



Dementia and psychiatric comorbidity symptoms assessment handbook



CAREGIVERSPRO-MMD PROJECT





Executive summary

D1.2 is the first deliverable of WP1, aimed to report the results of a thorough review on dementia and co-morbidity symptoms and on the most common validated scales to measure them (T.1.2).

The document is conceived as a practical handbook for consultation during the conceptual and technical development of the project: on its basis, the screening strategies (T.1.3) will be identified and its results integrated to those emerging from the PACT analysis (WP2). It will also contribute to the definition of functional and non-functional requirements of the platform (WP3) and provide important achievement towards M.5 *“Screening questionnaires and educational contents ready for deployment”*.

The document describes the approach, the methodology and the tools used to gather and analyse data, as well as the strategy used to classify symptoms and related scales. It also describes the target groups the review was addressed to, devoting a full chapter to the characterization of the dyad.

A full session is devoted to a literature review on *“the use of scales in ICT environment”*, given its relevance for the project purposes. Some final suggestions on relevant criteria for the selection of the scales to be included in the platform close the document.



List of Acronyms

Acronym	Title
ADL	Activities of Daily Living
CG	Care Giver
C-MMD	CAREGIVERSPRO-MMD
CR	Care Receiver
DSM-V	Diagnostic and Statistical Manual of Mental Disorders
GP	General Practitioner
HIV	Human Immunodeficiency Virus
HRQoL	Health-Related Quality of Life
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10th Revision
MCI	Mild Cognitive Impairment
NC	Neuro Cognitive
PLWD	Person Living With Dementia
QoL	Quality of Life



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1. Introduction

This document reports the results of a thorough review on dementia and co-morbidity symptoms, as well as on the most common validated scales to measure them.

D.1.2 addresses three different target groups: persons living with neuro-cognitive disorders, their caregivers and the dyads, i.e. the couple patient-caregiver, which is considered as the unit of care and represents the main target of the whole project. C-MMD gives high relevance to the dyad and to the relationship between Person Living with Dementia (PLWD) and caregiver: this deliverable proposes dedicated scales facilitating the dyad screening, profiling and assessment, to be tested during the pilots.

The term *neurocognitive disorder* (DSM-V and ICD-10) includes a wide range of symptoms associated with the decline of cognitive functionalities, which lead to the progressive reduction of a person's ability to perform everyday activities. This term is widely used, and often preferred, for conditions affecting younger people, such as impairment following traumatic brain injury or HIV infection. Differently, *dementia* is the customary term for progressive neurological impairment that usually affects older people. The term dementia has been retained within current classifications for continuity as it is more commonly used in clinical settings, where physicians and patients are accustomed to this term.

For the purposes of this document, the term *dementia* will be used because of its widespread public usage and prevalence in the research. For ease of reference, the word dementia is used to refer to MCI; however, not everyone with MCI will progress to develop dementia, though, given that monitoring is so important in patients with MCI, the platform will be of significant value to this group and their families.

The document is the result of a multidisciplinary approach, which professionals with different expertise and background contributed to. Decisions on terms to be used and classification strategies have been made in the perspective to satisfy both the interest of specialists and operators as well as the needs of technicians, who will draw valuable insights and suggestions from the document for their work on the C-MMD platform.

2. Methodology

In this chapter the methodology used to investigate, identify and list the symptoms of dementia and the co morbidity is described. Clinical, academic and social partners were involved in T.1.2 and contributed to D.1.2 with their specific competence and expertise. To facilitate the data gathering, the WP leader proposed a draft matrix to the partners (Table 1), which they were asked to complete for their field of expertise. Data required for both the PLWD and the caregivers.

Table 1. Matrix for the collection of data

Table A - Guide for the identification of Symptoms and related evaluation tools/scales already available							
AREAS	SYMPTOMS	SCALES	METODOLOGIES				References
	List of symptoms to be considered	AVAILABLE/EXISTING measurement scales	Who may submit/perform these scales?	Who can ANALYSE the scale results?	When/how often it has to be submitted?	Does the validated version exist in the different languages?	
CLINICAL Symptoms	Ex. Memory loss						
	...						
SOCIAL Symptoms	Ex. Isolation						
	...						
BEHAVIORAL Symptoms	Ex. Aggressiveness						
	...						
PSYCHOLOGICAL Symptoms	Ex. Depression						
	...						

The matrix proposed four main categories: clinical, social, behavioural and psychological, each to be filled in with the relevant symptoms. For each symptom, the matrix required specific information highly relevant for the future development of the platform, namely:

- The existing validated scales used to measure its level;
- The professionals qualified to submit and analyse the scale results;
- The availability of the scale in different languages (validated translations).

Focus groups and meetings were organized by each partner to collect the required information and to gather suggestions from the experts on the relevance of the proposed categorization of symptoms.

Due to the overlapping nature of given symptoms in different categories, the experts suggested a more pertinent classification, which resulted in the following grouping:

- **Clinical / Cognitive domain**, including health related symptoms;
- **Behavioural / Psychological domain**, including symptoms which frequently accompany the progress of dementia;
- **Functional domain**, including those symptoms related to Activities of Daily Living (ADL);
- **Quality of life domain**, including those symptoms affecting the ability to perform everyday tasks;
- **Comorbidity domain**, where comorbidity conditions are considered.

Symptoms and related information were aggregated in two final matrices collecting the PLWD and the caregivers' data respectively (Annex 1).

3. Analysis of symptoms

Analysis of symptoms associated with people living with dementia, including the following neurocognitive disorder categories:

- Mild Neurocognitive Disorder

This involves modest cognitive decline from previous levels of functioning in one or more cognitive domains (such as attention, executive function, learning and memory, language or perception). In mild neurocognitive disorder these difficulties do not interfere with a person's capacity to manage everyday activities or medication management.

- Major Neurocognitive Disorder

This involves a significant cognitive decline from previous levels of functioning in one or more cognitive domains. The cognitive deficits interfere with independence in everyday activities to an extent that a person may require assistance with the complex instrumental activities of daily living.

- Mild Cognitive Impairment

A further term, 'mild cognitive impairment' (or MCI) is recognised as an intermediate stage between 'normal' ageing and mild neurocognitive disorder (ICD-10). In MCI a person experiences measurable cognitive changes in memory beyond those expected in ageing. MCI does not impact upon a person's ability to care for oneself independently. MCI can have various aetiologies and may be managed or reversed; however, it can be prodromal for dementia and as such close follow up and review is important.

The neurocognitive disorder categories outlined above encompass multiple aetiologies and thus the classification of all its symptoms requires a multi-level approach and continuous monitoring.

For each domain (identified in previous chapter 2), symptoms are listed for PLWD and caregivers, and the related assessment scales are indicated.

3.1 Clinical-cognitive domain

This area includes the most relevant health-related symptoms, which cause the decrease of the PLWD cognitive functions, as well as the clinical aspects deriving from an impaired cognition (Table 2 and 3).

Table 2. Cognitive-Clinical symptoms in PLWD

Cognitive-Clinical symptoms in People Living with Dementia	Agnosia
	Aphasia
	Apraxia
	Attention disorders
	Disorientation (temporal or spatial)
	Executive dysfunction
	Memory loss
	Thinking and reasoning disorders



Table 3. Cognitive-Clinical symptoms in caregivers

Cognitive-Clinical symptoms in Caregivers	Caregivers' burden or strain
	Cognitive disorders

3.2 Behavioural-psychological domain

This area includes a series of symptoms, which can frequently accompany the progress of dementia. The scientific literature considers behavioural and psychological symptoms as both separate groups and as a single one; partners agreed to gather them under a single domain (Table 4 and 5).

Table 4. Behavioural-psychological symptoms in PLWD

Behavioural-Psychological symptoms in People Living with Dementia	Anosognosia
	Anxiety
	Appetite and eating disturbances
	Delusions
	Depression or dysphoria
	Disinhibition / Social behaviour disorders
	Elation or euphoria
	Hallucinations
	Irritability or lability
	Motor and behavioural inertia, apathy, indifference
	Night-time behaviours / sleep-wake cycle disruption
	Repetitiveness/motor disturbance
	Sexual behaviour disorders
	Verbal/physical aggressiveness / Agitation

Table 5. Behavioural-psychological symptoms in caregivers

Behavioural-Psychological symptoms in Caregivers	Affective distress
	Anxiety & stress
	Attitude to caregiving
	Sense of Competence
	Depression
	Emotional uneasiness
	Loneliness / Social isolation
	Self-esteem
	Self-efficacy

3.3 Functional domain

This area includes Activities of Daily Living (ADL). The measurement of ADL performance allows the assessment of treatment effects, caregiver burden, the targeting of interventions and care packages, and the elucidation of the link between cognition and everyday functional ability. ADL can be considered as the same for *PLWD* and caregivers.



Table 6. Functional activities in PLWD and caregivers

Activities of Daily Living in People Living with Dementia and caregivers	Food (preparing it)
	Eating
	Drink (preparing it)
	Drinking
	Dressing
	Hygiene
	Oral hygiene
	Bath / Shower
	Toilet
	Transfers
	Mobility
	Orientation-Time
	Orientation-Place
	Communication
	Using the telephone
	Houseworking/Gardening
	Shopping
	Managing finances
	Games/Hobbies
	Transport

3.4 Quality of Life domain

This area includes symptoms that influence the perceived Quality of Life (QoL) of both the targets and increases the caregivers' burden and distress.

Table 7. Quality of Life in PLWD

Quality of Life symptoms in People Living with Dementia	Functional autonomy
	Clothing
	Nutrition
	Mobility / risk of falls
	Personal Hygiene

Table 8. Quality of Life in caregivers

Quality of Life symptoms in Caregivers	Autonomy
	Mobility
	Nutrition
	Personal Hygiene



3.5 Co-morbidity in People Living with Dementia (PLWD) and Caregivers

Regarding the prevalence of co-morbidities between PLWD randomized clinical trial and most of papers, in general, provide a poor report on medical co-morbidities. Available data (Smith T. *et al* 2014, in a systematic review of 9 randomized clinical trials with 1474 people) shows this prevalence:

- Neurologic disorders: 91%
- Vascular disorders: 91%
- Cardiac disorders: 74%
- Depression: 59%
- Ischemic Cerebrovascular disease: 53%
- Hypercholesterolemia: 35%
- Hypertension: 47%
- Osteoporosis: 27%
- Diabetes: 15%
- Cancer: 11%

Other articles give more importance to Hypertension, Diabetes or Dyslipidaemia as main co-morbidities. There is no consensus because consistent randomized studies evaluating prevalence and course of other medical problems in PLWD and their caregivers are missing and, in almost any, there is stratification regarding age, cognitive impairment grade, etc.

Regarding health problems prevalence in caregivers, an interesting model is the study of Laks (*Laks et al. 2016*) realized through a National Health Survey with 10.853 responders, whom 209 were caregivers. Basically, but probably with different prevalence, the health problems and co-morbidities in PLWD and caregivers can be considered the same.

Therefore, such a category includes a list of health problems that can exist alongside neuro-cognitive disorder, which should be considered in order to provide tailored interventions.

Table 9. Comorbidities and health problems in PLWD and caregivers

Main comorbidities in People Living with Dementia and caregivers	Vascular (central and peripheral)	<ul style="list-style-type: none">• Hypertension• Coronary disease• Vascular extremities disease• Metabolic Syndrome
	Cardiac	<ul style="list-style-type: none">• Valvular heart diseases• Arrhythmias
	Respiratory	<ul style="list-style-type: none">• Pneumonia and other infections• Chronic obstructive pulmonary disease• Sleep Apnea
	Kidneys and Urinary	<ul style="list-style-type: none">• Kidney and urinary tract Infections• Chronic or acute kidney failure
	Metabolic and Endocrine	<ul style="list-style-type: none">• Diabetes Mellitus



		<ul style="list-style-type: none">• Obesity• Malnutrition• Osteoporosis
	Neurologic (central and peripheral)	<ul style="list-style-type: none">• Vascular (ischemic or haemorrhagic)• Epilepsy• Peripheral neuropathies
	Neuropsychiatric	<ul style="list-style-type: none">• Affective disorders (anxiety, depression)• Sleep disorders• Memory disorders
	Digestive	<ul style="list-style-type: none">• Dysphagia• Ulcer or gastritis• Bowel diseases• Liver diseases
	Infections	<ul style="list-style-type: none">• Local• Systemic
	Osteomioarticular	<ul style="list-style-type: none">• Osteoarthritis• Osteoarthritis• Bone fractures• Atrophy
	Malignancies	<ul style="list-style-type: none">• Localized or Metastatic
	Alcoholism and drug dependence	<ul style="list-style-type: none">• Alcoholism• Drugs abuse• Drugs dependence



4. Analysis of scales

4.1 Users/PLWD Symptoms and related Scales

The present section provides detailed information about assessment scales for user/PLWD.

4.1.1 Clinical and cognitive scales

Title/acronym	ACE-III - Addenbrooke's Cognitive Examination-III
Created by	Mathuranath et al, 2000 ; Hsieh et al., 2013
Purpose	To measure the global cognition. The assessment focuses on 5 cognitive domains: Attention, Memory, Verbal Fluency, Language and Visuospatial abilities. The total score is 100 with higher scores indicating better cognitive functioning.
Administration time	15 to 20 minutes
Submitted by	Assistant Psychologist, Clinical Psychologist, Neuropsychologist, Nurse, GP, Healthcare Assistant
Evaluated by	Clinical Psychologist, Neuropsychologist, GP
Validated in other languages	English, Italian, Spanish and French
References	Hsieh S., Schubert S., Hoon C., Mioshi E., Hodges J.R. (2013). Validation of the Addenbrooke's Cognitive Examination III in Frontotemporal Dementia and Alzheimer's Disease. <i>Dement Geriatr Cogn Disord</i> 2013;36:242-250 Mathuranath PS, Nestor PJ, Berrios GE, et al. A brief cognitive test battery to differentiate Alzheimer's disease and frontotemporal dementia. <i>Neurology</i> 2000;55:1613-20. Addenbrooke's Cognitive Examination-III <i>Occup Med (Lond)</i> (2015) 65 (5): 418-420.
Availability online	The ACE-III is available for free. The copyright is held by Professor John Hodges who is happy for the test to be used in clinical practice and research projects. The ACE-III scoring and administration guidelines can be obtained at the following website: http://www.neura.edu.au/frontier/research/test-downloads/ . Not available to fill in online, but is available to print out.

Title/acronym	ADAS-cog - Alzheimer's Disease Assessment Scale
Created by	Rosen & Davis, 1984
Purpose	To evaluate cognitive impairment in the assessment of Alzheimer's disease. Recommended for second stage or more detailed assessments and/or for particular research evaluations rather than for applications in routine care settings. The cognitive subscale consists of 11 subtests



	related to memory, praxis and language. The non-cognitive subscale of ADAS comprises 10 items evaluating mood and behavioural changes.
Administration time	30 to 45 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	1 month
Validated in other languages	English, French, Italian, Spanish and others
Availability online	No but related documents at: www.dementia-assessment.com.au/cognitive/ADAS_Packet.pdf

Title/acronym	AMQ - Auto-administered Memory Questionnaire
Created by	Van der Linden, Wijns, Von Frenkell, Coyette, & Seron, 1989
Purpose	To evaluate memory and attention in different activities of daily life. An abridged version was developed with two sections of questions: forgetfulness regarding conversations and forgetfulness concerning movies and books. It is validated with Mild Cognitive Impairment (MCI) and Alzheimer's Disease (AD) population.
Administration time	5 minutes
Submitted by	PLWD or caregivers
Evaluated by	Psychologist, GP or medical specialist
Submission schedule	4 times a year
Validated in other languages	English, French
References	Clément, F., Belleville, S., & Gauthier, S. (2008). Cognitive complaint in mild cognitive impairment and Alzheimer's disease. <i>Journal of the International Neuropsychological Society</i> , 14(2), 222-232 Van der Linden, M., Wijns, C., Von Frenkell, R., Coyette, F., & Seron, X. (1989). Un questionnaire d'auto-évaluation de la mémoire (QAM). Bruxelles: Editest
Availability online	www.criugm.qc.ca/images/stories/outils_cliniques/CRIUGM_44.pdf

Title/acronym	AMTS - Abbreviated Mental Test Score
Created by	Hodkinson, 1972
Purpose	Screening test to evaluate the global cognition. A score of six or less suggests delirium or dementia, although further tests are necessary to confirm the diagnosis.
Administration time	10 minutes
Submitted by	Psychologist, GP or medical specialist
Evaluated by	Psychologist, GP or medical specialist
Submission schedule	6 months
Validated in other languages	English
Availability online	www.ncbi.nlm.nih.gov/pmc/articles/PMC2560932/pdf/occpaper00113-0035.pdf



Title/acronym	BANSS - Bedford Alzheimer Nursing Severity Scale
Created by	Volicer, Hurley, Fabiszewski, Montgomery & Volicer, 1994
Purpose	To assess dementia severity in advanced dementia: a nonparametric item response analysis and a study of its psychometric characteristics. It is a 7- item scale, validated in nursing home, ranging from 7 (no impairment) to 28 (most severe impairment). It combines rating of interaction abilities, functional deficits and occurrence of pathological symptoms. It detects disease progression beyond severe stage. It has a good agreement of scores obtained from nursing staff and family.
Administration time	10 minutes
Analysed by	Caregiver
Evaluated by	GP or Specialist
Submission schedule	4 times a year
Validated in other languages	English
Availability online	No

Title/acronym	BECS - Batterie d'Evaluation des Connaissances Sémantiques
Created by	Merck <i>et al.</i> , 2011
Purpose	To evaluate semantic memory, verbal naming and to detect aphasia. The 40 items of the naming subtest (20 living and 20 non living) come from the Protocol Européen de Dénomination Orale d'Images (PEDOI) study (Kremin <i>et al.</i> , 2003), which proposes a data bank of pictures in different languages.
Administration time	45 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	French only but data bank in English, French, Italian, Spanish and others
Availability online	French version: http://site-greco.net/index.php?pageID=greco_fiche&id=f9158980ced69268f5e94340510644e1&from=recherche

Title/acronym	BNT – Boston Naming Test-2
Created by	Kaplan, Goodglass & Weintraub, 1983, 2000
Purpose	A 60-item test to determine the extent of client's visual confrontation naming abilities. A 15-item short form and multiple-choice version of the test can be used to retest comprehension of any words missed on the confrontation naming exercise.
Administration time	30 to 45 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English
References	Kaplan; Goodglass, Harold; Weintraub, Sandra (1983). Boston Naming



	Test. Philadelphia: Lea & Febiger.
Availability online	No

Title/acronym	Brixton Spatial Anticipation test (or Brixton test)
Created by	Burgess & Shallice, 1997
Purpose	To measure ability to detect and follow a rule, an important aspect of executive functioning. It is perceptually simple as it does not require a verbal response; it is appropriate for those suffering from a wide range of deficits such as those involving speech production or reading.
Administration time	10 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
Availability online	No

Title/acronym	BSEPA - Brief screening Scale Evaluating Praxis Abilities for use in memory clinics
Created by	Mahieux-Laurent <i>et al.</i> , 2007
Purpose	To evaluate praxis in memory clinics. It includes three subtests: symbolic gestures (five gestures), pantomimes (five gestures) and imitation of meaningless gestures (eight gestures). The BSEPA was validated with healthy older people, people with MCI and dementia.
Administration time	10 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	French
Availability online	No

Title/acronym	BTA - Brief Test of Attention
Created by	Schretien, 1989
Purpose	To assess severity of divided attentional impairment. It can be used with individuals with visual and motor impairments.
Administration time	5 to 10 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English
References	Schretlen, D. (1989). The Brief Test of Attention. Baltimore, MD: Author.
Availability online	No

Title/acronym	BVMT-R - Brief Visuospatial Memory Test-Revised
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Created by	Benedict <i>et al.</i> , 1996
Purpose	To measure visuospatial memory
Administration time	45 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, Italian
References	Benedict R.H.B., Schretlen D., Groninger L., Dobraski M. & Sphritz B. (1996). Revision of the Brief Visuospatial Memory Test: Studies of normal performance, reliability and validity. <i>Psychological Assessment</i> , 8, 145-153
Availability online	No

Title/acronym	BVRT – Benton Visual Retention Test
Created by	Benton, 1991
Purpose	To measure visual perception, memory and visuoconstructive abilities.
Administration time	15 to 20 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English
References	Benton, A. (1945). A Visual Retention Test for Clinical Use. <i>Archives of Neurology And Psychiatry</i> 54(3),212 Benton, AL. (1992). Benton Visual Retention Test (5th ed.). San Antonio: The Psychological Corporation
Availability online	No

Title/acronym	CDR - Clinical Dementia Rating Scale
Created by	Morris, 1993
Purpose	To characterize six domains of cognitive and functional performance applicable to Alzheimer's disease and related dementias: Memory, Orientation, Judgment & Problem Solving, Community Affairs, Home & Hobbies, and Personal Care. It is a semi-structured interview conducted with the PLWD and a reliable informant.
Administration time	20 to 30 minutes
Submitted by	GP or Medical Specialist
Evaluated by	GP or Medical Specialist
Submission schedule	6 months
Validated in other languages	60 languages, including English, French
Availability online	http://alzheimer.wustl.edu/cdr/cdr.htm

Title/acronym	CDS - Cognitive Difficulties Scale
Created by	McNair & Kahn, 1984
Purpose	Self-evaluation tool to screen age-associated memory impairment. It is



	sensitive and specific for detecting cognitive deficits in older people (Derouesne <i>et al.</i> , 1993). A reduced 25-item version was proposed to evaluate different cognitive domains: memory, attention, executive function, apraxia, aphasia, orientation to time and space.
Administration time	5 minutes
Submitted by	PLWD or caregiver
Evaluated by	Psychologist, GP or medical specialist
Submission schedule	4 times a year
Validated in other languages	English, French

Title/acronym	CDT - Clock Drawing Test
Created by	Goodglass, 1983
Purpose	To measure spatial dysfunction, neglect, executive dysfunction and abstraction difficulties.
Administration time	5 minutes
Submitted by	Neuropsychologist, GP or medical specialist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, Spanish, French No verbal scale so an international application is possible
Availability online	Yes

Title/acronym	CPM - Raven's Coloured Progressive Matrices
Created by	Raven, 1984
Purpose	To measure clear-thinking ability for young children and older adults. The test consists of 36 items in 3 sets.
Administration time	15 to 30 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Denes, F., Semenza, C., & Stoppa, E. (1978). Selective improvement by unilateral brain-damaged patients on Raven Coloured Progressive Matrices. <i>Neuropsychologia</i> , 16, 749-75 Raven, J.C. (1984). <i>Manual for The Coloured Progressive Matrices</i> (revised Windsor, UK: NFER-Nelson)
Availability online	No

Title/acronym	CTT - Color Trail Test
Created by	D'Elia <i>et al.</i> , 1996
Purpose	To measure sustained attention and sequencing. The CTT presents numbered colored circles and universal sign language symbols. The participant is required to alternate between the number and color sequences in completing the task.



