

# D1.2 Patient Clusters

## WP1 T 1.2

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Authors: FDG, HUG, MAC, SHG



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## Executive Summary

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This deliverable aims to define the target population of the DECI project, by giving the general definitions that will be used during the project and by specifying the inclusion/exclusion criteria. The deliverable also delineate the relevant dimensions, variables and tests that will be used to analyse the target population in the different pilot sites and subdivide it into clusters. In particular the DECI Minimum Data Set (MDS) is defined representing the minimum set of instruments (tests, scales, questionnaires, etc) needed for describing the target population during the pilot phase. MDS is used to standardize the data that each clinical partner will collect during the pilot phase in order to allow for comparisons across the test sites.

Finally the last paragraph includes a preliminary analysis of the target population in the four pilot sites.

## **1 Introduction**

This deliverable is the outcome of *Task 1.2: Definition of the patient clusters based on the intensity of the pathology and condition and lifestyle.*

This deliverable aims to define what is the target population of the DECI project, by giving the general definitions and specifying the inclusion/exclusion criteria, and to delineate the relevant dimensions, variables and tests that will be used to analyse the target population in the different pilot site and subdivide it into clusters. Such patient clustering will also represent the framework for the evaluation of the results of the pilot sites, that will allow to analyze what is the impact of the different solutions tested for the different typologies of patient.

## **2 General target population of the DECI project**

The general objective of the DECI project is to define an innovative business model to supply care and assistance services (with a remote based approach) for elderly people with Cognitive Impairment through the use of Information and Communication Technologies (ICTs). The DECI solutions aim to target continuum of population with cognitive decline ranging from early stages of MCI to mild dementia. The DECI solutions and the developed business model will be validated in the different test sites on different samples of such continuum. The preliminary population analysis done within this deliverable will help to define the specific target in the different pilot site. DECI will support the healthcare provider in early detection, evaluation, treatment and follow up and will support the patient and their families providing better care and quality of life. In the following we will give the general definitions that will be used throughout the project and the Inclusion/exclusion criteria for the recruitment of patients in the test sites.

### **2.1 Cognitive decline and cognitive impairment in the elderly**

#### **2.1.1 Age-related cognitive decline**

Age-Related Cognitive Decline (ARCD) is a label for the general modification of cognition which results from ageing. Physiological ageing is not responsible for causing cognitive disorders as such, but it's associated to a general cognitive modification with respect to young age.

For the DECI project the DSM – IV ARCD definition will be used [1]: This category can be used when the focus of clinical attention is an objectively identified decline in cognitive functioning consequent to the aging process that is within normal limits given the person's age. Individuals with this condition may report problems remembering names or appointments or may experience difficulty in solving complex problems. This category should be considered only after it has been

determined that the cognitive impairment is not attributable to a specific mental disorder or neurological condition.

### **2.1.2 Mild Cognitive Impairment (MCI)**

The term Mild Cognitive Impairment (MCI) refers to a clinical syndrome characterized by the presence of a subtle cognitive deficit, not related to physiological age associated cognitive modification, in a non demented person. The deficit can involve one or more cognitive functions and has a minimal impact on autonomy in daily life.

The clinical criteria widely used for the diagnosis of MCI in research and clinical settings have been the Mayo Clinic criteria [2]. This first criteria of MCI were focused on memory problems and detailed what today is called *amnestic-MCI*. More general criteria for MCI syndrome, less focused on memory impairment and broadened to include impairment in other areas of cognitive functioning, have been defined by Mayo clinic [3]. To better characterize MCI spectrum an international consensus conference was held in 2003 and revised core criteria were defined [4] that are useful to characterize different subtype of MCI: amnestic or non-amnestic (e.g. executive functions impairment, language impairment or attention impairment) single domain MCI, amnestic or non-amnestic multiple domains MCI.

For the DECI project the most recent clinical criteria for MCI, proposed by Albert et al. [5], will be used:

1. **Concern regarding a change in cognition** - There should be evidence of concern about a change in cognition, in comparison with the person's previous level. This concern can be obtained from the patient, from an informant who knows the patient well, or from a skilled clinician observing the patient.
2. **Impairment in one or more cognitive domains** - There should be evidence of lower performance in one or more cognitive domains that is greater than would be expected for the patient's age and educational background (objective evidence of impairment in single or multiple cognitive domains, with scores falling at least 1.5 standard deviations below age-matched norms and in reference to the individuals educational and socioeconomic background). If repeated assessments are available, then a decline in performance should be evident over time. This change can occur in a variety of cognitive domains, including memory, executive function, attention, language, and visuospatial skills. An impairment in episodic memory (i.e., the ability to learn and retain new information) is seen most commonly in MCI patients who subsequently progress to a diagnosis of AD dementia.
3. **Preservation of independence in functional abilities** - Persons with MCI commonly have mild problems performing complex functional tasks which they used to perform previously, such as paying bills, preparing a meal, or shopping. They may take more time, be less efficient, and make more errors

at performing such activities than in the past. Nevertheless, they generally maintain their independence of function in daily life, with minimal aids or assistance. It is recognized that the application of this criterion is challenging, as it requires knowledge about an individual's level of function at the current phase of their life. However, it is noteworthy that this type of information is also necessary for the determination of whether a person is demented.

4. **Non demented** - These cognitive changes should be sufficiently mild that there is no evidence of a significant impairment in social or occupational functioning. It should be emphasized that the diagnosis of MCI requires evidence of intraindividual change. If an individual has only been evaluated once, change will need to be inferred from the history and/or evidence that cognitive performance is impaired beyond what would have been expected for that individual. Serial evaluations are of course optimal, but may not be feasible in a particular circumstance.

### 2.1.3 Dementia

Dementia is a term that describes chronic and progressive dysfunction of cognitive and functional abilities due to a pathology of cortical and/or sub-cortical brain structures. These cognitive and functional changes are commonly accompanied by disturbances of mood, behaviour, and personality.

The DSM – IV and DSM – IV TR have no general criteria for Dementia syndrome but only specific criteria for Dementia due to a particular etiology (e.g. Alzheimer dementia, Vascular Dementia, and so on).

For the DECI project the recent clinical criteria for dementia proposed by the DSM V will be used [6]. The DSM V have general criteria for dementia. In the manual dementia is defined as “Major cognitive disorder” and the diagnostic criteria are:

- A. Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) based on:
  - i. Concern of the individual, a knowledgeable informant, or the clinician that there has been a significant decline in cognitive function; and
  - ii. A substantial impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another quantified clinical assessment.
- B. The cognitive deficits interfere with independence in everyday activities (i.e., at a minimum, requiring assistance with complex instrumental activities of daily living such as paying bills or managing medications).
- C. The cognitive deficits do not occur exclusively in the context of a delirium.
- D. The cognitive deficits are not better explained by another mental disorder (e.g., major depressive disorder, schizophrenia).

ICD – 10 diagnostic criteria for Dementia (for research) are also widely used and accepted but less simple to use [7]. They are:

G1. Evidence of each of the following:

1. A decline in memory, which is most evident in the learning of new information, although in more severe cases, the recall of previously learned information may be also affected. The impairment applies to both verbal and non-verbal material. The decline should be objectively verified by obtaining a reliable history from an informant, supplemented, if possible, by neuropsychological tests or quantified cognitive assessments. The severity of the decline, with mild impairment as the threshold for diagnosis, should be assessed as follows:
  - a. Mild: a degree of memory loss sufficient to interfere with everyday activities, though not so severe as to be incompatible with independent living. The main function affected is the learning of new material. For example, the individual has difficulty in registering, storing and recalling elements in daily living, such as where belongings have been put, social arrangements, or information recently imparted by family members.
  - b. Moderate: A degree of memory loss which represents a serious handicap to independent living. Only highly learned or very familiar material is retained. New information is retained only occasionally and very briefly. The individual is unable to recall basic information about where he lives, what he has recently been doing, or the names of familiar persons.
  - c. Severe: a degree of memory loss characterized by the complete inability to retain new information. Only fragments of previously learned information remain. The subject fails to recognize even close relatives.
2. A decline in other cognitive abilities characterized by deterioration in judgment and thinking, such as planning and organizing, and in the general processing of information. Evidence for this should be obtained when possible from interviewing an informant, supplemented, if possible, by neuropsychological tests or quantified objective assessments. Deterioration from a previously higher level of performance should be established. The severity of the decline, with mild impairment as the threshold for diagnosis, should be assessed as follows:
  - a. Mild. The decline in cognitive abilities causes impaired performance in daily living, but not to a degree making the individual dependent on others. More complicated daily tasks or recreational activities cannot be undertaken.

- b. Moderate. The decline in cognitive abilities makes the individual unable to function without the assistance of another in daily living, including shopping and handling money. Within the home, only simple chores are preserved. Activities are increasingly restricted and poorly sustained.
- c. Severe. The decline is characterized by an absence, or virtual absence, of intelligible ideation

The overall severity of the dementia is best expressed as the level of decline in memory or other cognitive abilities, whichever is the more severe (e.g. mild decline in memory and moderate decline in cognitive abilities indicate a dementia of moderate severity).

G2. Preserved awareness of the environment (i.e. absence of clouding of consciousness (as defined in F05, criterion A) during a period of time long enough to enable the unequivocal demonstration of G1. When there are superimposed episodes of delirium the diagnosis of dementia should be deferred.

G3. A decline in emotional control or motivation, or a change in social behavior, manifest as at least one of the following:

1. emotional ability;
2. irritability;
3. apathy;
4. Coarsening of social behaviour.

