



Project acronym	INCARE
Project number	AAL-2017-059-INCARE
Project full name	Integrated Solution for Innovative Elderly Care
Dissemination level	Public
Type of deliverable	Report
Contractual Date of Delivery	M9
Actual Date of Delivery	M9 with subsequent revisions brought about by BZN's late grant
	agreement signature, input from Lean start-up academy, COVID-
	19 pandemics
Deliverable Number	D1.1
Deliverable Name	End-user classification and recruitment report
Work package / Task	WP1 / Task 1.1
Work package responsible /	BZN/STOCZNIA
Task responsible	
Number of Pages	23
Contributors	CITST, IZRIIS, STOCZNIA, IZRIIS, BZN
Version	7

Abstract

This deliverable is identifying the most important target groups of end-users that will benefit from a particular service or group of services. Various selection and classification criteria are considered and justified. End-user recruitment criteria are established for each country taking into account national regulations (including economic ones which might influence commercialization) and particularities in elderly care. The target is to recruit 200-300 primary and secondary end-users from 4 countries (Poland, Romania, Hungary and Slovenia). The changes implemented following the onset of the current COVID-19 pandemics are outlined.

REPORT - PUBLIC

REPORT - PUBLIC

Table of Contents

1.	Executive summary	5
2.	Classification criteria for primary end-users	5
ź	2.1 Age	7
2	2.2 Physical and mental condition	7
2	2.3 Digital literacy	8
2	2.4 Other criteria	8
2	2.5 Summary	8
3.	Country-wise primary end-user classification and differentiation	9
	3.1 Poland	9
	3.1.1 Social policy towards the elderly in Poland	9
	3.1.2 Polish end-users	
	3.1.3 Recruitment	
	3.2 Slovenia	
	3.2.1 National policy towards the elderly in Slovenia	
	3.2.2 Slovenian end-users	
	3.2.3 Recruitment	
	3.3 Hungary	
	3.3.1 National policy towards the elderly in Hungary	
	3.3.2 Hungarian end-users	
	3.3.3 Recruitment	14
	3.4 Romania	
	3.4.1 National policy towards the elderly in Romania	
	3.4.2 Romanian end-users	
	3.4.3 Recruitment	
4.	Secondary end-user classification criteria	
4	ł.1 Poland	
4	ł.2 Slovenia	
4	ł.3 Hungary	20
4	ł.4 Romania	21
5.	Conclusions	22
6.	Document history	22

ABBREVIATIONS

AAL	Active Assisted Living
INCARE	Integrated Solution for Innovative Elderly Care
ІСТ	Information and Communication Technology
KSH	Hungarian Central Statistical Office
LTC	long-term care

LIST OF FIGURES

-

LIST OF TABLES

Table 1. INCARE functionalities versus users who can benefit from them	5
Table 2. Bi-dimensional criteria for primary end-user classification.	8
Table 3. Classification criteria for informal caregivers.	17
Table 4. Classification criteria of secondary users	20
Table 5. Classification criteria of secondary users	21
Table 6. Classification criteria of secondary users	22

1. Executive summary

The main goal of this task is to prepare for the user involvement in the pilots. Its goal is to identifying the most important target groups of end-users that will benefit from a particular service or group of services. Various selection and classification criteria are considered and justified. End-user recruitment will be done through the end-user organizations. Since, it is often difficult to find and attract the right users this task, we have also prepared alternative plans to face potential recruiting difficulties. The initial target was to recruit 300 primary and secondary end-users from 4 countries (Poland, Romania, Hungary and Slovenia). However, despite the alternative plans and strategies for ensuring a 10 % margin in the recruited users, the target had to be changed following the onset of the current COVID-19 pandemics. This has substantially impacted both the access to elderly users and the willingness of the elderly participate in projects because of contamination fear.

2. Classification criteria for primary end-users

The end-users can be classified according to a varying number of guiding principles or criteria, such as demographic separators (or categorical identifiers), health statuses, digital and technological literacy (including knowledge about robotic platforms), etc.

The first selection criterion is the one that defines the primary end-users of the INCARE starting from the proposed project:

"INCARE primary end-users are elderly people around the average retirement age in Europe (65+ yrs old) independent of their background and culture, both living in their homes or in elderly care facilities. Technological literacy is not a criterion for INCARE because the solution will be intuitive, intelligent, autonomous and operable through a multimodal interface. Both healthy elderly and those with common age-related impairments (reduced mobility, cardiovascular or diabetic conditions, low visual and hearing acuity, mild cognitive impairment, etc.) are among the target users. However, elderly with sever health problems (e.g. bed), although able to benefit from INCARE, are not among the main target users of the project. Users' financial situation is also not an exclusion criterion. The flexibility (e.g. from simple PC to advanced robotics) and modularity of the platform allow users to personalize the solution (pay for what they need) and make it affordable for a wide range of budgets."

Thus, age, as stated above is a criterion for the selection of primary users.

Additional criteria to the ones defined in the INCARE proposal arise from the support which can be offered through the INCARE functionalities to the needs of the end-users. These functionalities are presented together with the groups of primary users who can benefit from them in Table 1

No	Device	INCARE related features	User related features
1	Tablet	Provides multimodal interfaces (vocal, touch) for the interaction of the end- users with the INCARE platform	visual impaired or hearing impaired
		PHYSICAL CONDITION	

Table 1. INCARE functionalities versus users who can benefit from them.

2	Blood pressure meter with optional ECG	monitoring of blood pressure, heart rate with optional ECG recording	high blood pressure, cardiovascular diseases
3	Glucometer	monitoring of blood glucose levels	diabetes
4	Oximeter	monitoring of blood oxygen levels and heart rate	asthma, pneumonia
5	Weight scale	monitoring of body weight	heart failure, diabetes, mobility problems
6	Thermometer	monitoring of body temperature	flue, pneumonia, all conditions associated with fever
		ACTIVITY	
7	Xiaomi Mi Band	number of steps, heart rate	users leading a sedentary life, users who have a condition which requires them to keep active (diabetes, heart disease, obesity, depression), etc.
8	Indoor mobility sensors	indoor localization, fall detection and mobility patterns	users at risk of falling (mobility problems, vision problems, frequent bed exits at night), users with cognitive problems
9	Outdoor mobility sensors	outdoor localization and fall detection	users at risk of falling (mobility problems, vision problems, frequent bed exits at night), users with cognitive problems
10	Calendar	reminders and alerts for various tasks and activities	all users can benefit from this functionality
		WELLBEING	
11	Various single player game	gamification	cognitive stimulation and entertainment
12	Social and motivational team game	gamification coupled with calendar and activity monitoring	physical and cognitive stimulation, socialization, entertainment
		НОМЕ	
13	sensors and actuators for home automation	movement sensor, hazard (gas, water, etc.) detector, temperature and humidity sensor, etc	all users can benefit from this functionality
		ROBOTICS	
14	robotic apps	software for manipulation, navigation, image/video processing, communication	helping users with bringing/carrying, fall confirmation and support, hazard detection, gesture and activity understanding
15	robotic platforms with apps	manipulation, navigation, image/video processing, gesture understanding	helping users with bringing/carrying, fall confirmation and support, hazard detection, gesture and activity understanding

