

Suppl. Table 1: Harmonization of variables

	Variable	Study	Scale or question, Categories	Transformation	Harmonized
Resilience – Outcome	Psychological well-being	REMCARE MCSP 1 MCSP 2	GHQ-28 item version (<u>0</u> -28)	Dichotomized at clinically relevant threshold (5/6)	Poor / Good
		FAMCARE COMPAS	GHQ-12 item version (<u>0</u> -12)	Dichotomized at clinically relevant threshold (1/2)	
Resilience – Adversities	Severity of dementia	REMCARE FAMCARE	CDR (<u>0</u> -3) 0 No dementia 0.5 Very mild 1 Mild 2 Moderate 3 Severe	0/0.5/1 = Mild 2/3 = Moderate or severe	Mild / Moderate or severe
		COMPAS	MMSE (<u>0</u> - <u>30</u>) 21-30 Mild 11–20 Moderate 0–10 Severe	21-30 = Mild 0-20 = Moderate or severe	
		MCSP 1 MCSP 2	GDS (<u>1</u> -7) 1 No cognitive decline 2 Very mild 3 Mild 4 Moderate 5 Moderately severe 6 Severe 7 Very severe	1/2/3 = Mild 4/5/6/7 = Moderate or severe	
	Limitations in basic self-care	REMCARE FAMCARE COMPAS	EQ-5D item ‘Self-care’ 0 no problems with self-care 1 some problems washing or dressing themselves 2 unable to wash or dress themselves	0= No 1/2= Some or severe limitations	No / Some or severe limitations
		MCSP 1 MCSP 2	ASEP item ‘Needs help with dressing’ 0 Never 1 Sometimes	0= No 1/2= Some or severe	

		2 Frequently		
Behavioural/ mood problems	REMCARE MCSP 1 MCSP 2	CSDD (0-38)	Dichotomized at clinically relevant cut-point (Score higher than 7)	Clinically relevant or serious mood problems No / Yes
	FAMCARE COMPAS MCSP 2	NPI-Mood Domains (severity*frequency score per domain 0-12)	Two or more clinically relevant (≥ 4) or at least one serious (≥ 9) mood symptom	
Amount of care	REMCARE	How many hours do you spend each week performing care tasks for your relative?	Hours per week	Less than 40 hours of care per week / At least 40 hours of care per week
	FAMCARE	How many hours do you spend each week accompanying/ caring for your relative?	Hours per week	
	COMPAS	How many hours did you spend last week on ... [household activities, personal care, transport or visits outside the home]? Choose another week if your time spent on activities was very different than average.	Hours per week	
	MCSP 1 MCSP 2	How many days a week on average do you spend caring for the person with dementia? And how many hours per day?	Hours per week	
Socio-demographics	Caregiver age	REMCARE FAMCARE COMPAS MCSP 1 MCSP 2	Age on day of interview	Age in years
	Caregiver gender	REMCARE FAMCARE COMPAS MCSP 1 MCSP 2	Gender	Male/ female
	Caregiver (self) employed	REMCARE FAMCARE	Which of the following best describes your current employment status?	Paid / self-employed = Yes Yes / No

		Paid or self-employment / Unemployed / Homemaker / Retired	Other= No		
	COMPAS MCSP 1 MCSP 2	Do you have paid work at this moment? Yes / No			
Educational level	REMCARE FAMCARE	At what age did the caregiver leave full time education? Age (years)	0-15 = Lower or elementary 16 or older= Secondary or higher	Lower or elementary / Secondary or higher	
	COMPAS	What is the highest education you completed? 1 Less than 6 classes of primary school / 2 Six primary school classes / 3 More than primary school or primary school with uncompleted further education / 4 Practical training/ 5 Secondary vocational education/ 6 Pre-university education/ 7 University or higher professional education	1/2/3= Lower/ elementary 4-6= Secondary or higher		
	MCSP 1 MCSP 2	What is the highest education you completed? 0 Primary school / 1 Junior secondary pre-vocational education / 2 Secondary vocational education / 3 Junior general secondary education / 4 Pre-university education / 5 University or higher professional education	0=Lower/ elementary 1-5= Secondary or higher		
Context of care	Cohabiting with PwD	REMCARE FAMCARE	Do you live in the same household as your relative? Yes / No	Yes / No	
		COMPAS	Do you live together with the care receiver? Yes / No		
		MCSP 1 MCSP 2	Distance to the household of the person with dementia Living together/ Walking distance/ Same town/ Other town	Living together = Yes Other = No	
	Relationship with PwD	REMCARE FAMCARE	Relationship to patient: Spouse/ Son or daughter / Son or daughter in law/	Spouse/ Other Spouse / Other	

