ICHOM

International Consortium for
Health Outcomes Measurement

DEMENTIA
DATA COLLECTION
REFERENCE GUIDE

Version 1.0.1
Revised: April 3rd, 2017

Measuring
results
that matter

Quality of
Life

Dementia

ICHOM

DEMENTIA

We are thrilled that you are interested in measuring outcomes for persons with Dementia according to ICHOM standards. It is our hope that this Reference Guide will facilitate the process of implementing our Standard Set and ensure collection of comparable data for global benchmarking and learning.

Introducing ICHOM and the Reference Guide

ICHOM brings together patient representatives, clinician leaders, and registry leaders from all over the world to develop Standard Sets, comprehensive yet parsimonious sets of outcomes and case-mix variables we recommend all providers track.

Each Standard Set focuses on patient-centered results, and provides an internationally-agreed upon method for measuring each of these outcomes. We do this because we believe that standardized outcomes measurement will open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care we provide our patients.

Our Standard Sets include initial conditions and risk factors to enable meaningful case-mix adjustment globally, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions. We also include high-level treatment variables to allow stratification of outcomes by major treatment types. A comprehensive data dictionary is included in the appendix.

Working Group Members for Dementia

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Dementia in partnership with ICHOM, under the leadership of Dr. Alistair Burns, Professor of Old Age Psychiatry, Vice Dean for the Faculty of Medical and Human Sciences at The University of Manchester and National Clinical Director for Dementia in NHS England.

Australia
Jan Sansoni
Kate Swaffer

France
Philippe Robert

Ireland
Helen Rochford
Brennan

Japan
Kentaro Horibe

Peru
Mariella Guerra

South Korea
Ki-Woong Kim

Sweden
Maria Eriksdotter
Miia Kivipelto

Switzerland
Norman Sartorius

United Kingdom
Beth Britton
Alistair Burns
Geoff Huggins
Vicky Leah
Gary Morrison
Ann Netten
Keith Oliver
Emma Revnish
Robert Woods

United States
Soo Borson
Laura Gitlin
Nancy Hodgson

Supporting Organizations

The Dementia Standard Set is made possible only through the support of the Scottish Government.

Thank you.

Conditions Covered for Dementia

We developed this set with the aim of measuring the outcomes that matter most to persons with Dementia across the full care cycle. However, we recognize the significant practical constraints on doing so given the variety of care providers and settings in which people and their carers seek care throughout the course of this condition, and the variety of interventions and management options. Therefore, the set was designed to provide valid and beneficial outcomes data for a wide range of interventions and care settings.

For Dementia, the following conditions are covered by our Standard Set.

Conditions	Alzheimer's disease | Vascular dementia | Dementia in other diseases classified elsewhere (e.g. dementia with Lewy bodies and fronto-temporal dementia) Stages: Early | Middle | Late

ICHOM Standard Set for Dementia
Case-Mix Variables

Patient Population	Measure	Supporting Information	Timing	Data Source
Demographic Factors				
All patients	Age	Date of birth	Baseline	Clinical, Administrative data or patient/caregiver reported
	Sex	Sex at birth		
	Level of education	Highest level of schooling completed		Administrative data or patient/caregiver reported
	Living status and location	Most recent living arrangements	Baseline and annually	Patient/caregiver reported
	Smoking status	Smoking status (of cigarettes, cigars or tobacco)		
	Alcohol use	How much alcohol is consumed regularly		
	Body mass index	Body mass index		Clinical
Baseline Clinical Status				
All patients	Type of dementia	Using ICD classification	Baseline	Clinical or administrative
	Level of dementia	Tracked via the Clinical Dementia Rating scale		
Associated Clinical History				
All patients	Previous head injury	Has the person with dementia sustained a traumatic brain injury prior to dementia diagnosis, classified as mild/minor, moderate or severe	Baseline	Clinical or administrative
	Cardiovascular event incidence	Incidence of a cardiovascular event	Baseline and annually	Patient/caregiver-reported, clinical or administrative
	Comorbidities	Comorbidities (these include high blood pressure, diabetes, depression, and high cholesterol)		
Medication Variables				
	Total number of medications prescribed	What is the total number of (non-topical, and not over-the-counter) medications (for dementia and/or other conditions) the person with dementia has been prescribed		
	Acetylcholinesterase inhibitors	Indicate if the person with dementia is currently prescribed an acetylcholinesterase inhibitor		
	NMDA receptor antagonists	Indicate if the person with dementia is currently prescribed a NMDA receptor antagonist		