2.1 Age

The INCARE project is addressed to elderly 65+. However, it has turned out that the definition of elderly differs among the end-user countries. For example, in Poland, the age limit for classifying a person as a senior is 60 years while in Romania 65. As stated in the senior policies of several countries,¹ seniors cannot be treated as homogeneous group. Moreover, seniors at different stages of life have different needs. According to the World Health Organization (WHO), seniors can be grouped in the following age groups: between the age of 60-74, a person is considered to be elderly; between 75-89 years we talk of old age; between 90-99 years the very old age comes; and over 100 years one enters the age of Methuselah. Based on the definition of the WHO, the time of retirement in European societies coincides with the elderly age - as in the states of the continent the completion of labor market activity takes place between 60-67 years of age.

2.2 Physical and mental condition

This group includes primary end-users who have various health conditions which can be psychological (e.g. memory loss due to Alzheimer, degenerative dementia, etc.), physical (reduced mobility) or combined which requires monitoring of those parameters offered through the INCARE functionalities.

In the NITICS project, which we are partially exploiting here, a multinational survey has investigated the health condition of 153 from Poland, Romania, Slovenia and France. In Romania, for example, 78.7% of all respondents, reported one or more chronic diseases. 52.5% also reported co-existing mobility problems. Overall, 68% of the respondents reported permanent health complaints. All these users, could benefit by being included in the INCARE pilots and using the functionalities 2-10 in Table 2.

Many people suffer from visual and hearing deficiencies and have some kind of heart condition (e.g. high blood pressure, ischemia). In this case, the multimodal interface can facilitate the interaction with the user.

Other quite often encountered medical conditions were related to rheumatoid arthritis, rheumatism and osteoporosis. These are expected to be associated with mobility problems in which case the INCARE functionalities 7-19 and 12 in Table 2 can be useful in supporting the users. Additionally, end-users in the survey groups exhibited also mental health conditions such as memory loss or cognitive impairment. For these users the functionalities 10-13 can be useful.

Regarding gender related distribution. some conditions are exhibiting a higher incidence among one gender. For example, high blood pressure, cardiovascular diseases and dementia are more prevalent in women than in men. According to Eurostat²:

- In 2016, circulatory diseases were the main cause of death for the elderly population within the EU-27, while for persons aged less than 65 years, cancer was the leading cause of death.
- In 2016, around two fifths (40.3 %) of all deaths among the elderly population in the EU-27 were from circulatory diseases, compared with almost one quarter (23.4 %) from cancer and less than one tenth (8.1 %) from respiratory diseases. A higher proportion of the total number of deaths among elderly women could be attributed to circulatory diseases (43.3 % compared

¹ Social policy towards the elderly 2030. Safety - Participation – Solidarity, Ministry of Health

and Ministry of Digitalization, adopted by the Council of Ministers on 26 October 2018.

with 36.8 % for elderly men), whereas a higher share of elderly men (than women) died from cancer (28.1 % compared with 19.3 %) or from diseases of the respiratory system (9.2 % compared with 7.2 %).

Thus, we will try to also have a non-biased gender balance in our end-user selection.

2.3 Digital literacy

Last but not least, we have identified digital literacy as a criterium to consider in the result analysis of the pilot study but not in the inclusion/exclusion of the users. One of the main issues raised in reference to older members of society is digital exclusion. In 2009 only 8% of those over 65 were regular Internet users. Despite many positive changes senior citizens are still the most likely to be unfamiliar with ICT possibilities. In addition, there is a visible difference between the Western and the Eastern parts of EU in the use of ICT elderly, a conclusion reached also by NITICS. However, fair distributions of goods, including ICT products, is one of the elements of social justice. As proven in RAPP pilots, Error! Bookmark not defined., Error! Bookmark not defined. robotic apps and platforms can help to bridge the gap between the ICT illiterate seniors and the rest of society. This will provide them better quality of life and improve independent living to aging citizens, open new possibilities and allow them to participate in the digital revolution.

2.4 Other criteria

In addition to the physical and mental condition of the users, a further differentiation is required in order to sort the INCARE primary end-users, as defined above, and characterize them for consequent analyses. In this respect, we have identified an additional criterium, *i.e.* independent living users and users in long-term care (LTC) facilities (e.g. nursing homes, senior villages, etc.). For the independent living users, we have additional criteria:

- existence of a caregiver who can be informal or formal.
- living conditions as described below.

The fact that senior apartments are not adjusted to their needs as well as the inefficiency of public social services and health care offered to seniors in their local area, are some of the reasons why elderly people move – or are transferred – to facilities. In most cases such a decision is in opposition to their preferences to stay with their families and to receive support from their family members.³ If it were possible to ensure systematic and effective care offered to seniors in their place of living, it might reduce the number of residents in Social Welfare Homes⁴ in the future. This is one of the areas where INCARE solution can help.

2.5 Summary

The above outlined criteria are summarized as a table of bi-dimensional criteria which can be considered when identifying primary end-users selected for the pilots (see Table 2).

³Dezinstytucjonalizacja usług opiekuńczych - wyniki deskresearch przeprowadzonego w ramach projektu: Diagnoza i analiza funkcjonowania formalnych i nieformalnych instytucji opieki w Polsce

współfinansowanego ze środków Unii Europejskiej w ramach Europejskiego Funduszu Społecznego (https://www.academia.edu/33927353/Deinstytucjonalizacja_usług_opiekuńczych_w_Polsce_Nieformal na_opieka_rodzinna_nad_osobami_starszymi)

⁴Raport na temat sytuacji osób starszych w Polsce, Warsaw, IPiSS 2012, Link: <u>http://senior.gov.pl/source/raport_osoby%20starsze.pdf</u>

Criteria of separating into groups	Criteria type (categorical)
Existence of long-term care facility	YES / NO
Existence of informal caregiving services	YES / NO
Existence of professional caregiving services	YES / NO
Existence of a physical or mental condition	YES/NO
Existence of age limiter (60+ or 65+)	YES/NO

Table 2. Bi-dimensional criteria for primary end-user classification.