G4. For a confident clinical diagnosis, G1 should have been present for at least six months; if the period since the manifest onset is shorter, the diagnosis can only be tentative.

## ***2.2 Cognitive Impairment in DECI: inclusion and exclusion criteria***

In the DECI project both people with MCI and mild Dementia will be included in the Pilot testing. The DECI project will develop a solution that can serve wide range of patients with cognitive decline and therefore we will include patients at different stages of the disease. General inclusion/exclusion criteria are given in the following. Each of the 4 clinical partners will then be free to decide whether to restrict the population to be recruited at his pilot site.

### Inclusion criteria

- Age  $\geq$  65;
- Diagnosis of MCI according to Petersen 2004 or Albert et al. 2011 criteria [3, 5] (possibly, specification of MCI sub-type with Winblad et al. 2004 criteria[4]) OR Diagnosis of Dementia according to DSM V criteria [6] (or ICD – 10 criteria[7]);

- Clinical Dementia Rating (CDR), a numeric scale widely used to stage dementia in clinical and research settings, [8],  $\leq 1$ ;
- Living at home;
- Ability to provide an informed consent or availability of a proxy for informed consent.

#### Exclusion criteria

- Living in nursing home;
- CDR  $> 1$ ;
- Previous or actual major psychiatric illness (e.g. schizophrenia, bipolar disorder, recurrent major depression episodes);
- Previous or actual major neurological illness other than MCI or dementia (e.g. major stroke, multiple sclerosis, brain tumor, traumatic brain injury);
- Presence of serious comorbidity with important impact on basic Activity of Daily Living (ADL) and Instrumental Activity of Daily Living (IADL) (e.g. severe chronic obstructive pulmonary disease (COPD), severe heart diseases, chronic severe kidney failure);
- History of drugs or alcohol abuse;
- Inability to provide an informed consent or unavailability of a proxy for informed consent;
- Severe sensory impairments (mainly visual, auditory, etc);
- History of intellectual disability and/or other developmental diseases;
- Life expectancy less than 1 year as judged by the clinician<sup>1</sup>

### **3 Describing and Clustering the target population**

#### ***3.1 Dimensions, variables and tests for describing people with cognitive impairment***

Comprehensive geriatric assessment (CGA) is a multidimensional interdisciplinary diagnostic process focused on determining elderly person's medical, psychological and functional capability in order to develop a coordinated and integrated plan for treatment and long-term follow-up [9]. According to Ramani et al. [10] the CGA should include different dimensions ranging from the medical, to the psychological, the social and environmental, and the functional area. The aim of the DECI's pilots is not to develop a new care plan, but to provide tools to support diagnosis, treatment and follow up of patients enrolled in the pilots and usually supported by standard model of care delivered by patient's families and partner healthcare organization.

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<sup>1</sup> The "surprise question" method, defined in the Gold Standard Framework prognostic indicator guidance [46], can be used to assess if life expectancy of the patient is less than one year

This, to improve sustainability of integrated social-care services, detecting risky trends and lowering speed of patients' disease decay curve. For this purposes DECI's partners need to share a Data set of measures in different domains; measures (i.e. tests, scores, questionnaires and so on) need to be close to the assessment model that each partner uses in patients with cognitive impairment and oriented to specific DECI's aims. This approach will provide an adaptive system that can be easily implemented in different care organizations with different structure and workflows and enable implementation of best practice in treatment of large populations in different countries.

In the following we list the different variables, scores, tests, questionnaire that are more frequently used in the clinical practice to investigate the different dimensions involved in the assessment of people with cognitive impairment.

### 3.1.1 Medical dimension

For what concerns the clinical dimension, the most relevant variables, and relative measurement tests or methods most frequently used, are the following:

- **Clinical diagnosis** of Mild Cognitive Impairment or Dementia determined according to internationally accepted criteria such as the one defined by Petersen, Albert et al., DSM V, ICD – 10, etc [3][5][6][7];
- **Dementia staging** can be determined according to the Clinical Dementia Rating (CDR) [8];
- **Cognitive status** can be determined according to one or more of the following test:
  - Mini-Mental State Examination (MMSE) [11], a 30-point cognitive test widely used in clinical and research settings to measure cognitive impairment;
  - Montreal Cognitive Assessment (MoCA) [12], a 30-point cognitive test to shortly assess several cognitive domains;
  - Clock Drawing Test (CDT) [13], a brief cognitive task to assess global cognitive disfunction;
- Presence of **comorbidity** (such as COPD, Diabets, Chronic Heart Failure (CHF), etc) can be measured according to one or more of the following tests:
  - Charlson Score Index (CCI)[14], a measure to predict the ten-year mortality for a patient who may have a range of comorbidity conditions;
  - Cumulative Illness Rating Scale (CIRS) [15], a standardized tool to calculate the number and severity of chronic illnesses;
- **Medical instability** can be determined according to the interRAI Home Care assessment system [16], a structured protocol for the multidimensional assessment of geriatric patients;
- **Behavior and mood** can be determined according to one or more of the following:

- Geriatric Depression Scale short form (GDS 15) [17], a 15-item self-report assessment used to identify depression in the elderly;
- Neuropsychiatric Inventory (NPI) [18][19], a questionnaire to assess dementia-related behavioural symptoms;
- Level of **anosognosia** for cognitive deficit can be measured with the Clinical Insight Rating Scale [20], a measure of patient insight pertaining to their cognitive and functional problems;
- Risk of **malnutrition** can be determined according to the Malnutrition Universal Screening Toll (MUST) [21], a five-step screening tool to identify adults who are malnourished, at risk of malnutrition, or obese.

### 3.1.2 Functional dimension

The functional dimension represents the ability of the person to cope with daily living activities. The instruments most frequently used in the clinical practice to measure such ability are:

- Autonomy in the Instrumental Activities of Daily Living (IADL)[22], a questionnaire to assess the patient ability to perform complex activities (e.g. managing money, preparing meals);
- Autonomy in the basic Activities of Daily Living (BADL) [23] a questionnaire to assess the patient ability to perform basic activities (e.g. dressing, self-feeding);
- Barthel index [24], an ordinal scale used to measure performance in activities of daily living;
- Functional Assessment Staging (FAST) [25], a seven stage system based on level of functioning and daily activities;
- Tinetti Gait and Balance [26], a fall risk index for elderly patients;
- Hendrich II Falls Risk Model [27], a protocol used in the acute care setting to identify adults at risk for falls.

### 3.1.3 Care network dimension

For what concerns the care network, i.e. the network of people assisting in different ways a person with cognitive impairment, we can identify three situations:

- Informal network only: people living alone or with one or more relatives, without any kind of formal service (including people living with non professional workers or receiving limited help in housekeeping);
- Formalized social home care services: professional social workers depending from home care services operating within a care-plan;
- Formalized health home care services: professional and specialized health home care services;

To measure the caregiver burden it is possible to use the Caregiver Burden Inventory (CBI) [28], a questionnaire to assess the burden of caregivers of elderly

patients with dementia, and/or the Relative Stress Scale [29], an instrument to identify various aspects of carer burden in dementia.

### **3.1.4 Needs dimension**

For what concerns the assessment of needs one of the most recently developed instrument is the Camberwell Assessment of Need for the Elderly (CANE) [30]. The CANE instrument is a comprehensive, person-centred needs assessment tool that has been designed for use with older people. Needs are assessed in 24 areas of life and cover a broad range of health, social and psychological domains.

### **3.1.5 Frailty and socio-economic dimension**

To evaluate frailty of elderly people the following instrument can be used:

- Fried Frailty Criteria [31], a screening tool used to measure frailty;
- Frail Non-Disabled (FiND) Questionnaire [32], a self-reported screening tool for detecting *non-disabled frail* older persons living in the community;
- Canadian Study of Health and Aging (CSHA) Clinical Frailty Scale [33], a judgment-based measure to estimate frail in elderly people.

The socio economic dimension can be investigated by interviews with the patient of their caregivers.

### **3.1.6 The dimension of ICT literacy and acceptance**

Another important factor that should be taken into consideration is related to the "digital" literacy (i.e. the level of knowledge and the competences in using ICT devices) and to the level of acceptance of ICT among patient and caregivers . One of the instrument that can be used to evaluate the attitude of the person towards technology is the Survey of Technology Use (SOTU) included in the Matching Person and Technology (MPT) assessment process [34]. Other ad hoc questionnaire have been used in projects involving the use of technology. For example the Maccabi institute in Israel has used in previous projects [35] a questionnaire for the evaluation of elderly people attitude for technology (see Appendix 1), to ensure that the users will be able to use the system. This questionnaire evaluates the subject's current usage of technical devices in daily life. Fulfilling this questionnaire will enable the research team to better understand the basic attitude and acceptance of the subject towards using new technology.

## **3.2 Variables and tests currently in use in the four pilot sites**

A survey of the instruments currently used in the organization responsible for the four pilot site to assess people with cognitive impairment has been done. The results are summarized in Table 1.