All patients	Antipsychotic drugs (also known as neuroleptics or major tranquilizers)	Indicate if the person with dementia is currently prescribed any antipsychotic drugs (also known as neuroleptics or major tranquilizers)	Baseline and annually	Clinical or administrative data
	Antidepressants	Indicate if the person with dementia is currently prescribed an antidepressant		
	Anticonvulsant medications	Indicate if the person with dementia is currently prescribed an anticonvulsant medication		
	Hypnotics	Indicate if the person with dementia is currently prescribed a hypnotic		

Symptoms, Functioning & Quality of Life

All patients	Neuropsychiatric	Includes anxiety, depression, behaviour, apathy and psychosis (tracked via the Neuropsychiatric Inventory)	Baseline and annually	Clinical
	Cognitive	Includes memory, orientation, verbal fluency and executive function (tracked via the Montreal Cognitive Assessment)		
	Social	Includes community affairs and relationships		
	Daily living	Includes activities of daily living such as sleeping, eating and financial resource. Tracked via the Bristol Activity Daily Living Scale		
	Overall quality of life and wellbeing	Patient reported dementia specific and general health-related QOL Includes enjoyment of activities, pain, financial resource and side effects of medications (tracked via the Quality of Life-AD and Quality of Wellbeing Scale-Self-Administered)	Baseline and 6-monthly	Patient/caregiver reported

Carer

All patients	Carer quality of life	Carer-reported health related QOL (Tracked via the EuroQol-5D). Refer to Data Dictionary for alternative options.	Baseline and annually	Patient/caregiver reported

Sustainability

All patients	Full-time care	Does the person with dementia require 24 hour care (delivered in any setting)	Baseline and annually	Patient/caregiver reported

Safety				
All patients	Falls	How many falls has the person with dementia sustained in the last 12 months	Baseline and annually	Caregiver-self-reported
Clinical Status				
	Disease progression	Level of dementia (tracked via the Clinical Dementia Rating)		Patient/caregiver reported
All patients	Hospital admissions	How many times has the person with dementia been admitted and readmitted to hospital in the last 12 months	Baseline and annually	Administrative data
	Overall survival	All-cause mortality		Administrative data (e.g.death registry)

Cognitive Outcomes

The Working Group recommend the Montreal Cognitive Assessment (MoCA) for measurement of cognitive outcomes, however the following limitations of this tool should be considered:

- There is emerging evidence of limitations of using the MoCA in sub-populations (Rossetti et al 2011).
- As with many cognitive tools, the MoCA is influenced by education bias of test (Zhou et al 2015, Rossetti et al 2011, http://www.mocatest.org/faq/).
- For some language translations of the MoCA, there are multiple versions of the test with unclear differences, and the subsequent validity and reliability of different versions.
- There is a strong need to ensure the tool is administered reliably in routine clinical settings.
- As with many cognitive tools, there may be increasing limitations of the MoCA in persons with very late stages of dementia.
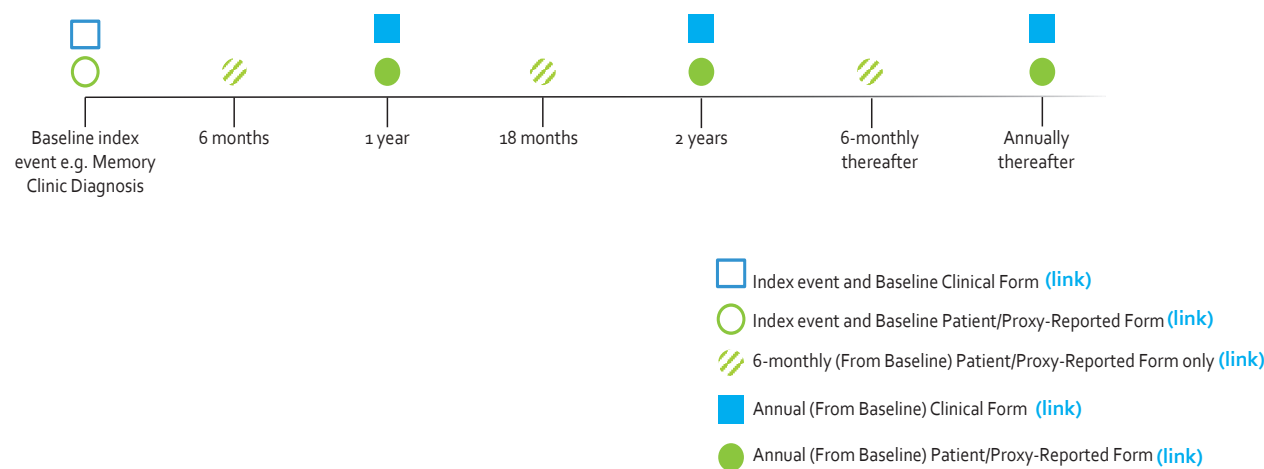
Health-related Quality of Life