3. Country-wise primary end-user classification and differentiation

We are presenting in the following sections the national policy regarding elderly which will influence not only our classification and differentiation criteria but also the attitude of various stakeholders towards the INCARE pilots. We will also present the country specific situation with respect to the criteria outlined in section 2. The recruitment strategy takes into account attaining the first milestone of the project (M1.1) which targets provisions for having a min 10% backup margin.

3.1 Poland

3.1.1 Social policy towards the elderly in Poland

In 2018, the Polish government adopted the document "Social policy towards the elderly 2030. Safety - Participation - Solidarity" that defines directions and priorities of social policy towards seniors.

One of the priorities of senior policy is to enable older people to maintain their independence for as long as possible by accessing self-reliant services. One of the specific objectives is the development of various forms of day care for the elderly, such as daytime stays, but also the development of support services for the elderly and their caregivers provided in the place of residence. **The adopted policy also assumes the implementation of new technologies to care for the elderly, and the development of telemedicine and tele-care to monitor the health of seniors.**

It should be stressed that experts note that when conducting activities addressed to this group, it is necessary to take into account the diversity of seniors' population and, consequently, heterogeneous needs. One of the differentiating criteria is age. Seniors aged 60-70 and 70-80 and 80+ differ in their level of education, health, housing situation, marital status and lifestyle. Therefore, it is necessary to adapt programs and activities to the seniors' life phase. The second very important criterion specified in the document is the level of independence. The type of support offered must be adapted to the level of independence and the type of needs arising from it.

- Activities aimed at dependent elderly people should focus on:
- Reducing the scale of dependence on others by facilitating access to services strengthening independence and adjusting the living environment to the functional capabilities of dependent older people;

- Ensuring optimal access to health, rehabilitation and care services tailored to the needs of dependent older people;
- A network of environmental and institutional services provided to dependent older people;
- Support system for informal caregivers of dependent elderly by public institutions.

3.1.2 Polish end-users

According to data⁵, in 2016 in Poland almost every second household was inhabited by people over 60 years old. What's more, every fourth consisted only of seniors among which 15% lived alone. According to the population projection, this process will continue to deepen and until 2030 seniors are expected to lead more than a half (53%) of all single-family homes in Poland⁶.

The fact that senior apartments are not adjusted to their needs as well as the inefficiency of public social services and health care offered to them in their local area, are some of reasons why elderly people move – or are transferred – to facilities.

In most cases such a decision is in opposition to elderly people preferences to stay with their families and to receive support from their family members⁷.

If it were possible to ensure systematic and effective care over seniors in their place of living, it might reduce the number of residents in Social Welfare Homes⁸ in future. We expect that this is one of the areas where INCARE solution might help.

3.1.3 Recruitment

The initial end-user target number for the Polish pilots was 60 end-users with 50 being primary (elderly) and secondary (caregivers). Considering the situation outlined in section 3.1.2 and the constrains imposed by the allocated budget and time, the initial pilots in Poland were planned to include elderly in care facilities (daycare, nursing homes) along with independent living users. Their formal and informal caregivers were also considered. Users for the three age group categories were considered, *i.e.* 60-70, 70-80 and 80+ years old, for recruitment. In addition, primary users under all categories in Table 2 would have been selected. In order to comply with the 10% margin, we have considered both a nursing home and a daycare center for users under professional care. The latter, represent a category which is in between independent users and users in long-term care. They would have ensured the required margin the pilots.

Subsequent to the COVID-19 pandemics the above strategy was revised because access to users in care facilities became restricted and strictly regulated. Thus, the users foreseen at this moment for the

⁵The material and income situation of pensioners' households in 2016, Statistics Poland, <u>https://stat.gov.pl/obszary-tematyczne/warunki-zycia/dochody-wydatki-i-warunki-zycia-</u>

<u>ludnosci/sytuacja-materialna-i-dochodowa-gospodarstw-domowych-emerytow-i-rencistow-w-2016-r-</u> _27,1.html

⁶ Raport na temat sytuacji osób starszych w Polsce, Warsaw, IPiSS 2012, Link: <u>http://senior.gov.pl/source/raport_osoby%20starsze.pdf</u>

⁷Dezinstytucjonalizacja usług opiekuńczych - wyniki deskresearch przeprowadzonego w ramach projektu: Diagnoza i analiza funkcjonowania formalnych i nieformalnych instytucji opieki w Polsce

współfinansowanego ze środków Unii Europejskiej w ramach Europejskiego Funduszu Społecznego (<u>https://www.academia.edu/33927353/Deinstytucjonalizacja_usług_opiekuńczych_w_Polsce_Nieformal</u> <u>na_opieka_rodzinna_nad_osobami_starszymi</u>)</u>

⁸Raport na temat sytuacji osób starszych w Polsce, Warsaw, IPiSS 2012, Link: <u>http://senior.gov.pl/source/raport_osoby%20starsze.pdf</u>

pilots have to be independent living seniors/elderly and their caregivers. This poses an additional time and financial burden on the end-user organization because:

- more replica of the INCARE platform have to be available for the pilots which will increase the financial load;
- individual training and support have to be offered as opposed to group training and support.

Consequently, the number of primary and secondary users to be involved in the Polish pilots was decreased to 40 - 50 and the duration of the pilots to a minimum of six months as compared to a minimum of one year. In this situation, ensuring recruitment of users with a 10% margin might imply:

- 1) involving a recruitment agency
- 2) involving users from a larger area
- 3) looking for daycare facilities which might allow a minimal interaction with STOCZNIA.

Considering the above points and in particular points 2 and 3, a revised the design of the INCARE platform has evolved towards having a minimal deployable solution which requires close to zero installation and configuration at the users' premises.