Area	Test	Partners			
		FDG (Italy)	HUG (Spain)	Maccabi (Israel)	SHG (Sweden)
Medical	Mini Mental State Examination (MMSE)	x	x	x	x
	Montreal Cognitive Assessment (MoCA)		x	x	x
	Clock Drawing Test	x	x	x	x
	Clinical Dementia Rating (CDR)	x	x		x
	Cornell Scale for Depression in Dementia	x	x		
	Clinical Insight Rating Scale	x			
	Charlson Score Index (CCI)		x		
	Cumulative Illness Rating Scale (CIRS)	x			
	Malnutrition Universal Screening Toll (MUST)	x		x	
	Mini Nutritional Assessment			x	
	Neuropsychiatric Inventory (NPI)	x	x		
	Geriatric Depression Scale (short form 15 items)	x	x	x	x
	Hachinski ischemic score	x			
	Sweet 16- cognitive			x	
Functional	Basic ADL (BADL)	x	x	x	x
	Instrumental ADL (IADL)	x	x	x	x
	Barthel Index	x	x	x	x
	Functional Assessment Staging (FAST)	x	x		
	Tinetti Gate and Balance				
	Hendrich II Falls Risk Model	x		x	x
	Get-up-and-go Risk Fall (included in Hendrich II)			x	
Needs	Camberwell Assessment of Need for the Elderly - Short form (CANE-S)				
Care Network	Caregiver Burden Inventory (CBI)				
	Relative Stress Scale	x			
	Questionnaire				
Frailty and socio economic	Fried Frailty Criteria		x		
	Frail Non-Disabled (FIND) Questionnaire	x			
	Frail Scale		x		x
	EuroQL 5D 5L		x		

Area	Test	Partners			
		FDG (Italy)	HUG (Spain)	Maccabi (Israel)	SHG (Sweden)
	Algorithm for identifying population at risk			x <sup>2</sup>	
Technology	Technology questionnaires			x	

**Table 1.** The test currently used by the clinical partners

### 3.3 The DECI minimum dataset

The DECI Minimum Data Set (MDS) represents the minimum set of instruments (tests, scales, questionnaires, etc) needed for describing the target population during the pilot phase. The definition of a MDS common to all test sites is needed to standardize the data that each clinical partner will collect and therefore allow for comparisons across the test sites.

The details of how each instrument should be used (e.g. which version, what kind of score, etc) is also part of the Minimum dataset.

Domain	Test
Cognition	Mini Mental State Examination (MMSE)
	Clock Drawing Test (CDT)
Staging	Clinical Dementia Rating (CDR)
Functionality	Basic ADL (BADL)
	Instrumental ADL (IADL)
Needs Assessment	Camberwell Assessment of Need for the Elderly - Short form (CANE-S)

**Table 2.** The DECI Minimum Data Set (MDS)

The set of instrument that compose the minimum dataset has been chosen by taking into consideration the objective of the DECI project on the one side, and sustainability issues on the other (in order to minimize the impact on current organizational processes in the different test site). The minimum dataset is therefore composed of instruments already used in the organization responsible for the pilot sites, with the exception of the CANE instrument that has been considered essential to capture the needs of patients and subsequently match those against the technologies to be provided. The instrument composing the minimum dataset are reported in Table 2.

<sup>2</sup> Population at risk is identified according to 7 criteria: Age>75; 2 or more chronic diseases; 2 or more hospitalizations\emergencyroom visits in the last year; 2 or more physician home visits; Malnutrition; above 8 medications; Permanente use in one of the following drugs: Insulin, NSAID, Diuretic agent, digoxin, anti-platelet, coumadin, sulfonilureas, heparin antithrombotic agent. A patient is considered at risk if at least 4 out of 7 criteria are satisfied.

For the **Mini Mental State Examination (MMSE)** the score not adjusted for age and education will be used [11]. The reasons for that is twofold: most published researches and survey in litteratue use raw score, and adjustment indexes need to be validated in local population.

For the **Clock drawing test (CDT)** the score 0-5 according to Shulman et al, 2000 [13] will be used.

For what concerns the **Clinical Dementia Rating (CDR)** the score will be adjusted according to Morris, 1993 [8] that considers the impairment level as the decline from the subject's usual level of functioning: CDR is equal to the *Memory* score unless three or more of the secondary categories scores are above or below the Memory score, in which case the CDR equals the majority of the secondary categories.

For the **Basic activities of daily living (BADL)** the Katz index will be used [23].

For the **Instrumental activities of daily living (IADL)** the score 0-8 will be used (according to Lawton [22]), without gender differences.

Finally, for what concerns the Camberwell Assessment of Need for the Elderly (CANE) instrument, the short form will be used [30]. For aggregated analysis items will be clustered as described by Van der Ploeg et al [36](Table 3).

Clustered CANE items
<p><b>A. Environmental needs</b></p> <ul style="list-style-type: none"> <li>• Accommodation</li> <li>• Looking after the home</li> <li>• Food</li> <li>• Money budgeting</li> <li>• Benefits</li> <li>• Caring for someone else</li> </ul>
<p><b>B. Physical needs</b></p> <ul style="list-style-type: none"> <li>• Pshysical health</li> <li>• Drugs</li> <li>• Eyesight/hearing/Communication</li> <li>• Mobility, Falls</li> <li>• Self-care</li> <li>• Continence</li> </ul>
<p><b>C. Psychological needs</b></p> <ul style="list-style-type: none"> <li>• Psychological distress</li> <li>• Memory</li> <li>• Behaviour</li> <li>• Alcohol</li> <li>• deliberate self-harm</li> <li>• inadvertent self-harm</li> <li>• Psychotic symptoms</li> </ul>

Clustered CANE items
<p><b>D. Social needs</b></p> <ul style="list-style-type: none"> <li>• Company</li> <li>• Intimate relationship</li> <li>• Day-time activities</li> <li>• Information on condition and treatment</li> <li>• Abuse/Neglect</li> </ul>

**Table 3.** Clustered CANE items

### **3.4 Clustering patients**

Patients suffering from progressive cognitive impairment due to MCI or Dementia are usually elderly, and for this reason a certain level of comorbidity can be present. Therefore, from a clinical point of view, several variables can be used to sort this kind of patients in different groups. In the international research literature on MCI and Dementia, a widely used variable to group this kind of patients is the stage of cognitive impairment, because it allows to define a quite homogeneous and different groups in terms, for example, of patterns of behavioural performance. CDR is the principal tool to stage dementia. As in DECI we will focus on patients with MCI and Dementia and the variable of behavioural performance is crucial for his impact on several every day activities (e.g. use of tools and social interaction), we decided to use the stage of cognitive impairment, in terms of CDR score, as the primary variable for clustering the target population in different subgroups. In particular, patients will be subdivided into three groups:

1. patients with CDR score 0.5 "non amnestic";
2. patients with CDR score 0.5 "amnestic";
3. Patients with CDR score 1.

The first and second group include patients with MCI (amnestic MCI and non-amnestic MCI) while the third includes patients with mild dementia. We decided to define two sub-groups with CDR score of 0.5 because MCI patients without amnesia (non-amnestic MCI) usually present executive function deficits, a condition that potentially has more impact on several behavioural performances in daily living (e.g. to initiate a behaviour or to plan even a simple task) [37].

The use of ICT devices to support the cognitive inclusion of elderly patients with cognitive impairment is a central aim of the DECI project. To define specific areas of patient daily living where a technology could be introduced we decided to investigate the needs usually expressed by elderly patients with cognitive impairment and their caregivers, because the dimension of need could be a useful tool to map critical areas in patient daily performances. The dimension of need, in terms of CANE-S report, will be the second variable we will use in DECI with the aim of define critical areas of daily living where ICT solutions could be introduced.

### **3.5 Preliminary Population analysis at each pilot site**

In the following we report a preliminary population analysis in the different pilot site obtained by applying the DECI MDS and in particular the CANE-S questionnaire. This preliminary analysis is not intended to give a detailed and precise description of the target population in the different pilot sites but rather a rough estimate of the types of patients being cared in the different sites and the kind of needs they have. The objectives of this preliminary analysis are:

- Understanding the feasibility of applying the proposed methodology in the different pilot sites;
- Providing input for the detail definition of the experimental protocol;
- Providing useful information for the activities of WP2 related to the scouting of technologies and the matching of those technologies with patient needs.

Unfortunately, due to the differences in the legislation frameworks and in the clinical practices of the various countries of the DECI consortium, it was not possible to define a unique procedure for conducting the preliminary analysis in the different pilot sites. At FDG (Italy) data for the population analysis were extracted from a sample of patient records. At MAC (Israel) this was not possible due to the requirement of obtaining the approval from the local ethical committee (which was not possible within the timeframe of the task), while at HUG (Spain) and SHG (Sweden) the data included in the patient records were not sufficient to infer patient needs according to the CANE-S items. In those countries the preliminary analysis of patient needs has been done by interviewing a number of clinicians and exploiting their experience of the needs of people with cognitive impairments. For the pilot sites where patients data have been reported, inclusion and exclusion criteria previously defined have been applied to select patients.

#### **3.5.1 Italy**

The estimated number of people suffering from dementia in Italy in 2012 has been 1.272.317 and this represent 2.09% of total population [38]. In the city of Milan the Local Health Service estimated that people with dementia, among those aged 65 or older, are about 20,000 which means a prevalence of 6.3%. The prevalence of MCI in Italy has been estimate around 6 % in people aged 65 or older [39] but a lot of heterogeneity have been reported [40].

