasons behind the low numbers.

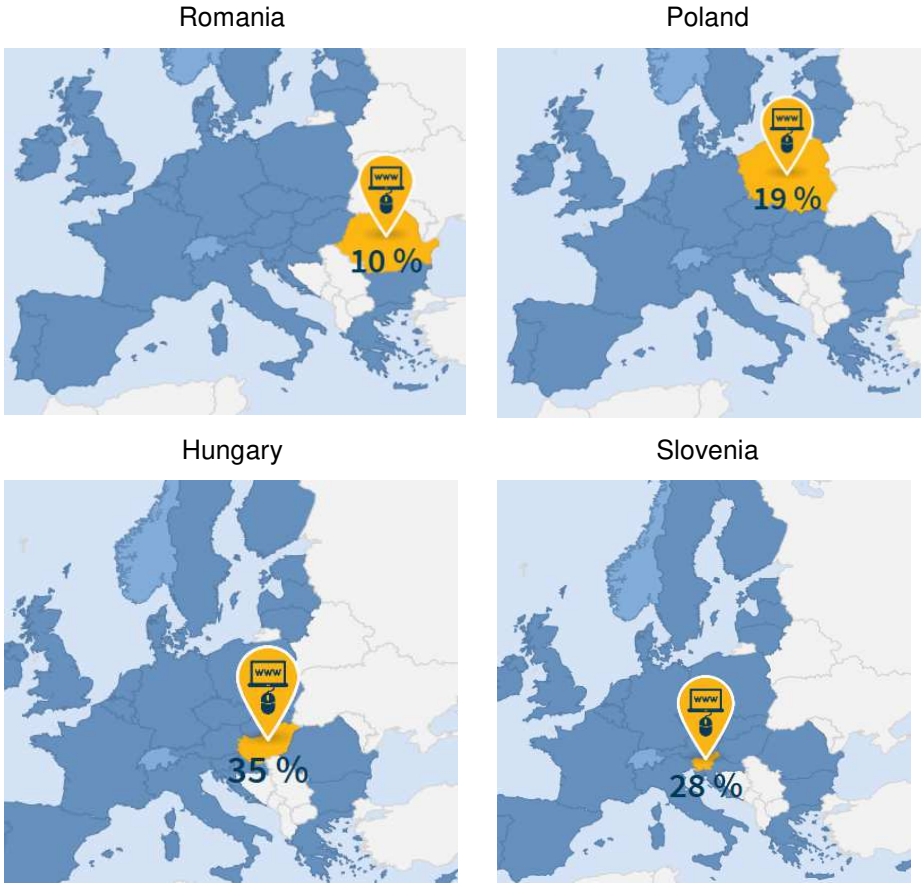


Figure 23. The share of the elderly who use the Internet at least once a week.

3 Secondary end-user groups

IONIS secondary end-users have been defined as being mainly informal caregivers but also formal ones. Informal caregivers are any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with mild cognitive impairment or mild dementia. These individuals may live with, or separately from, the person receiving care although in later stages of dementia permanent care is needed. This can complement by formal caregivers who are typically paid providers but they may also be volunteers from a government or nonprofit organization. Depending on the country, when informal care is no longer possible, formal caregivers come into play on a full-time basis. This may be in the form of a congregate living arrangement, assisted living, a continuing care retirement community or a nursing home. It is at this point that long term care can have a significant impact on the finances of the care recipient and a healthy spouse living at home.

Another reality of providing informal care services in the home is the increasing need for physical and emotional support that often goes unrecognized until too late. As care needs increase, both in the number of hours required and in the number or intensity of activities requiring help, there is a greater need for the services of formal caregivers.

The need for a caregiver among IONIS primary users has been assessed during the multinational survey in T1.2. The results of the survey confirm that for mild cognitive impairment and mild dementia mainly informal carer services come into play. Only 14 out of 86 persons living at home are supported by formal caregivers (Figure 24).