The international nature of this effort is reflected in our recommendation of instruments for measuring health-related quality of life. We recommend using the EQ-5D-5L/3L, SF-12, or VR-12. The EQ-5D-3L is more commonly used in European countries while the SF-12 and VR-12 are commonly used in the United States. As cross walks have been developed enabling translation between these instruments, we present them here as equally valid instruments (Le QA, 2014). EQ-5D scores can be predicted from PROMIS global items, the PROMIS-10 (Revicki et al 2009).

The Euro-Qol group has also published a 5 level version of the EQ-5D in addition to the 3 level version which demonstrates valid redistribution, reduced ceiling, and improved discriminatory power and convergent validity (Janssen et al 2012). Scores of the 5D version can be translated to the 3D version (van Hout et al 2012 and on the EuroWol website www.euroqol.org), and therefore the EQ-5D-3L could also be used as a measure of health-related quality of life in this Standard Set.

1. **Probabilistic mapping of the health status measure SF-12 onto the health utility measure EQ-5D using the US-population-based scoring models.** Le QA. Qual Life Res. 2014 Mar;23(2):459-66. doi: 10.1007/s11136-013-0517-3. Epub 2013 Sep 13.
2. **Measurement properties of the EQ-5D-5L compared to the EQ-5D-3L across eight patient groups: a multi-country study.** M. F. Janssen, A. S Pickard, D Golicki, C Gudex, M Niewada, L Scalone, P Swinburn, J Busschbach. Qual Life Res 2012 DOI 10.1007/s11136-012-0322-4
3. **Predicting EuroQol (EQ-5D) scores from the patient-reported outcomes measurement information system (PROMIS) global items and domain item banks in a United States sample.** Revicki DA1, Kawata AK, Harnam N, Chen WH, Hays RD, Cella D.Qual Life Res. 2009 Aug;18(6):783-91. doi: 10.1007/s11136-009-9489-8. Epub 2009 May 27.
4. **Interim scoring for the EQ-5D-5L: Mapping the EQ-5D-5L to EQ-5D-3L value sets.** van Hout B, Janssen MF, et al. Value in Health 2012 Jul-Aug;15(5):708-15."Neurology. 2011 Sep 27;77(13):1272-5. doi: 10.1212/WNL.0b013e318230208a. Epub 2011 Sep 14.
5. **Normative data for the Montreal Cognitive Assessment (MoCA) in a population-based sample**. Rossetti HC1, Lacritz LH, Cullum CM, Weiner MF.
6. **Use of the MoCA in Detecting Early Alzheimer's Disease in a Spanish-Speaking Population with Varied Levels of Education.** Yan Zhou,a,* Freddy Ortiz,a Christopher Nuñez,a,c,d David Elashoff,a,b Ellen Woo,a Liana G. Apostolova,a Sheldon Wolf,a Maria Casado,a Nenette Caceres,a Hemali Panchal,a and John M. Ringmana Dement Geriatr Cogn Dis Extra. 2015 Jan-Apr; 5(1): 85–95.

Follow-Up Timeline and Sample Questionnaires

The following timeline illustrates when Standard Set variables should be collected from patients, clinicians, and administrative sources. Links to the sample questionnaires may be found in the legend below.