At FDG a preliminary analysis of needs with CANE-S have been done on a small group of patients with MCI and Mild Dementia (CDR 0.5 and 1 respectively). 20 assessment reports of patients diagnosed with MCI (10 amnesic-MCI and 10 non amnesic-MCI) and 20 assessment reports of patients diagnosed with Mild dementia have been randomly extracted from the pool of all assessment reports of patients screened for cognitive impairment in the FDG "Memory clinic" in 2014. Demographic data and Minimum dataset data for each group are presented in Table 4

	N	Gender (M/F)	Age (Mean ± SD)	Education (Mean years ± SD)	MMSE (Mean raw score ± SD)	CDT (Mean raw score ± SD)	ADL (Mean raw score ± SD)	IADL (Mean raw score ± SD)
MCI	20	7/13	79.6 ± 6.1	8.9 ± 3.8	26.4 ± 1.8	3.2 ± 0.7	5.7 ± 0.9	6.1 ± 2.0
a-MCI	10	7/3	80.7 ± 7.3	10 ± 4.7	25.6 ± 2.1	3.6 ± 0.8	5.9 ± 0.5	6.4 ± 2.1
na-MCI	10	3/7	78.4 ± 4.6	7.8 ± 2.5	27.2 ± 0.8	3.0 ± 0.5	5.6 ± 1.3	5.7 ± 1.9
Mild Dem.	20	10/10	80.1 ± 6.4	7.8 ± 3.8	22 ± 2.3	2.4 ± 0.9	5.3 ± 0.8	3.5 ± 1.8

**Table 4.** Demographic data and distribution of the MDS for the sample of patients

For each assessment report, behavioral-cognitive anamnesis reported by the caregiver of the patient and functional scales (ADL and IADL) collected during the assessment session have been examined in the attempt to map each need dimension of the CANE-S questionnaire.

A first result (Table 5) showed that the mean number of needs (± SD) for MCI patients is 4.35 (±2.4) and for Mild Dementia patients is 7.6 (±1.7). A further analysis for MCI patients showed that the mean number of needs for amnesic-MCI (a-MCI) patients is 3.4 (±1.6) and for non amnesic-MCI (na-MCI) patients is 5.3 (±2.8).

		CDR 0.5		CDR 1
		MCI		Mild Dementia
		a-MCI	na-MCI	
N	20	10	10	20
	4.35 ± 2.4	3.4 ± 1.6	5.3 ± 2.8	7.6 ± 1.7

**Table 5.** Mean number of needs (±SD) on CANE-S for MCI and Mild Dementia patients. For MCI patients a subgroups analysis is shown for amnesic MCI (a-MCI) and non-amnesic MCI (na-MCI)

A second result (Table 6) showed that needs related to memory impairment, drugs management and psychological distress (depression and anxiety in particular) are quite common in MCI patients. Less common but also present are needs in the areas of looking after home, self care, mobility and money management. In an analysis for MCI sub-groups emerged that for a-MCI patients common needs areas are related to memory impairment, drugs management and psychological distress almost without any other area, whereas for na-MCI patients in addition to these needs are also common the needs areas of looking after home, self care, mobility, behavioral disturbances and money management. For Mild Dementia patients common areas of needs are drugs management, money management, memory impairment, looking after home, mobility, self care, psychological distress, behavioral disturbances and

continence. Less common but also present are needs related to food intake and psychotic symptoms.

<b>CANE - S</b>	<b>MCI</b>	<b>a-MCI</b>	<b>na-MCI</b>	<b>Mild Dementia</b>
<b>Accommodation</b>	0%	0%	0%	0%
<b>Food</b>	15%	0%	30%	35%
<b>Looking after the home</b>	25%	0%	50%	85%
<b>Self-care</b>	30%	0%	60%	55%
<b>Caring for someone else</b>	5%	0%	10%	0%
<b>Daytime activities</b>	5%	0%	10%	10%
<b>Memory</b>	85%	100%	70%	90%
<b>Eyesight/Hearing/Communication</b>	20%	30%	10%	10%
<b>Mobility/Falls</b>	25%	10%	40%	75%
<b>Continence</b>	5%	0%	10%	40%
<b>Physical health</b>	10%	0%	20%	0%
<b>Drugs</b>	55%	70%	40%	100%
<b>Psychotic symptoms</b>	15%	20%	10%	30%
<b>Information on condition and treatment</b>	5%	0%	10%	0%
<b>Psychological distress</b>	55%	50%	60%	50%
<b>Deliberate self-harm</b>	0%	0%	0%	5%
<b>Inadvertent self-harm</b>	0%	0%	0%	5%
<b>Abuse/Neglect</b>	0%	0%	0%	10%
<b>Behaviour</b>	15%	0%	30%	40%
<b>Alcohol</b>	15%	20%	10%	0%
<b>Company</b>	15%	20%	10%	15%
<b>Intimate relationships</b>	0%	0%	0%	5%
<b>Money/budgeting</b>	30%	20%	40%	100%
<b>Benefits</b>	0%	0%	0%	0%

**Table 6.** Percentage of patients presenting a specific need on CANE-S

The results of this preliminary analysis suggest that MCI and Mild dementia patients have different profiles at MDS and this suggests that defined measures are able to differentiate each group. Moreover, as emerged from the need assessment, MCI patients have less needs with respect to dementia patients, and a quite different patterns of needs are present for the three sub-groups (a-MCI, na-MCI and Mild dementia).

The major limitation of this analysis is related to the data recollection procedure. CANE-S is a semi-structured interview aimed at recollecting information about the presence of met and unmet needs directly from patients and caregivers. As described above, we used an indirect procedure to map the patient needs, collecting

them from a report containing data about diagnostic workup for subjects with suspected dementia or MCI. This procedure could underestimate the presence of specific needs related to areas not specifically mapped during the diagnostic workup protocol (e.g. intimate relation area or social life area). Nevertheless, the majority of needs emerged in our preliminary analysis have also been reported in other studies using the CANE-S with dementia patients [41][36] and this suggests that the preliminary results obtained with our procedure are, at least in part, congruent with what usually is observed in patient suffering from cognitive impairment.

### **3.5.2 Spain**

In a recent study conducted at the Region of Madrid, it is stated that the prevalence of MCI is 7,0% (3,1% amnesic MCI, 0,1% non-amnesic MCI). Moreover, a survey including people aged 65 or more in the Region of Madrid displayed a prevalence of illiteracy of 7,0% and a prevalence of primary education level of 20,7%) [42][43][44].

In the University Hospital of Getafe (Hospital Universitario de Getafe, HUG), patients with cognitive impairment are attended by 3 different services: the Geriatrics Service (in case patients are older than 65 years old), the Neurology Service (in case patients are younger than 65 years old) and the Psychiatry Service (in case the patient presents other major psychiatric diseases). As patients with major psychiatric diseases are excluded from their participation in the DECI project, we will focus on our preliminary analysis mainly on patients attended by the Geriatrics Service.

Patients can be referred to the Geriatrics Service from many different points in the care continuum at the Regional Health Service of Madrid, i.e. Primary Care, the Emergency Room, the Acute Care Unit of the Geriatrics Service, etc. When referred to the Geriatrics Service, patients are assessed in the General Consultation of the Geriatrics Service. In the first visit, the professional in the general consultation of the Geriatrics Service performs a Comprehensive Geriatrics Assessment (CGA), in order to get a full picture of the status of the patient. Depending on the results of the CGA, the patient can be referred to other units of the Geriatrics Service, that comprises units such as the Falls and Fracture Unit or the Cognitive Impairment Unit.

In order to elicit the average needs of the patients served by the Cognitive Impairment of the Geriatrics Service, we have conducted an analysis of the medical history of 20 patients of the CI Unit, chosen randomly. The results of the baseline characteristics of the patients show that the average population of the CI Unit at the Geriatrics Service are very old (mean 85 years old) and frail; plus, most of these patients have a low to basic educational level. Table 7 displays the baseline characteristics of the patients analyzed. It is worth noticing that MMSE results are in raw score and that the GDS is the scale utilized for classifying patients with cognitive impairment. The first row displays the results for all patients analyzed (20 in total),

while the second row presents the baseline characteristics of the subset of all patients analyzed classified as Mild Cognitive Impairment (5 over 20).

	<b>MMSE</b>	<b>ADL<sup>3</sup></b>	<b>IADL<sup>4</sup></b>	<b>GDS<sup>5</sup></b>
All patients at CI Unit (20/20)	21.3 (mean raw score)	Mean 3.8	no	5-6
Patients with MCI (5/20)	Mean raw score only MCI 26.5	Mean 5.84	Women- mean 6 Men –mean 4	3-4

**Table 7.** Baseline characteristics of analysed patients (20, random)

The Geriatrics Assessment conducted at the Geriatrics Service does not include the CANE-s scale. In order to elicit the needs of the patients according to the CANE-S classification, we extracted some information from the clinical history of the patient, and completed it with interviews with six geriatricians with experience on the assessment of patients in the Geriatrics Service. Table 8 depicts the estimated needs for patients with Mild Dementia.

	<b>Mild Dementia</b>	<b>Health care/medical history</b>	
	<b>No needs n (%)</b>	<b>met needs n (%)</b>	<b>unmet needs n (%)</b>
<b>Accommodation</b>	10	90	0
<b>Food</b>	20	50	30
<b>Looking after home</b>	10	30	60
<b>Self care</b>	0	70	30
<b>Caring for someone else</b>	40	10	50
<b>Daytime activities</b>	0	80	20
<b>Memory</b>	20	60	20
<b>Eyesight/hearing/communication</b>	10	70	20
<b>Mobility/falls</b>	10	30	60
<b>Continence</b>	10	60	30
<b>Physical Health</b>	30	30	40
<b>Drugs</b>	10	60	30
<b>Psychotic symptoms</b>	50	30	20

<sup>3</sup> KATZ ; Index of ADL .