3.2 Slovenia

3.2.1 National policy towards the elderly in Slovenia

In Slovenia, many rights derive from compulsory social and pension insurance, which is included in the public law system. Rights, obligations and legal relations are regulated by law and other legal acts adopted by law. The public compulsory insurance system and the social security system are combined in most countries. Three systems predominate: the single state pension system, where the amount of the basic pension is the same for all beneficiaries; a pension system based on past income and a mixed system (first and second, typical of Scandinavian countries).

For the older population responsibilities would primarily fall under the Ministry for Work, Family, Social Affairs and Equal Opportunities as well as Ministry of Health. The latter has been without an operative Minister for the last three years, contributing to almost alarming state in the public health sector. In addition, the Slovenian legislation requires certain obligations in the field of health and social care to be carried out at a local level. These include supplementary payments for institutional care, provision of family assistance at home as well as subsidisation of both services.

Therefore, there is no single governmental body or institution, which would be responsible for comprehensively monitoring the situation of older persons and would be concerned with enjoyment of their rights. Also, there is no operational strategy or national programme, which would focus specifically on active ageing or exclusively on the social inclusion of older people.

3.2.2 Slovenian end-users

According to the statistical data of the Republic of Slovenia, Slovenia today counts a little more than 2,062,000 inhabitants. 17.5 % of persons aged at least 65 and women accounted for a larger share. Today, people over the age of 64 make up one sixth of the population of Slovenia, and this share will increase to one third in the next five decades. Eurostat's EUROPOP 2010 population projections predicted that in 2035 there would be twice as many older people as children in Slovenia. The population of Slovenia is expected to start declining after 2045, but the number of the elderly is expected to increase until 2055, when it is expected to be 30.1%, and among these the oldest, *i.e.* aged 80 or over, 38.3 %.

Adequate standard of living and social services: Older persons, particularly older women, are at the higher risk of poverty than general population. In 2013 14.5% of people were living at risk of poverty, which presents an increase compared to 2009 level, when the at-risk-of-poverty rate was 11.3%, among them 22% of people were above 64 years of age or older. With increasing number of people entering the pension system, higher risk of poverty can be also attributed to the low pensions.

Health: The share of people aged over 65 years whose every-day activities in the last six months have been moderately or greatly obstructed due to health problems, is in Slovenia higher than in the EU (2012: 61.6%, compared to 55% EU average). This percentage is increasing.

Housing: Elderly also often live in apartments that are not adjusted to their situation and problems, and cannot afford to cover the costs of their adjustments. In Slovenia, on one hand, there is a high level of owned accommodations, low accommodation mobility and mentality that the elderly need to leave their estate to future generations.

Care system: Slovenia has a strong institutional orientation in the forms of providing assistance to the elderly. According to research conducted in Slovenia by Simona Hvalič Touzery (2009), as many as 12% of people over the age of 65 can no longer take care of themselves. In 2013, 16,554 persons aged 65 and over lived in old people's homes in Slovenia, of which 24.1% were men and 75.9% were women (Statistical Office of the Republic of Slovenia 2014). Demand for accommodation or care in old people's homes is growing, which is also a consequence of the growing elderly population (Statistical Office of the Republic of Slovenia 2014).

3.2.3 Recruitment

Pilots is Slovenia are targeting involvement of 20-25 primary (65+) and secondary end-users. In the initial plan the testing was to be conducted in full number in the elderly facilities, nursing homes as well as in the private individual facilities with individuals or/and couples. Due to the restrictions in communication and physical connection with general population and especially strict regulations concerning working within the elderly facilities - entering as an outside expert had to be adjusted. Thus, a new concept and a new plan was developed by IZRIIS based on the following principles:

- Testing will be carried out in the homes of individual users, using all the advised rules in the social contacts.
- Testing will be carried out in the living lab / laboratory.
- Testing in the elderly facilities will be carried out in the limited scope when the professional workers within the facilities will have enough manpower / resources to support the efforts of Slovenia partner in leading the testing in the facilities.

3.3 Hungary

3.3.1 National policy towards the elderly in Hungary

The National Strategy concerning Senior Citizens was adopted by the Parliament in 2009 (Decision No 81/2009 (X.2) of the Parliament). This paper defines long-term goals until 2034, such as aligning life expectancy with the EU average; increasing the number of years spent in good health; keeping active life longer; ensuring financial security in elderly age; promoting social integration; harmonizing different services (healthcare, social, educational, cultural, etc.) considering the interests and needs of the elderly and old people; supporting lifelong learning by making digital studies accessible for the

elderly; promoting active ageing (meaning not only labor activity, but also social, cultural, and civil activity); calling the attention of younger generations to 'age management'; changing social attitude regarding ageing in an economic and social sense.

The policy framework of the Strategy is in conformity with the ageing principles of the United Nations and the EU, as well as the main WHO documents. In order to obtain useful application in practical work, the Strategy draws on the opinion of the elderly and elderly care experts, as well as on practical knowledge related to 'good practices' existing nationally or adapted from abroad. The vision, scopes and goals of the Strategy adopt both pro-active (preventive) and reactive approaches. The Strategy outlines main areas of action at public, social, political and individual level. The basic direction is intended to ensure the well-being of older people through a wide range of personalized services available, taking also into account the individual differences in social and cultural needs among the elderly.

One of the main principles of the Strategy is the 'neither-more-nor-less-than-exactly-what-you-need' notion, that is, elderly people should have access to a variety of services best adapted to their individual needs. Another important approach is that the elderly should also be informed properly about the quality, the reliability and accessibility of the services. A further goal is to ensure the possibility for elderly people to gain helpful knowledge in various ways, including training in order to have access to self-help tools and techniques to preserve their quality of life. Conditions for lifelong learning, self-help and self-care, and a variety of options for the wider application of voluntary work should be developed.

In this regard, the Government's programme stresses the need for a change in approach. It emphasizes the importance of social attitudes concerning ageing (especially social inclusion and participation of the elderly). The Strategy underlines the importance of maintenance of activity, the encouragement of volunteering and the cooperation activities of church and civil organizations.

Elderly people have less advocacy and often find themselves in vulnerable situations. Thus, the **Commissioner for Fundamental Rights** launched a project called 'Dignity in old age' in 2010 with the aim to promote the enforcement of rights of elderly with the support of the ministry responsible for elderly affairs. In order to promote a self-conscious attitude towards applicable legislation of elderly and people dealing with them, the Commissioner examined complaints and held focal studies to identify the key problems and to raise awareness amongst policy makers.