Baseline index event e.g. Memory Clinic Diagnosis — 6 months — 1 year — 18 months — 2 years — 6-monthly thereafter — Annually thereafter

☐ Index event and Baseline Clinical Form **(link)**

○ Index event and Baseline Patient/Proxy-Reported Form **(link)**

▨ 6-monthly (From Baseline) Patient/Proxy-Reported Form only **(link)**

▪ Annual (From Baseline) Clinical Form **(link)**

● Annual (From Baseline) Patient/Proxy-Reported Form **(link)**

Collecting Clinician and Patient-Reported Outcome Measures

Survey(s) Used	Licensing Information	Scoring Guide
Neuropsychiatric Inventory (NPI)	The NPI is copyrighted by Jeffrey L Cummings, MD. The NPI can be downloaded and used without charge by any academic investigator using the instrument in noncommercial studies. No licensing fee is necessary to include the NPI in investigator-initiated trials. A licensing fee is required for use of the NPI as an outcome measure in industry-sponsored research.	http://npitest.net
Bristol Activity Daily Living Scale (BADLS)	Licensing information not required.	Bucks RS, Ashworth DL, Wilcock GK, Siegfried K. (1996) Assessment of activities of daily living in dementia: Development of the Bristol activities of daily living scale. Age Ageing, 25, 113-120
Quality of Life-AD (QOL-AD)	Use of the scale in clinical practice or by academic users is free as long as no funding is received from commercial users, however a license is required for us. Contact information and permission to use: Mapi Research Trust, Lyon, France. E-mail: PROinformation@mapi-trust.org – Internet: www.proqolid.org	Logsdon RG, Gibbons LE, McCurry SM, Teri L. Quality of Life in Alzheimer's disease: Patient and Caregiver Reports. Journal of Mental Health and Aging. 1999;5(1):21-32
Quality of Wellbeing Scale-Self Administered (QWB-SA)	The QWB-SA may be used free of charge by non-profit organizations that provide evidence of their non-profit status and agree to provide a copy of relevant, non-identifiable project data with UCSD	Scoring instructions are provided free of charge after a signed copyright agreement is received. https://hoap.ucsd.edu/qwb-info/NotforProfit-Copyright.pdf
EuroQol-5D (EQ-5D)	Free for non-profits and academic research, but a license is required for use. Please visit http://www. euroqol.org/eq-5d-products/how-to-obtain-eq-5d.html	See link at left
Veterans RAND 12 (VR-12)	Free for all health care organisations, no license needed.	The scoring guide may be found at http://www.bu.edu/sph/research/research-landing-page/vr-36-vr-12-and-vr-6d/

Survey(s) Used	Licensing Information	Scoring Guide
Clinical Dementia Rating (CDR)	The Washington University The Charles F. and Joanne Knight Alzheimer's Disease Research Center (Knight ADRC) holds the United States Copyright for the Clinical Dementia Rating (CDR). The CDR may be used for clinical care without formal permission of the ADRC.	Scoring rules can be found here http://knightadrc.wustl.edu/cdr/PDFs/Assignment%20of%20CDR%20rating.pdf and translations of the tool can be found here http://knightadrc.wustl.edu/cdr/PDFs/Translations/
Montreal Cognitive Assessment	For clinical and educational use, MoCA© may be used, reproduced, and distributed without permission. Written permission and Licensing Agreement is required if funded by commercial entity or pharma.	http://www.mocatest.org/paper-tests/moca-test-full/

The Growing ICHOM Community

By implementing the ICHOM Standard Sets, you become part of an expanding, international community of innovative health care providers dedicated to improving value for patients. To learn more about how ICHOM can assist your organization in implementing outcome measurement, contact us at **implement@ichom.org**, or visit **http://www.ichom.org/measure**.

Appendix

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Dementia as consistently as possible to the Working Group recommendation. ICHOM is actively preparing for benchmarking efforts based on this data, and all data submitted for comparisons will need to be transformed into the following data structure if not already structured as such. **We are happy to provide an Excel version of this data dictionary for technical use.**

Please timestamp all variables. Some Standard Set variables are collected at multiple timepoints, and we will ask you to submit these variables in a concatenated VARIABLEID_TIMESTAMP form for future analyses. For example, VARIABLEID_BASE (baseline); VARIABLEID_6MO (6 month follow-up); VARIABLEID_1YR (1 year follow-up), etc.