<sup>4</sup> Lawton & Brody : Index of IADL in men <5 and women <8 considered abnormal

<sup>5</sup> GDS; Global Deterioration Scale Reisberg

	<b>Mild Dementia</b>	<b>Health care/medical history</b>	
	<b>No needs n (%)</b>	<b>met needs n (%)</b>	<b>unmet needs n (%)</b>
<b>Information on condition and treatment</b>	0	60	40
<b>Psychological distress</b>	0	70	30
<b>Deliberate self-harm</b>	0	80	20
<b>Inadvertent self-harm</b>	20	60	20
<b>Abuse/Neglet</b>	30	60	10
<b>Behavior</b>	20	50	30
<b>Alcohol</b>	70	20	10
<b>Company</b>	10	60	30
<b>Intimate relationships</b>	60	20	20
<b>Money/budgeting</b>	0	70	30
<b>Benefits</b>	80	20	10

**Table 8.** Distribution of patients with Mild Dementia according to their needs

As presented in Table 8, patients with Mild dementia have relevant needs in terms of accommodation, risk of neglect, managing money, behavior, daytime activities, sensory difficulties, continence and psychological distress. It is worth noticing that this assessment is extracted from the point of view of professionals and from the medical history, and does not include any inference about the point of view of the patient and the caregiver.

Regarding patients with amnesic MCI, it has been estimated that needs are more related to the environment (accommodation and self-care), to psychological needs, (memory, psychological distress), to company and, less frequently, to alcohol, mobility and falls.

	<b>Amnesic MCI(aMCI)</b>		
	<b>No needs n (%)</b>	<b>Met needs n (%)</b>	<b>Unmet needs n (%)</b>
<b>Accommodation</b>	10	90	0
<b>Food</b>	40	40	20
<b>Looking after home</b>	10	30	60
<b>Self care</b>	0	70	30
<b>Caring for someone else</b>	60	20	20
<b>Daytime activities</b>	90	10	0
<b>Memory</b>	0	90	10
<b>Eyesight/hearing/communication</b>	20	60	20
<b>Mobility/falls</b>	10	30	60

	Amnesic MCI(aMCI)		
	No needs n (%)	Met needs n (%)	Unmet needs n (%)
<b>Continence</b>	20	60	20
<b>Physical Health</b>	50	40	10
<b>Drugs</b>	10	70	20
<b>Psychotic symptoms</b>	20	50	30
<b>Information on condition and treatment</b>	30	50	20
<b>Psychological distress</b>	10	70	20
<b>Deliberate self-harm</b>	0	90	10
<b>Inadvertent self-harm</b>	60	20	20
<b>Abuse/Neglect</b>	70	10	20
<b>Behavior</b>	30	50	20
<b>Alcohol</b>	80	20	10
<b>Company</b>	20	60	20
<b>Intimate relationships</b>	70	10	20
<b>Money/budgeting</b>	40	40	20
<b>Benefits</b>	60	20	20

**Table 9.** Estimated needs of patients with aMCI

To sum up, the characteristics in our preliminary population are similar to others [41] [45]. The differences between health care systems and the needs of patients with cognitive impairment are related to demographic changes and changes in the care network. For instance, accommodation in our case is higher than in other studies, due to the socioeconomic limitations of most patients (i.e. many older adults live in houses built during the 60s, with no elevator or accessibility features and with no budget for reformations).

### 3.5.3 Sweden

The prevalence of dementia in Sweden among people older than 65 years is 7%, which corresponds to more than 15000 inhabitants in Skaraborg with varying degrees of cognitive impairment.

The main centre for dementia at SHG is located at the Falköping hospital with an inpatient clinic that has the capacity to care for 12 patients simultaneously. This unit – the Centre for Elderly Patients in need of Psychiatric care (CEPP) – serves the entire Skaraborg County and supports the municipalities and the primary care units in various ways. CEPP also has an outpatient clinic consisting of a senior physician, a specialized nurses, psychologists, welfare officers and occupational therapists. The outpatient clinic is responsible for the care of around 450 patients at any time and there is a continuous flow of 15 referrals/week. The clinic carries out 200 investigations each year out of which 100 patients/year are diagnosed with MCI and

the 100 with specific forms of dementia. CEPP is the main knowledge centre for cognitive impairment in the county. Currently, CEPP is also the home base for the hospital mobile team that specializes in patients with cognitive impairment. This team consists of a senior physician and a specialized nurse and serves the entire county. In addition, there are three other mobile teams in Skaraborg (that belong organizationally to SHG) that care for instable elderly patients with multiple diseases. All these teams will probably constitute the core of the future networked mobile care model for patients with MCI and dementia in Skaraborg.

The basic examination of patients with MCI/dementia rests on the ambition to involve multiple perspectives on the patients' current condition including his or her social situation:

- A structured anamnesis including interviews with nearest and dearest
- An assessment of the physiological and psychological condition of the patient
- Cognitive tests including MMSE and the Clock test
- A structured assessment of patient activities of daily life and level of activity

In addition, tests to exclude other conditions include:

- A CT scan
- Relevant neuropsychological tests
- Blood tests to exclude hypercalcemia, high levels of homocystein as well as of thyroid hormones
- In case of clinical suspicion, the basal investigation also includes liquor tests for Borrelia and Syphilis

If the diagnose is still unclear, a more advanced examination according to the national guidelines is pursued:

- Individually adapted neuropsychological tests (NTB – Neurological Test Battery)
- Bio structural imaging of the brain using MRI
- Analysis of liquor regarding various essential biomarkers (e.g. CSV A-Beta 42 (beta amyloid), CSV-Tau, CSV-Fosfo-Tau)
- Functional brain imaging using SPEC.

In order to describe the characteristics of the DECI target population at SHG, a sample of 40 patients has been selected. Table 10 shows mean and standard deviation for i) amnesic-MCI (a-MCI) patients, ii) non amnesic-MCI (na-MCI) patients and patients with mild dementia pertaining to the following categories: gender, age, length of education, MMSE, CDT, ADL and i-ADL.

	Gender F/M (n=40)	Age	Education	MMSE	CDT	ADL	iADL
a-MCI	4/6	76 ± 4	9,5 ± 3,5	27 ± 2,2	3,8±0,9	5,8±0,4	6,4
na-MCI	2/8	78,5 ± 6	8,1 ± 2,6	26,2± 1,4	3 ± 0,6	5,6±1,2	5,9
Mild dementia	11/9	79,6 ± 5,5	8,5 ± 3,2	23,5 ± 2,8	2,6±0,8	5,1±1,1	4,1

**Table 10.** Mean and range in age, education, MMSE, CDT, ADL and i-ADL for patients with a-MCI/na-MCI/mild dementia

Moreover, three senior physicians of SHG have carried out a preliminary estimation of needs according to CANE-S in patients with MCI and Mild Dementia. They have based the analysis on their experience. Results are reported in Table 11.

CANE - S	MCI	a-MCI	na-MCI	Mild Dementia
<b>Accommodation</b>	0%	0%	0%	0%
<b>Food</b>	20%	20%	20%	40%
<b>Looking after the home</b>	20%	20%	20%	75%
<b>Self-care</b>	25%	10%	40%	55%
<b>Caring for someone else</b>	5%	0%	10%	40%
<b>Daytime activities</b>	5%	0%	10%	15%
<b>Memory</b>	70%	100%	40%	90%
<b>Eyesight/Hearing/Communication</b>	25%	10%	40%	45%
<b>Mobility/Falls</b>	15%	0%	30%	60%
<b>Continenence</b>	5%	0%	10%	25%
<b>Physical health</b>	25%	15%	35%	40%
<b>Drugs</b>	45%	40%	50%	100%
<b>Psychotic symptoms</b>	5%	0%	10%	20%
<b>Information on condition and treatment</b>	5%	0%	10%	50%
<b>Psychological distress</b>	50%	55%	45%	80%
<b>Deliberate self-harm</b>	0%	0%	0%	5%
<b>Inadvertent self-harm</b>	0%	0%	0%	15%
<b>Abuse/Neglect</b>	0%	0%	0%	10%
<b>Behaviour</b>	15%	0%	30%	50%
<b>Alcohol</b>	15%	20%	10%	25%
<b>Company</b>	20%	30%	10%	35%
<b>Intimate relationships</b>	10%	0%	20%	25%

CANE - S	MCI	a-MCI	na-MCI	Mild Dementia
Money/budgeting	20%	20%	20%	70%
Benefits	10%	10%	10%	15%

**Table 11.** An estimation of CANE-S in patients with MCI and mild dementia in Skaraborg

### 3.5.4 Israel

The prevalence of dementia in Israel has been estimated at approximately 12% of those aged 65 and over. The prevalence increases with age from about 5% aged 65-74 to 30% at age 85 and older. Rarely, the disease is already apparent at younger ages (under 60). Today in Israel, the number of dementia patients is estimated at 150,000. In the coming years, with the aging of the population in Israel, the number suffering from dementia is expected to increase greatly. In Israel there is a National Strategic Plan to Address

Dementia. The recommendations offer a holistic perspective and emphasize collaboration among all relevant agencies: government ministries, the health plans and other organizations in both the volunteer and private sectors.

The plan recognizes the need to address dementia from the stages of prevention of risk factors and early detection, to diagnosis and patient care, and through assurance of quality of end of life. It proposes to do so by implementing interdisciplinary work principles and care, and boosting the coordination and cooperation of all the parties involved.

National Strategic Plan to Address Alzheimer's and Other Types of Dementia. The recommendations offer a holistic perspective and emphasize collaboration among all relevant agencies: government ministries, the health plans and other organizations in both the volunteer and private sectors.

Maccabi healthcare services provide care for 25% of the populations. Currently, there are 210,000 pat. in Maccabi aged 65 and over and 20,000 diagnosed dementia patients at different levels of the disease. Among them, ~6000 are patients with MCI. In light of increased life expectancy and an aging population there is a need for Maccabi in responding to the unique needs this population. According to the care plan, Maccabi aim to have early detection to provide treatment and prevention of deterioration of cognitive decline and improve the quality of life and ability of these patients to stay independent at home.