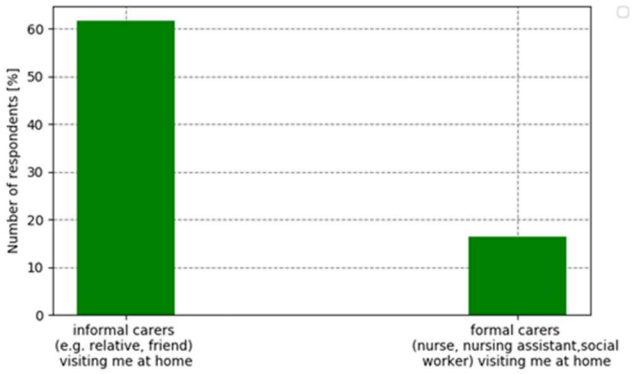


Figure 24. Support from formal and informal caregivers based on the T1.2 results.

Moreover, 60% of the elderly live with their informal caregiver. The other 40% of elderly receive support from informal caregivers during visits. Typically visits last less than two hours and take place few times a month (Figure 25).

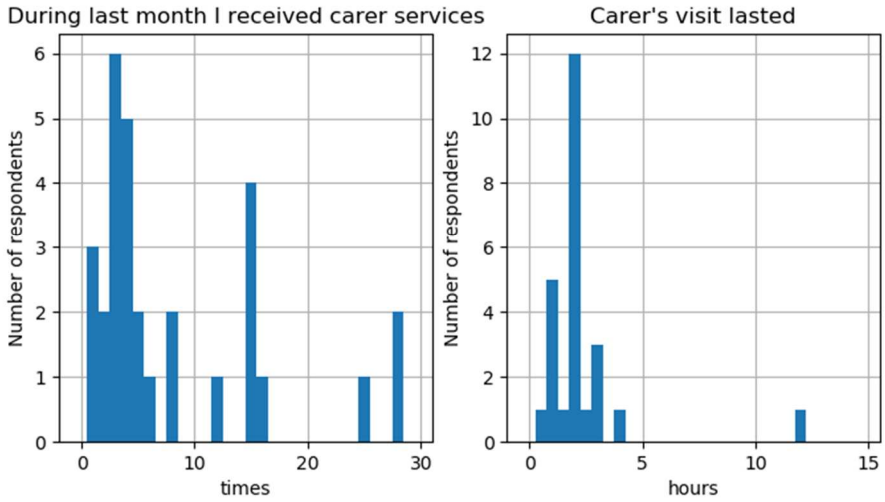


Figure 25. Time and intensity of informal caregivers' visits according to T1.2.

4 References

[1] L. M. Allan, C. G. Ballard, E. N. Rowan, R. A. Kenny, Incidence and Prediction of Falls in Dementia: A Prospective Study in Older People, PLoS One. 2009; 4(5): e5521.

[2] Y. Jirong, H. Changquan, W. Hongmei, D. Bi-Rong D, Association of sleep quality and dementia among long-lived Chinese older adults, Age (Dordr). 2013; 35(4):1423-32.

[3] K.M. Kinnunen, A. Vikhanova, G. Livingston, The management of sleep disorders in dementia: an update, Current Opinion in Psychiatry, 30(6), 2017, 491-497.

[4] https://www.tuck.com/dementia/

[5] https://pxweb.stat.si/pxweb/Dialog/Saveshow.asp

[6] People in the EU – statistics on an ageing society (link)

[7] Alzheimer Europe, "National policies covering the care and support of people with dementia and their carers", 2013, (link)

[8] Indoor and outdoor NITICSplus solution for dementia challenges (IONIS); AAL Call 2016; project proposal description; 2016.

5 Document History

Date	Changes	Version	Author
01.08.2018	Table of contents initialized	1	Oana Cramariuc
14.09.2018	Partners, contributions added	2	ALL
23.10.2018	Final version for review by partners	3	Oana Cramariuc
30.11.2018	Final version with reviews by partners	4	Oana Cramariuc, Neja Samar-Brencic, Katarzyna Broczek, Zsuzsanna Nagymáté

- End of document -