Case-Mix Variables

Variable ID:	N/A
Variable:	Patient ID
Definition:	Indicate the patient's medical record number
Supporting Definition:	This number will not be shared with ICHOM. In the case patient-level data is submitted to ICHOM for benchmarking or research purposes, a separate ICHOM Patient Identifier will be created and cross-linking between the ICHOM Patient Identifier and the medical record number will only be known at the treating institution
Inclusion Criteria:	All patients
Timing:	On all forms
Data Source:	Administrative or clinical
Type:	Numerical
Response Options:	According to institution

Demographic Factors

Variable ID:	AGE
Variable:	Age
Definition:	Date of birth
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Data Source:	Clinical, Administrative data or patient/caregiver reported
Type:	Date
Response Options:	DD/MM/YYYY
Variable ID:	SEX
Variable:	Sex
Definition:	Sex at birth
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Data Source:	Clinical, Administrative data or patient/caregiver reported
Type:	Single answer
Response Options:	0=Male
	1=Female
Variable ID:	LEVEDC

Variable:	Level of education
Definition:	What is the highest level of schooling the person with dementia has completed?
Supporting Definition:	The level of schooling is defined in each country as per ISCED [International Standard Classification]
Inclusion Criteria:	All patients
Timing:	Baseline
Data Source:	Administrative data or patient/caregiver reported
Type:	Single answer
Response Options:	0=None
	1=Primary
	2=Secondary
	3=Tertiary
Variable ID:	LIVINGSTATLOC
Variable:	Living status and location
Definition:	Which statement best describes the person with dementia's living arrangement?
Supporting Definition:	Item is phrased as a patient/caregiver reported measure. However, if the patient is unable to
	answer, this information can be abstracted from the medical records.
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient/caregiver reported
Type:	Single answer
Response Options:	0=Lives alone
	1=Lives with partner/spouse/family/friends
	2=Lives in nursing home, hospital or long-term care home
	888=Other
Variable ID:	SMOKE
Variable:	Smoking status
Definition:	Smoking status (of cigarettes, cigars or tobacco)
Supporting Definition:	Item is phrased as a patient/caregiver reported measure. However, if the patient is unable to
	answer, this information can be abstracted from the medical records.
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient/caregiver reported
Type:	Single answer
Response Options:	0=Never smoked
	1=Ex-smoker
	2=Current smoker
Variable ID:	BMI
Variable:	Body mass index
Definition:	Body mass index
Supporting Definition:	Height and weight are used to calculate BMI
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Clinical
Type:	Numerical value
Response Options:	Numerical value of body mass index in kg/m2
Variable ID:	ALCUSE
Variable:	Alcohol use
Definition:	Which statement best matches the amount of alcohol consumed regularly (in units) by the person with dementia?
Supporting Definition:	One alcohol unit is measured as 10ml or 8g of pure alcohol. This equals one 25ml single measure of whisky (ABV 40%), or a third of a pint of beer (ABV 5-6%) or half

a standard (175ml) glass of red wine (ABV 12%).

Item is phrased as a patient/caregiver reported measure. However, if the patient is unable to answer, this information can be abstracted from the medical records

Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient/caregiver reported
Type:	Single answer
Response Options:	0=0 units of alcohol per week
	1=0-14 units of alcohol per week
	2= 14-21 units of alcohol per week
	3=>21 units of alcohol per week

Baseline Clinical Factors

Variable ID:	DEMTYPE
Variable:	Type of dementia
Definition:	Type of dementia diagnosis and subtype using ICD classification
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Data Source:	Clinical or administrative
Type:	Single answer
Response Options:	0=Dementia in Alzheimer's disease with early onset
	1=Dementia in Alzheimer's disease with late onset
	2=Dementia in Alzheimer's disease, atypical or mixed type
	3=Dementia in Alzheimer's disease, unspecified
	4=Vascular dementia of acute onset
	5=Multi-infarct dementia
	6= Subcortical vascular dementia
	7=Mixed cortical and subcortical vascular dementia
	8=Other vascular dementia
	9= Vascular dementia, unspecified
	10=Dementia in Pick's disease
	11=Dementia in Creutzfeldt-Jakob disease
	12=Dementia in Huntington's disease
	13=Dementia in Parkinson's disease
	14=Dementia in human immunodeficiency virus [HIV] disease
	15=Dementia in other specified diseases classified elsewhere
	16=Unspecified dementia
Variable ID:	DEMLEVEL
Variable:	Level or stage of dementia
Definition:	Level of dementia tracked via the Clinical Dementia Rating scale
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Data Source:	Clinical or administrative
Type:	Single answer
Response Options:	0=None
	1=Questionable
	2=Mild
	3=Moderate
	4=Severe