Since there is a shortage of geriatric physicians, and most patients, especially in early stages of the disease visit the primary care physicians (GP) we recently, launched a project called "75 birthday visit" in which every elderly person reaching 75Y is invited to the GP for screening visit with the aim of:

- Create a trust between doctor, patient and their family
- Raising awareness of preventive care for elderly population
- Early detection of geriatric symptoms

- Reducing the need for acute and prolonged hospitalization ( long term care) due to early detection and timely intervention
- Improve daily function of the elderly patient.

The visit at the GP clinic designed to last 45 minutes during which the GP performs screening of the following measures: cognitive assessment, mental assessment of depression, functional assessment, stress testing , motor evaluation , nutritional assessment and assessment of caregiver burden

In addition to 75 birthday screening program we are using the following channels for early detection:

- Self report
- Family report.

Once the patient is diagnosed for cognitive decline he is addressed for further assessment, in the clinics where patient care plan is adapted for individual or group treatment according to patient's need.

Cognitive training is based on the theories of plasticity of brain that can create new connections between brain cells active aid and challenging practice, while performing activities that are automated. Such practice activities should be defined as a productive activity significantly challenging the overall thinking process initiated in running memory, the ability to problem-solving and reasoning ability

The basic examination of patients with CI

- An anamnesis including interviews with nearest and dearest
- Assessment of the physiological and psychological condition of the patient
- Cognitive tests including MMSE, SWEET16 and the Clock drawing test
- A structured assessment of patient activities of daily life and level of activity.

In order to analyze the needs of the patients with MCI of Maccabi Healthcare Services, our geriatric department estimated their needs and level of main problems patients with MCI are facing, results are reported in Table 12. Since in Israel it is not possible to analyze patient record without prior approval of the ethical committee, which was not possible to obtain within the timeframe of the task T1.2, the estimation is build upon the experience of geriatrician working at Maccabi Healthcare Services.

<b>Problem\need</b>	<b>Level % of population</b>	<b>Comments</b>
<b>Accommodation</b>	0-3%	
<b>Food</b>	5%	Problems cooking for themselves
<b>Looking after the home</b>	11%	
<b>Self-care</b>	5-10%	
<b>Caring for someone else</b>	1-2%	
<b>Daytime activities</b>	1-2%	
<b>Memory</b>	50-70%	
<b>Mobility/Falls</b>	10%	

Problem\need	Level % of population	Comments
Drugs	30-40%	Due to other chronic diseases. Normally these patients are not treated with medications at MCI stage
Psychological distress	30%	Due to memory decline
Inadvertent self-harm	0%	
Abuse/Neglect	0-5%	Self neglect due to MCI
Behaviour	1%	Rare at this stage
Alcohol	15%	Due to MCI and depression
Company	0%	
Intimate relationships	unknown	
Money/budgeting	10%	

**Table 12.** Estimation of patient needs at Maccabi Healthcare Services according to the CANE-S items

## 4 Conclusions

The different tests, instruments, scores and variables used for the assessment of people with cognitive impairment in the clinical practice worldwide, and in particular in the four test sites, have been deeply analyzed in order to define a common set of standardized instrument to be used by all partners within the DECI project (i.e. the DECI Minimum Data Set - MDS). In building the DECI MDS the following principles have been taken into account:

- Scientific relevance: the tools included in the MDS should be widely used in the clinical practice worldwide (as demonstrated by literature), and be already available and validated in different languages;
- Sustainability: The impact of introducing the MDS in the clinical practice of the pilot site partners should be as little as possible;
- Matching needs and technologies: to support the objectives of the DECI project, the MDS should be able to describe the target population in a way that allows to match user needs with available technologies.

The DECI MDS together with the clustering of patients in three subgroups (i.e. CDR 0.5 amnesic, CDR 0.5 non amnesic, and CDR 1) represent the framework for the definition of the detailed protocol of the pilot tests and for the analysis of results.

The preliminary population analysis at each pilot site reveals three major results:

- The prevalence of MCI and Dementia in the four pilot sites is in line with the recent data of the international scientific literature [40], in particular with the data for the European population (see Figure 1);
- MCI patients and Mild Dementia patients have different profiles at the MDS and the profiles give back a coherent characterization of the two groups (see

Table 13). Beside the expected differences at the level of MMSE score, which reflect the global cognitive functioning level, the main differences between MCI and Mild Dementia patients are related to the IADL. Usually people with mild dementia are impaired in almost all areas of IADL (e.g. housekeeping, food preparation, ability to use the telephone or laundry), while people with MCI usually find difficulties limited to the areas of responsibility for own medications or ability to handle finances;

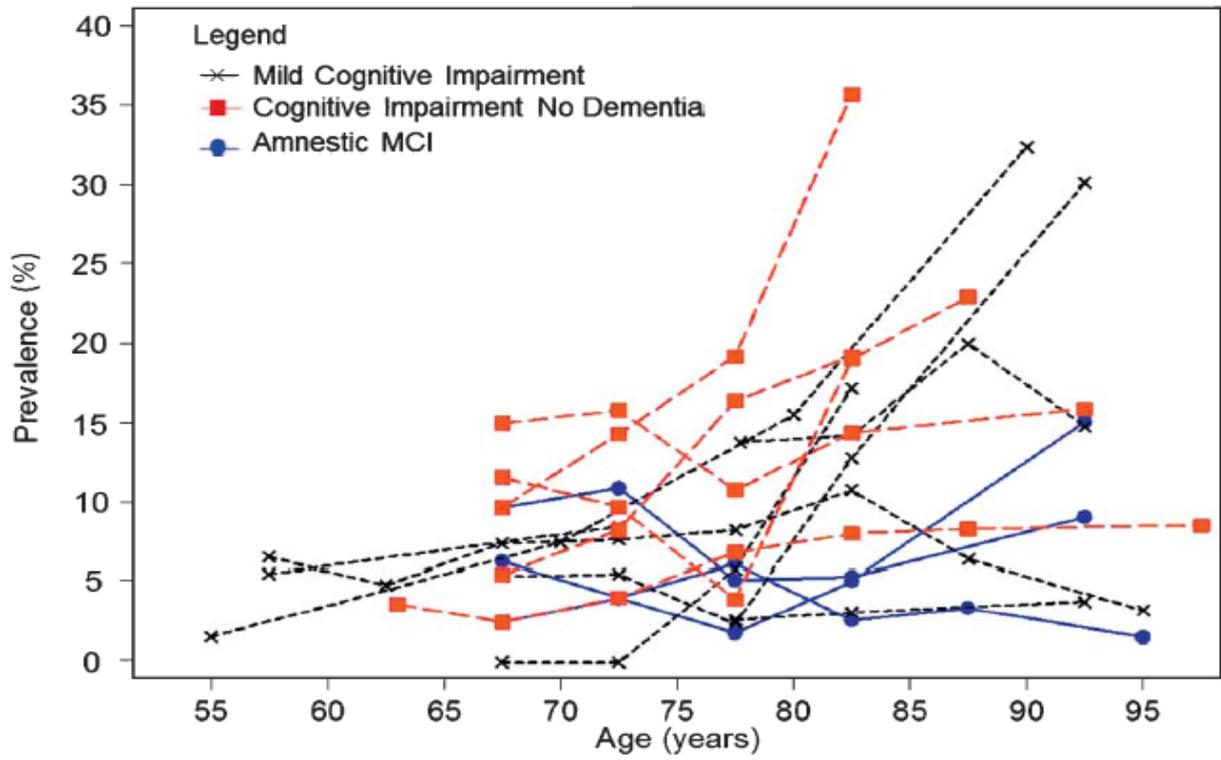
- The preliminary needs analysis shown, as expected, that there are more needs in patients with mild dementia and that there are differences in the number and quality of needs between a-MCI and na-MCI patients.

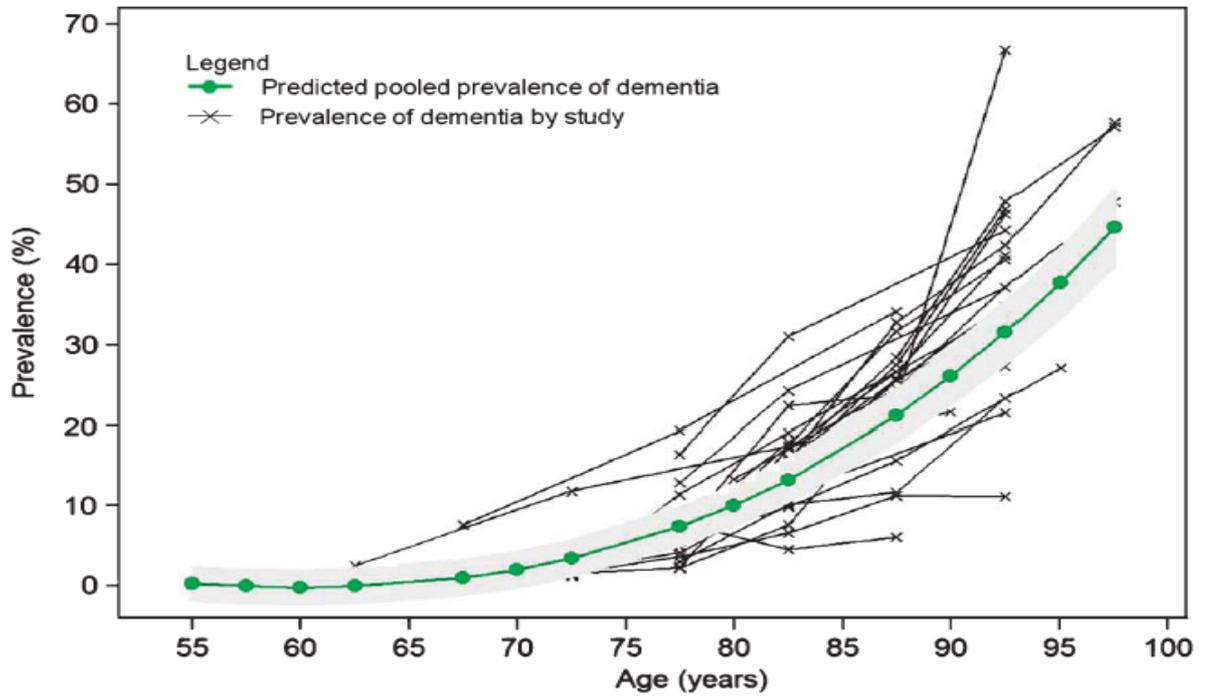
In particular, needs related to memory impairment (e.g. remember appointments), drugs management (e.g. getting the right dose of medicine), psychological distress (e.g. depression) and looking after home are quite common in MCI patients. The analysis also shown that the needs areas of looking after home, self care (e.g. keeping neat and tidy), mobility (e.g. to walk autonomously), behavioural disturbances (e.g. agitation or aggression) and money management (e.g. managing payments) are more present within the na-MCI sub-group than within the a-MCI patients.