Administration time	3 to 8 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English (but no verbal test)
References	D'Elia LF., Satz P., Uchiyama CL. & White T. (1996). Color Trails Test. Professional manual, Psychological Assessment Resources, Odessa, FL (1996)
Availability online	No

Title/acronym	CVLT - California Verbal Learning Test (second edition)
Created by	Delis <i>et al.</i> , 1987, 2000
Purpose	To measure verbal learning and memory.
Administration time	60 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French
References	Delis, D. C., Kramer, J. H., Kaplan, E., & Ober, B. A. (1987). CVLT, California Verbal Learning Test: Adult Version: Manual. Psychological Corporation Delis, DC., Kramer, JH., Kaplan, E., Ober, BA. (2000). California Verbal Learning Test – second edition. Adult version. Manual Psychological Corporation, San Antonio, TX
Availability online	No

Title/acronym	DO 80 - Denomination Orale 80 items
Created by	Deloche & Hannequin, 1997
Purpose	To evaluate verbal naming. It is an 80-items test, which in vast majority come from Snodgrass & Vanderwart data bank (1980).
Administration time	15 minutes
Submitted by	Neuropsychologist, GP or medical specialist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	French only but data bank in English language
Availability online	No

Title/acronym	DVT – Digit Vigilance Test
Created by	Lewis and Rennick, 1979
Purpose	To measure attention during rapid visual tracking and accurate selection of target stimuli.
Administration time	15 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist



Submission schedule	6 months
Validated in other languages	English (but no verbal test)
References	Lewis, R., Rennick, LM. (1979). Manual for the Repeatable Cognitive-Perceptual-Motor Battery. Axon, Grosse Point, MI
Availability online	No

Title/acronym	FAB - Frontal Assessment Battery
Created by	Dubois <i>et al.</i> , 2000
Purpose	To evaluate bedside screening of a global executive dysfunction; it is a short cognitive and behavioural six-subtest battery assessing: Similarities, Phonological Fluency, Luria's Motor Series, conflicting Instructions, Go-No-Go task and Prehensile Behaviour.
Administration time	15 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
Availability online	English form: www.dementia-assessment.com.au/frontotemporal/frontal_fab_scale.pdf French form: www.sepec.ca/bref.pdf

Title/acronym	FCSRT-W - Free and Cued Selective Reminding Test - Word version
Created by	Van der Linden <i>et al.</i> , 2004
Purpose	To test verbal episodic memory; it differs from other tests of episodic memory with a <i>controlled learning</i> study procedure that maximize encoding specificity and learning through the promotion of deep semantic processing. It identifies prevalence and incidence of dementia and MCI, and can distinguish AD from other sub-types of dementia.
Administration time	30 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
Availability online	French version: http://site-greco.net/index.php?pageID=greco_fiche&id=rlri16&from=recherche

Title/acronym	Forward and Backward Digit Span
Created by	Wechsler, 2011
Purpose	To evaluate both the phonological loop and central administrator of the Working Memory (Baddeley, 1986, 2000).
Administration time	10 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months



Validated in other languages	20 languages included English, French, Italian, Spanish
Availability online	No

Title/acronym	FT5 - The 5-Figure Test
Created by	Croisile <i>et al.</i> , 2009
Purpose	To test the visual memory, through a quick memory evaluation for people with mild AD. In the FT5, subjects have to remember an abstract picture and immediately recognize it: the target figure is presented with three similar foils. After a 5-10 minutes' delay, the subjects are asked again to indicate which pictures are correct.
Administration time	15 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	French
Availability online	No

Title/acronym	FWT - Five-Words Test
Created by	Dubois <i>et al.</i> , 2002
Purpose	To test verbal episodic memory. In the FWT, subjects have to remember five words with a semantic encoding. An immediate and delayed recall (in 5 to 10 minutes) is proposed.
Administration time	15 minutes
Submitted by	Neuropsychologist, GP or medical specialist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	French, Italian A list exists in English, but is not validated
Availability online	French form: http://site-greco.net/index.php?pageID=greco_fiche&id=15aa1dd43200cf5352081f05fb0f6366&from=recherche

Title/acronym	HDS - Hierarchic Dementia Scale
Created by	Cole & Dastoor, 1983
Purpose	To measure cognitive function, to classify the remaining abilities in dementia and to detect change over time. It consists of twenty subscales arranged in a hierarchic fashion from easy to difficult. Areas measured are: orientation, memory, praxis, gnostic abilities, language, motor abilities.
Administration time	30 minutes to 1 hour
Submitted by	GP, medical specialist or psychologist
Evaluated by	GP, medical specialist or psychologist
Submission schedule	4 times a year
Validated in other languages	English, French



Availability online	No
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Title/acronym	HSCT - Hayling Sentence Completion test
Created by	Burgess and Shallice 1997
Purpose	A test of executive functioning. It measures response initiation and response suppression. It consists of two sets of 15 sentences each having the last word missing. In the first section the examiner reads each sentence aloud and the participant has to simply complete the sentences, yielding a simple measure of response initiation speed. The second part of the Hayling requires subjects to complete a sentence with a nonsense ending word (and suppress a sensible one), giving measures of response suppression ability and thinking time.
Administration time	5 to 10 minutes
Submitted by	Assistant Psychologist, Clinical Psychologist, Neuropsychologist, Nurse, GP, Healthcare Assistant
Evaluated by	Clinical Psychologist, Neuropsychologist
Submission schedule	6 months
References	Burgess, PW., & Shallice, T. (1997). The Hayling and Brixton Tests. Thurston, Suffolk: Thames Valley Test Company Bielak, AAM., Mansueti, L., Strauss, E., & Dixon, RA. (2006). Performance on the Hayling and Brixton tests in older adults: Norms and correlates. <i>Archives of Clinical Neuropsychology</i> , 21, 141–149
Validated in other languages	English, French, Italian, Spanish
Availability online	No

Title/acronym	IQCODE (short) - Informant Questionnaire on Cognitive Decline in the Elderly - Short Form
Created by	Jorm, 1994
Purpose	To evaluate cognitive impairment in dementia, it is used as a screening test. It reflects past cognitive decline and predicts incident dementia. It compares the actual abilities (memory, executive function and reasoning) of the subject with his/her abilities ten years ago.
Administration time	5 minutes
Submitted by	Caregiver
Evaluated by	Psychologist, GP or medical specialist
Submission schedule	4 times a year
Validated in other languages	French, English

Title/acronym	M-ACE Mini - Addenbrooke's Cognitive Examination
Created by	Neuroscience Research Australia (NeuRA; www.neura.edu.au)
Purpose	The Mini-ACE (M-ACE) is a shorter version of the ACE-III, and it was developed for use in settings where administration of the full ACE-III is not practical. The total score of the M-ACE is 30, with higher scores indicating better cognitive performance.



Administration time	5 minutes
Submitted by	Assistant Psychologist, Clinical Psychologist, Neuropsychologist, Nurse, GP, Healthcare Assistant
Evaluated by	Clinical Psychologist, Neuropsychologist, GP
Submission schedule	6 months. Alternative versions available on repeat.
Validated in other languages	English, Spanish and others (not French, Italian).
Availability online	The M-ACE is available for free. The copyright is held by Professor John Hodges who is happy for the test to be used in clinical practice and research projects. The M-ACE scoring and administration guidelines can be obtained at the following website: http://www.neura.edu.au/frontier/research/test-downloads/ . Not available to fill in online, but is available to print out.

Title/acronym	MCST - Modify Card Sorting Test
Created by	Nelson, 1976
Purpose	To evaluate the executive functions in people with focal, traumatic and degenerative brain diseases. It is a shortened version of the Wisconsin Card Sorting Test (Grant & Berg, 1948), proposed by Nelson (1976). It is a neuropsychological test widely used in clinical settings.
Administration time	20 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
Availability online	No

Title/acronym	MDRS - Mattis Dementia Rating Scale
Created by	Mattis, 1988
Purpose	To measure the global cognition based on performances across five domain subtests: Attention, Initiation/Perseveration, Construction, Conceptualization and Memory.
Administration time	30 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
Availability online	www.site-greco.net/index.php?pageID=greco_fiche&id=mattis&from=recherche

Title/acronym	MMPI-2 – Minnesota Multiphasic Personality Inventory 2
Created by	Butcher et al., 2001
Purpose	To help identify personal, social, and behavioral problems in psychiatric patients.
Administration time	60 to 90 minutes



Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	1 month
Validated in other languages	
References	James N. Butcher, PhD, John R. Graham, PhD, Yossef S. Ben-Porath, PhD, Auke Tellegen, PhD, W. Grant Dahlstrom, PhD, Beverly Kaemmer, Coordinator for the Press (2001) . Minnesota Multiphasic Personality Inventory®-2 (MMPI®-2). University of Minnesota Press
Availability online	No

Title/acronym	MMSE - Mini-Mental State Examination
Created by	Folstein & Folstein, 1975
Purpose	To screen dementia, conceived as brief test for cognitive impairment. It includes questions about orientation, attention, recall and language.
Administration time	20 minutes
Submitted by	Neuropsychologist, GP or medical specialist
Evaluated by	Neuropsychologist
Submission schedule	12 months
Validated in other languages	76 languages included English, French, Italian, Spanish

Title/acronym	MoCA - Montreal Cognitive Assessment
Created by	Nasreddine <i>et al.</i> , 2005
Purpose	To assist health professionals in the detection of MCI in people scoring between 24 and 30 points on the MMSE. Compared to MMSE, it has more emphasis on tasks of frontal executive functioning and attention, which may make it more sensitive in detecting non-AD dementia.
Administration time	10 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish and many others
Availability online	www.mocatest.org/paper-tests/moca-test-full

Title/acronym	OT-SRT - Open Trial Selective Reminding Test
Created by	Chiaravalloti <i>et al.</i> , 2009
Purpose	It is a modification of the SRT that also evaluates new learning abilities. The examinee is asked to learn a list of 10 words over a maximum of 15 trials. Recall and recognition is then tested 30 and 90 minutes following the learning trials.
Administration time	90 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other	English



languages	
References	Chiaravalloti, ND., Balzano, J., Moore, NB., & DeLuca, J. (2009). The Open-Trial Selective Reminding Test (OT-SRT) as a tool for the assessment of learning and memory. Clin Neuropsychol., 23(2), 231-54. doi: 10.1080/13854040802121158.
Availability online	No

Title/acronym	PASAT - Paced Auditory Serial Addition Test
Created by	Gronwall, 1977
Purpose	To measure of cognitive function that specifically assesses auditory information processing speed and flexibility, as well as calculation ability.
Administration time	10 to 15 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian (27 languages)
References	Diehr, MC., Heaton, RK., Miller, W., & Grant, I. (1998). The Paced Auditory Serial Addition Task (PASAT): Norms for age, education, and ethnicity Assessment, 5,375–387 Gronwall, D. (1977). Paced auditory serial-addition task: a measure of recovery from concussion. Perceptual and Motor Skills, 44, 367–373.
Availability online	No

Title/acronym	PEGV - Protocole Montréal-Toulouse d'Evaluation des Gnosies Visuelles
Created by	Agniel <i>et al.</i> , 1992
Purpose	To test visual agnosia. It is composed of four subtests; identical figures, category matching, semantic matching and tangled figures.
Administration time	20 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	French
Availability online	No

Title/acronym	RBANS - Repeatable Battery for the Assessment of Neuropsychological Status
Created by	Randolph et al., 1998
Purpose	To measure cognitive decline or cognitive impairment across immediate memory, attention, language, delayed memory, and visuospatial/constructional skills
Administration time	30 minutes
Submitted by	Assistant Psychologist, Clinical Psychologist, Neuropsychologist
Evaluated by	Clinical Psychologist, Neuropsychologist



Submission schedule	6 months
Validated in other languages	English, Italian, Spanish http://www.pearsonclinical.com/pharma-licensing/content-and-translations.html
Availability online	No

Title/acronym	RBMT - Rivermead Behavioural Memory Test
Created by	Wilson, Cockburn & Baddeley, 1985
Purpose	To predict everyday memory problems in people with acquired, non-progressive brain injury, and to monitor change over time. The third edition (Wilson et al., 2010) includes 14 subtests assessing aspects of visual, verbal, recall, recognition, immediate and delayed everyday memory.
Administration time	30 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish and others
Availability online	No

Title/acronym	RFFT – Ruff Figural Fluency Test
Created by	Ruff, 1987
Purpose	To provide clinical information regarding nonverbal capacity for fluid and divergent thinking, ability to shift cognitive set, planning strategies, and executive ability to coordinate this process.
Administration time	5 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English (but no verbal test)
References	Ruff, R.M., Evans, R.W. and Light, R.H. Automatic detection vs. controlled search: A paper-and-pencil approach. <i>Perceptual and Motor Skills</i> 62, 407-416. (1986) Ruff, R.M., Light, R.H. & Evans, R.W. (1987) The Ruff Figural Fluency Test: A normative study with adults. <i>Developmental Neuropsychology</i> , 3, 37-51
Availability online	No

Title/acronym	ROCF - Rey-Osterrieth Complex Figure
Created by	Rey, 1941
Purpose	To evaluate the visuo-spatial construction ability and executive function (spatial planning). It consists of three test conditions: copy, immediate recall and delayed recall.
Administration time	10 minutes
Submitted by	Neuropsychologist



Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
Availability online	No

Title/acronym	SCWT - Stroop Color and Word Test
Created by	Golden, 1978
Purpose	It is a brief five minute to determine cognitive flexibility, inhibition capacity, and reaction to cognitive pressures.
Administration time	5 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Fisher, L. M., Freed, D. M., & Corkin, S. (1990). Stroop Color–Word Test performance in patients with Alzheimer’s disease. <i>Journal of Clinical and Experimental Neuropsychology</i> , 12, 745–758 Golden, C. (1978). Stroop color and word test manual (Cat.30150M). Chicago: Stoelting Co Stroop, JR. (1935). Studies of interference on serial verbal reaction. <i>J. Exp. Physiol.</i> , 18, 643-662
Availability online	No

Title/acronym	SDMT - Symbol Digit Modalities Test
Created by	Smith, 1973
Purpose	To screen selective attention capacity and speed of treatment.
Administration time	1,5 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English (but no verbal test)
References	Smith, A. (1968). The symbol-digit modalities test: a neuropsychologic test of learning and other cerebral disorders. J. Helmuth (Ed.), <i>Learning disorders</i> , Special Child Publications, Seattle, 83 Smith, A. (1982). <i>Symbol Digits Modalities Test</i> Western Psychological Services, Los Angeles
Availability online	No

Title/acronym	SIB - Severe Impairment Battery
Created by	Saxton <i>et al.</i> , 1990
Purpose	To assess people with significant cognitive impairment who are unable to complete conventional neuropsychological testing, designed for those with more advanced dementia (MMSE<13). It is composed of simple one-step commands and gestures and it allows for a variety of



	simple responses. The six major subscales are: attention, orientation, language, memory, visual-spatial ability and construction; there are also brief evaluations of praxis, social interaction and orientation to name.
Administration time	20 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
Availability online	No

Title/acronym	SMMSE - Severe Impairment Mini-Mental State Examination
Created by	Harrell <i>et al.</i> , 2000
Purpose	The Severe Mini-Mental State Examination (SMMES) is an instrument based on the original MMSE developed with the objective of evaluating cognition in patients with more advanced Alzheimer's Disease.
Administration time	10 minutes
Submitted by	Doctor or Psychologist
Evaluated by	Psychologist
Submission schedule	6 months
Validated in other languages	English, French
References	Folstein, MF., Folstein, SE., & McHugh, PR. (1975). 'Mini-mental state': a practical method for grading the cognitive state of patients for the clinician. <i>J Psychiatr Res</i> , 12, 189-198 Harrell, EL., Marson, D., Chatterjee, A., & Parrish, JA. (2000). The Severe Mini-Mental State Examination : A New Neuropsychologic Instrument for the Bedside Assessment of Severely Impaired Patients with Alzheimer's Disease. <i>Alzheimer Disease and Associated Disorders</i> , 2, 31-38. Sales M., Suernoto, C., Topciu, F., & Morillo, L. (2011). Severe Mini-Mental State Examination: brief cognitive assessment for patients with moderate and severe dementia, <i>Alzheimer's & Dementia</i> , 7(4), S263
Availability online	No

Title/acronym	SRT - Selective Reminding Test
Created by	Buschke, 1973
Purpose	To measures verbal learning and memory using a multiple-trail list-learning paradigm.
Administration time	30 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish (Campo & Morales, 2004)
References	Bushke, H. (1973). Selective reminding for analysis of memory and learning. <i>Journal of verbal learning and verbal behaviour</i> , 12, 543-550



	Ruff, RM., Light, RH., & Quayhagen, M. (1989). Selective Reminding Tests: a normative study of verbal learning in adults. <i>J Clin Exp Neuropsychol.</i> , 11(4), 539-550
Availability online	No

Title/acronym	The Doors test
Created by	Baddeley <i>et al.</i> , 1994
Purpose	To test verbal episodic memory by recognition of each target door from a set of four doors varying in similarity and hence difficulty. It is a subtest of the Doors and People test; the subject attempts to memorize a series of coloured doors photographs.
Administration time	10 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French
Availability online	No

Title/acronym	TMT - Trail Making Test
Created by	Reitan, 1958
Purpose	To evaluate the speed of processing (part A), visual attention and reactive mental flexibility (part B). Both parts consist of 25 circles distributed over a sheet of paper. In Part A, the person should draw lines to connect the numbers 1 to 25 in ascending order. In Part B, should draw lines to connect the circles in an ascending pattern, but with the added task of alternating between the numbers and letters as quickly as possible.
Administration time	15 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French
Availability online	http://doa.alaska.gov/dmv/akol/pdfs/uiowa_trailmaking.pdf

Title/acronym	TT - Token Test
Created by	Spreen & Benton, 1969
Purpose	To assess the verbal comprehension of commands of increasing complexity. The test employs a set of 20 plastic tokens consisting of 5 colours, two shapes and two sizes.
Administration time	10 minutes for the short version
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish



Availability online	No
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Title/acronym	TYM - Test Your Memory
Created by	Brown & Brown, 2009
Purpose	To assess tasks such as orientation, ability to copy a sentence, semantic knowledge, calculation, verbal fluency, similarities, naming, visuo-spatial abilities and recall of a copied sentence. It is a series of 10 tasks on a double-sided sheet of card with spaces for the subject to fill in.
Administration time	10 minutes
Submitted by	Neuropsychologist, GP or medical specialist
Evaluated by	Neuropsychologist, GP or medical specialist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
Availability online	www.tymtest.com

Title/acronym	VF - Verbal Fluency test: animals and "P" letter
Created by	Cardebat <i>et al.</i> , 1990
Purpose	To measure mainly the speed and ease of verbal production, language functioning (naming, extent of vocabulary), search strategies (executive functions) and semantic memory. It involves the generation of as many words as possible at a phonologic and/or semantic level.
Administration time	5 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French
Availability online	French form: www.sgca.fr/outils/fluence.pdf

Title/acronym	VST - Stroop Colour-Word Test-Victoria version
Created by	Spreen & Strauss, 1998
Purpose	To assess psychometric properties, including excellent test-retest reliability, sensitivity to amnesic mild cognitive impairment, Alzheimer Disease and aging (Troyer <i>et al.</i> , 2006). It is a brief version of the Stroop task; it uses 3 conditions in naming the colour of dots, of neutral words and of colour words printed in incongruent colours. This version seems appropriate for use with older and brain-damaged populations who may be prone to fatigue during neuropsychological examination.
Administration time	5 minutes
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 months
Validated in other languages	English, French
Availability online	French form: http://nca.recherche.univ-lille3.fr/uploads/File/Mat%C3%A9riel%20Stroop%20Victoria.pdf



Title/acronym	WAIS IV - Wechsler Adult Intelligence Scale, Fourth edition
Created by	Wechsler, 2008
Purpose	The WAIS -IV is an instrument designed to assess the cognitive ability of adolescents and adults. It provides subtest and composite scores that represent intellectual functioning in specific cognitive domains.
Administration time	60 to 90 minutes
Submitted by	Psychologist
Evaluated by	Psychologist
Submission schedule	1 year
Validated in other languages	English, French, Italian and Spanish www.pearsonclinical.com/pharma-licensing/content-and-translations.html
References	Wechsler, D. (1939). The Measurement of Adult Intelligence. Baltimore (MD): Williams & Wilkins. Wechsler, D. (2008). Wechsler Adult Intelligence Scale (4th ed.). San Antonio, TX: Psychological Corporation.
Availability online	No

Title/acronym	WMS IV - Wechsler Memory Scale, Fourth edition
Created by	Wechsler, D., 1945 ; Pearson Education, 2008
Purpose	The WMS-IV measures the ability to learn and remember information presented both verbally and visually. It exist an old-age version.
Administration time	1 to 2,5 hours
Submitted by	Neuropsychologist
Evaluated by	Neuropsychologist
Submission schedule	6 month
Validated in other languages	English, French, Italian and Spanish http://www.pearsonclinical.com/pharma-licensing/content-and-translations.html
References	Efklides, A., Yiultsi, E., Kangelidou, T., Kounti, F., Dina, F., & Tsolaki, M. (2002). Wechsler Memory Scale, Rivermead Behavioral Memory Test, and Everyday Memory Questionnaire in Healthy Adults and Alzheimer Patients. European Journal of Psychological Assessment, Volume 18, Issue 1, Pages 63-77 Pearson Education. (2008). Wechsler Memory Scale, Fourth Edition: Clinical features of the new edition. Wechsler, D. (1945). A standardized memory scale for clinical use. Journal of Psychology, 19, 87 – 95
Availability online	No

4.1.2 Psychological and behavioural scales

Title/acronym	AI - Apathy Inventory
Created by	Robert <i>et al.</i> , 2002
Purpose	To evaluate apathy and emotional blunting, lack of initiative and lack of interest in older people with and without dementia.