The **Equal Treatment Authority** conducts proceedings when the principle of equal treatment might have been violated, either at the request of the injured party or upon its own motion (ex officio) in cases set forth by law. The proceedings aim to establish whether any discrimination occurred. The Authority publishes its decisions which may – through information contained therein – contribute to the prevention similar violations of law in the future. Publishing contribute to the redress of grievances suffered by the individual or group that suffered discrimination. Moreover, the Authority is also entitled to impose sanctions.

3.3.2 Hungarian end-users

Hungary has an ageing and decreasing population, according to the Central Statistical Office (KSH), which expects the ratio of the population over age 65 to minors under 18 to reach 1.66 to 1 by 2030. According to the KSH, the aging index, which compares these two proportions of the population, is the most reliable method for predicting long-term demographic changes. There have been more

Hungarians over 65 than under 18 since 2006, and the aging index has been increasing constantly since 1990 and is not expected to change in the coming decades. In 1990 the ratio was 100 minors to 64 elderly people. By 2016 the ratio had flipped and there were 126 elderly to every 100 minors.

Between 1990 and 2017 the number of those aged 65 and older in Hungary increased from 13 % to 19 % (ca. 1.8 million people) and according to predictions it is set to reach 29 % (2.7 million people) by 2070. An examination of the internal dynamics of this age group shows that both the number and relative proportion of those aged 80 and above – the very elderly – is increasing rapidly. While this group numbered just 260 000 in 1990, there were 412,000 by 2016 (KSH).

The difference between the sexes is significant: 57 % of those aged between 65 and 69, and 73 % of those aged 85 and above, are women. For men at age 65, average future life expectancy rose from 12 to 14.4 years between 1990 and 2016, while among women it rose from 15.3 to 18.2 years. In the years since 2000, women have lived an average of 3.6 - 3.8 years longer than men.

3.3.3 Recruitment

The average retirement age of people in Hungary is 61 year for women and 64 for men. There are 55.170 people in retirement homes which corresponds to ca. 3 % of the total elderly population. Due to very limited access to elderly and nursing homes because of the COVID-19 pandemics (recruitment started later in Hungary because of late national grant agreements) initially we have chosen to access 50 people in closed communities with whom we have access to and visit them regularly even out of the scope of the INCARE project. One community is from Western Transdanubia Region and one from Southern Great Plain Region of Hungary.

Exclusion criteria:

- Users below the age of 65;
- Non-consent of handling data;
- Acute or chronic symptoms, which excludes the use of the equipment (e.g. septic status, severe impairment, acute incident, etc.);
- Participating in the study represents a health, safety or security hazard to the primary, secondary end users or the facilitator of the study;
- Participating in the study or continuing it would violate the dignity of the person;
- The user denies further participation in the study.

Based on the targeting criteria we contacted the specific individuals and institutions with an initial advantage statement requesting a commitment for a virtual or face-to-face meeting. Based on the targeting criteria we contact the specific individuals and institutions with an initial advantage statement requesting a commitment for a virtual or face-to-face meeting. The outcome of end-user identification step is a date, time and channel for a first contact. During the first contact the facilitator of the meeting is introducing him/herself, explains the purpose of the meeting and the test clarifies decision making process and roles and asks for commitment to continue with the person in charge who are familiar with the needs of the primary and secondary users. Special processes and actions are clarified in order to have minimal disruption of daily life, building trust, and comply with all regulations

(e.g. health, hygiene, data etc.). This facilitates end-users' involvement and builds trust for being part of the pilots.

In order to reach the target of recruiting 130 – 135 users (primary and secondary) plus 10 % margin, we are planning to extend the contacts towards other communities and also to long-term care facilities (once the pandemic situation becomes more relaxed). Further details about recruitment are provided in D1.2.

3.4 Romania

3.4.1 National policy towards the elderly in Romania

At national level, there are a number of national public policies for the social inclusion of the elderly, including measures and actions in various fields (social protection, employment, housing, education, health, mobility, security, justice, culture, communication-information) for combating social exclusion. The National Strategy for the Promotion of Active Aging and the Social Protection of the Elderly (2015-2020) and the National Strategy for Social Inclusion and Poverty Reduction (2015-2020) are documents that recognize the importance of making changes to this category of the population, from the point of view of:

- increasing the level of participation in social life for the elderly, which implies changes in mentality and perception, both among the elderly and especially among other members of society;
- preventing abuse of the elderly and combating social exclusion among the elderly;
- development of a complex system of social and socio-medical services, in which it is important to conduct regular studies to monitor the social, behavioral aspects of aging, while monitoring providers and how to implement quality standards.⁹

3.4.2 Romanian end-users

The period of old age can be considered to start around the retirement age which in Romania is around the age of 65. The term 'elderly' is defined by the Law 17/2000 as referring to all persons at or above the Romanian official age of retirement.

Thus, elderly in Romania can be classified into 3 main age groups: elderly (65-74 years), old age (75-90 years) and longevity (over 90 years).¹⁰ In 2017, the number of elderly (over 65 years) residents in Romania represented 17.8 % of the country's population. Among them, 60.1 % were women and 39.9 % men. Approximately 47.7 % of the elderly live in urban areas, while over 52.4 % live in rural areas.¹¹ The duration of active life in Romania was, in 2017, lower by 2.5 % compared to the EU 28 average. The percentage of the population over 65 years old, which participates in the country's economic activity, in 2016 was 29.6 %.

From the point of view of the use of information technology, at the level of 2018, the percentage of those who used the internet is 53.8%. The devices used for internet use, in 2018, for the 55-74 age group were: mobile phone or smartphone.

⁹ Ministerul Muncii si Justitiei Sociale. (2018). Masuri destinate cresterii incluziunii sociale a persoanelor varstnice.

¹⁰ Apostiu, A. (2015). ACTIVE AGEING – A necessity for economic and social progress. Revista română de sociologie(1-2), 55-72.

¹¹ Institutul National de Statistică. (2020). Anuarul statistic al României 2019. Bucuresti: INS.