		Brother or sister/ Other relative/ Friend/ Neighbour/ Other, please specify		
	COMPAS	What is your relationship with the care receiver? I am..	Husband, wife or life partner = Spouse	
		Husband, wife or life partner/ Sister (in law) or brother (in law) / Daughter (in law) or son (in law)/ Other, please specify	Others= Other	
	MCSP 1 MCSP 2	What is your relationship with the care receiver? I am..	Life partner or spouse= Spouse	
		Life partner or spouse/ Daughter/ Son/ Other relative/ Neighbour/ Friend/ Acquaintance/ Son in law/ Daughter in law	Others= Other	
Quality of patient-caregiver relationship	REMCARE	QCPR item "There is a big distance in the relationship between my relative and myself" [9]	Converted to a 4-point score with the formula: (3/4)* score + (1/4)	Continuous score 1-4
	FAMCARE COMPAS	SSCQ item "I wish that my relative and I had a better relationship"	Converted to a 4-point score with the formula: (3/4)* score + (1/4)	
	MCSP 1 MCSP 2	SSCQ item "I wish that my relative and I had a better relationship"	Continuous score 1-4	
Care burden	REMCARE	RSS (0-60)	Z-score	Standardized scale
	FAMCARE COMPAS MCSP 2	NPI-D (0-60)	Z-score	
	MCSP 1	CSI (0-13)	Z-score	
Type of dementia	REMCARE FAMCARE	n/a		Harmonized across COMPAS and MCSP studies.

				Alzheimer's disease / Other or not specified
	COMPAS	Type of dementia	Alzheimer's disease / Other or not specified	
		Alzheimer's disease / Vascular/ Mixed/ Not known	or not specified	
	MCSP 1 MCSP 2	Diagnosis of dementia	Alzheimer's disease / Other or not specified	
		Alzheimer's disease/ Vascular/ Mixed/ Frontal temporal/ Lewy body/ Other or not specified	or not specified	
Time since first symptoms	REMCARE FAMCARE	n/a		<i>Harmonized across COMPAS and MCSP studies.</i>
	COMPAS	How long ago did your relative started to have dementia symptoms (e.g. changes in behavior or memory problems)?	Converted in years	Years since symptoms
		Months since symptoms		
	MCSP 1 MCSP 2	Months since symptoms	Converted in years	
Use of home care	REMCARE FAMCARE	Has your relative used services provided by a home care worker or care over the past 3 months?	1 or more = Yes 0 = No	Yes / No
		Number of visits		
	COMPAS	Does your relative receive home care?		
		No / Yes, ... hours per week (past three months)		
	MCSP 1 MCSP 2	Use of home care services?		
		No / Yes		
Use of day care	REMCARE FAMCARE	Has your relative used day care services provided by a local authority social services department, voluntary organization, or NHS (not hospital) over the past 3 months?	1 or more days = Yes 0 days = No	Yes / No
		Number of days received per week		
	COMPAS	Does your relative use day care services?		
		No / Yes, ... hours per week		
	MCSP 1	Inclusion criteria of the original study (all participants)		

Social & community resources

	MCSP 2	used day care services)		
Use of case management	REMCARE	Have you or your relative care used services from a care manager over the past 3 months?	1 or more = Yes 0 = No	<i>Harmonized across REMCARE, FAMCARE and COMPAS.</i>
	FAMCARE			
		Number of visits		
	COMPAS	Receiving care from a case manager (recruitment criterion)	Yes / No	
		No / Yes		
	MCSP 1	n/a		
	MCSP 2			
Loneliness caregiver	COMPAS	Jong-Gierveld loneliness scale (0-11)		<i>Harmonized across COMPAS and MCSP studies.</i>
	MCSP 1			
	MCSP 2			
	REMCARE	n/a		Continuous score 0-11
	FAMCARE			
Social support / Help or support from family or friends	REMCARE	Other than yourself, do any other people (such as friends or relatives) regularly provide help for your relative		<i>Harmonized across REMCARE, FAMCARE, COMPAS</i>
	FAMCARE			
		Yes / No	Yes / No	
	COMPAS	Does your relative receive help from other informal caregivers or volunteers?		
		Yes / No		
	MCSP 1	SSL-12 (12-48)		<i>In MCSP studies:</i>
	MCSP 2			Continuous score 12-48
Caregiver's individual resources	REMCARE	n/a		<i>Harmonized across FAMCARE, COMPAS, MCSP studies</i>
	FAMCARE	SSCQ (0-7)		Continuous scale 0-7
	COMPAS			
	MCSP 1	SSCQ (0-7)		
	MCSP 2			
Use of coping styles	MCSP 1	Jalowiec scale (0-180)		<i>Not harmonized</i>
	MCSP 2			
	REMCARE	n/a		

	FAMCARE COMPAS		
Mastery	COMPAS	Pearlin mastery scale (5- <u>25</u>)	<i>Not harmonized</i>
	REMCARE FAMCARE MCSP 1 MCSP 2	n/a	
Feelings of guilt	FAMCARE	Guilt scale (<u>0</u> -40)	<i>Not harmonized</i>
	REMCARE COMPAS MCSP 1 MCSP 2	n/a	

More positive scores are underlined.
 Abbreviations: ASEP, Assessment Scale for Elderly Patients; CDR, Clinical Dementia Rating; CSDD, Cornell Scale for Depression in Dementia; CSI, Caregiver Strain Index; EQ-5D, EuroQol- 5D; GDS, Global Deterioration Scale; GHQ, General Health Questionnaire; MMSE, Mini Mental State Examination; NPI, Neuropsychiatric Inventory; NPI-D, Neuropsychiatric Inventory- Distress; QCPR, Quality Caregiver Patient Relationship; SSCQ, Short Sense of Competence Questionnaire; SSL, Social Support List; RSS, Relatives' Stress Scale