Administration time	10 minutes
Submitted by	Subject /Caregiver / GP or psychologist or medical specialist (3 versions)
Evaluated by	GP, psychologist or medical specialist
Submission schedule	1 month
Validated in other languages	French, English, Italian and Spanish
Availability online	www.cmrr-nice.fr/doc/IA3vFrenchMis%C3%A0jour070611.pdf

Title/acronym	BEHAVE-AD - Behavioural Pathology in Alzheimer's Disease
Created by	Reisberg <i>et al.</i> , 1987
Purpose	To measure behavioural and psychological symptoms that may occur in dementia: paranoid and delusional ideation, hallucinations, activity disturbances, aggressiveness, diurnal rhythm disturbances, affective disturbance, anxiety and phobias.
Administration time	20 minutes
Submitted by	Caregiver
Evaluated by	Psychologist / GP/Medical specialist
Submission schedule	1 month
Validated in other languages	English, French, Spanish
Availability online	http://dementia-assessment.com.au/behavioural/BEHAVE-AD.pdf

Title/acronym	CMAI - Cohen-Mansfield Agitation Inventory
Created by	Cohen-Mansfield, 1986
Purpose	To assess the frequency of agitated behaviours in older persons., through a 29-item scale. The older person is rated by a primary caregiver regarding the frequency with which they may present with physically aggressive, physically non-aggressive and verbally agitated behaviours.
Administration time	10 minutes
Submitted by	Psychologist/ GP or Specialist
Evaluated by	Psychologist/GP or Specialist
Submission schedule	3 months
Validated in other languages	English, French, Spanish and others
Availability online	Copyrights: Memory Resources and Research Centre - C.H.U NICE . Email: massa.i@chu-nice.fr

Title/acronym	CSDD - Cornell Scale for Depression in Dementia
Created by	Alexopoulos, 1988
Purpose	To evaluate depression in moderate or severe dementia. It is a 19-item scale that utilises information from an interview with the PLWD and caregiver.
Administration time	10 minutes
Submitted by	Psychologist /GP/Medical specialist
Evaluated by	Psychologist/ GP/Medical specialist
Submission schedule	3 months



Validated in other languages	French, Spanish
Availability online	http://geropsychiatriceducation.vch.ca/docs/edu-downloads/depression/cornell_scale_depression.pdf

Title/acronym	GDS - Geriatric Depression Scale
Created by	Yesavage <i>et al.</i> , 1982
Purpose	To evaluate depression in older people. It is a 30-item test; scores of 0-4 are considered average, depending on age, education, and complaints; 5-8 indicate mild depression; 9-11 indicate moderate depression; and 12-15 indicate severe depression. A Short Form consisting of 15 questions was developed in 1986. Physically ill and people with mild to moderate dementia, who have short attention spans and/or feel easily fatigued, find it more easy to use.
Administration time	10 to 20 minutes
Submitted by	Subject or caregiver
Evaluated by	Psychologist / GP/Medical specialist
Submission schedule	1 month
Validated in other languages	Yes, all languages
Availability online	http://web.stanford.edu/~yesavage/GDS.html

Title/acronym	LARS - Lille Apathy Rating Scale
Created by	Sockeel <i>et al.</i> , 2006
Purpose	To assess apathy. It comprises 33 queries belonging to nine domains, each corresponding to a clinical manifestation of apathy.
Administration time	10 minutes
Submitted by	Subject/ Caregiver/ GP or Specialist
Evaluated by	GP or Specialist
Submission schedule	1 or 2 months
Validated in other languages	French Spanish in Parkinson disease- http://cmrr-nice.fr/doc/LARSpatient-english[1].pdf
Availability online	http://www.cmrr-nice.fr/doc/LARSpatient-french[1].pdf http://cmrr-nice.fr/doc/LARSpatient-english[1].pdf http://www.hindawi.com/journals/tswj/2014/849834/

Title/acronym	MADRS - Montgomery-Åsberg Depression Rating Scale
Created by	Montgomery & Åsberg, 1979
Purpose	To evaluate severity of depressive symptoms.
Administration time	10 minutes
Submitted by	Psychologist
Evaluated by	Psychologist
Submission schedule	1 month
Validated in other languages	English, French, Spanish



Availability online	Yes https://outcometracker.org/library/MADRS.pdf
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Title/acronym	NPI - NeuroPsychiatric Inventory
Created by	Cummings, 1984
Purpose	To assess behavioural domains common in dementia, in 2 versions: 10 domains (10-item NPI) or 12 domains (12-item NPI). These include: hallucinations, delusions, agitation/aggression, dysphoria/depression, anxiety, irritability, disinhibition, euphoria, apathy, aberrant motor behaviour, sleep and night-time behaviour change (10-item), appetite and eating change (12-item)
Administration time	20 to 30 minutes
Submitted by	Caregiver
Evaluated by	Psychologist / medical specialist
Submission schedule	1 month
Validated in other languages	English, French, Italian, Spanish and other languages
Availability online	http://npitest.net/

4.1.3 Functional scales

Title/acronym	ADCS - Activities of Daily Living Inventory
Created by	Galasko, 1997
Purpose	ADCS-ADL scale is a 23-item scale rated 0-78 validated in Alzheimer's disease. A short version exists with 19-item. This scale is more complex and detailed than ADL and IADL. Trained observers are necessary.
Administration time	15 minutes
Submitted by	Nurse, GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Galasko <i>et al.</i> An inventory to assess activities of daily living for clinical trials in Alzheimer's disease. <i>Alzheimer Disease and Associated Disorders</i> 1997 ; 11 : S33-S39.
Availability online	www.dementia-assessment.com.au/function/ADCS-ADL_scale.pdf

Title/acronym	ADL-PI - Activities of Daily Living-Prevention Instrument
Created by	Galasko et al 2006
Purpose	ADL-PI has been developed to assess instrumental activities of daily living in prevention clinical trials in dementia. Because ADL are intact or minimally impaired for complex activities, this scale assesses 15 ADL and 5 physical functions.
Administration time	10 minutes
Submitted by	Auto questionnaire
Evaluated by	GPs or specialist



Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Galasko et al. ADCS Prevention instrument project: assessment of instrumental activities of daily living for community-dwelling older individuals in dementia prevention clinical trials. <i>Alzheimer Dis Assoc Disord</i> 2006, 20; S152-69
Availability online	Scale not available online for free

Title/acronym	ADLQ - Activities of Daily Living Questionnaire
Created by	Johnson, 2004
Purpose	ADLQ assess functional abilities of subjects with neurocognitive disorders. ADLQ measures functioning in six-areas: self-care, household care, employment and recreation, shopping and money, travel and communication, with different subscales
Administration time	5 to 10 minutes
Submitted by	Nurse, GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Johnson N <i>et al.</i> The activities of daily living questionnaire. A validation study in people living with dementia. <i>Alzheimer Dis Assoc Disord</i> 2004, vol 18; 223-230
Availability online	Johnson's article: www.otat.org/images/column_1259639711/ADLQ.pdf

Title/acronym	AGGIR - Autonomie Gérontologie Groupes Iso-Ressources
Created by	Vetel, 1990
Purpose	To assess difficulties in 17 domains (coherent speech and behaviour, orientation, toileting, dressing, cooking and eating, continence, transfers, indoor and outdoor movement, communication, treatment follow-up, housekeeping, budget management, ability to request assistance, leisure time activities, shopping). For each domain, if the person is not able to do the task alone, it categorises the degree of support needed (stating whether the person completes the task spontaneously, fully and usually). It categorises 6 levels of dependency and helps to determine the level of benefit received.
Administration time	10 to 15 minutes
Submitted by	Nurses, social worker, GPs, psychologist
Evaluated by	Nurses, social worker, GPs, psychologist
Submission schedule	6 months
Validated in other languages	French
Availability online	http://medco5962.free.fr/GIR2/gir.php

Title/acronym	BADL - Barthel ADL Index / Barthel Index of Activities of Daily Living
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Created by	Mahoney & Barthel, 1965
Purpose	To measure performance in activity of daily living. It takes into account the level ability of 10 current tasks (bowel and bladder continence, grooming, toilet use, feeding, transfer, mobility, dressing, stairs, bathing). Possible total scores range from 0-20. Changes of more than 2 points reflect an improvement or impairment of functional status. Lower scores indicate increased difficulties.
Administration time	10 minutes
Submitted by	Caregivers (relatives, professional), nurses
Evaluated by	Nurses / GPs, psychologists
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
Availability online	www.ncbi.nlm.nih.gov/pmc/articles/PMC2560924/

Title/acronym	BADLS - Bristol Activities of Daily Living Scale
Created by	Bucks, R. S., Ashworth, D. L., Wilcock, G. K., and Siegfried, K. (1996)
Purpose	The BADLS scale has been developed specifically for use with people living with dementia. The assessment is a carer rated instrument consisting in 20 daily-living abilities. BADLS is a carer-rating scale.
Administration time	15 to 20 minutes
Submitted by	Caregiver
Evaluated by	Nurses, social worker, GPs, psychologist
Submission schedule	Monthly
Validated in other languages	English
Availability online	http://ageing.oxfordjournals.org/content/25/2/113.full.pdf

Title/acronym	DAD - Disability Assessment for Dementia
Created by	Gelinas, Gauthier, McIntire & Gauthier, 1999
Purpose	To measure disability for community-dwelling individuals with dementia. Basic and instrumental activities of daily living are examined in relation to executive skills. It includes basic activities of daily living, instrumental activities of daily living and leisure activities. These activities are assessed according to executive functions.
Administration time	15 minutes
Submitted by	Nurses
Evaluated by	Nurses/ Psychologist/ GPs
Submission schedule	6 months
Validated in other languages	English, French, Spanish, Italian
Availability online	www.dementia-assessment.com.au/function/dad_scale.pdf

Title/acronym	GERRI - Geriatric Evaluation by Relative's Rating Instrument
Created by	Schwartz, 1983
Purposes	This 49-item scale assesses cognitive and social functioning, mood and somatic functioning. Frequency of typical behavioural changes and



	complaints are evaluated.
Administration time	30 minutes
Submitted by	Caregivers
Evaluated by	Clinicians
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Schwartz. Development and validation of the geriatric evaluation by relatives rating instrument (GERRI). Psychol Rep 1983; 53:479-88
Availability online	No availability online

Title/acronym	IADL - Lawton Instrumental Activities of Daily Living Scale
Created by	Lawton & Brody, 1969
Purpose	Appropriate instrument to assess the ability to perform tasks necessary to live independently in the community. It takes into account 8 instrumental tasks (ability to use the telephone, shopping, food preparation, housekeeping, laundry, using transport, responsibility for own medications, ability to handle finances). Because of gender differences, a short version with 4 items (telephone, medication, budget, transportation) can be used.
Administration time	10 minutes
Submitted by	Caregivers (relatives, professional)
Evaluated by	Nurses / GPs, psychologists
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
Availability online	www.abramsoncenter.org/PRI/documents/IADL.pdf

Title/acronym	Katz Index of ADL / Independence in Activities of Daily Living
Created by	Katz, 1970, 1983
Purpose	To assess the functional status in basic activities. It takes into account 6 tasks (bathing, dressing, toileting, transferring, continence, feeding). Total possible scores range from 0-6. A score of 6 reflects an independent person, 4 indicates moderate impairment, 2 or less indicates significant functional impairment.
Administration time	5 minutes
Submitted by	Caregivers (relatives, professional), nurses
Evaluated by	Nurses / GPs, psychologists
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
Availability online	http://clas.uiowa.edu/socialwork/files/socialwork/NursingHomeResource/documents/Katz%20ADL_LawtonIADL.pdf

Title/acronym	RDRS-2 - Rapid Disability Rating Scale
Created by	Linn 1967, revised in 1982
Purposes	RDRS-2 contains 18 items with 8 questions on activity daily living,



	three questions on sensory abilities, three on mental abilities, and one dietary changes, continence, confinement to bed and medication. The questions are rated on four points and score range from 18 to 72
Administration time	2 minutes
Submitted by	Nurse, GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Linn. The rapid disability rating scale-2. JAGS 1982; 30: 378-382
Availability online	No

Title/acronym	TMT - Tinetti Mobility Test or Tinetti balance and Gait Scale
Created by	Tinetti, 1986
Purpose	To determine an older persons risk for falls through an evaluation of the gait steppage and drift (with the evaluator walking close behind) and of the balance (with the evaluator again standing close).
Administration time	15 minutes
Submitted by	Caregiver or Specialist
Evaluated by	Specialist
Submission schedule	4 times a year
Validated in other languages	English, French, Italian, Spanish and others
Availability online	www.bhps.org.uk/falls/documents/TinettiBalanceAssessment.pdf

4.1.4 Quality of Life scales

Many questionnaires are validated to evaluate quality of life. Here follow scales that have been validated in neurocognitive disease in community; those validated only in care settings have been excluded.

Title/acronym	ADRQL - Alzheimer's Disease Related Quality of Life
Created by	Rabins and Kasper, 1997
Purpose	ADRLQ is a 47-item scale that can be applied to people living with dementia. Five domains are studied: social interaction (12 items), awareness of self (8 items), enjoyment of activities (15 items), feelings and mood (5 items) and response to surroundings (7 items). It measures quality of life (QoL) in the last 2 weeks rated from 0 to 100 (good QoL).
Administration time	10-15 minutes
Submitted by	Psychologists, GPs
Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Rabins P, Kasper <i>et al.</i> Measuring quality of life in dementia:



	conceptual and practical issues. Alzheimer Dis Assoc 1997; 11 (Suppl6): 100-4
Availability online	To obtain the scale send an email to bblack@jhmi.edu

Title/acronym	AQoL - Assessment of Quality of Life
Created by	Hawthorne 1999
Purpose	To measure health-related quality of life (HRQoL). The AQoL measures 5 dimensions: illness, independent living, social relationships, physical senses and psychological wellbeing. Each has three items. The AQoL is easy to understand and is quickly completed.
Administration time	<5 min
Submitted by	Self-administered
Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English
References	Hawthorne et al. The Assessment of Quality of Life (AQoL) instrument: a psychometric measure of health-related quality of life. Qual Life Res 1999; 8: 209-24
Availability online	www.aqol.com.au (licence fee and no cost. To register the project)

Title/acronym	CBS - Cornell Brown Scale for Quality of Life
Created by	Ready 2002
Purpose	The CBS scale gives a global assessment of Quality of Life. It is adapted from the Cornell Scale for Depression. The scale assesses five domains: mood related signs, ideational disturbance, behavioural changes, physical signs, and cyclic functions. Negative and positive effects are evaluated.
Administration time	5 min
Submitted by	Clinician
Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English, Italian, Spanish
References	Ready <i>et al.</i> The Cornell-Brown Scale for Quality of life dementia. Alzheimer Dis Assoc Disord 2002; 16: 109-15
Availability online	Med.brown.edu/neurology/articles/cbsmanual.pdf

Title/acronym	DEMqoL - Dementia Quality of Life
Created by	Smith 2005
Purpose	The 28-item DEMqoL assesses quality of life of people with mild to moderate dementia, but not with severe dementia. It evaluates five domains: daily activities and looking after yourself, health and well-being, cognitive functioning, social relationships and self-concept.
Administration time	10 to 15 minutes
Submitted by	Psychologists, GPs
Evaluated by	Psychologists, GPs



Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Smith et al. Measurement of health-related quality of life for people living with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. Health Technol Assess 2005 9:1-93
Availability online	www.hta.ac.uk - www.dementia-assessment.com.au/quality/

Title/acronym	DEMQoL-proxy - Dementia Quality of Life
Created by	Smith 2005
Purpose	The 31-item DEMQoL-proxy provides an evaluation of carers' view of PLWD quality of life. People with mild to severe dementia can be evaluated. The use with DEMQoL-proxy is recommended. It is well correlated with DEMQoL
Administration time	10 to 15 minutes
Submitted by	Psychologists, GPs
Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Smith et al. Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. Health Technol Assess 2005 9:1-93
Availability online	www.hta.ac.uk - www.dementia-assessment.com.au/quality/

Title/acronym	DQoL - Dementia Quality of Life Instrument
Created by	Brod 1999
Purpose	DQoL is a 29-item scale. It measures 5 domains of QoL: positive affect (5 items), negative affect (11 items), feeling of belonging (3 items), self-esteem (4 items) and sense of aesthetics (5 items) and a global item. The scale can be self-administered, with items very simple, and choice on visual scale. It can be used in cases of mild to moderate dementia.
Administration time	10 minutes
Submitted by	Psychologists, GPs
Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Brod <i>et al.</i> Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DqoL). The Gerontologist 1999; 39: 25-35
Availability online	No

Title/acronym	EQ5D - European Quality of Life
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Created by	EuroQol Research Foundation, 1990
Purpose	To measure health outcome. Applicable for a wide range of health conditions and treatments, it provides a simple descriptive profile and a single index value for health status. EQ5D is primarily designed for self-completion by respondents and is ideally suited for use in postal surveys, in clinics and face-to-face interviews. It is cognitively simple, taking only a few minutes to complete.
Administration time	5 minutes
Submitted by	Self- Administered
Evaluated by	GP or Specialist or Psychologist
Submission schedule	4 times a year
Validated in other languages	170 languages, included English, French, Italian, Spanish
Availability online	The EQ5D valuation questionnaire is only distributed in instances where researchers specifically wish to elicit evaluations of health. It should not be used in routine clinical or economic studies or population health surveys. www.euroqol.org/eq-5d-products/how-to-obtain-eq-5d.html

Title/acronym	PQoL - Perceived Quality of Life
Created by	Danis M, Patrick DL., 1981
Purpose	To measure quality of life based on the evaluation of major categories of fundamental life needs; scale items are developed using human needs theory.
Administration time	10 minutes
Submitted by	Self-administered, interviewer-administered
Evaluated by	Self-evaluated
Submission schedule	3 months
Validated in other languages	English, Spanish
References	Kajiyama <i>et al.</i> (2013)
Availability online	http://depts.washington.edu/seaqol/docs/PQOL-Sample-page.pdf

Title/acronym	PWB-CIP (Psychological Well-Being in Cognitively Impaired Persons)
Created by	Burgener 2002
Purpose	The PWB-CIP measures aspects of QoL related to psychological well-being. It is an observer-rated 11-item scale. It measures positive and negative affective states and engagement behaviours. It can be used for people in the mild to moderate stages of dementia.
Administration time	5 to 10 minutes
Submitted by	Caregivers
Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English
References	Burgener et al. Alzheimer Disease and Associated Disorders 2002; 16: 88-102



Availability online	No
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Title/acronym	QoL-AD - Quality of life Alzheimer's Disease Scale
Created by	Logsdon, Gibbons, McCurry & Terry, 1999
Purpose	To obtain a rating of the PLWD quality of life from both the PLWD and the caregiver. It is a brief, 13-item measure, developed for individuals with dementia. It uses simple and includes assessments of the individual's relationships with friends and family, concerns about finances, physical condition, mood, and an overall assessment of life quality. The PLWD can usually complete the questionnaire if MMSE>10. Is below, caregivers can complete it.
Administration time	5 minutes in self-administrated; 10 to 15 minutes in interview version
Submitted by	Caregiver or GP or Specialist
Evaluated by	GP or Specialist or Psychologist
Submission schedule	4 times a year
Validated in other languages	English, French, Italian, Spanish and others
References	Logsdon et al. Quality of life in Alzheimer's disease: patient and caregiver reports. Journal of mental health and Aging, 1999; 5 : 21-32
Availability online	www.dementia-assessment.com.au/quality/qol_handout_guidelines_scale.pdf

Title/acronym	QOLAS - Quality of Life Assessment Schedule
Created by	Selai 2001
Purpose	The QOLAS scale is administrated to people with mild to moderate dementia. The scale is completed by the PLWD or by the caregiver who evaluate a proxy rating of the QOL of the PLWD. It employs both qualitative and quantitative measurement approaches in domains such as physical, psychological, social/family, usual activities and cognitive functioning. Each domain is rated from 0 to a 6 point-scale.
Administration time	5 to 10 minutes
Submitted by	Self-administered or caregiver
Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English
References	Selai. Assessing quality of life in dementia: preliminary psychometric testing of Quality of Life Assessment Schedule (QOLAS). Neuropsychological Rehabilitation 2001; 11: 219-43
Availability online	No

Title/acronym	QOLS - Quality of Life Scale
Created by	Flanagan 1978
Purpose	The QOLS is a 7-item scale, rated from 16 to 112. It is used in chronic diseases in order to evaluate quality of life. Validated for dementia
Administration time	5 minutes with informant
Submitted by	Self-administered



Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English
References	Flanagan. A research approach to improving our quality of life. Am psychologist 1978, 33:138-47
Availability online	www.qolid.org (for members)

Title/acronym	SF12 - Short Form Health Survey
Created by	Ware & Sherbourne, 1992
Purpose	SF-12 is a shortened form (12 items) of the SF-36 Health Survey. It is a generic assessment of health-related quality of life (HRQOL) from the caregiver/PLWD perspective. It addresses the same 8 domains as identified in the SF-36v2: physical functioning, role – physical, bodily pain, general health perceptions, vitality, social functioning, role – emotional, mental health
Administration time	5 minutes
Submitted by	Self-administered
Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish and many others
References	Ware JE, Snow KS, Kosinski M, Gandek B.: SF-36 Health Survey Manual and Interpretation Guide, Boston, The Health Institute, New England Medical Center, 1993 Ware J, Jr, Kosinski M, Keller SD.: A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med Care 34: 220–233, 1996
Availability online	www.sf-36.org/demos/SF-12.html

4.1.5 Comorbidities and health problems scales

Title/acronym	CI - Charlson Index
Created by	Charlson <i>et al.</i> , 1987
Purpose	The Charlson Index takes into account the number of comorbidity and weights the seriousness of each disease. It is a predictor of mortality used in longitudinal studies. The scale is validated in geriatric populations.
Administration time	10 minutes
Submitted by	Nurse, GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Charlson ME. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. J Chronic Dis 1987;40(5):373-383.