Associated clinical history

Variable ID:	PRIORHEADINJ
Variable:	Previous head injury
Definition:	Has the person with dementia sustained a traumatic brain injury prior to dementia

	diagnosis, classified as mild/minor, moderate or severe?
Supporting Definition:	As per Glasgow Coma Scale classification:
	GCS 13-15: Mild/minor
	GCS 9-12: Moderate
	GCS <9: Severe
Inclusion Criteria:	All patients
Timing:	Baseline
Data Source:	Clinical or administrative
Type:	Single answer
Response Options:	0=No
	1=Yes, classification unknown
	2=Yes, classified as mild/minor
	3=Yes, classified as moderate
	4=Yes, classified as severe
	999=unknown

Variable ID:	CARDEVEINC
Variable:	Cardiovascular event incidence
Definition:	Has the person with dementia sustained a cardio-vascular event in the previous year?
Supporting Definition:	Has the patient had a cardiovascular death, non-fatal myocardial infarction, sustained ventricular arrhythmia, any coronary intervention, hospitalization for congestive heart failure, angina requiring hospital admission, peripheral vascular or cerebrovascular event in the last year
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient/caregiver-reported, clinical or administrative
Type:	Single answer
Response Options:	0=No
	1=Yes
	999=unknown

Variable ID:	COMORBCOND
Variable:	Co-morbid conditions
Definition:	Have you ever been told by a doctor that you have any of the following? (select all that apply)
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sanga et al, 2003) Item is phrased as a patient reported measure. However, if the patient is unable to answer, this information can be abstracted from the medical records.
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient/caregiver-reported, clinical or administrative
Type:	Multiple answers
Response Options:	0=The person with dementia has no other diseases
	1=Heart disease (for example angina, heart attack or heart failure)
	2=High blood pressure (sometimes referred to as 'hypertension')
	3=Lung disease (for example asthma, chronic bronchitis or emphysema)
	4=Leg pain when walking due to poor circulation
	5=Diabetes (Type I or Type II)
	6=Kidney disease
	7=Disease of the nervous system (for example Parkinson's disease or multiple sclerosis
	8=Liver disease
	9=Cancer (within the last 5 years)
	10=Depression before diagnosis of dementia
	10=High cholesterol (sometimes referred to as hyperlipidemia)
	11=Problems caused by stroke

12=Substance abuse

Medication variables

Variable ID:	DEMMEDTOT
Variable:	Total number of medications prescribed
Definition:	What is the total number of (non-topical, and not over-the-counter) medications (for dementia and/or other conditions) the person with dementia has been prescribed
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical or administrative data
Type:	Numerical value
Response Options:	

Variable ID:	DEMMEDACE
Variable:	Acetylcholinesterase inhibitors
Definition:	Indicate if the person with dementia is currently prescribed an acetylcholinesterase inhibitor
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical or administrative data
Type:	Single answer
Response Options:	0=No 1=Yes

Variable ID:	DEMMEDNMD
Variable:	NMDA receptor antagonists
Definition:	Indicate if the person with dementia is currently prescribed a NMDA receptor antagonist
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical or administrative data
Type:	Single answer
Response Options:	0=No 1=Yes

Variable ID:	DEMMEDPSY
Variable:	Antipsychotic drugs (also known as neuroleptics or major tranquillizers)
Definition:	Indicate if the person with dementia is currently prescribed any antipsychotic drugs (also known as neuroleptics or major tranquillizers)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical or administrative data
Type:	Single answer
Response Options:	0=No 1=Yes

Variable ID:	DEMMEDDEP
Variable:	Antidepressants
Definition:	Indicate if the person with dementia is currently prescribed an antidepressant
Supporting Definition:	N/A
Inclusion Criteria:	All patients

Timing:	Baseline
	Annually
Data Source:	Clinical or administrative data
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	DEMMEDCON
Variable:	Anticonvulsant medications
Definition:	Indicate if the person with dementia is currently prescribed an anticonvulsant medication
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Clinical or administrative data
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	DEMMEDHYP
Variable:	Hypnotics
Definition:	Indicate if the person with dementia is currently prescribed a hypnotic
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Clinical or administrative data
Type:	Single answer
Response Options:	0=No
	1=Yes