For Mild Dementia patients common areas of needs were drugs management, money management, memory impairment, looking after home, mobility, self care, psychological distress, behavioural disturbances (e.g. aggression or wandering) and continence (e.g. incontinence). Less common but also present are needs related to food intake (e.g. getting enough food) and psychotic symptoms (hallucinations or delusions).

Even if data about needs have been recollected whit some methodological difference in the four pilot sites, the data are quite homogeneous with just some slight difference in the sites. For example, in the Israel site the areas of Psychological distress and Drugs management are quite absent for MCI patients' needs. Needs in the area of Benefits (e.g. getting all the money a person is entitled to) are very common in the Spain site, where, for Mild Dementia patients, the areas of Memory, Drugs and Money/budgeting are less present than in the other pilot sites. Finally, in Italy, for Mild Dementia patients, needs in the areas of Caring for someone else (e.g. the ability to care for another person), Physical health (e.g. perceived physical wellness) and need of Information on condition and treatment are almost absent (see Table 14 and Table 15 for a comparison of results).

The results of the preliminary needs analysis, even though suffering from the methodological limitations already mentioned above, are in line with previous studies on patient with cognitive decline [36][41], and suggest that specific patterns of needs are related to different stages of cognitive decline.





**Figure 1.** Prevalence of MCI and Dementia in European population according to Alexander et al. 2015 systematic review [40]

	N	Gender (M/F)	Age (Mean)	Education (Mean years)	MMSE (Mean raw score)	CDT (Mean raw score)	ADL (Mean raw score)	IADL (Mean raw score)
<b>ITALY</b>								
MCI	20	7/13	79.6	8.9	26.4	3.2	5.7	6.1
a-MCI	10	7/3	80.7	10	25.6	3.6	5.9	6.4
na-MCI	10	3/7	78.4	7.8	27.2	3.0	5.6	5.7
Mild Dem.	20	10/10	80.1	7.8	22	2.4	5.3	3.5
<b>SPAIN</b>								
a-MCI	5	NA	NA	NA	26.5	3.2	5.8	5
Total group (MCI/Mild Dem)	20	NA	NA	NA	21.3	2.4	3.8	NA
<b>SWEDEN</b>								
MCI	20	14/6	77.25	8.8	26.6	3.5	5.7	6.1
a-MCI	10	6/4	76	9.5	27	3.8	5.8	6.4
na-MCI	10	8/2	78.5	8.1	26.2	3.0	5.6	5.9
Mild Dem.	20	9/11	79.6	8.5	23.5	2.6	5.1	4.1
<b>ISRAEL</b>								
NA								

**Table 13.** Demographic data and distribution of the MDS for the samples of patients recollected in the preliminary population analysis.  
NA = data not available

CANE - S	ITALY			SPAIN	SWEDEN			ISRAEL
	MCI	a-MCI	na-MCI	a-MCI	MCI	a-MCI	na-MCI	MCI
<b>Accommodation</b>	0%	0%	0%	0%	0%	0%	0%	0-3%
<b>Food</b>	15%	0%	30%	20%	20%	20%	20%	5%
<b>Looking after the home</b>	25%	0%	50%	60%	20%	20%	20%	11%
<b>Self-care</b>	30%	0%	60%	30%	25%	10%	40%	5-10%
<b>Caring for someone else</b>	5%	0%	10%	20%	5%	0%	10%	1-2%
<b>Daytime activities</b>	5%	0%	10%	0%	5%	0%	10%	1-2%
<b>Memory</b>	85%	100%	70%	10%	70%	100%	40%	50-70%
<b>Eyesight/Hearing/Communication</b>	20%	30%	10%	20%	25%	10%	40%	-
<b>Mobility/Falls</b>	25%	10%	40%	60%	15%	0%	30%	10%
<b>Contenance</b>	5%	0%	10%	20%	5%	0%	10%	-
<b>Physical health</b>	10%	0%	20%	10%	25%	15%	35%	-
<b>Drugs</b>	55%	70%	40%	20%	45%	40%	50%	30-40%
<b>Psychotic symptoms</b>	15%	20%	10%	30%	5%	0%	10%	-
<b>Information on condition and treatment</b>	5%	0%	10%	20%	5%	0%	10%	-
<b>Psychological distress</b>	55%	50%	60%	20%	50%	55%	45%	30%
<b>Deliberate self-harm</b>	0%	0%	0%	10%	0%	0%	0%	-
<b>Inadvertent self-harm</b>	0%	0%	0%	20%	0%	0%	0%	0%
<b>Abuse/Neglect</b>	0%	0%	0%	20%	0%	0%	0%	0-5%
<b>Behaviour</b>	15%	0%	30%	20%	15%	0%	30%	1%
<b>Alcohol</b>	15%	20%	10%	10%	15%	20%	10%	15%
<b>Company</b>	15%	20%	10%	20%	20%	30%	10%	0%
<b>Intimate relationships</b>	0%	0%	0%	20%	10%	0%	20%	unknown
<b>Money/budgeting</b>	30%	20%	40%	20%	20%	20%	20%	10%
<b>Benefits</b>	0%	0%	0%	20%	10%	10%	10%	-

**Table 14.** Estimation of CANE-S in patients with MCI in the four pilot sites

	ITALY	SPAIN	SWEDEN
<b>CANE - S</b>	Mild Dementia	Mild Dementia	Mild Dementia
<b>Accommodation</b>	0%	0%	0%
<b>Food</b>	35%	30%	40%
<b>Looking after the home</b>	85%	60%	75%
<b>Self-care</b>	55%	30%	55%
<b>Caring for someone else</b>	0%	50%	40%
<b>Daytime activities</b>	10%	20%	15%
<b>Memory</b>	90%	20%	90%
<b>Eyesight/Hearing/Communication</b>	10%	20%	45%
<b>Mobility/Falls</b>	75%	60%	60%
<b>Continence</b>	40%	30%	25%
<b>Physical health</b>	0%	40%	40%
<b>Drugs</b>	100%	30%	100%
<b>Psychotic symptoms</b>	30%	20%	20%
<b>Information on condition and treatment</b>	0%	40%	50%
<b>Psychological distress</b>	50%	30%	80%
<b>Deliberate self-harm</b>	5%	20%	5%
<b>Inadvertent self-harm</b>	5%	20%	15%
<b>Abuse/Neglect</b>	10%	10%	10%
<b>Behaviour</b>	40%	30%	50%
<b>Alcohol</b>	0%	10%	25%
<b>Company</b>	15%	30%	35%
<b>Intimate relationships</b>	5%	20%	25%
<b>Money/budgeting</b>	100%	30%	70%
<b>Benefits</b>	0%	10%	15%

**Table 15.** Estimation of CANE-S in patients with Mild Dementia in three pilot sites

The results of this deliverable, and in particular the preliminary population analysis, are the starting-point for the activities of the task T1.3 aimed at identifying patient needs and caregiver requirements. This will be the basis for defining, within WP2 and WP3, a relation between need dimensions and ICT solutions in the effort to develop an effective model of intervention to support the patient and their families providing better care and quality of life.

The results of this deliverable represent the framework that will be used for the characterization of patients, from a clinical point of view, during the validation in the pilot sites (WP5).