Availability online	http://touchcalc.com/calculators/cci_js
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Title/acronym	CIRS - Cumulative Illness Rating Scale
Created by	Linn, 1968
Purpose	CIRS is used a tool to measure and rate multi-morbidity . It evaluates 13 medical conditions weighted 0 (no problem) to 4 (extremely severe problem). This scale has been validated in older people and people with cognitive impairment.
Administration time	15 minutes
Submitted by	Nurse, GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Lin. Cumulative illness rating scale. JAGS 1968 may; 16 (5): 622-6
Availability online	www.crhc.pitt.edu/psf/CI/ci.aspx

Title/acronym	ICED - Index of Coexistent Disease
Created by	Greenfield et al., 1987
Purpose	The ICED aggregates the presence and severity of 19 medical conditions and 11 physical impairments within two scales: the Index of Disease Severity (IDS) and the Index of Physical Impairment (IPI). It has been tested in renal diseases and in older people.
Administration time	
Submitted by	Nurse, GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French
References	Albertsen PC, Fryback DG, Storer BE, Kolon TF, Fine J. The impact of co-morbidity on life expectancy among men with localized prostate cancer. J Urol 1996;156:127-32. Joudi FN, Allareddy V, Kane CJ, Konety BR. Analysis of complications following partial and total nephrectomy for renal cancer in a population based sample. J Urol 2007;177:1709-14.
Availability online	N

Title/acronym	KFI - Kaplan Feinstein Index
Created by	Kaplan & Feinstein, 1974
Purpose	The KFI is a 12-item scale that evaluates and weights from 0 (no problem) to 3 (severe failure). It is validated in older people.
Administration time	10 minutes
Submitted by	GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, <i>Italian</i> , Spanish



References	Kaplan MH, Feinstein AR. The importance of classifying initial comorbidity in evaluating the outcome of diabetes mellitus. J Chron Dis 1974; 27:387-404.
Availability online	N

Title/acronym	MNA^{sf} - Mini Nutritional Assessment short form
Created by	Rubenstein
Purpose	The MNA test is useful to detect malnutrition. It is validated for use with older people.
Administration time	5 to 10 minutes
Submitted by	Older Person/ Caregiver
Evaluated by	Nurse /GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Rubenstein <i>et al.</i> Screening for under nutrition in geriatric practice developing the short form mini nutritional assessment (MNA-sf). J Gerontol A Biol Sci Med Sci 2001; 56: M366-372 Kaiser <i>et al.</i> Validation of the Mini Nutritional assessment. J Nutr Health Aging 2009 Nov 13 (9): 782-8
Availability online	www.mna-elderly.com

Title/acronym	TIBI - Total illness burden index
Created by	Greenfield <i>et al.</i> , 1995
Purpose	The TIBI is a 63-item comprehensive summary measure of severity of illness. It aggregates conditions, people and diseases, which are weighted by severity.
Administration time	15 to 20 minutes
Submitted by	Nurse, GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, <i>Italian, Spanish</i>
References	Greenfield S: Development and testing of a new measure of case mix for use in office practice. Med Care 33(suppl): AS47-AS55, 1995.
Availability online	No



4.2 Caregivers Symptoms and related Scales

The present section provides detailed information about assessment scales for caregivers.

4.2.1 Clinical and cognitive scales

Title/acronym	BSFC - Burden Scale for Family Caregivers
Created by	Moniz-Cook <i>et al.</i> , 2008
Purpose	To measure the levels of perceived burden of informal caregivers, mainly family members who take care of individuals at home. It focuses on the identification of caregiver service needs, the evaluation of service effectiveness and the prediction of caregiver health.
Administration time	10 to 15 minutes
Submitted by	Self-administered
Evaluated by	Clinical practitioners and researchers
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish and many other languages
References	Moniz-Cook E., Vernooij-Dassen M., Woods R., Verhey F., Chattat R., De Vugt M., Mountain G., O'Connell M., Harrison J., Vasse E., Dröes RM., Orrell M. (2008); Chiu <i>et al.</i> (2009); Chiu & Eysenbach (2010); Gräßel, E., Adabbo, R. (2011)
Availability online	www.psychiatrie.uk-erlangen.de/med-psychologie-soziologie/psychometrische-versorgungsforschung/burden-scale-for-family-caregivers-bsfc/

Title/acronym	CDS - Cognitive Difficulties Scale
Created by	McNair & Kahn, 1984
Purpose	To screen age-associated memory impairment; it is sensitive and specific enough to detect cognitive deficits in older people. A reduced 25-item version was proposed to evaluate different cognitive domains: memory, attention, executive function, apraxia, aphasia, orientation to time and space.
Administration time	5 minutes
Submitted by	Self-administered
Evaluated by	Psychologist / GP or medical specialist
Submission schedule	4 times a year
Validated in other languages	English, French
References	Derouesne, C., De Alberto, MJ., Boyer, P., Lubin, S., Sauron, B., Piette, B., Kohler, F., & Alperovitch, A. (1993); Israël, L. (1986) ; MacNair, DM., Khan, RJ. (1984); Poitrenaud, J., Israël, L., Barrere, H., Le Roc'h, K. (1997).
Availability online	No

Title/acronym	CSI - Caregiver Strain Index
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Created by	Savla, 2012
Purpose	To measure strain related to care provision, with domains relating to employment, financial, physical, social and time pressures, in a 13-item questionnaire
Administration time	5 minutes
Submitted by	Self-administered
Evaluated by	GP or Specialist, Psychologist
Submission schedule	1 month
Validated in other languages	English, French, Spanish
References	Beauchamp <i>et al.</i> (2005)
Availability online	www.npcrc.org/files/news/caregiver_strain_index.pdf www.hipocampo.org/CSI.asp

Title/acronym	RMBPC - Revised Memory and Behaviour Problems Checklist
Created by	Teri <i>et al.</i> , 1992
Purpose	To assess both the presence of behavioural problems in people with dementia, and the extent of caregiver “subjective burden” or “ <i>distress</i> ” associated with those problems. It focuses three subscales: memory-related problems, affective distress and disruptive behaviours.
Administration time	5 to 10 minutes
Submitted by	Self-administered
Evaluated by	Neuropsychologist / GP or medical specialist
Submission schedule	3 months
Validated in other languages	Chinese, English, German, Japanese, Mandarin, Spanish
References	Mahoney <i>et al.</i> (2003); Finkel <i>et al.</i> (2007); Kajiya <i>et al.</i> (2013)
Availability online	www.alz.org/national/documents/C_ASSESS-RevisedMemoryandBehCheck.pdf

Title/acronym	RSS - Relative Stress Scale
Created by	Green <i>et al.</i> , 1982
Purpose	To identify carer and care recipient characteristics associated with various aspects of burden. It focuses on emotional distress, social distress and negative feelings.
Administration time	5 minutes
Submitted by	Self-administered
Evaluated by	GP or Specialist or Psychologist
Submission schedule	1 month
Validated in other languages	English, Italian
References	Green <i>et al.</i> , 1982; Ulstein <i>et al.</i> , 2007
Availability online	No

Title/acronym	ZBI - Zarit Burden Interview
Created by	Zarit, Reever & Bach-Peterson, 1980



Purpose	To assess the level of burden experienced by the principal caregivers of older people living with dementia, through a 29-item scale. The revised version contains 22 items and is commonly used. Each item on the interview is a statement that the caregiver is asked to endorse using a 5-point scale (0=Never; 4 =Nearly Always).
Administration time	5 to 10 minutes
Submitted by	Self-administered
Evaluated by	Psychologists, GPs
Submission schedule	2-3 months
Validated in other languages	Almost all languages, including English, French and Spanish.
References	Lai <i>et al.</i> (2013); O'Connor <i>et al.</i> (2014); Cristancho-Lacroix <i>et al.</i> (2015); Griffiths <i>et al.</i> (2015)
Availability online	http://scale-library.com/pdf/Zarit_Burden_Interview.pdf

4.2.2 Psychological and behavioural scales

Title/acronym	BDI - Beck Depression Inventory
Created by	Beck, A.T., Steer, R.A., & Brown, G., 1996
Purpose	To measure the severity of depression in adolescents and adults. The 21-item survey is self-administered and is scored on a scale of 0-3 in a list of four statements arranged in increasing severity about a particular symptom of depression. The cut-offs used are: 0–13: minimal depression; 14–19: mild depression; 20–28: moderate depression; and 29–63: severe depression.
Administration time	10 to 15 minutes
Submitted by	Self-administered
Evaluated by	Psychologist / GP or medical specialist
Submission schedule	1 or 2 months
Validated in other languages	English, French, Spanish, Italian
References	Beck, A.T., Steer, R.A., & Brown, G.K. (1996).
Availability online	www.ibogaine.desk.nl/graphics/3639b1c_23.pdf www.deploie-tes-ailles.org/test/depression.php Italian: www.stateofmind.it/wp-content/uploads/2012/05/BDI-13.pdf Spanish: http://telemedicinadetampico.files.wordpress.com/2011/12/inventariodedepresiondebeck.pdf

Title/acronym	CBI – Caregiver Burden Inventory
Created by	Novak & Guest, 1989
Purpose	To measure the assistive burden, through a multidimensional approach, addressing the primary and main caregiver of the person with Alzheimers or dementia.
Administration time	10 minutes
Submitted by	Self-administred
Evaluated by	Psychologist



Submission schedule	
Validated in other languages	English, French (incomplete; 2/3 scales), Spanish, Italian and others
Availability online	www.arbejdsmiljoforskning.dk/upload/cbi-scales.pdf

Title/acronym	CBI - Copenhagen Burnout Inventory
Created by	Kristensen, Borritz, Villadsen & Christensen, 2005
Purpose	To measure personal, work-related and client-related burnout. It is a 19-items scale, consisting of three scales measuring personal burnout, work-related burnout, and client-related burnout, for use in different domains.
Administration time	10 to 15 minutes
Submitted by	Self-administrated
Evaluated by	GP, Psychologist
Submission schedule	4 months
Validated in other languages	English, French (incomplete; 2/3 scales), Spanish, Italian and others
References	Kristensen, Borritz, Villadsen & Christensen, 2005
Availability online	www.arbejdsmiljoforskning.dk/upload/cbi-scales.pdf

Title/acronym	CES-D - Centre for Epidemiologic Studies Depression Scale
Created by	Radloff LS, 1977
Purpose	To screen and measure caregivers depression and depressive disorders, through a 20-items scale. Response options range from 0 to 3 (0 = Rarely or None of the Time, to 3 = Most or Almost All the Time). Scores range from 0 to 60, with high scores indicating greater depressive symptoms.
Administration time	5 to 10 minutes
Submitted by	Clinician and caregiver
Evaluated by	Clinician
Submission schedule	1 or 2 months
Validated in other languages	English, French, Italian, Spanish
References	Radloff LS. 1977
Availability online	CESD- R is in the public domain so that it is free to use in your search- Web site design and development by the Research Centre for innovative public. http://cesd-r.com/

Title/acronym	GAD7 - Generalized Anxiety Disorder scale
Created by	Spitzer <i>et al.</i> , 2006
Purpose	To screen and measure generalised anxiety disorder (GAD).
Administration time	5 minutes
Submitted by	Self-administered
Evaluated by	Psychologists, GPs
Submission schedule	4 months
Validated in other languages	English, Spanish



References	Swinson RP, 2006; Spitzer RL, Kroenke K, Williams JB, <i>et al</i> , 2006; Kroenke K, Spitzer RL, Williams JB, <i>et al</i> . 2007.
Availability online	www.integration.samhsa.gov/clinical-practice/GAD708.19.08Cartwright.pdf

Title/acronym	GDS - Geriatric Depression Scale
Created by	Yesavage <i>et al.</i> , 1982
Purpose	To evaluate depression in older people. It is a 30-item test; scores of 0-4 are considered average, depending on age, education, and complaints; 5-8 indicate mild depression; 9-11 indicate moderate depression; and 12-15 indicate severe depression. A Short Form consisting of 15 questions was developed in 1986. People who are physically ill and living with mild to moderate dementia, who have short attention spans and/or feel easily fatigued, find it more easy to use.
Administration time	10 to 20 minutes
Submitted by	PLWD or caregiver
Evaluated by	Psychologist / GP/Medical specialist
Submission schedule	1 month
Validated in other languages	Yes, all languages
Availability online	http://web.stanford.edu/~yesavage/GDS.html

Title/acronym	HADS - Hospital Anxiety and Depression Scale
Created by	Snaith RP; Zigmond AS, 1983
Purpose	To detect anxiety and depression
Administration time	5 minutes
Submitted by	Clinician and caregiver
Evaluated by	Clinician
Submission schedule	1 or 2 months
Validated in other languages	Yes, all
References	Zigmond AS, Snaith RP. The hospital anxiety and depression scale. <i>Acta Psychiatrica Scandinavica</i> 1983;67:361-70
Availability online	www.nice.cnge.fr/IMG/pdf/echelle-had.pdf french www.strokengine.ca/pdf/zigmondAndSnaith1983.pdf

Title/acronym	NPI-Q - Neuropsychiatric Inventory Questionnaire
Created by	Cummings, 1994
Purpose	To assess behavioural changes in neurologic illnesses. To evaluate caregiver distress associated with behavioural changes in the person for whom they care. Investigated items are: hallucinations, delusions, agitation/aggression, dysphoria/depression, anxiety, irritability, disinhibition, euphoria, apathy, and aberrant motor behaviour.
Administration time	30 minutes
Submitted by	Psychologist, GP, Specialist or Nurse



Evaluated by	Psychologist / Medical specialist
Submission schedule	1 month
Validated in other languages	Danish, Dutch, English, Finnish, French, Japanese, Spanish, Swedish
References	Cummings, JL., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, DA., Gornbein, J. (1994). The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. <i>Neurology</i> , 44, 2308-2314 Cummings, JL. (1997). The Neuropsychiatric Inventory: assessing psychopathology in dementia patients. <i>Neurology</i> , 48, S10-S16 Kaufer, DI., Cummings, JL., Christine, D., Bray, T., Castellon, S., Masterman, D., MacMillan, A., Ketchel, P., & DeKosky, ST. (1998). Assessing the impact of neuropsychiatric symptoms in Alzheimer's disease: the Neuropsychiatric Inventory Caregiver Distress Scale. <i>J Am Geriatr Soc</i> , 46, 210-215
Availability online	http://npitest.net/

Title/acronym	OERS - Observed Emotion Rating Scale
Created by	Lawton, Van Haitsma & Klapper, 1996
Purpose	To rate two positive emotions (pleasure and general alertness) and three negative emotions (anger, anxiety or fear, and sadness). Also known as Apparent Affect Rating Scale.
Administration time	10 minutes
Submitted by	Psychologist
Evaluated by	Psychologist
Submission schedule	1 month
Validated in other languages	No English
References	Lawton, Van Haitsma & Klapper, 1996, Lawton <i>et al.</i> , 1999
Availability online	www.abramsoncenter.org/media/1199/observed-emotion-rating-scale.pdf

Title/acronym	PACS - Positive Aspects of Caring Scale
Created by	Pallant & Reid, 2014
Purpose	To assess carers' positive beliefs and attitudes regarding the value of the caring role, to supplement the negative aspects of burden measured by the ZBI. It consisted of six items, using a 4-point response scale (1 =strongly disagree to 4 =strongly agree), with a scale range of 6 to 24.
Administration time	5 minutes
Submitted by	Self-administered
Evaluated by	Psychologist, GP
Submission schedule	1 month
Validated in other languages	English
References	Pallant & Reid, 2014
Availability online	No



Title/acronym	PHQ-9 - Patient Health Questionnaire
Created by	Jason Raad; updated by Jon Walmsley and Mike Weiler; updated with references for the TBI population by Erin Donnelly; updated with references for Parkinson's Disease, dementia and stroke by Rachel Mason.
Purpose	To assesses the presence and intensity of depressive symptoms. It is designed to diagnose both the presence of depressive symptoms as well as to characterise the severity of depression.
Administration time	5 minutes
Submitted by	Self-administered
Evaluated by	Clinician
Submission schedule	1 month
Validated in other languages	English, French, Italian, Spanish
References	Kroenke K, Spitzer RL, Williams JB; The PHQ-9: validity of a brief depression severity measure. Gen Intern Med. 2001 Sep;16(9):606-13. Cameron IM, Crawford JR, Lawton K, et al; Psychometric comparison of PHQ-9 and HADS for measuring depression severity in primary care. Br J Gen Pract. 2008 Jan;58(546):32-6. doi: 10.3399/bjgp08X263794. Haddad M, Walters P, Phillips R, et al; Detecting depression in patients with coronary heart disease: a diagnostic evaluation of the PHQ-9 and HADS-D in primary care, findings from the UPBEAT-UK study. PLoS One. 2013 Oct 10;8(10):e78493. doi: 10.1371/journal.pone.0078493. de Man-van Ginkel JM, Gooskens F, Schepers VP, et al; Screening for poststroke depression using the patient health questionnaire. Nurs Res. 2012 Sep-Oct;61(5):333-41. Maurer DM; Screening for depression. Am Fam Physician. 2012 Jan 15;85(2):139-44. Pinto-Meza A, Serrano-Blanco A, Penarrubia MT, et al; Assessing depression in primary care with the PHQ-9: can it be carried out over the telephone? J Gen Intern Med. 2005 Aug;20(8):738-42.
Availability online	English: www.cqaimh.org/pdf/tool_phq9.pdf French: www.phqscreeners.com/sites/g/files/g10016261/f/201412/PHQ9_French%20for%20France.pdf Spanish: http://lphi.org/CMSuploads/phq_9_spanish-66322.pdf Italian: www.multiculturalmentalhealth.ca/wp-content/uploads/2013/11/PHQ-9-Italian.pdf

Title/acronym	PMS - Pearlin Mastery Scale
Created by	Pearlin & Schooler, 1978
Purpose	To measure self-concept and references of the extent to which individuals perceive themselves in control of forces that significantly impact upon their lives.
Administration time	5 minutes
Submitted by	Self-administered
Evaluated by	Psychologist or GP
Submission schedule	1 month



Validated in other languages	No
References	Pearlin LI and Schooler C (1978) The structure of coping. <i>Journal of Health and Social Behaviour</i> 19: 2-21.
Availability online	No

Title/acronym	PSS - Perceived Support Scale
Created by	Krause & Markides, 1990
Purpose	To measure the social support provided and received by older caregivers. The test includes Tangible Support, such as help with transportation (3 items); Emotional Support, such as having others listen and show interest (4 items); Informational Support, such as sharing suggestions and information (4 items); Satisfaction with Support (3 items), and Negative Social Interaction, such as criticisms and demands by others (3 items).
Administration time	10 minutes
Submitted by	Social worker
Evaluated by	Social worker
Submission schedule	3 months
Validated in other languages	English
References	Krause, N. (1995). Negative interaction and satisfaction with social support among older adults. <i>Journal of Gerontology: Psychological Sciences</i> , 50B, 59-73. Krause, N., & Borawski-Clark, E. (1995). Social class differences in social support among older adults. <i>The Gerontologist</i> , 35, 498-508. Pinquart, M., & Sorensen, S. (2010). Correlates of physical health of informal caregivers: A meta-analysis. <i>Journal of Gerontology: Psychological Sciences</i> , 62, 126-137. Roth, D. L, Mittelman, M. S., Clay, O. J., Madan, A., & Haley, W. E. (2005). Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. <i>Psychology and Aging</i> , 20, 634-644.
Availability online	No

Title/acronym	STAI - State Trait Anxiety Inventory
Created by	Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983
Purpose	To measure trait and state anxiety. It can be used in clinical settings to diagnose anxiety and to distinguish it from depressive syndromes. It also is often used in research as an indicator of caregiver distress.
Administration time	2 to 6 minutes
Submitted by	Self-administrated
Evaluated by	Psychologists, GPs
Submission schedule	2 weeks
Validated in other languages	English, French, Italian, Spanish and many others languages
References	Elliott, T, Shewchuk, R, & Richards, J.S. (2001); Spielberger, C. D.