In Romania, in 2019, the average total pension was 1292 lei / person, increasing by 10.2 % compared to the year previous.¹¹

Only 23.4 % of the Romanian population over 65 rates their health condition as good or very good. At the same time, the EU average is 41.4 %. Most of the elderly, 54.7 %, consider their health to be satisfactory, surpassing the EU average of 40.1 %. The remaining 21.9 % reported that their health condition is bad or very bad. In comparison, only 18.5 % of the EU's elderly population fell into this category. ¹² The main causes of death in Romania are (in order): circulatory diseases, cancer, respiratory diseases, mental illnesses and behavioral disorders. Higher life expectancy for women leads to a higher percentage of older women living alone. The data collected in the 2011 Census shows a high share of people aged 65 and over living alone - 26.6 % of all people over the age of 65. Only 11.9 % of men age 64-74 live alone, compared to almost a third (27.7 %) of women of similar ages. The difference is accentuated for the age group 75-84 years, in which case 18.1 % of men live alone, compared to 40.6 % for women.

In 2011, 3.8 % of older women (aged 65 years or more) in the EU-28 were living in an institutional household. According to the data published by the Ministry of Labor and Social Protection, the number of accredited and licensed care units in Romania in 2019 was 353, increasing by over 60% compared to the previous year. Of these, over 68% are private.¹³

3.4.3 Recruitment

Taking the above into consideration the recruitment of primary end-users was going to balance the following categories:

- Age groups: elderly 65-74; 75-90; 90+
- Gender: higher number of women will be involved
- Living conditions: both independent (with and without caregiver) and in nursing homes
- Income: users having an income which is below and above the average pension
- Health condition: users who have conditions addressed by the INCARE platform

The target number of primary and secondary users involved in the Romanian pilots is 20-25. In order to ensure that we have a 10% margin, CITST has already contacted via phone users from its network to inquire about their availability. These are users who have participated in previous projects and are acquainted with AAL ICT. In addition, CITST has contacted 3 nursing homes (2 private and 1 belonging to the Bucharest Municipality) in order to ensure a good user balance and also the needed participation. Unfortunately, the COVID-19 pandemics has restricted the access to the elderly care institutions and has also made independent users reluctant to participate in the pilots. Thus, the employed strategy was to identify, based on the discussions with end-users, the INCARE functionalities which are suitable for the pandemic situation (keeping users entertained and connected at home, monitoring of temperature and oxygen saturation levels, etc). and which need minimum interaction at deployment.

¹² Sarany, O. (2020, 01 27). Transylvania Now. Retrieved from Romanian population ageing accelerating – Eurostat: https://transylvanianow.com/a-look-at-the-lives-of-romanian-elders.

¹³ Ministerul Muncii. (2019). Cămine pentru persoane vârstnice licențiate la 11.03.2019 (cod serviciu social 8730 CR-V-I). Retrieved from <u>Link.</u>

4. Secondary end-user classification criteria

INCARE secondary end-users are defined in the project as being both informal (family, friends) and formal (professionals) caregivers.

Informal care forms a cornerstone of all LTC systems in Europe and is often seen as a cost-effective way of preventing institutionalization and enabling users to remain at home.¹⁴ Most recent LTC reform packages have included important components focused on informal carers. A common trend is to introduce cash payments as support for people in need of LTC or directly to informal carers. These have often been motivated by a desire to offer care users more choice of their care package, but also in an effort to incentivize and support care provided by family or friends.

Informal care, also known as unpaid care or family care, constitutes a significant share of the LTC provision in European countries. Estimates suggest that as much as 80 % of all long-term care in Europe is provided by informal carers.¹⁵ The available estimates of the number of informal caregivers ranges from 10 % up to 25 % of the total population in Europe. The average varies significantly between countries, groups of countries and depending on how informal care is defined and measured. Informal carers are often women, either providing care to a spouse, parents or parents-in-law, and a large share is provided by people who are older than standard retirement age.

Informal care is likely to become even more important in the future due to demographic change, health care advances, LTC policy and cost-containment pressures leading to the favoring community care options over institutionalization where possible.¹⁶

The definition of "informal care" is broad. In INCARE we will consider informal carers those who provided to older people (family or otherwise) on a regular basis (at least once per week). The age as well as the lack of co-habitation are not considered exclusion criteria in INCARE but will be taken into account when analyzing the pilot data and when classifying the informal caregivers involved in the pilots. Another classification takes into account if the carers are working or retired. Last but not least, considering the current trends in informal care, we will also distinguish between formalized care (payed by the municipality or other entities) and not formalized one. Thus, the classification criteria for the informal caregivers are summarized in Table 3.

Classification criteria	Criteria type
Frequency of care	> 1 / week
Co-habitation	YES / NO
Employment	YES / NO
Formalized	YES/NO
With own family	YES/NO
Age	-
Gender	-

Table 3. Classification criteria for informal caregivers.

¹⁴ Informal care in Europe, Exploring Formalisation, Availability and Quality, Publications Office of the European Union, 2018, ISBN: 978-92-79-86583-1

¹⁵ Hoffmann, F., & Rodrigues, R. (2010). Informal carers: who takes care of them? POLICY BRIEF APRIL 2010 European Centre for Social Welfare Policy and Research, Vienna.

¹⁶ Riedel, M. (2012). Financial support for informal care provision in European countries: a short overview. Health and Ageing Newsletter, 27: 1-4.

However, despite the existing tendency of increasing informal care, it is also recognized that providing informal care can, affect caregivers' quality of life. On the one hand, it can be rewarding; on the other hand, it may be difficult to carry out caregiving tasks in combination with other daily activities. Providing informal care can lead to mental health problems such as stress, fear, gloominess, depression, and concerns about the future and the caregiving tasks. Caregiving can also affect physical health of the caregiver, as they can be more often sick, tired or can experience physical stress.

Informal caregivers will benefit physically, psychologically and economically by being able to receive timely alerts upon detection of emergencies (by the platform or triggered by the user), receive alerts in case of abnormal health parameters (e.g. high glucose, etc.), receive alerts from the home sensors (e.g. open entrance door), keep in contact with their caretakers through email, robotic platform, etc. They will be able to add remotely (from a web interface) events or TODOs in the personal calendar of the user. All these will relieve stress and will allow caregivers to remain active in their profession, spend time with their families and friends and also engage in other activities.

Professional caregivers will also benefit from the INCARE services by receiving regular health information, being able to consult the history of the user activity and physical health in between visits. They will be able to follow the "trends", understand the primary user better, advice on activities that sustain the condition (and not the activities that are stressful to the caretaker).