## 5 References

1. American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition Text Revision (DSM-IV-TR)*. American Psychiatry Association, Washington DC.
2. Petersen, R.C., Smith, G.E., Waring, S.C., et al. (1999). Mild cognitive impairment: clinical characterization and outcome. *Archives of Neurology*, 56, 303–308
3. Petersen, R.C. (2004). Mild cognitive impairment as a diagnostic entity. *Journal of Internal Medicine*, 256, 183–194
4. Winblad, B., Palmer, K., Kivipelto, M., et al. (2004). Mild cognitive impairment: beyond controversies, towards a consensus: report of the International Working Group on Mild Cognitive Impairment. *Journal of Internal Medicine*, 256, 240–246
5. Albert, M.S., DeKosky, S.T., Dickson, D., et al. (2011). The diagnosis of mild cognitive impairment due to Alzheimer’s disease: recommendations from the National Institute on Aging – Alzheimer’s Association workgroups on diagnostic guidelines for Alzheimer’s disease. *Alzheimers and Dementia*, 7, 270–279
6. American Psychiatric Association (2013). *DSM-V: Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> ed.* Washington, DC: American Psychiatric Association.
7. World Health Organization (1992). *The ICD–10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. WHO.
8. Morris, J.C. (1993). The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology*, 43, 2412–2414
9. Ellis, G. & Langhorne, P. (2005). Comprehensive geriatric assessment for older hospital patients. *British Medical Bulletin*, 71 (1), 45-59
10. Ramani, L., Furmedge, D.S. and Reddy, S.P.H. (2014). Comprehensive geriatric assessment. *British Journal of Hospital Medicine*, 75, 122 – 125
11. Folstein, M., Folstein, S.E., McHugh, P.R. (1975). “Mini-Mental State” a Practical Method for Grading the Cognitive State of Patients for the Clinician. *Journal of Psychiatric Research*, 12(3); 189-198.
12. Nasreddine, Z.S., Phillips, N.A., Be’dirian, V., et al. (2005). The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of American Geriatric Society*, 53, 695–699
13. Shulman, K. I. (2000). Clock-drawing: is it the ideal cognitive screening test? *International Journal of Geriatric Psychiatry*, 15, 548–561.
14. Charlson, M.E., Pompei, P., Ales, K.L., MacKenzie, C.R. (1987) A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of Chronic Disease*, 40, 373–383
15. Linn, B.S., Linn, M.W., Gurel, L. (1968). Cumulative Illness Rating Scale. *Journal of American Geriatric Society*, 16, 622–626
16. Morris, J.N., Fries, B.E., Bernabei, R., et al. (1996). *RAI–Home care assessment manual*. InterRAI Corporation, Washington, DC.

17. Sheikh, J.I., Yesavage, J.A. (1986). *Geriatric Depression Scale (GDS): recent evidence and development of a shorter version*, in *Clinical Gerontology: A Guide to Assessment and Intervention*. In: Brink TL, editor. New York: The Haworth Press; 1986. pp. 165–173.
18. Cummings, J. L. (1997). The Neuropsychiatric Inventory: Assessing psychopathology in dementia patients. *Neurology*, 48, S10-S16
19. Cummings, J., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A., & Gornbein, J. (1994). The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology*, 44, 2308-2314.
20. Ott, B.R., Lafleche, G., Whelihan, W.M., et al. (1996). Impaired awareness of deficits in Alzheimer disease. *Alzheimer Disease and Associated Disorders*, 10, 68 – 76
21. Elia, M. (2003). *Screening for Malnutrition: A Multidisciplinary Responsibility. Development and Use of the Malnutrition Universal Screening Tool ('MUST') for Adults*. Redditch: BAPEN.
22. Lawton, M.P., & Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, 9(3), 179-186.
23. Katz, S., Down, T.D., Cash, H.R., & Grotz, R.C. (1970) Progress in the development of the index of ADL. *The Gerontologist*, 10(1), 20-30
24. Mahoney, F.I., Barthel, D.W. (1965). A functional evaluation: The Barthel Index. *Maryland State Medical Journal*, 14, 61-71
25. Reisberg B (1998). Functional Assessment Staging. *Psychopharmacology Bulletin*, 24, 653
26. Tinetti, M.E.; Williams, T. Frankin; Mayewski, R. (1986). Fall risk index for elderly patients based on number of chronic disabilities. *American Journal of Medicine*, 80 (3), 429–434
27. Hendrich, A.L. Bender, P.S. & Nyhuis, A. (2003). Validation of the Hendrich II Fall Risk Model: A large concurrent case/control study of hospitalized patients. *Applied Nursing Research*, 16(1), 9-21.
28. Novak, M., & Guest, C. I. (1989). Application of a multidimensional caregiver burden inventory. *The Gerontologist*, 29, 798-803.
29. Greene, J.G., Smith, R., Gardiner, M., Timbury, G.C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: a factor analytic study. *Age Ageing*, 11, 121–126
30. Reynolds, T., Thornicroft, G., Abas, M., Woods, B., Hoe, J., Leese, M., & Orrell, M. (2000). Camberwell assessment of need for the elderly (CANE) development, validity and reliability. *The British Journal of Psychiatry*, 176(5), 444-452.
31. Fried, L.P., Tangen, C.M., Walston, J., Newman, A.B., Hirsch, C., Gottdiener, J., Seeman, T., Tracy, R., Kop, W.J., Burke, G., McBurnie, M.A., Cardiovascular Health Study Collaborative Research Group (2001). Frailty in older adults: evidence for a phenotype. *The Journal of Gerontology Series A Biological Sciences and Medical Sciences*, 56, M146–M156.

32. Cesari, M., Demougeot, L., Boccalon, H., Guyonnet, S., Abellan Van Kan, G., et al. (2014). A Self-Reported Screening Tool for Detecting Community-Dwelling Older Persons with Frailty Syndrome in the Absence of Mobility Disability: The FiND Questionnaire. *PLoS ONE*, 9(7), e101745. doi: 10.1371/journal.pone.0101745
33. Rockwood, K., Xiaowei, S., MacKnight, C., et al. (2005). A global clinical measure of fitness and frailty in elderly people. *Canadian Medical Association Journal*, 173, 489–95
34. Scherer, M. J., & Craddock, G. (2002). Matching Person & Technology (MPT) assessment process. *Technology and Disability*, 14, 125-131
35. EU FP7 KSERa project. [http://cordis.europa.eu/project/rcn/93796\\_en.html](http://cordis.europa.eu/project/rcn/93796_en.html)
36. Van der Ploeg, E. S., Bax, D., Boorsma, M., Nijpels, G., & van Hout, H. P. (2013). A cross-sectional study to compare care needs of individuals with and without dementia in residential homes in the Netherlands. *BMC geriatrics*, 13(1), 51.
37. Gilbert, S. J. and Burgess, P. W. (2008). Executive function. *Current Biology*, 18, R110-R114.
38. Alzheimer Europe (2014). The prevalence of dementia in Europe, Italy. Available at: <http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/The-prevalence-of-dementia-in-Europe/Italy>
39. Moretti, F., de Ronchi, D., Palmer, K., Forlani, C., Morini V., Ferrari, B., Atti, A. (2013). Prevalence and characteristics of mild cognitive impairment in the general population. Data from an Italian population-based study: The Faenza Project. *Aging & Mental Health*, 17(3), 267-275.
40. Alexander, M., Perera, G., Ford, L., Arrighi, H. M., Foskett, N., Debove, C., Novak, G., and Gordon, M. F. (2015). Age-Stratified Prevalence of Mild Cognitive Impairment and Dementia in European Populations: A Systematic Review. *Journal of Alzheimer's Disease*, 48, 355–359
41. Miranda-Castillo, C., Woods, B. & Orrell, M. (2013). The needs of people with dementia living at home from user, caregiver and professional perspectives: a cross-sectional survey. *BMC Health Services Research*, 13, 43
42. Morales, J. M., Bermejo, F. P., Benito-León, J., Rivera-Navarro, J., Trincado, R., Vega, S., & NEDICES Study Group. (2004). Methods and demographic findings of the baseline survey of the NEDICES cohort: a door-to-door survey of neurological disorders in three communities from Central Spain. *Public health*, 118(6), 426-433.
43. National Institute of Statistics. (2014) [Web page in Spanish]. Available at: [www.ine.es](http://www.ine.es)
44. Olazarán, J., Valentí, M., Frades, B., Zea-Sevilla, M. A., Ávila-Villanueva, M., Fernández-Blázquez, M. Á., ... & Martínez-Martín, P. (2015). The Vallecas Project: A Cohort to Identify Early Markers and Mechanisms of Alzheimer's Disease. *Frontiers in aging neuroscience*, 7.

45. Stein, J., Luppá, M., König, H. H., & Riedel-Heller, S. G. (2014). Assessing met and unmet needs in the oldest-old and psychometric properties of the German version of the Camberwell Assessment of Need for the Elderly (CANE)–a pilot study. *International Psychogeriatrics*, 26(02), 285-295.
46. Thomas, K. (2010). The GSF prognostic indicator guidance. *End of Life Care*, 4(1), 62-64.

## Annex 1 Attitude towards technology questionnaire

1. Please indicate the technical devices you use during your daily living

- TV
- Mobile phone
- Computer
- Radio
- Medical Reminder
- Physical Measurement Tools

Others: \_\_\_\_\_

2. Do you have an internet connection in your home

- yes
- no

3. What is the TOTAL number of hours a week that you spend on a computer?

0	Less than 1	1-3	4-6	7-10	11-15	16-20	20+
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4. What is your most common activity when using a computer? (check ONLY ONE)

- Internet surfing
- Email
- Games
- Writing
- Getting information
- Social activities

Others? \_\_\_\_\_

5. Do you use the internet more or less often than your friends/relatives?

more                      less                      same as

6. How many hours a week do you spend doing the following activities:

Internet surfing

0	Less than 1	1-3	4-6	7-10	11-15	16-20	20+
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Using email

0	Less than 1	1-3	4-6	7-10	11-15	16-20	20+
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Searching for information in the internet

0	Less than 1	1-3	4-6	7-10	11-15	16-20	20+
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How many hours a week do you spend talking on the telephone?

0	Less than 1	1-3	4-6	7-10	11-15	16-20	20+
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How many hours a week do you spend watching television?

0	Less than 1	1-3	4-6	7-10	11-15	16-20	20+
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How many hours a week do you spend watching television with friends / family?

0	Less than 1	1-3	4-6	7-10	11-15	16-20	20+
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How many hours a week do you spend socializing with friends / family?

0	Less than 1	1-3	4-6	7-10	11-15	16-20	20+
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