	(1989); Spielberger, C. D., Gorsuch, R. L., Lushene, R., Vagg, P. R., & Jacobs, G. A. (1983).
Availability online	www.scalesandmeasures.net/files/files/HADS.pdf

Title/acronym	UCLA - Loneliness scale
Created by	Russell, D., Peplau, L. A. & Ferguson, M. L. (1980)
Purpose	To assess subjective feelings of loneliness or social isolation, through 20-items scale.
Administration time	10 minutes
Submitted by	Self-administrated
Evaluated by	Psychologist
Submission schedule	1 month
Validated in other languages	English, French (Canada)
References	Russell, D , Peplau, L. A.. & Ferguson, M. L. (1978). Developing a measure of loneliness. Journal of Personality Assessment, 42, 290-294.
Availability online	www.fetzer.org/sites/default/files/images/stories/pdf/selfmeasures/Self_Measures_for_Loneliness_and_Interpersonal_Problems_UCLA_LONELINESS.pdf

4.2.3 Functional scales

Title/acronym	SF12 - Short Form Health Survey
Created by	Ware & Sherbourne, 1992
Purpose	To generically assess health-related quality of life (HRQOL) from the client/PLWD perspective. It addresses the same 8 domains as identified in the SF-36v2: physical functioning, role – physical, bodily pain, general health perceptions, vitality, social functioning, role – emotional, mental health. SF-12 is a shortened form (12 items) of the SF-36 Health Survey.
Administration time	5 minutes
Submitted by	Self-administered
Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish and many others
References	Ware JE, Snow KS, Kosinski M, Gandek B.: SF-36 Health Survey Manual and Interpretation Guide, Boston, The Health Institute, New England Medical Center, 1993 Ware J, Jr, Kosinski M, Keller SD.: A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med Care 34: 220–233, 1996
Availability online	www.sf-36.org/demos/SF-12.html



4.2.4 Quality of life scales

Title/acronym	ACQLI - Alzheimer's Carer's Quality of Life Instrument
Created by	Doward 2001
Purpose	The ACQLI is a 30-item scale to assess the quality of life of people who care for people living with Alzheimer's disease. It was developed in 1997 by Galen Research and has been used in studies investigating the effects of pharmacological treatment
Administration time	10 minutes
Submitted by	Auto-questionnaire
Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English, French, Spanish, Italian.
References	Doward <i>et al.</i> The development of the Alzheimer's Carers Quality of Life Instrument (ACQLI). <i>Proc Br Psychol Soc.</i> 2001; 9:65
Availability online	no

Title/acronym	Caregiver's QoL (Caregiver's Quality of Life)
Created by	Thomas, 2006
Purpose	Caregiver's QoL is a 20-item scale. The quality of life of caregivers is correlated to the quality of life of care recipients, the importance of behavioural changes and duration of dementia journey.
Administration time	10-15 minutes
Submitted by	Self-administered
Evaluated by	Psychologists, GPs
Submission schedule	6 months
Validated in other languages	English, French,
References	Thomas Ph et al. dementia patients caregiver quality of life: the PIXEL study. <i>Int J Geriatr Psychiatry</i> 2006;21-50-56
Availability online	no

Title/acronym	EQ5D - European Quality of Life
Created by	EuroQol Research Foundation, 1990
Purpose	To measure a wide range of health conditions and treatments, providing a simple descriptive profile and a single index value for health status. It comprises the following 5 dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. It is a standardised, generic health-related quality of life scale for both describing and valuing health status.
Administration time	5 minutes
Submitted by	Self-administered
Evaluated by	GPs, Health specialists, Researchers, Psychologist
Submission schedule	6 or 12 months
Validated in other languages	English, French, Italian, Spanish and others (170 languages)



References	Balestroni, G., & Bertolotti, G. (2012). EuroQol-5D (EQ-5D): an instrument for measuring quality of life. <i>Monaldi Arch Chest Dis</i> , 78(3), 155-159
Availability online	English: www.euroqol.org/eq-5d-products/how-to-obtain-eq-5d.html

Title/acronym	PQoL - Perceived Quality of Life
Created by	Danis M, Patrick DL, 1981
Purpose	To measure quality of life based on the evaluation of major categories of fundamental life needs; scale items are developed using human needs theory.
Administration time	10 minutes
Submitted by	Self-administered, interviewer-administered
Evaluated by	Self-evaluated
Submission schedule	3 months
Validated in other languages	US English, Norwegian, US Spanish
References	Kajiyama et al. (2013)
Availability online	http://depts.washington.edu/seaqol/docs/PQOL-Sample-page.pdf

Title/acronym	QoL-AD - Quality of life Alzheimer's Disease Scale
Created by	Logsdon, Gibbons, McCurry & Terry, 1999
Purpose	To obtain a rating of the PLWD quality of life from both the PLWD and the caregiver. It is a brief, 13-item measure, developed for individuals with dementia. It is easy to use and includes assessments of the individual's relationships with friends and family, concerns about finances, physical condition, mood, and an overall assessment of life quality.
Administration time	5 minutes in self-administrated; 10 to 15 minutes in interview
Submitted by	Self-administered or GP or Specialist
Evaluated by	GP or Specialist or Psychologist
Submission schedule	2 months
Validated in other languages	English, French, Italian, Spanish and others
References	Logsdon, R.G., Gibbons, L.E., McCurry, S.M., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. <i>Journal of Mental Health & Aging</i> , 5(1), 21-32. Logsdon, R.G., Gibbons, L.E., McCurry, S.M. & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. <i>Psychosomatic Medicine</i> , 64, 510-519
Availability online	www.dementia-assessment.com.au/quality/qol_handout_guidelines_scale.pdf

Title/acronym	SQCRC - Scale for the Quality of the Current Relationship in Caregiving
Created by	Spruytte, Van Audenhove & Lammertyn, 2000
Purpose	To ask carers opinions about the relationship between the caregiver and the person that they are caring for, giving equal weight to positive



	and negative aspects. A higher score implies the presence of warmth and affection and the absence of conflict and criticism in the relationship.
Administration time	<i>No information</i>
Submitted by	Psychologist, GP
Evaluated by	Psychologists, GPs
Submission schedule	3 months
Validated in other languages	<i>No information</i>
References	Spruytte, N., Van Audenhove, C., & Lammertyn, F. (2000). Internal Report: The Scale for the Quality of the Current Relationship. Leuven: LUCAS-KULeuven Spruytte, N., Van Audenhove, C., Lammertyn, F., & Storms, G. (2002). The quality of the caregiving relationship in informal care for older adults with dementia and chronic psychiatric patients. <i>Psychology and psychotherapy</i> , 75(3), 295-311
Availability online	No

4.2.5 Comorbidities and health problems scales

Title/acronym	ADKs/ADKt - Alzheimer's Disease Knowledge scale / test
Created by	Dieckmann, Zarit and Gatz, 1988; Carpenter et al., 2009
Purpose	To examine what people know about AD, such as the effectiveness of public information campaigns, the education needs or the success of education efforts and familiarity with AD.
Administration time	5 to 10 minutes
Submitted by	Self-administrated
Evaluated by	Psychologist or Medicine specialist
Submission schedule	1 month
Validated in other languages	Chinese, Dutch, English, Greek, Iceland, Polish, Portuguese, Spanish
References	Dieckmann, Zarit and Gatz, 1988 ; Carpenter et al., 2009
Availability online	https://pages.wustl.edu/geropsychology/adks

Title/acronym	ADQ_Hope - Approaches to Dementia Quest. (Hope sub scale)
Created by	Lintern and Woods, 1996
Purpose	To measure hopefulness and person-centred approaches; it is a 19-items scale used with care home staff in the UK.
Administration time	
Submitted by	
Evaluated by	Psychologist, Specialist medicine
Submission schedule	1 month
Validated in other languages	English, Chinese
References	Lintern T, Woods B, Phair L. Before and after training: a case study of intervention. <i>Journal of Dementia Care</i> . 2000;8:15–17



Availability online	No
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Title/acronym	CI - Charlson Index
Created by	Charlson <i>et al.</i> , 1987
Purpose	The Charlson Index takes into account the number of comorbidity and weights the seriousness of each disease. It is a predictor of mortality used in longitudinal studies. The scale is validated in geriatric populations.
Administration time	10 minutes
Submitted by	Nurse, GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Charlson ME. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. J Chronic Dis 1987;40(5):373-383.
Availability online	http://touchcalc.com/calculators/ci_js

Title/acronym	CIRS - Cumulative Illness Rating Scale
Created by	Linn, 1968
Purpose	CIRS is used as a tool to measure and rate multi-morbidity. It evaluates 13 medical conditions weighted 0 (no problem) to 4 (extremely severe problem). This scale has been validated in older people and people with cognitive impairment.
Administration time	5 minutes
Submitted by	Nurse, GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Lin. Cumulative illness rating scale. JAGS 1968 may; 16 (5): 622-6
Availability online	www.crhc.pitt.edu/psf/CI/ci.aspx

Title/acronym	CSS - Caregiving Satisfaction Scale
Created by	Strawbridge, W. J. (1991)
Purpose	To measure caregiving satisfaction.
Administration time	10 minutes
Submitted by	Self-administrated
Evaluated by	GP, medical specialist or psychologist
Submission schedule	1 month
Validated in other languages	English, Korean
References	Strawbridge W. <u>The Effects of Social Factors on Adult Children Caring for Older Parents</u> Unpublished doctoral dissertation. University of Washington, Seattle, WA, 1991.
Availability online	No



Title/acronym	GHQ - General Health Questionnaire
Created by	McDowell & Newell, 1996; Goldberg, 1970
Purpose	To indicate psychological well-being and detect possible cases of psychiatric diagnoses (psychiatric morbidity). It is a 28-item self-report questionnaire to assess four aspects of distress: depression, anxiety, social impairment, and hypochondriasis.
Administration time	10 Minutes
Submitted by	Self-evaluated
Evaluated by	Clinician
Submission schedule	1 month
Validated in other languages	English, French, Italian, Spanish
References	McDowell & Newell, 1996 ; Goldberg, 1970
Availability online	No

Title/acronym	ICED - Index of Co-Existent disease
Created by	Greenfield <i>et al.</i> , 1993
Purpose	The ICED aggregates the presence and severity of 19 medical conditions and 11 physical impairments within two scales: the Index of Disease Severity (IDS) and the Index of Physical Impairment (IPI). It has been tested in renal diseases and in older people.
Administration time	10 minutes
Submitted by	Nurse, GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, <i>French, Italian, Spanish</i>
References	Athienites NV, Miskulin DC, et al. Comorbidity assessment in hemodialysis and peritoneal dialysis using the Index of Coexistent Disease. <i>Seminars in Dialysis</i> . 2000; 13: 320-326. Greenfield S, Apolone G, et al. The importance of co-existent disease in the occurrence of postoperative complications and one-year recovery in patients undergoing total hip replacement. <i>Medical Care</i> . 1993; 31: 141-154.
Availability online	No

Title/acronym	KFI - Kaplan Feinstein Index
Created by	Kaplan & Feinstein, 1974
Purpose	The KFI is a 12-item scale that evaluates and weights from 0 (no problem) to 3 (severe failure). It is validated with older people.
Administration time	10 minutes
Submitted by	GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, <i>French, Italian, Spanish</i>



References	Kaplan MH, Feinstein AR. The importance of classifying initial comorbidity in evaluating the outcome of diabetes mellitus. <i>J Chron Dis</i> 1974; 27:387-404.
Availability online	No

Title/acronym	MECS - Motivations in Elder Care Scale
Created by	Lyonette & Yardley, 2003
Purpose	To evaluate extrinsic (EMECS) and intrinsic (IMECS) motivations, including extrinsic pressures to provide care, such as perceived disapproval of others, and intrinsic desires for care role adoption, such as a sense of responsibility.
Administration time	10 minutes
Submitted by	Self-administrated
Evaluated by	GP, medical specialist or psychologist
Submission schedule	1 month
Validated in other languages	English
References	Lyonette, C. & Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. <i>Ageing & Society</i> , 23, 487-506.
Availability online	No

Title/acronym	MNA_{sf} - Mini Nutritional Assessment short form
Created by	Rubenstein
Purpose	To detect malnutrition. It is validated with older people.
Administration time	5 to 10 minutes
Submitted by	Older person/ Caregiver
Evaluated by	Nurse /GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, Italian, Spanish
References	Rubenstein et al. Screening for undernutrition in geriatric practice developing the short form mini nutritional assessment (MNA-sf). <i>J Gertontol A Biol SCI Med SCI</i> 2001; 56: M366-372 Kaiser et al. Validation of the Mini Nutritional assessment short form: a practical tool for identification of nutritional status. <i>J Nutr Health Aging</i> 2009 Nov 13 (9): 782-8
Availability online	www.mna-elderly.com

Title/acronym	MSPSS - Multidimensional Scale of Perceived Social Support
Created by	Zimet, Dahlem, Zimet & Farley, 1988
Purposes	To assess an individual's perception of the social support he or she receives from family, friends and significant others; it is a 12-items self-report questionnaire.
Administration time	5 minutes
Submitted by	Self-evaluated
Evaluated by	Psychologist



Submission schedule	1 month
Validated in other languages (y/n, list of languages)	English, French, Italian, Spanish and others
References	Marziali et al. (2006), Marziali et al. (2011) ; T. Anderson, L. Merkerson-Miller, D. Paniagua and M. Ivins-Lukse (2015) Canty-Mitchell, J. & Zimet, G.D. (2000). Psychometric properties of the Multidimensional Scale of Perceived Social Support in urban adolescents. American Journal of Community Psychology, 28, 391-400. Zimet, G.D., Powell, S.S., Farley, G.K., Werkman, S. & Berkoff, K.A. (1990). Psychometric characteristics of the Multidimensional Scale of Perceived Social Support Journal of Personality Assessment, 55, 610-17
Availability online	www.yorku.ca/rokada/psycstest/socsupp.pdf

Title/acronym	SCB - Screen for Caregiver Burden
Created by	Vitaliano <i>et al.</i> , 1991
Purpose	To quickly identify distressing caregiver experiences; it is a 25-item questionnaire, created specifically for spouse caregivers of people with Alzheimer's disease, providing scores for objective and subjective burden. It evaluates six domains: PLWD cognition concerns, behavioural issues, and the caregiver's social, emotional, financial and physical status.
Administration time	10 minutes
Submitted by	Self-evaluated
Evaluated by	Psychologist, GP or Specialist
Submission schedule	1 month
Validated in other languages	English, Spanish
References	Vitaliano <i>et al.</i> , 1991; Hirschman <i>et al.</i> , 2004; Guerra-Silla <i>et al.</i> , 2011
Availability online	No

Title/acronym	TIBI - Total illness burden index
Created by	Greenfield <i>et al.</i> , 1995
Purpose	The TIBI is a 63-item comprehensive summary measure of severity of illness. It aggregates conditions, people and diseases that are weighted by severity.
Administration time	<i>No information</i>
Submitted by	Nurse, GPs or specialist
Evaluated by	GPs or specialist
Submission schedule	6 months
Validated in other languages	English, French, <i>Italian, Spanish</i>
References	Greenfield S: Development and testing of a new measure of case mix for use in office practice. Med Care 33(suppl): AS47-AS55, 1995.
Availability online	No

5. The Dyad as the care unit

5.1 Evidence for the necessity to assess dyadic relationship and treatment adherence

Successful dementia assessment and management requires that the target of care to be broadened to include both partners in the dyad composed by the patient and the caregiver (Sadovoy et al. 2012). A framework developed by Callahan and colleagues (Callahan et al. 2014), entitled “*Common Components of Best Practice Models for Dementia Care*”, highlights 15 recommended evidence-based dementia care components drawn from the literature, underscoring support of the care recipient caregiver dyad as the core principle guiding effective dementia care (Odenheimer et al., 2013). As listed below, 5 of these recommendations concern dyadic relationship and treatment.

Table 10. Recommended component of best practices

Best Practices in Dementia Care		Care recipient	Caregiver	Doctor
1	Make a formal diagnosis using a standardized instrument and with input from a family member	X	X	X
2	Evaluate the PLWD for treatable causes of cognitive impairment or excess disability			X
3	Consider referral to a specialty memory care practice			X
4	Educate the PLWD and family about the diagnosis and care options	X	X	X
5	Accept the caregiver-care recipient dyad as the target of care (unit of care)			X
6	Refer the PLWD to relevant community support services	X	X	X
7	Regularly assess the PLWD for problem behaviours and train the caregiver in identifying and managing these behaviours		X	X
8	Discuss goals of care	X	X	X
9	Discuss driving and home safety		X	X
10	Consider cognition-enhancing drugs	X	X	X
11	Regularly reassess the psychoactive side effects of prescription and non-prescription medications, alcohol, and other substance abuse			X
12	Facilitate regular cognitive, physical and social activity	X	X	
13	Detect and treat vascular risk factors			X
14	Manage the PLWD comorbid conditions in the context of dementia	X	X	X
15	Track the PLWD outcomes and adjust goals of care as appropriate	X	X	X



5.2 Dyadic relationship assessment and interventions

The importance of relationship quality and PLWD - caregiver congruence remains current in the dementia scientific literature. In a population-based study of NC disorder progression, a closer caregiving relationship was associated with slower progression of cognitive and functional symptoms, particularly for persons with spouse caregivers. Interventions designed to enhance the caregiving dyadic relationship may help slow the decline in NC disorders (Maria C. Norton, 2009). The quality of relationship seems to be an important factor in quality of care that can affect the well-being of the PLWD (Walsh and Shutes, 2013); some studies have also supported the benefits of dyadic interventions for caregivers' wellbeing.

It seems also that there is little disagreement over the care recipient's needs, but there is a significant amount of variation in how much the PLWD and caregiver agree on their appraisals of caregiving difficulties. Relationship strain perceived by the caregiver, but not by the PLWD, was significantly associated with this disagreement (Karen S. Lyons, 2002).

Under a broader diagnostic approach, the live-in family caregiver-care recipient dyad is therefore to be considered. Basic clinical and diagnostic assessment protocols of the person with dementia have been well established. While essential, the effective clinical management would require a broader diagnostic approach that incorporates the system of care and, most especially, the live-in family caregiver-care recipient dyad unit of care. This means using an expanded model of clinical dementia assessment and diagnosis.

5.3 Dyads' characteristics

5.3.1 PLWD and caregivers' characteristics

Basic demographic characteristics about both the caregiver and the PLWD (*e.g.*, age, gender, ethnicity, relationship to each other, living arrangement of PLWD, employment status of caregiver) are key elements to understand the caregiving context and to describe the characteristics of the population served. This can include levels of PLWD demands and needs that exceed caregiver's capacity, areas of other responsibilities (*e.g.*, family members in charge) or personal health that may be barriers to care.

In France (Thomas et al. 2005), the dyad *PLWD - caregiver* has been well described in the PIXEL study and in INPES study (Institut National de Prévention et d'Education pour la Santé, <http://alzheimer.inpes.fr/pdf/fr/rapport-aidant.pdf>).

According to the INPES Study (sample of 305 carers), caregivers:

- 55% are >65 years,
- 31% are 55-65 years,
- 11% between 45-55 years
- 3% < 44 years.
- 66% are women
- 76% help everyday

As concerning the duration of the caregiving:



- 44% from 3 to 8 years;
- 15% from 8 to 11 years.
- 33% less than 3 years
- 30% are no professional caregivers

In PIXEL study, 2 groups of caregivers are described:

- o The first group is composed of caregivers aged from 50 to 60 years. They have professional activity in 50% of cases. 75% of the caregivers are the daughters. They had to reorganize their working time in ¼ of cases. Only 12% of caregivers are working full-time.
- o The second group is the spouse and mostly the wife (2/3). They are older than in the first group.

If the caregiver is a child, s/he often lives with the person with dementia(25%) or s/he lives near his/her parents (<30 minutes). Ten per cent of them moved from their home in order to provide care. 70% of spouses and 50% of children work more than 6 hours a day in providing care (Lamura et al. 2008).