4.1 Poland

Most of care services for seniors are delivered either by family members or other informal caregivers. In our pilot studies we define informal caregivers as an adult taking care of a dependent person (senior) who is not a professional caregiver and does not receive salary for the work, most often a family member.¹⁷

Due to very little data regarding informal care in Poland, we present some basic facts about this phenomenon using available statistics referring to regional level (Greater Poland Voivodship – Polish *Województwo Wielkopolskie*).¹⁸ However we – as well as the author of the report we quote - believe that the main conclusions from regional perspective might picture trends that apply also to the national level.

Referring to regional research, informal care is mostly dominated by women (67 % of caregivers who took part in the research), aged 41 to 71 years old (70 % of caregivers who took part in the research), specifically: 18.4% caregivers aged 31 to 40 years old; 24.9 % caregivers aged 41 to 50 years old; 30% caregivers aged 51 to 60 years old; 20 % are caregivers above 61 years old.¹⁹

Informal caregivers are often family members (83.1 %) who provide care to their parents (50.8 %), another family member (16 %) and a spouse (13.4 %). In less than half of the cases (48.9 %), the senior lives with the caregiver (most often with his/her son or daughter). The older the caregiver, the more

¹⁷ Pogłębione studium usług opiekuńczych skierowanych do osób starszych, Poznań 2017, link: <u>https://rops.poznan.pl/wp-content/uploads/2018/06/raport Pogłębione-studium-usług-opiekuńczych-skierowanych-do-osób-starszych.-Środowiskowa-opieka-formalna-i-nieformalna wersja-końcowa.pdf</u> ¹⁸ Pogłębione studium usług opiekuńczych skierowanych do osób starszych, Poznań 2017, link: <u>https://rops.poznan.pl/wp-content/uploads/2018/06/raport Pogłębione-studium-usług-opiekuńczych-skierowanych-do-osób-starszych.-Środowiskowa-opieka-formalna-i-nieformalna wersja-końcowa.pdf</u> ¹⁹Pogłębione studium usług opiekuńczych skierowanych do osób starszych, Poznań 2017, link: <u>https://rops.poznan.pl/wp-content/uploads/2018/06/raport Pogłębione-studium-usług-opiekuńczych-skierowanych-do-osób-starszych.-Środowiskowa-opieka-formalna-i-nieformalna wersja-końcowa.pdf</u> ¹⁹Pogłębione studium usług opiekuńczych skierowanych do osób starszych, Poznań 2017, link: <u>https://rops.poznan.pl/wp-content/uploads/2018/06/raport Pogłębione-studium-usług-opiekuńczych-skierowanych-do-osób-starszych.-Środowiskowa-opieka-formalna-i-nieformalna wersja-końcowa.pdf</u>

often he or she lives with the senior. Caregivers above 50 years old much more often live together with their pupil.

Gender, age and family relationship between informal caregiver and senior will be taken into account as recruitment criteria for INCARE pilot studies.

When the family for various reasons cannot look after their older family member and no one can replace them in this care, the elderly move – or are transferred – to all-day facilities (retirement homes) like Social Welfare Homes (*Domy Pomocy Społecznej – DPS*) organized and funded mainly by local government (county level, polish *powiat*) or non-public entities. Social Welfare meet the needs of people who require 24-hour care because of their age, illness or disability and which the family is unable to provide. It provides living, care services and specialist care services, support and educational services.

At the end of 2017 there were 791 Social Welfare Homes in which the number of residents amounted 78 167. Among these group people aged 61 to 74 years old constituted 29% of the total population and people over 74 years - 28% of the total residents.²⁰ Another facility dedicated to elderly care services as well as support, food and entertainment is Day Care Centre (polish *Dzienny Dom Pomocy*) organized by only 10% of municipalities (the lowest level of local government - polish *gmina*). In 2016 around 20 thousand elderly people benefited from services offered by 295 Day Care Centres.²¹

Both types of facilities - Social Welfare Cares and Day Cares (public as well as non-public) will be

4.2 Slovenia

In Slovenia, new forms of care for older people living in own homes such as home care services were introduced and promoted in recent years. The most developed of all formal forms of care in Slovenia is institutional care of the older people with its long tradition.²² After 1991 institutional care was supplemented by a series of new services, which focused predominantly on the development of services in the home of the person in need of care. In addition to community health care, which is, similarly to institutional care, traditionally present in Slovenia, social home care is also available within the community. There is also an array of possibilities for the relatives – family caregivers of dependent older people, e.g. they can take sick-leave for their period of care, or become a family aid or a personal assistant. Apart from the aforementioned services for the older people and their family members Slovenia also has a long tradition in personal lifeline systems or panic buttons for the older people.

Together with marital partners, children are also legally obliged to provide economic support for their financially dependent parents. According to the estimate found in Nagode et al.,²³ 16,199 people over the age of 65 received different forms of formal community care in their homes in 2011, which is 4.7 % of the entire over 65 population. In 2011 institutional care was provided for 5% of this population

https://www.gov.pl/web/rodzina/statystyka-za-rok-2017

²⁰Ministry of Labor, Family and Social Policy Statistics. Link:

²¹ OPIEKA NAD OSOBAMI STARSZYMI W DZIENNYCH DOMACH POMOCY. Informacja o wynikach kontroli. DEPARTAMENT PRACY, SPRAW SPOŁECZNYCH I RODZINY Narodowej Izbyt Kontroli 8.05.2017. Źródło: https://www.nik.gov.pl/plik/id.13998,vp.16444.pdf

²² V. Hlebec, A. Srakar, B. Majcen, Care for the Elderly in Slovenia: A Combination of Informal and Formal Care, Rev. soc. polit., god. 23, br. 2, str. 159-179, Zagreb 2016.

²³ Nagode, M., Zver, E., Marn, S., Jacović, A., & Dominkuš, D. (2014). Dolgotrajna oskrba - uporaba mednarodne definicije v Sloveniji. Ljubljana: Urad RS za makroekonomske analize in razvoj.

over the age of 65 (21,093 people). Financial aid was given to 18,334 people of the over 65s. This information indicates a slow growth of formal home care forms, but fails to reveal anything as regards informal care or the combination of informal and formal care.

Based on the above outlined particularities, the selection (balanced distribution) and classification criteria for secondary users in the Slovenian pilots will consider the characteristics presented in Table 4.

Informal caregiver		Formal caregiver	
Frequency of care	no. of visits per week (>1)	Institutionalized	YES/NO
Co-habitation	YES / NO	At home	YES/NO
Employment	YES / NO		
Own family	YES/NO		
Age	-		
Gender	-		

Table 4. Classification criteria of secondary users.