In Italy, the care of PLWD is mainly based on the family efforts; the caregiver in Italy is a cohabitant person in 65% of cases. 74% of caregivers are women, usually the wives (25%) or a female family assistant. 50% of sons/daughters deal with caregiving and they are 46-60 years old in average. Caregivers in Italy:

- 65% are co-habitant
- 74% are woman
- 35% of caregivers has a similar age to the PLWD
- 32% are a pensioner
- 30% are employed
- In most of the cases, female caregivers leave their job earlier, with the consequence of increased indirect costs for the families to be added to the direct costs of care (CENSIS, 2009). Dyads composed by coeval persons are the most problematic because risks connected to comorbidities are doubled.

The local memory clinic data of University of Hull reveal that caregivers of PLWD:

- 46% are son / daughter
- 42% are partner / spouse
- 3.6% are friend
- 3.6% are brother/sister
- 2.9% are niece/nephew
- 1.5% are sister in-law
- 0.7% are son-in-law

In Spain, the care of people is mainly provided within the family (http://gredos.usal.es/jspui/bitstream/10366/22615/1/DSC_UnderstandingCare.pdf).

Concerning caregivers in Spain:

- 78% are women (spouse or daughter)

- 59% are 40-59 years old
- 46% are daughters
- 10% are sons
- 21% are spouse.

5.3.2 Dyads scenarios

The changes that occur as dementia progresses may influence both individual factors and factors shared between the caregiver and PLWD, such as their relationship, reciprocal interaction, and level of interdependence. The balance and the care burden varies according to the progress and severity of dementia.

Thus, for C-MMD purposes, 3 scenarios are considered, based on PLWD cognitive decline: MCI, mild dementia and moderate dementia.

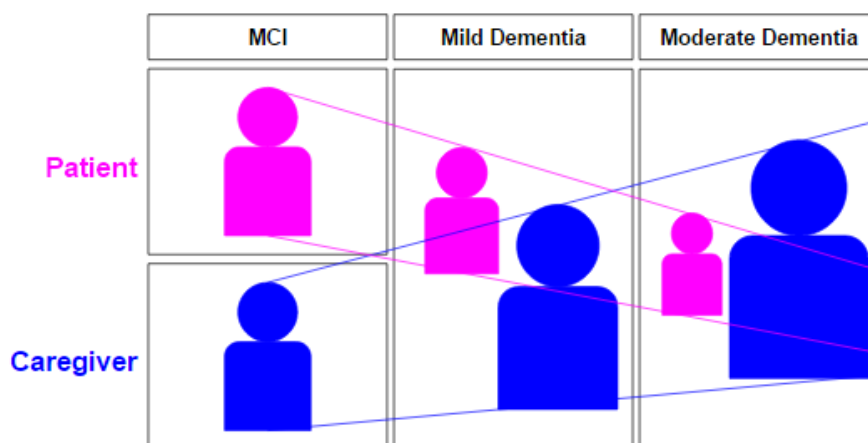


Fig. 1 Evolution of the dyad

Understanding the relationship between the caregiver and PLWD will help to generate tailored interventions within C-MMD platform supporting the development of coping strategies.

These interventions should encourage, for example, PLWD and caregiver to think about how they can better work together to solve problems.

Scenario 1: mild cognitive impairment - MCI

In this scenario, the dyad may be not clearly identified: the caregiver is a potential ‘team player’. Cognitive rehabilitation intervention for people with MCI and their family members seems to have a positive impact. The analysis of the dyadic relationship and the proposal of tailored interventions will help individuals with MCI and their caregivers to learn ways to continue engaging in meaningful activities, to address the priority needs for efficacious interventions to prevent premature disengagement and depressive symptoms. (Lu *et al.*, 2007). These interventions may be key factors in preventing MCI from going forward, as illness perceptions are likely key factors on which individuals will plan for the future or base medical decisions (Yueh-Feng Lu *et al.* 2014).

Scenario 2: Mild Dementia



A review of 12 studies reporting on interventions for caregiver and PLWD with early-stage dementia showed that dyadic interventions have the potential to benefit caregivers (*e.g.* by decreasing depression and anxiety, increasing knowledge and coping skills, and improving the relationship with PLWD) and also the potential to benefit PLWD with early-stage dementia (*e.g.* by improving the relationship with caregiver and cognitive function, increasing knowledge and coping skills - Heehyul et al., 2012). The team (dyad) is in place and roles are clearly identified. As a team, PLWD and caregiver are working together. C-MMD will assess strength and weakness of the team and provide tailored intervention based on assessment to improve team performance.

Scenario 3: Moderate Dementia

Although the team is in place, the PLWD role is less evident and the caregiver may support the PLWD. Tips on how to effectively communicate with someone who has moderate dementia should be developed.



5.4 Relationship assessments tools

Title/acronym	CRRS - Care Recipient Relationship Strain
Created by	Berscheid E, 1989
Purpose	To observe the care recipient's perception of the caregiving relationship he or she has with his or her primary caregiver. (Caregiving as a Dyadic Process: Perspectives From Caregiver and Receiver - Karen S. Lyons 2002)
Administration time	3 minutes
Submitted by	Self-administrated
Evaluated by	Psychologist
Submission schedule	unknown
Validated in other languages	unknown
References	Berscheid, Ellen; Snyder, Mark; Omoto, Allen M. The Relationship Closeness Inventory: Assessing the closeness of interpersonal relationships. Journal of Personality and Social Psychology, Vol 57(5), Nov 1989, 792-807. http://dx.doi.org/10.1037/0022-3514.57.5.792 Archbold PG, Stewart BJ, Greenlick MR, Harvath TA. Mutuality and preparedness as predictors of caregiver role strain. Research in Nursing & Health. 1990;13:375–384 Lyons KS, Zarit SH, Sayer AG, Whitlatch CJ. Caregiving as a Dyadic Process: Perspectives From Caregiver and Receiver. Journal of Gerontology: PSYCHOLOGICAL SCIENCES 2002, Vol. 57B, No. 3, P195–P204

Title/acronym	DAS - Dyadic Adjustment Scale
Created by	Spanier GB, 1976
Purpose	To measure marital adjustment; unmarried or same-sex partners can also use it. Subjects rate the extent to which they and their partner agree or disagree on a range of issues and the frequency they engage in specific interactions, such as quarrelling.
Administration time	5 to 10 minutes
Submitted by	Self-administrated
Evaluated by	Psychologist
Submission schedule	unknown
Validated in other languages	Spanish (Moral J, 2009), Italian (Garbarini C, 2014), French (Antoine P, 2008)
References	Spanier GB. Measuring Dyadic Adjustment: New Scales for Assessing the Quality of Marriage and Similar Dyads. Journal of Marriage and Family. 1976;38(1):15-28.
Availability online	http://www.rebeccajorgensen.com/wp-content/uploads/2012/09/DAS+1.pdf

Title/acronym	DAS-4 - brief version of the dyadic adjustment scale with a nonparametric item analysis model
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Created by	Sabourin S, 2005
Purpose	Abbreviated form of the Dyadic Adjustment Scale (DAS) with nonparametric item response theory. Compared with the 32-item version of the DAS (DAS-32), it is as effective in predicting couple dissolution and significantly reduces the socially desirable responding contamination.. In addition, structural equation modelling demonstrated that the underlying latent construct measured by the DAS-4 was very stable over a 2-year period. This brief version has the advantage of being less time consuming and constitutes a promising alternative to the original DAS-32 for clinicians and researchers.
Administration time	3 to 5 minutes
Submitted by	Self-administrated
Evaluated by	Psychologist
Submission schedule	unknown
Validated in other languages	unknown
References	Sabourin S, Valois P, Lussier Y. Development and validation of a brief version of the dyadic adjustment scale with a nonparametric item analysis model. Psychol Assess. 2005 Mar;17(1):15-27.
Availability online	https://researchingparents.wordpress.com/2013/02/21/dyadic-adjustment-scale-das-das-4/

Title/acronym	DR - Dyadic Relationship Scale
Created by	Sebern MD & Whitlatch, 2007
Purpose	To measure relationship strain between the care recipient and caregiver during the past month, with items such as: <i>"Because of helping my relative I felt angry toward her/him."</i> A 10 item care recipient version is also available (using yes/no or 4-point scale responses)
Administration time	20 minutes
Submitted by	Self-administrated: care recipient and caregiver (2 versions)
Evaluated by	Psychologist
Submission schedule	unknown
Validated in other languages	Turkish (Haskan Avci, Ö. 2014), French, English
References	Poulshock, S. W., & Deimling, G. T. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology, 39, 230-239. Sebern MD, Whitlatch CJ. Dyadic relationship scale: a measure of the impact of the provision and receipt of family care. Gerontologist. December 2007; 47(6):741-51. Haskan Avci, Ö. (2014). Development of dyadic relationship scale. Eurasian Journal of Educational Research. 56, 1-24
Availability online	Yes



Title/acronym	DRS - Dyadic Relationship Strain
Created by	Bass MD, 1994
Purpose	To measure the quality of the caregiver and care recipient relationship with 3 positive items and 6 negative items. Caregivers are asked whether they feel appreciated for caregiving and get pleasure out of helping, as well as whether they feel angry or resentful.
Administration time	5 minutes
Submitted by	Self-administrated
Evaluated by	Psychologist
Submission schedule	unknown
Validated in other languages	unknown
References	<p>Bass D. M., Tausig M. B., Noelker L. S. (1989). Elder impairment, social support and caregiver strain: A framework for understanding support's effects. <i>Journal of Applied Social Sciences</i>. 13, 80–117</p> <p>Bass DM, McClendon MJ, Deimling GT, Mukherjee S., The influence of a diagnosed mental impairment on family caregiver strain. <i>J Gerontol</i>. May 1994; 49(3):S146-55.</p> <p>Bass DM, Noelker LS, McCarthy CA., The Influence of Formal and Informal Helpers on Primary Caregivers' Perceptions of Quality of Care. <i>Journal of Applied Gerontology</i>. 6 /1/1999;18(2):177-99.</p> <p>Feinberg L, Whitlatch C, Tucke S. Making Hard Choices: Respecting Both Voices: Final Report. San Francisco: Family Caregiver Alliance; 2000.</p>
Availability online	No

Title/acronym	PAI - Positive Affect Index
Created by	Bengtson & Schrader, 1982
Purpose	10-item questionnaire that asks how well they and their family members understand, like and trust one another. Responses are given on a 6-point scale. Affect is only conceptualised in a positive sense. There are no questions regarding conflicts, arguments or disagreements.
Administration time	3 minutes
Submitted by	Self-administrated
Evaluated by	Self-report - Psychologist
Submission schedule	Unknown
Validated in other languages	Unknown
References	<p>Bence SL, Thomas JL (1988, November). Grandparent-parent relationship as predictors of grandparent-grandchild relationships. Paper presented at the annual meeting of the Gerontological Society of America, San Francisco</p> <p>Sabourin S, Valois P, Lussier Y. Development and validation of a brief version of the dyadic adjustment scale with a nonparametric item analysis model. <i>Psychol Assess</i>. 2005 Mar;17(1):15-27.</p>



	<p>Bengtson VL, Allen KR. The life course perspective applied to families over time. In: Boss P, Doherty W, LaRossa R, Schumm W, Steinmetz S, editors. Sourcebook of family theories and methods: A contextual approach. New York: Plenum Press; 1993. pp. 469–498</p> <p>Bengtson VL, Schrader SS. Parent-child relationship. In: Mangon DJ, Peterson WA, editors. Research instruments in social gerontology. Vol. 2. Minneapolis: University of Minnesota Press; 1982. pp. 115–185.</p>
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Title/acronym	SCI-R - Shared Care Instrument-Revised
Created by	Sebern MD, 2008
Purpose	To measure the construct of shared care, which is a system of three constructs (communication, decision making, reciprocity) used in family care to exchange support. Measures the caregiver's and care recipient's perceptions of the care recipients' decision-making capacity, with items such as, " <i>when my family member is not feeling well, s/he decides when to call the doctor.</i> "
Administration time	10 to 15 minutes
Submitted by	Self-administrated: care recipient and caregiver (2 versions)
Evaluated by	Psychologist
Submission schedule	unknown
Validated in other languages	English, Spanish
References	<p>Sebern MD. Psychometric evaluation of the Shared Care Instrument in a sample of home health care family dyads. J Nurs Meas. 2005; 13(3):175-91.</p> <p>Sebern MD. Refinement of the Shared Care Instrument-Revised: a measure of a family care interaction. J Nurs Meas. 2008; 16(1):43-60.</p>
Availability online	No

Title/acronym	URCS - Unidimensional Relationship Closeness Scale
Created by	Noelker (1996) and Whitlach et al. (2001).
Purpose	The relationship Closeness Inventory is six-item short survey to evaluate the frequency, diversity and strength of a relationship to another person.
Administration time	3 minutes
Submitted by	Self-administrated
Evaluated by	Self-report - Psychologist
Submission schedule	unknown
Validated in other languages	unknown
References	<p>Noelker LS. Promoting positive relationships between nursing assistants and the families of cognitively impaired nursing home residents. Final report to the Cleveland Foundation. Cleveland, OH: A Benjamin Rose Institute; 1996.</p> <p>Whitlatch CJ, Schur D, Noelker LS, Ejaz FK, Looman WJ. The stress process of family caregiving in institutional settings. The</p>



	<p>Gerontologist. 2001;41:462–473</p> <p>Norton, M.C. , Piercy, K.W. , Rabins, P.V. , Green, R.C. , Breitner, J.C.S. , Østbye, T., Corcoran, C., Welsh-Bohmer, K.A. , Lyketsos, C.G. , & Tschanz, J.T. (2009). Caregiver – recipient closeness and symptom progression in alzheimer disease. The cache county dementia progression study. <i>Journal of Gerontology: Psychological Sciences</i>, 64B(5), 560–568, doi:10.1093/geronb/gbp052. Advance Access publication on June 29, 2009.</p> <p>Dibble, J.L., Levine, T.R., & Park, H.S. (2012). The Unidimensional Relationship Closeness Scale (URCS): Reliability and validity evidence for a new measure of relationship closeness. <i>Psychological Assessment</i>, 24(3), 565-672</p>
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Table 11. Other scales of potential interest

Team Climate Questionnaire - TCQ	Carron, 1986; Grand & Carron, 1982- include psychometric properties.
Sport Cohesiveness Questionnaire - SCQ	Martens, Landers, & Loy, 1971
Sport-modified Bass Orientation Inventory - BOI	Bass, 1962; SBOI: Ball & Carron, 1976
Group Environment Questionnaire - GEQ	Assess the perceived cohesion of sport teams Carron et al. (1985).
GRPI Framework - GRPI	Assessing team performance – strengths and weakness
Empowering leadership Behaviour Assessment - ELQ	The empowering leadership questionnaire
Leader Behaviour Description Questionnaire - LBDQ	It can be used to describe the behaviour of the leader, or leaders, in any type of group or organization, provided the followers have had an opportunity to observe the leader in action as a leader of their group.
Leadership Skills Inventory - LSI	Karnes & Chauvin, 1985
Leader member exchange - LMX7	The LMX 7 scale assesses the degree to which leaders and followers have mutual respect for each other's capabilities, feel a deepening sense of mutual trust, and have a sense of strong obligation to one another.
Multifactor leadership questionnaire - MLQ	Bass & Avolio, 1985
Leadership Practices Inventory - LPI	Posner & Kouzes, 1993





6. Use of scales in ICT environment: a literature review

Most of literature on ICT interventions is conducted on either PLWD or caregivers. Thus, an extensive literature review on dyads would not provide much evidence due to the limited amount of studies. However, the small amount of studies including both PLWD and caregivers is included in this deliverable as part of the systematic review on caregivers.

6.1 People Living with Dementia

Introduction

Over the past decades, life expectancy is increasing in years, resulting not only in an increased number of adults over 65 and 80 years old, but also in an increased number of older adults with age-related impairments in physical or cognitive levels (Armstrong, Nugent, Moore, & Finlay, 2010). In 2009, 35 million people worldwide had dementia, while the number of PLWD reached 850.000 in the United Kingdom (Alzheimer's Society, 2014), 900.000 in France (INSERM, 2015), more than 1 million in Italy (Alzheimer's Association, 2016), and more than 800.000 in Spain (Alzheimer's Association, 2016).

Research on PLWD has focused on cost-effective methods, including information and communication technologies (ICT), such as smart phones, to support PLWD and help them improve their quality of life and retain their independence for longer (Armstrong *et al.*, 2010). Several ICT interventions have been developed to improve dementia symptoms, such as depression and anxiety (see Botella *et al.*, 2009).

Although published reviews discuss the effectiveness of these ICT interventions on common dementia related symptoms, it is still unclear which symptoms these interventions were targeting to improve, and which they actually managed to improve. Therefore, the present review aims to identify and summarise the symptoms explored in research with people living with dementia through ICT interventions.

Methods

An initial search identified reviews on ICT interventions with people living with dementia. No cut-off for year of publication was set. The search strategy was adopted by similar systematic reviews using the following databases: Web of Science, PubMed, ScienceDirect, and the Cochrane Library. The search strategies are summarised in Table 12.

Inclusion criteria for reviews were: i) focus on PLWD, ii) report and discuss outcome measures and outcome on PLWD, and iii) have used ICT interventions.

Exclusion criteria for reviews were: i) reviews on papers where data were collected through ICT tools, and ii) reviews written in other languages than English.



Table 12. Search strategies for people living with dementia

Database	Search terms
Web of Science	TS=(review AND ICT) AND TS=(dement* OR Alzheimer*)
PubMed	(review AND ICT) AND (dement* OR Alzheimer*)
ScienceDirect	(dement* OR Alzheimer*) AND review AND ICT
Cochrane Library	dement*/Alzheimer* ICT review

Web of Science provided 17 results, PubMed 11 reviews, ScienceDirect 609 reviews, and the Cochrane Library 2 reviews. From the total of 639 reviews collected, 634 reviews were excluded according to the criteria above. The majority of the exclusions concerned reviews on older adults without dementia, or on non-ICT interventions. The 5 that met the criteria of this review are summarized in Table 13.



Table 13. Reviews on the symptoms and scales used in ICT research

Author/ year	Interventions	PLWD Symptoms	PLWD scales	PLWD outcome	Authors' conclusions
Garcia-Casal <i>et al.</i> (2016)	Computer-based programs delivered through personal computers, laptops, tablets, mobile phones, or interface screens	Cognitive impairment Depression Anxiety Daily living activities Quality of life	CES-D MMSE ADL BAPM Digit span Cornell scale DRS	Significant improvement in cognitive functioning, depression and anxiety. Non-significant improvement in daily activities	Computer-based interventions are not always effective. Longer follow up periods are required to explore the long-term effectiveness of the interventions
Topo (2009)	Monitoring systems	Challenging behaviour Anxiety Depression Psychotic symptoms Short-term memory Social inclusions	Katz's ADL GDS MMSE RBMT NAI BMD CAPE CAS Barthel scale CMAI SDVB WAIS BEHAVE-AD Cornell scale IADL	Authors could not compare the results of the studies due to the large variety of technologies and outcome measures used	Further research needs to be conducted in community-dwelling PLWD
Cook <i>et al.</i> (2013)	Alarm and sensor devices Telecare GPS and phone tracking	Daily activities Quality of life	IADL MMSE QOL	Technology-based interventions can benefit PLWD if their needs are identified and targeted	ICT interventions targeting specific dementia symptoms provided successful



	devices				outcomes
Lauriks <i>et al.</i> (2007)	Informational websites Phones & videophones Robots Web monitoring systems Electronic memory aids & agendas Music and messages by IC recorders GPS	Memory functioning Daily activities Social participation Anxiety	Unknown	Significant improvement in memory impairment, daily activities, social participation/contact, anxiety	Need for testing ICT interventions in real life situations before implementation
Pillai & Bonner-Jackson (2015)	Portable & wearable sensors Smart homes	Cognitive impairment Daily activities Sleep Medical adherence Spatial navigation	MMSE CSI SWLS CBI	Significant improvement in cognitive domains (memory), but not in medical outcomes	More ICT interventions should be adopted in PLWD care, such as GPS, speech recorders, and electronic pill boxes

CES-D= Centre for Epidemiologic Studies Depression Scale (Radloff, 1977); MMSE= Mini Mental State Examination (Folstein et al., 1975); ADL= Activities of Daily Living (Katz et al., 1963); BAPM= Brief Assessment of Prospective Memory (Man et al., 2011); DRS= Dementia Rating Scale (Schmidt, 2004); GDS= Geriatric Depression Scale (Sheikh & Yesavage, 1986); RMBPC= Revised Memory and Behaviour Problems Checklist (Teri et al., 1992); NAI= Nuremberg Aging Inventory (Oswald & Fleischmann, 1986); BMD= Behaviour and Mood Disturbance scale (Greene et al., 1982); CAPE= Clifton Assessment Procedures for the Elderly (Pattie, 1975); CAS= Cognitive Assessment Scale (Naglieri, 1997); CMAI= Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 1997); SDVB= Survey of Disruptive Vocal Behaviour (Cariaga et al., 1991); WAIS= Wechsler Adult Intelligence Scale (Wechsler, 1955); QoLS= Quality of Life Scale (Flanagan, 1982); CSI= Caregiver Strain Index (Thornton & Travis, 2003); SWLS= Satisfaction with Life Scales (Diener et al., 1985).



6.2 Caregivers

Introduction

There are estimated to be over 670,000 primary, unpaid caregivers of people living with dementia (PLWD) in the United Kingdom alone, saving to the country approximately £11 billion per year (Alzheimer's Society, 2014). In a similar way, informal caregivers in France provide to the country 14 billion Euros annually (Mederic Alzheimer Association, 2015).

Research has started to explore whether caregivers can benefit from low cost effective tools to support their quality of life, including information and communication technology (ICT; see Cristancho-Lacroix *et al.*, 2015). ICT interventions for dementia caregivers include psycho-educational interventions (see Cristancho-Lacroix *et al.*, 2014) and psychosocial interventions (Marziali & Donahue, 2006; Van Mierlo, Meiland, Van de Ven, Van Hout, & Dröes, 2015). Previous systematic reviews have explored the effectiveness of ICT measures for caregivers (Boots, de Vugt, van Knippenberg, Kempen, & Verhey, 2014; McKechnie, Barker, & Stott, 2014; Peacock & Forbes, 2003; Powell, Chiu, & Eysenbach, 2008). Other systematic reviews focused on the effectiveness of internet-based interventions on specific caregivers' outcomes, such as reducing caregivers' burden (Hu, Kung, Rummans, Clark, & Lapid, 2014; Lee, 2015).

Although the systematic reviews above provided an insight on the effectiveness of web-based ICT interventions, there are currently no reviews summarising caregivers' outcome measures explored in the literature. Therefore, the present systematic review aims to investigate i) what outcome variables have been explored in ICT techniques supporting dementia caregivers, ii) which were the inclusion criteria for caregivers in literature, and iii) what are the follow up periods in pre- and post-intervention stages.

Methods

A systematic literature search was conducted using the following databases; Web of Science, PubMed, and ScienceDirect. The systematic search included studies written in English. No cut-off for year of publication was set. The inclusion criteria for papers were:

- ICT interventions should be administered through web,
- caregivers should care for persons with dementia (PLWD) who live in their own homes,
- papers should include outcome measures for caregivers.

Exclusion criteria were:

- non web-administered ICT interventions such as telephone interventions,
- interventions based on emails, videoconferencing, or virtual pets,
- caregivers of PLWD living in nursing or care homes,
- papers for caregivers of mixed populations, including caregivers of people with dementia or strokes,
- papers about PLWD without reporting outcome measures for the caregivers,
- reviews of papers,
- papers stating protocols of interventions,



- meeting abstracts and proceeding papers with results which are also reported in papers,
- papers presenting similar outcome measures for the same web-based ICT interventions.

The search terms are presented in Table 14. Search terms were generated from previous systematic reviews in the area (Hawley-Hague, Boulton, Hall, Pfeiffer, & Todd, 2014; Lauriks *et al.*, 2007).

Table 14. Search strategies for caregivers

Database	Search terms
Web of Science	TS= (dement* OR Alzheimer*) AND TS= (carer* OR caregiver*) AND TS= (ICT OR website OR internet OR software OR wireless OR ehealth)
PubMed	(ICT OR website OR internet OR software OR wireless OR ehealth) AND (dement* OR Alzheimer*) AND (carer* OR caregiver*)
ScienceDirect	(dement* OR Alzheimer*) AND (carer* OR caregiver*) AND (ICT OR website OR internet OR software OR wireless OR ehealth)

Web of Science provided 309 results, PubMed 246 results, and ScienceDirect provided 266 papers. From the total number of 821 papers found, 810 were excluded according to the above exclusion criteria, or as duplicates. The 11 selected papers are summarized in Table 15.



Table 15. Caregivers' criteria, outcome measures & outcomes from web-based interventions

Author/ year	Study population	Criteria for caregivers	Design	Intervention	Caregiver outcome measures	Caregiver outcome
Beauchamp <i>et al.</i> (2005)	Dementia family caregivers, (IG: n= 150, CG: n= 149), mean age= 46.9 years (SD= 12.2 years), age range= 19.2-84.3 years, 73% females, 7% spouses, 67% children, 23% relatives, 3% nonrelatives	Work at least part-time as family caregivers, contact the PLWD at least 4 times a month	Pre-test/post-test, RCT, with 30-day follow up	Caregivers' friend, provides material and videos for caregiving	7. PAC 8. STA-I 9. CES-D 10. CSI Two questions for stress Six questions for self-efficacy RWC (problem-focused strategies and social support)	Significant improvement in caregiver' strain, anxiety, depressive symptoms, stress, self-efficacy and positive attitude toward caregiving. Non-significant improvement in the frequency of employing specific stress-reduction strategies
Blom <i>et al.</i> (2015)	Dementia family caregivers, IG: n= 149, mean age= 61.54 years (SD= 11.93 years) CG: n= 96, mean age= 60.77 years (SD= 13.07 years), overall 69.4% females, 58.4% spouses, 39.6% children (in-law), 60.4% lived with PLWD	Family caregivers, At least mild symptoms of depression, anxiety or burden	Pre-test/post-test, RCT, with 5- to 6-month follow up	MoD (Mastery over Dementia), an online training program receiving feedback on exercises	HADS-A CES-D SPPIC RMBPC SSCQ PMS	Significant improvement in depressive and anxiety symptoms



Cristancho-Lacroix <i>et al.</i> (2015) 10.1.1	Alzheimer's family caregivers, IG: n= 25, mean age= 64.2 years (SD= 10.03 years), 64% females, 64% children CG: n= 24, mean age= 59.0 years (SD= 12.4 years), 67% females, 54% children	French-speaking, spend at least 4 hours per week with their relative, 18 years old or older, score 12 or more on PSS, not professionals	Pre-test/post-test, RCT, with 3-& 6-month follow up	Diapason program, a web-based psychoeducational program	RSCS PSS-14 BDI-II ZBI NHP RMBPC Visual analogue scales	Significant improvement in disease knowledge Non-significant difference in stress, self-efficacy, carer burden, depression, social isolation, emotional reactions, sleep quality, coping with illness, and relationship quality with the PLWD
Hattink <i>et al.</i> (2015) 10.1.2	Informal carers, volunteers in dementia care, professional caregivers (n= 142), 50.7% informal carers, 16.9% volunteers, 32.4% professional caregivers	Current carer or volunteer with direct contact with PLWD	Pre-test/post-test, among Dutch and English users, with 2- to 4-month follow up	STAR training portal for caregivers, communication with care professionals through Facebook and LinkedIn communities	ADKS Alzheimer's disease survey ADQ IRI SSCQ Two questions for carer's quality of life One question for carer burden	Significant decrease in sense of competence Significant improvement on empathy subscales for distress, empathy, and perspective; and on attitudes toward dementia Non-significant difference in burden, quality of life, knowledge of



						disease
Kajiyama <i>et al.</i> (2013)	Dementia family caregivers, IG: n= 75, mean age= 55.22 years (SD= 11.31 years), 83% females, 56% spouses, 33% children, 4% other relative, 7% non relative CG: n= 75, mean age= 57.02 years (SD= 12.53 years), 86% females, 51% spouses, 37% children, 7% other relative, 5% non relative	Caring for people with Alzheimer's disease, vascular dementia, or other types of dementia	Pre-test/post-test, RCT, with 3-month follow up	iCare, a web-based training program with video-taped segments illustrating specific skills	PSS RMBPC CES-D PQoL	Significant improvement in perceived stress Non-significant difference in depressive symptoms, and quality of life
Lai <i>et al.</i> (2013)	Primary dementia caregivers IG: n=3 CG: n=8	Able to read and write Chinese	Pre-test/post-test, RCT, with 7-week follow up	Ginkgo website, provides training workshops	CES-D ZBI WHO-QoL Alzheimer's disease knowledge test GHQ-30	Significant improvement in knowledge Non-significant difference in depression, burden, quality of life and wellbeing
Mckechnie <i>et al.</i> (2014)	Informal (unpaid) dementia	Over 18 years old, fluent in English,	Pre-test/post-test, single group, with	UK Alzheimer's Society's online	GAD-7 PQH-9	Significant improvement in the



	caregivers (n= 61), mean age= 56 years (SD= 11.29 years), age range= 22-86 years, 83.2% females, caring for: 18.5% father, 37.8% mother, 31.9% partner, 2.5% grandparent, 2.5% aunt or uncle, 4.2% sibling, 5.0% mother- or father-in-law, 2.5% other	Involved in significant amount of care of the people with dementia	12-week follow up	forum	SQCRC	quality of relationship with the PLWD Non-significant difference in depression and anxiety
Meiland <i>et al.</i> (2012)	Dementia family caregivers from Amsterdam, Belfast, and Lulea in three 1-year field tests (n= 16, 13, 12 respectively), mean age= 59, 66, 67 years respectively, 7, 4, 5 females, 11, 9, 11 spouses, 4, 3, 1 children, 1, 1, 0 other	Regular contact/ care for people with Alzheimer's disease	Pre-test/post-test, single group, with 3 field tests in 1-year circles	COGKNOW Day Navigator (CDN), a digital prosthetic with memory, social contacts, daily activities and safety aspects	SSCQ The item psychological distress from the CANE One question for carer's quality of life	Non-significant difference in quality of life and in carer burden
O'Connor <i>et al.</i> (2014)	Dementia family caregivers (n=7),	Caring for an immediate family	Pre-test/post-test, single group, with	Second Life platform, a virtual	UCLA PSS	Significant decrease in stress levels



	mean age= 60.86 years (SD= 12.64 years), age range= 54-70 years, 100% females, 71% daughters, 43% spouses, 14% sisters	member with age-related dementia	9-week follow up	real-time chat with avatars	GDS ZBI	Non-significant difference in depressive symptoms, carer burden and loneliness
Torkamani <i>et al.</i> (2014)	Dementia caregivers IG: n=30, mean age= 57.57 years (SD= 12.50 years) CG: n=30, mean age= 63.93 years (SD= 14.74 years)	Full time carers, Living with the PLWD	Pre-test/post-test, RCT, with 3- & 6-month follow ups	ALADDIN platform, provides information and educational material, carers' forum, online questionnaire, send requests for contact with health professionals	ZBI NPI BDI SDS EQ5D QOLS	Significant decrease in carer burden. Significant improvement in quality of life. Non-significant difference in distress associated with NPI scores, and depressive symptoms
Van der Roest <i>et al.</i> (2010)	Dementia informal carers, IG: n= 14, mean age= 60.2 years (SD= 14.3 years), 64.3% females, 14.3% spouses, 64.3% children, 21.4% others CG: n= 14, mean	Caring for a PLWD for at least 4 hours per week	Pre-test/post-test, with control group, with 2-month follow up	DEM-DISC, provides web-based information about dementia, practical support	CMS GHQ-28 CES-D PMS QoL-AD CANE SSCQ Use & knowledge of services list	Significant improvement in competence (also supported by van Mierlo <i>et al.</i> , 2015b) Non-significant difference in the number of needs, self-efficacy, care



	age= 66.9 years (SD= 13.2 years), 92.9% females, 64.3% spouses, 21.4% children, 14.3% others					use, quality of life and services knowledge
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IG= intervention group; CG= control group; PAC= Positive Aspects of Caregiving (see Tarlow et al., 2004); STA-I= State-Trait Anxiety Inventory (Spielberger et al., 1970); CES-D= Center for Epidemiologic Studies Depression Scale (Radloff, 1977); CSI= Caregiver Strain Index (Thornton & Travis, 2003); HADS= Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); RMBPC= Revised Memory and Behaviour Problems Checklist (Teri et al., 1992); SSCQ= Short Sense of Competence Questionnaire (Vernooij-Dassen et al., 1999); PMS= Pearlin Mastery Scale (Pearlin & Schooler, 1978); RSCS= Revised Scale for Caregiving Self-efficacy (Steffen et al., 2002); PSS= Perceived Stress Scale (Cohen et al., 1983); BDI= Beck Depression Inventory (Beck et al., 1996); ZBI= Zarit Burden Interview (Zarit et al., 1980; Bédard et al., 2001); NHP= Nottingham Health Profile (Bucquet et al., 1990); ADKS= Alzheimer's Disease Knowledge Scale (Carpenter et al., 2009); ADQ= Approaches to Dementia Questionnaire (Lintern & Woods, 1996); IRI= Interpersonal Reactivity Index (Davis, 1980); PQoL= Perceived quality of life (Patrick et al., 1988); WHO-QoL-brief version (World Health Organization Quality of Life); GHQ= General Health Questionnaire (Goldberg & Hillier, 1979; Krol et al., 1994; Shek, 1989); GAD-7= Generalized Anxiety Disorder (Löwe et al., 2008); PQH= Patient Health Questionnaire (Kroenke et al., 2001); SQCR= Scale for the Quality of the Current Relationship in Caregiving (Spruytte et al., 2000); UCLA= Loneliness Scale (Russell et al., 1980); GDS= Geriatric Depression Scale (Sheikh & Yesavage, 1986); NPI= Neuropsychiatric Inventory (Cummings et al., 1994); SDS= Zung Depression Self Rating Scale (Zung, 1965); EQ5D= EuroQoL (EuroQoL group, 1990), QoLS= Quality of Life Scale (Flanagan, 1982); CMS= Caregiver Management Style Questionnaire (De Vugt et al., 2004); QoL-AD= Quality of Life Alzheimer's Disease scale (Thorgrimsen et al., 2003); CANE= Camberwell Assessment of Need for the Elderly (Reynolds et al., 2000).



7. Recommendations

The systematic assessment of PLWD and caregivers is crucial to determine the assistance needed as well as the assistance provided; it is even more crucial and valuable when the systematic assessment is implemented within a dyad, to monitor the relationship balance and evolution. C-MMD proposes an innovative approach to PLWD and caregiver dyads, based on previous researches suggesting that dyads would benefit from interventions increasing the active participation of PLWD in the care plan and supporting positive communication patterns enhancing knowledge and understanding. Furthermore the dyad approach appears to be significant in terms of analysis, programming and evaluating the long term care plans, processes and practices developed for PLWD.

In the framework of C-MMD, the collection and categorisation of symptoms and scales presented in this deliverable must be considered as the starting point for the selection assessment of tools, for the generation of tailored interventions and for the clinical follow up both of the dyad and of its individual members. For the C-MMD purposes, the selection of scales will consider those on line assessment tools which are of most potential value for the dyad, besides taking into account the recommendations resulting from the Usability studies (incoming D1.1). The Screening Strategy will also include social information, treatment assessment and dyadic relationship analysis, in order to obtain a consistent dyad profile, on which to build tailored intervention (T1.5) and propose symptoms progression and treatment adherence monitoring techniques, to be used by health and social professionals.

The selection of scales to be adapted within the C-MMD environment, should consider the following domains, related to the burden of care:

- *Context of care*: the social, demographic and cultural characteristics of the dyad, up to the evolved living habits and conditions;
- *Assistive burden*: the network of available services (health system, social care services) and the territorial intervention units to activate for assistance;
- *Developmental burden*: the individual feelings and the personal perception of frustration and loneliness, namely experienced within the dyad;
- *Physical burden*: the chronic fatigue, the damages to physical and somatic health, the physical efforts, in particular in terms of unbalance weight within the dyad;
- *Social burden*: the social distress, the feeling of isolation, the lack of social relationship a part from the dyad, the conflict of roles within and outside the dyad;
- *Emotional burden*: the negative feelings experienced within the dyad relationship, and the emotional consequences of these socially unacceptable feelings.

Besides, the following prioritisation criteria are recommended :

- To prefer screening and assessment tools rather than monitoring of outcomes or evaluation of intervention (with a view to pilot recruitment);
- To prefer scales asking for a short administration time (possibly, not exceeding 15 minutes);



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- To prefer scales with a degree of flexibility and adaptation to the varying levels of severity of PLWD;
 - To prefer tools with a degree of flexibility and adaptation to an ICT environment and to the on-line filling-in (but taking into account the possible digital gap of the dyad);
 - To prefer self-reporting and self-administrable tools, to be completed directly as self-assessment (but taking into account the possible illiteracy of the dyad);
 - To prefer scales not requiring any special or specialist skills for administration or extensive training session (allowing in case some basic skills are required);
 - To prefer validated scale and without copyright restrictions (or with regular permission) and available in different languages;
 - To prefer tools free of charge or eventually with limited cost for commercial use.

The above mentioned criteria are intended to be presented, explored and discussed within Focus Group and thematic workshops, in order to achieve the most effective selection (complementarily with usability requirements provided in Del1.1) for a valuable and multidisciplinary Screening Strategy for the dyad profiling.



8. Appendices

1. Original matrix as working tool
2. Symptoms and Scales for PWLD
3. Symptoms and Scales for Caregivers
4. List of scales
5. Glossary
6. List of references



8.1 Original matrix as working tool



Table A - Guide for the identification of Symptoms and related evaluation tools/scales already available

AREAS	SYMPTOMS	SCALES	METODOLOGIES				Ref.
	List of symptoms to be considered	AVAILABLE/EXISTING measurement scales	Who may submit/perform these scales?	Who can ANALYSE the scale results?	When/how often it has to be submitted?	Does the validated version exist in the different languages?	
CLINICAL Symptoms	<i>Ex. Memory loss</i>						
	...						
SOCIAL Symptoms	<i>Ex. Isolation</i>						
	...						
BEHAVIORAL Symptoms	<i>Ex. Aggressiveness</i>						
	...						
PSYCHOLOGICAL Symptoms	<i>Ex. Depression</i>						
	...						



8.2 Symptoms and Scales for PLWD

Clinical and Cognitive Scales	ACE-III - Addenbrooke's Cognitive Examination-III
	ADAS-cog - Alzheimer's Disease Assessment Scale
	AMQ - Auto-administered Memory Questionnaire
	AMTS - Abbreviated Mental Test Score
	BANSS - Bedford Alzheimer Nursing Severity Scale
	BECS - Batterie d'Evaluation des Connaissances Sémantiques
	BNT - Boston Naming Test-2
	Brixton Spatial Anticipation test (or Brixton test)
	BSEPA - Brief screening Scale Evaluating Praxis Abilities for use in memory clinics
	BTA - Brief Test of Attention
	BVMT-R - Brief Visuospatial Memory Test-Revised
	BVRT – Benton Visual Retention Test
	CDR - Clinical Dementia Rating Scale
	CDS - Cognitive Difficulties Scale
	CDT - Clock Drawing Test
	CPM - Raven's Coloured Progressive Matrices
	CTT - Color Trail Test
	CVLT - California Verbal Learning Test (second edition)
	DO 80 - Denomination Orale 80 items
	DVT – Digit Vigilance Test
	FAB - Frontal Assessment Battery
	FCSRT-W - Free and Cued Selective Reminding Test - Word version
	Forward and Backward Digit Span
	FT5 - The 5-figure test
	FWT - Five-Words test
	HDS - Hierarchic Dementia Scale
	HSCT - Hayling Sentence Completion test
	IQCODE (short) - Informant Questionnaire on Cognitive Decline in the Elderly - Short Form
	M-ACE Mini - Addenbrooke's Cognitive Examination
	MCST - Modify Card Sorting Test
	MDRS - Mattis Dementia Rating Scale
	MMPI-2 – Minnesota Multiphasic Personality Inventory 2
	MMSE - Mini-Mental State Examination
	MoCA - Montreal Cognitive Assessment
	OT-SRT - Open Trial Selective Reminding Test
	PASAT - Paced Auditory Serial Addition Test
	PEGV - Protocole Montréal-Toulouse d'Evaluation des Gnosies Visuelles
	RBANS - Repeatable Battery for the Assessment of Neuropsychological Status
	RBMT - Rivermead Behavioural Memory Test
	RFFT – Ruff Figural Fluency Test
	ROCF - Rey-Osterrieth complex figure ()
	SCWT - Stroop Color and Word Test
	SDMT - Symbol Digit Modalities Test



	SIB - Severe Impairment Battery
	SMMSE - Severe Impairment Mini-Mental State Examination
	SRT - Selective Reminding Test
	The Doors test
	TMT - Trail Making Test
	TT - Token Test
	TYM - Test Your Memory
	VF - Verbal Fluency test: animals and "P" letter
	VST - Stroop Colour-Word Test-Victoria version
	WAIS IV - Wechsler Adult Intelligence Scale, Fourth edition
	WMS IV - Wechsler Memory Scale, Fourth edition
Psychological and Behavioural Scales	AI - Apathy Inventory
	BEHAVE-AD - Behavioural Pathology in Alzheimer's Disease
	CMAI - Cohen-Mansfield Agitation Inventory
	CSDD - Cornell scale for Depression in Dementia
	GDS - Geriatric Depression Scale
	LARS - Lille Apathy Rating Scale
	MADRS - Montgomery-Åsberg Depression Rating Scale
	NPI - NeuroPsychiatric Inventory
Functional Scales	ADCS - Activities of Daily Living Inventory
	ADL-PI - Activities of daily living-prevention instrument
	ADLQ - Activities of daily living Questionnaire
	AGGIR - Autonomie G�rontologie Groupes Iso-Ressources
	BADL - Barthel ADL Index / Barthel Index of Activities of Daily Living
	BADLS - Bristol Activities of Daily Living Scale
	DAD - Disability Assessment for Dementia
	GERRI - Geriatric Evaluation by Relative's rating Instrument
	IADL - Lawton Instrumental Activities of Daily Living Scale
	Katz Index of ADL / Independence in Activities of Daily Living
	RDRS-2 - Rapid Disability Rating Scale
	TMT - Tinetti Mobility Test or Tinetti balance and Gait Scale
Quality of Life Scales	ADRQL - Alzheimer's disease Related Quality of Life
	AQoL - Assessment of Quality of Life
	CBS - Cornell Brown Scale for Quality of Life
	DEMqoL - Dementia Quality of Life
	DEMqoL-proxy - Dementia Quality of Life
	DQoL - Dementia Quality of Life Instrument
	EQ5D - European Quality of Life
	PQoL - Perceived Quality of Life
	PWB-CIP - Psychological Well-Being in Cognitively Impaired Persons
	QoL- AD - Quality of life Alzheimer's Disease Scale
	QOLAS - Quality of Life Assessment Schedule
	QOLS - Quality of Life Scale