4.3 Hungary

In Hungary, the social care system (state-managed institutions, financial allowances, services, rights, number of accommodation spaces, opening hours etc.) is regulated by Act III of the 1993 law on social care (Social Law or Szt). This law provides for financial support, including a care allowance for family carers. Other non-state institutions (NGOs, churches, business associations etc.) may also maintain social services, but are obliged to first obtain an operating license. Thus, these organizations are also included on the national register of operating licenses (MŰKENG) (regardless of whether or not they receive state subsidies.) Services provided within the domain of personal care are covered by a separate decree (29/1993. (II. 17.) Gov. Decree) which stipulates that certain defined collective costs (institutional or personal costs, which in the case of retirement homes may also include entrance fees) must be reimbursed to the carer. Among basic social services, those affecting the elderly include the village and rural caretaking service, catering, home help (including on-call home help) and daytime care. Daytime care (elderly club) must be provided by all municipalities of over 3000 inhabitants to disadvantaged elderly people who require help in maintaining their independent lives and social connections. Specialist care comprises nursing provisions, including that provided by residential care homes, as well as institutions ensuring the availability of temporary accommodation (nursing homes for the elderly).

Nationwide, 7324 municipalities offer in 2015 some form of care service for the elderly. Only 7% of those within the eligible age group, however, are able to take advantage of home help provisions, and only 3% can make use of residential care facilities. The problem, however, is only partly down to a lack of capacity. What exacerbates this lack is the unequal territorial distribution of services, characterized both by mismatches between need and availability in certain areas, and by inequalities in service provision even where facilities do exist. Elderly clubs are provided by 41% of municipalities.

Professional caregivers were, according to data from HCSO OSAP12 no. 2023 of December 31st 2013, 92,102 people employed in the sector's various institutions. The largest category of work (39,000 or 42% of the total) was in specialist social care, followed by basic social care (29,000, or 31%).

Based on the above outlined particularities, the selection (balanced distribution) and classification criteria for secondary users in the Hungarian pilots will consider the characteristics presented in Table 5. It is important to note that in Hungary also formalized care exists.

Informal caregiver		Formal caregiver	
Frequency of care	no. of visits per week (>1)	Institutionalized	YES/NO
Co-habitation	YES / NO	At home	YES/NO
Employment	YES / NO		
Own family	YES/NO		
Formalized care	YES/NO		
Age	-		
Gender	-		

Table 5. Classification criteria of secondary users.

4.4 Romania

The LTC system in Romania includes all medical and social services delivered over a long period of time to those in need such as the chronically ill, disabled and dependent elderly who need help with activities of daily living or instrumental activities of daily living.

The available settings for LTC are institutional and home-based, the latter being either formal or informal.²⁴ The types of services for the elderly include:

- home care temporary or permanent services
- nursing home care (old-age home) temporary or permanent services
- institutional care (residential care) in day care centers, clubs for the elderly,
- temporary care homes, assisted living arrangements, social apartments and dwellings, as well as other similar settings (Law 17/2000).

Romania has a major deficit of institutionalized services. Home care is the most commonly used care option for dependent elderly because of the comfort the family provides and the reduced costs as compared to institutionalized care. This, however, raises many problems. Most family caretakers are women, the wives or daughters of the dependent. Many caretakers are elderly persons themselves and may also become dependent. Family care is most common in the rural areas, where the traditions and moral values are maintained to a greater extent.

Community services provided for the elderly include:

- social services, particularly for the prevention of social marginalization and supporting social reintegration, legal and administrative counseling, payment of some services and current obligations, home and household attendance, help for the household, and food making;
- medical-social services, especially help with personal hygiene, adaptation of the home to the elderly person's needs, encouraging economic, social and cultural activities plus temporary attendance in day care centers, night shelters or other specialized centers;

²⁴ D. Popa, Long-term care in Romania, ENEPRI research report No. 85, ISBN 978-94-6138-027-2

• medical services, such as medical consultations provided in public health institutions or in the home by the General Practitioner, dentistry consultations, medicine administration, supporting sanitary materials and medical devices.

LTC for the elderly is funded through both public and private means. There are no cash benefits legalized in Romania for elderly care at this time. Legalized cash benefits and greater in-kind benefits are available for persons who were officially recognized as having a disability. Many elderly who are chronically or terminally ill or have multiple comorbidities are granted a degree of disability and the number of these cases has risen consistently in recent years. Therefore, there is a legal delimitation between care for the elderly (Law 17/2000) and care for the disabled (Law 448/2006), but in reality, many services and classifications overlap and the beneficiary could combine other benefits (old age, invalidity or survivor) with disability benefits.

Based on the above outlined situation of LTC in Romania, we will use the following classification for the secondary users.

Informal caregiver		Formal caregiver	
Frequency of care	no. of visits per week (>1)	Institutionalized	YES/NO
Co-habitation	YES / NO	At home	YES/NO
Employment	YES / NO		
Own family	YES/NO		
Age	-		
Gender	-		

Table 6. Classification criteria of secondary users.

5. Conclusions

This deliverable is presenting the selection and classification criteria for the end-users to be involved in the INCARE pilots. These will take place in Poland, Slovenia, Hungary and Romania. The involved end-users will be both primary (elderly) and secondary (carers). Provisions on how to ensure a sufficient number of end-user involvement have been made during the current task. Still, the number had to be reconsidered because of the current COVID-19 pandemics which has influence the access to end-users and also their availability to participate in the pilots.

The presented criteria also take into account the situation of elderly (national policies, income, digital literacy) and that of their informal caregivers. Professional caregivers are also considered although their involvement will be less important considering also the business plan developed in WP4.

6. Document history	
---------------------	--

Date	Changes	Version	Author
December 2018	ToC initiated	1	CITST
February 2019	description of the Polish criteria and general considerations about end-user classification	2	STOCZNIA

May 2019	description of the Slovenian and Romanian criteria and national level situation	3	IZRIIS, CITST
June 2019	first draft submitted after revision by the end-user partners	4	CITST, STOCZNIA, BZN, IZRIIS
October 2019	Hungarian criteria and national level framework for elderly support (after the signature of the Grant Agreement by BZN)	5	BZN
December 2019	revisions by CITST best on the identified customers and end-users during the AAL2business coaching	6	CITST
June 2020	revision because of the COVID pandemics	7	all end-user organizations