	SF12 - Short Form Health Survey
Comorbidity and health problems Scales	CI - Charlson Index
	CIRS - Cumulative Illness Rating Scale
	ICED - Index of coexistent disease
	KFI - Kaplan Feinstein Index
	MNAsf - Mini Nutritional Assessment short form
	TIBI - Total illness burden index



8.3 Symptoms and Scales for Caregivers

Clinical and Cognitive Scales	BSFC - Burden Scale for Family Caregivers
	CDS - Cognitive Difficulties Scale
	CSI - Caregiver Strain Index
	RMBPC - Revised Memory and Behaviour Problems Checklist
	RSS - Relative Stress Scale
	ZBI - Zarit Burden Interview
Psychological and Behavioural Scales	BDI - Beck Depression Inventory
	CBI - Caregiver Burden Inventory
	CBI - Copenhagen Burnout Inventory
	CES-D - Centre for Epidemiologic Studies Depression Scale
	GAD7 - Generalized Anxiety Disorder scale
	GDS - Geriatric Depression Scale
	HADS - Hospital Anxiety and Depression Scale
	NPI-Q - Neuropsychiatric Inventory Questionnaire
	OERS - Observed Emotion Rating Scale
	PACS - Positive aspects of caring scale
	PHQ-9 - Patient Health Questionnaire
	PMS - Pearlin Mastery Scale
	PSS - Perceived Support Scale
	STAI - State Trait anxiety inventory
	UCLA - Loneliness scale
Functional Scales	SF12 - Short Form Health Survey
Quality of Life Scales	ACQLI (Alzheimer's Carer's Quality of Life Instrument)
	Caregiver's QoL (Caregiver's Quality of Life)
	EQ5D - European Quality of Life
	PQoL - Perceived Quality of Life
	QoL-AD - Quality of life Alzheimer's Disease Scale
	SQCRC - Scale for the Quality of the Current Relationship in Caregiving
Comorbidity and health problems Scales	ADKs/ADKt - Alzheimer's Disease Knowledge Scale / Test
	ADQ_Hope - Approaches to Dementia Quest. (hope sub scale)
	CI - Charlson Index
	CIRS - Cumulative Illness Rating Scale ()
	CSS - Caregiving Satisfaction Scale
	GHQ - General Health Questionnaire
	ICED - Index of coexistent disease
	KFI - Kaplan Feinstein Index
	MECS - Motivations in Elder Care Scale
	MNASf - Mini Nutritional Assessment short form
	MSPSS - Multidimensional Scale of Perceived Social Support
	SCB - Screen for Caregiver Burden
	TIBI - Total illness burden index



8.4 List of scales

Acronym	Full name
ACE-III	Addenbrooke's Cognitive Examination-III
ACQLI	Alzheimer's Carer's Quality of Life Instrument
ADAS-cog	Alzheimer's Disease Assessment Scale
ADCS	Activities of Daily Living Inventory
ADKs/ADKt	Alzheimer's Disease Knowledge Scale / Test
ADL-PI	ADL-PI - Activities of daily living-prevention instrument
ADLQ	Activities of daily living Questionnaire
ADQ_Hope	Approaches to Dementia Quest. (hope sub scale)
ADRQL	Alzheimer's disease Related Quality of Life
AGGIR	Autonomie G�rontologie Groupes Iso-Ressources
AI	Apathy Inventory
AMQ	Auto-administered Memory Questionnaire
AMTS	Abbreviated Mental Test Score
AQoL	Assessment of Quality of Life
BADL	Barthel ADL Index / Barthel Index of Activities of Daily Living
BADLS	Bristol Activities of Daily Living Scale
BANSS	Bedford Alzheimer Nursing Severity Scale
BDI	Beck Depression Inventory
BECS	Batterie d'Evaluation des Connaissances S�mantiques
BEHAVE-AD	Behavioural Pathology in Alzheimer's Disease
BNT	Boston Naming Test-2
BRIXTON	Brixton Spatial Anticipation test (or Brixton test)
BSEPA	BSEPA - Brief screening Scale Evaluating Praxis Abilities for use in memory clinics
BSFC	Burden Scale for Family Caregivers
BTA	Brief Test of Attention
BVMT-R	Brief Visuospatial Memory Test-Revised
BVRT	Benton Visual Retention Test
CaQoL	Caregiver's QoL (Caregiver's Quality of Life)
CBI	Caregiver Burden Inventory
CBI	Copenhagen Burnout Inventory
CBS	Cornell Brown Scale for Quality of Life
CDR	Clinical Dementia Rating Scale
CDS	Cognitive Difficulties Scale
CDT	Clock Drawing Test
CES-D	Centre for Epidemiologic Studies Depression Scale
CI	Charlson Index
CIRS	Cumulative Illness Rating Scale ()
CMAI	Cohen-Mansfield Agitation Inventory
CPM	Raven's Coloured Progressive Matrices
CSDD	Cornell scale for Depression in Dementia
CSI	Caregiver Strain Index
CSS	Caregiving Satisfaction Scale
CTT	Color Trail Test
CVLT	California Verbal Learning Test (second edition)



DAD	Disability Assessment for Dementia
DEMqoL	DEMqoL Dementia Quality of Life
DEMqoL-proxy	DEMqoL-proxy Dementia Quality of Life
DO 80	Denomination Orale 80 items
DQoL	Dementia Quality of Life Instrument
DVT	Digit Vigilance Test
EQ5D	European Quality of Life
FAB	Frontal Assessment Battery
FCSRT-W	Free and Cued Selective Reminding Test - Word version
FBDS	Forward and Backward Digit Span
FT5	The 5-figure test
FWT	Five-Words test
GAD7	Generalized Anxiety Disorder scale
GDS	Geriatric Depression Scale
GERRI	Geriatric Evaluation by Relative's rating Instrument
GHQ	General Health Questionnaire
HADS	Hospital Anxiety and Depression Scale
HDS	Hierarchic Dementia Scale
HSCT	Hayling Sentence Completion test
IADL	Lawton Instrumental Activities of Daily Living Scale
ICED	Index of coexistent disease
IQCODE (short)	Informant Questionnaire on Cognitive Decline in the Elderly - Short Form
Katz	Katz Index of ADL / Independence in Activities of Daily Living
KFI	Kaplan Feinstein Index
LARS	Lille Apathy Rating Scale
M-ACE	Mini - Addenbrooke's Cognitive Examination
MADRS	Montgomery-Åsberg Depression Rating Scale
MCST	Modify Card Sorting Test
MDRS	Mattis Dementia Rating Scale
MECS	Motivations in Elder Care Scale
MMPI-2	Minnesota Multiphasic Personality Inventory 2
MMSE	Mini-Mental State Examination
MNA _{sf}	Mini Nutritional Assessment short form
MoCA	Montreal Cognitive Assessment
MSPSS	Multidimensional Scale of Perceived Social Support
NPI	Neuropsychiatric Inventory
NPI-Q	Neuropsychiatric Inventory Questionnaire
OERS	Observed Emotion Rating Scale
OT-SRT	Open Trial Selective Reminding Test
PACS	Positive aspects of caring scale
PASAT	Paced Auditory Serial Addition Test
PEGV	Protocole Montréal-Toulouse d'Evaluation des Gnosies Visuelles
PHQ-9	Patient Health Questionnaire
PMS	Pearlin Mastery Scale



PQoL	Perceived Quality of Life
PSS	Perceived Support Scale
PWB-CIP	Psychological Well-Being in Cognitively Impaired Persons
QoL-AD	Quality of life Alzheimer's Disease Scale
QOLAS	Quality of Life Assessment Schedule
QOLS	Quality of Life Scale
RBANS	Repeatable Battery for the Assessment of Neuropsychological Status
RBMT	Rivermead Behavioural Memory Test
RDRS-2	Rapid Disability Rating Scale
RFFT	Ruff Figural Fluency Test
RMBPC	Revised Memory and Behaviour Problems Checklist
ROCF	Rey-Osterrieth complex figure
RSS	Relative Stress Scale
SCB	Screen for Caregiver Burden
SCWT	Stroop Color and Word Test
SDMT	Symbol Digit Modalities Test
SF12	Short Form Health Survey
SIB	Severe Impairment Battery
SMMSE	Severe Impairment Mini-Mental State Examination
SQCRC	Scale for the Quality of the Current Relationship in Caregiving
SRT	Selective Reminding Test
STAI	State Trait anxiety inventory
The Doors Test	The Doors test
TIBI	Total illness burden index
TMT	Tinetti Mobility Test or Tinetti balance and Gait Scale
TT	Token Test
TYM	Test Your Memory
VF	Verbal Fluency
VST	Stroop Colour-Word Test-Victoria version
WAIS IV	Wechsler Adult Intelligence Scale, Fourth edition
WMS IV	Wechsler Memory Scale, Fourth edition



8.5 Glossary

<i>Awareness</i>	Conscious knowledge of one's own character, feelings, motives, desires and health status.
<i>Cognitive abilities</i>	The individual's capacity to think, reason, and solve problems. Cognitive ability is measured through tests of intelligence and cognitive skills.
<i>Cognitive impairment</i>	When a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe.
<i>Comorbidity</i>	It refers to more than one disorder or diseases that exist alongside a primary diagnosis. The additional disorders can be of psychological or purely physiological nature.
<i>Dementia</i>	It's an overall term that describes a wide range of symptoms associated with a decline in memory or other skills severe enough to reduce a person's ability to perform everyday activities.
<i>Digital skills</i>	The set of skills and capabilities needed to fully interact with digital devices and contents. In particular they are linked to the capability to manage information, communicate, purchase goods, create, identify and solve problems via digital devices/solutions.
<i>Dyad – care unit</i>	The person with dementia and the caregiver.
<i>Functional abilities</i>	The ability to perform everyday routines generally involving functional mobility and personal care, such as bathing, dressing, toileting, and meal preparation.
<i>Functional requirements</i>	The list of functions requested to a technological solution.
<i>Gamification</i>	Gamification is the application of game elements and digital game design techniques to non-game problems, such as health problems, social impact challenges and business.
<i>Health Care Professionals</i>	Health professionals maintain health in humans through the application of the principles and procedures of evidence-based medicine and caring. (e.g., Doctors, Psychologists, Geriatricians, Psychiatrists Nurses)



<i>Informal caregiver</i>	Any relative, partner, friend or neighbour who provides a broad range of assistance to an older person or an adult living with a chronic or disabling condition.
<i>Mild dementia</i>	A stage of dementia including increased forgetfulness, slight difficulty in concentrating, decreased work performance.
<i>Moderate dementia</i>	A stage of dementia including difficulty in concentrating, in remembering recent events, in managing finances, traveling alone to new locations, or completing complex tasks efficiently or accurately.
<i>Non-Functional requirements</i>	The list of required aspects of a given technological solutions such as shape, dimension, colour, usability and accessibility elements.
<i>Person Living with Dementia (PLWD)</i>	A 65+ year old individual, living with mild to moderate dementia, who is receiving professional services from a qualified medical or allied health practitioner to maintain, improve or protect their health or reduce illness, disability or pain.
<i>Platform</i>	A "platform" is a system that can be programmed and customized by developers in close cooperation with final users; it can provide set of services and contents, tailored to users' requirements.
<i>Professional caregiver</i>	A care provider associated with a formal service system (health system or welfare system), either as paid worker or as volunteer.
<i>Social Care Professionals</i>	Professionals intended to advance the social conditions of a community, and especially of the disadvantaged, by providing counselling, guidance, and assistance (care professionals, social assistants, family carers)
<i>Social Network</i>	An online service or site through which people create and maintain interpersonal relationships. They are used to share personal information, or to interact with specific communities.
<i>Socialization</i>	A continuing process whereby an individual acquires a personal identity and learns the norms, values, behaviour, and social skills appropriate to his or her social position.



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Yvonne Yueh-Feng Lu, PhD, RN, Joan E. Haase, PhD, RN, FAAN, and Michael Weaver, PhD, RN, FAAN - Pilot Testing a Couples-focused Intervention for Mild Cognitive Impairment
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8.6.1 *References for Scales*

ADAS-COG - Alzheimer's Disease Assessment Scale

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AMQ - Auto-administered Memory Questionnaire

Clément, F., Belleville, S., & Gauthier, S. (2008). Cognitive complaint in mild cognitive impairment and Alzheimer's disease. Journal of the International Neuropsychological Society, 14(2), 222-232
Van der Linden, M., Wijns, C., Von Frenkell, R., Coyette, F., & Seron, X. (1989). Un questionnaire d'auto-évaluation de la mémoire (QAM). Bruxelles: Editest

AMTS - Abbreviated Mental Test Score

Hodkinson, HM. (1972). Evaluation of a mental test score for assessment of mental impairment in the elderly. Age Ageing, 1(4), 233-238
Jitapunkul, S., Pillay, I., Ebrahim, S. (1991). The abbreviated mental test: its use and validity. Age Ageing, 20(5), 332-336
MacKenzie, DM., Copp, P., Shaw, RJ., & Goodwin, GM. (1996). Brief cognitive screening of the elderly: a comparison of the Mini-Mental State Examination (MMSE), Abbreviated Mental Test (AMT) and Mental Status Questionnaire (MSQ). Psychol Med, 26(2), 427-430

BANSS - Bedford Alzheimer Nursing Severity Scale

Volicer L., Hurley A.C., Lathi D.C., Kowall N.W. (1994). Measurement of severity in advanced Alzheimer's disease. J.Gerontology, 49:M223-M226.

BECS - Batterie d'Evaluation des Connaissances Sémantiques

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BRIXTON - Brixton Spatial Anticipation test (or Brixton test)

- Burgess, PW., & Shallice, T. (1997). *The Hayling and Brixton Tests*. Thurston, Suffolk: Thames Valley Test Company
- Bielak, AAM., Mansueti, L., Strauss, E., & Dixon, RA. (2006). Performance on the Hayling and Brixton tests in older adults: Norms and correlates. *Archives of Clinical Neuropsychology*, 21, 141–149

BSEPA - Brief screening Scale Evaluating Praxis Abilities for use in memory clinics

- Mahieux-Laurent, F., Fabre, C., Galbrun, E., Dubrulle, A., & Moroni, C. (2009) Validation of a brief screening scale evaluating praxic abilities for use in memory clinics. Evaluation in 419 controls, 127 mild cognitive impairment and 320 demented patients. *Revue neurologique*, 16(5), 60-67

CDR - Clinical Dementia Rating Scale

- Hughes, CP., Berg, L., Danziger, WL., Coben, LA., & Martin, RL. (1982). A new clinical scale for the staging of dementia. *Brit J Psychiat*, 140, 566-572
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CDS - Cognitive Difficulties Scale

- Derouesne, C., De Alberto, MJ., Boyer, P., Lubin, S., Sauron, B., Piette, B., Kohler, F., & Alperovitch, A. (1993). An empirical evaluation of the « cognitives difficulties scale » to assess memory complaints in general practice. A study of 1 628 cognitively normal subjects aged 45-75 years. *Int J Geriatr Psychiatr*, 8, 599-607



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CDT - Clock Drawing Test

- Goodglass, H., & Kaplan, E. (1983). The Assessment of Aphasia and Related Disorders, 2nd Edition. Oxford, UK, Williams & Wilkins, vii–70
- Shulman, KI. (2000). Clock-drawing: Is it the ideal cognitive screening test? International Journal of Geriatric Psychiatry, 15, 548-561
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DO80 - Denomination Orale 80 items

- Deloche, G., Metz-Lutz, MN., Kremin, H., Hannequin, D., Ferrand, L., Perrier, D., Dordain, M., Quint, S., Cardebat, D., Lota, AM., Van Der Linden, M., Larroque, C., Bunel, G., Pichard, B., & Naud, E. (1989). Test de dénomination orale de 80 images : DO 80. Paris : ECPA.
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- Snodgrass, JG., Vanderwart, M. (1980). Standardized Set of 260 Pictures: Norms for Name Agreement, Image Agreement, Familiarity, and Visual Complexity. Journal of Experimental Psychology: Human Learning and Memory, 6(2), 174-215

FAB - Frontal Assessment Battery

- Appollonio, I., Leone, M., Isella, V., Piamarta, F., Consoli, T., Villa, L., Forapani, E., Russo, A., & Nichelli, P. (2005). The Frontal Assessment Battery (FAB): normative values in an Italian population sample. Neurol Sci, 26, 108-116. DOI 10.1007/s10072-005-0443-4
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FCSRT-W - Free and Cued Selective Reminding Test - Word version

- Buschke, H. (1984). Cued recall in Amnesia. *Journal of Clinical and Experimental Neuropsychology*, 6, 433-440.
- Girtler, N., De Carli, F., Amore, M., Arnaldi, D., Bosia, LE., Bruzzaniti, C., Cappa, SF., Cocito, L., Colazzo, G. Ghio, L., Magi, E., Mancardi, GL., Nobili, F., Pardini, M., Picco, A., Rissotto, R., Serrati, C., Brugnolo, A. (2015). A normative study of the Italian printed word version of the free and cued selective reminding test. *Neurological Sciences*, 36(7), 1127-1134
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FBD - Forward and Backward Digit Span

- Grégoire, J., & Van Der Linden, M. (1997). Effect of age on forward and backward digit spans. *Aging, Neuropsychology, and Cognition: A Journal on Normal and Dysfunctional Development*, 4(2), 140-149
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F5T - The 5-figure test

- Croisile, B., Milliery, M., Collomb, K., & Mollion, H. (2009). The 5-figure test: a visuo-spatial memory test in Alzheimer's disease. *La Revue de Gériatrie*, 34(6), 495-503

FWT -Five-Words test

- Croisile, B., Astier, JL., & Beaumont, C. (2007). Standardization of the 5-word test in a group of 191 normal subjects aged 50 to 90 years. *Revue Neurologique*, 163(3), 323-333
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Mazzoleni, R., Peeters, J.C., Lakaye, A., Decock, C., Uytendaele, P., & Jacq, J. (2004). The Five-Word test in memory deficiency. *Rev Med Brux*, 25, 437-441

HDS - Hierarchic Dementia Scale

Bickel, H. (1996). The Hierarchic Dementia Scale: Usage, *International Psychogeriatrics* / , 8(2), 213-224

Cole, M.G., Dastoor, D.P., & Koszycki, D. (1983). The Hierarchic Dementia Scale. *Journal of Clinical Experimental Gerontology*, 5(3), 219-234.

IQCODE - Informant Questionnaire on Cognitive Decline in the Elderly - Short Form

Jorm, A.F., & Jacomb, P.A. (1989). The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE): Socio-Demographic Correlates, Reliability, Validity and Some Norms. *Psychological Medicine*, 19(4), 1015-1022

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MCST - Modified Card Sorting Test

Caffara, P., Vezzadini, G., Dieci, F., Zonato, F., & Venneri, A. (2004). Modified Card Sorting Test: normative data. *Journal of Clinical and Experimental Neuropsychology*, 26(2), 246-250

Hartman, M., Bolton, E., Fehnel, S.E. (2001). Accounting for age differences on the Wisconsin Card Sorting Test : decreased working memory, not inflexibility. *Psychology and Aging*, 16(3), 385-399

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Nelson, H.E. (1976). A modified card sorting test sensitive to frontal lobe defects. *Cortex*, 12(4), 313-324



MDRS - Mattis Dementia Rating Scale

- Arnold, BR., Cuellar, I., & Guzman, N. (1998). Statistical and Clinical Evaluation of the Mattis Dementia Rating Scale-Spanish Adaptation: An Initial Investigation. *Journal of Gerontology*, 53B(6), 364-369
- Franzen, MD. (2000). *Reliability and Validity in Neuropsychological Assessment* (2nd ed.). New York: Kluwer Academic/Plenum Publishers
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MMSE -Mini-Mental State Examination

- Derouesné, C., Poitreneau, J., Hugonot, L., Kalafat, M., Dubois, B., & Laurent, B. (1999). Le Mental-State Examination (MMSE): un outil pratique pour l'évaluation de l'état cognitif des patients par le clinicien. Version française consensuelle. *Presse Médical*, 28, 1141-1148
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MoCA - Montreal Cognitive Assessment

- Luis, CA., Keegan, AP., & Mullan M. (2009). Cross validation of the Montreal Cognitive Assessment in community dwelling older adults residing in the Southeastern US. *International Journal of Geriatric Psychiatry*, 24, 197-201
- Nasreddine, ZS., Phillips, NA., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, JL., & Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc.*, 53, 695-699
- Smith, T., Gildeh, N., & Holmes, C. (2007). The Montreal Cognitive Assessment: Validity and Utility in a Memory Clinic Setting. *The Canadian Journal of Psychiatry*, 52(5), 329-332

PEGV - Protocole Montréal-Toulouse d'Evaluation des Gnosies Visuelles

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RBMT - Rivermead Behavioural Memory Test

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VF - Verbal Fluency test: animals and "P" letter

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