Outcome

Variable ID:	OVERQOLWB
Variable:	Overall quality of life and wellbeing
Definition:	Patient reported question for financial resource
Supporting Definition:	Financial resources
	How hard is it for you to pay for the very basics like food, housing, medical care, and heating? Choose the statement which is most relevant
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient/caregiver reported
Type:	Single answer
Response Options:	0=Very hard
	1=Somewhat hard
	2=Not hard at all
	999=unknown

Variable ID:	FULLCAR
Variable:	Full-time care
Definition:	Does the person with dementia require 24 hour care?
Supporting Definition:	24 hour care could be provided at home by a formal/informal carer, family or friends, or in a institution, for example, a nursing home
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient/caregiver reported
Type:	Single answer

Response Options:	0=No
	1=Yes
	999=unknown
Variable ID:	FALLS
Variable:	Falls
Definition:	How many falls has the person with dementia sustained in the last 12 months?
Supporting Definition:	Using the WHO (2007) definition of an fall; "In- advertently coming to rest on the ground, floor or other lower level, excluding intentional change in position to rest in furniture, wall or other objects"
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient/caregiver reported
Type:	Numerical
Response Options:	N/A
Variable ID:	DISPROG
Variable:	Disease progression
Definition:	Level of dementia (tracked via the Clinical Dementia Rating)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Clinical
Type:	Single answer
Response Options:	0=None
	1=Questionable
	2=Mild
	3=Moderate
	4=Severe
Variable ID:	HOSPADM
Variable:	Hospital admissions
Definition:	How many times has the person with dementia been admitted and readmitted to hospital in the last 12 months?
Supporting Definition:	How many times has the person with dementia been admitted to a hospital requiring an overnight stay, in the last 12 months
	How many times has the person with dementia been readmitted to hospital within 30 days of first admission to hospital, in the last 12 months?
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Administrative or patient/caregiver reported
Type:	Numerical
Response Options:	Admissions
	Readmissions
Variable ID:	OVERALLSURV
Variable:	Overall survival
Definition:	Indicate if the patient has died
Supporting Definition:	All cause mortality
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Administrative (e.g. death registry)
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	DATEOFDEATH

Variable:	Date of death
Definition:	Indicate date of death
Supporting Definition:	N/A
Inclusion Criteria:	All patients if answered 'yes' to overall survival (OVERALLSURV)
Timing:	Annually
Data Source:	Administrative (e.g. death registry)
Type:	Date by DD/MM/YYYY or by MM/YYYY (in case exact date is unknown)
Response Options:	DD/MM/YYYY or MM/YYYY

Overall Quality of Life and Wellbeing

Variable ID:	OVERQOLWB
Variable:	Overall quality of life and wellbeing
Definition:	Dementia specific QOL (tracked via the Quality of Life-AD)
Supporting Definition:	QOL-AD
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient/caregiver reported
Type:	Numerical
Response Options:	13-52

Variable ID:	QOLADPATIENT_Q01
Variable:	Question 1 of QOL - Person with Dementia
Definition:	When you think about your life, there are different aspects, some of which are listed below. Please think about each item, and rate your current quality of life in each area using one of four words: poor, fair, good, or excellent. Please rate these items based on your life at the present time (e.g. within the past few weeks). If you have questions about any item, please ask the person who gave you this form for assistance.
	1. Physical Health
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent

Variable ID:	QOLADPATIENT_Q02
Variable:	Question 2 of QOL - Person with Dementia
Definition:	2. Energy
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent

Variable ID:	QOLADPATIENT_Q03
Variable:	Question 3 of QOL - Person with Dementia
Definition:	3. Mood
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported

Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent

Variable ID:	QOLADPATIENT_Q04
Variable:	Question 4 of QOL - Person with Dementia
Definition:	4. Living situation
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent

Variable ID:	QOLADPATIENT_Q05
Variable:	Question 5 of QOL - Person with Dementia
Definition:	5. Memory
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent

Variable ID:	QOLADPATIENT_Q06
Variable:	Question 6 of QOL - Person with Dementia
Definition:	6. Family
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent

Variable ID:	QOLADPATIENT_Q07
Variable:	Question 7 of QOL - Person with Dementia
Definition:	7. Marriage
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent

Variable ID:	QOLADPATIENT_Q08
Variable:	Question 8 of QOL - Person with Dementia
Definition:	8. Friends
Supporting Definition:	N/A

Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADPATIENT_Q09
Variable:	Question 9 of QOL - Person with Dementia
Definition:	9. Self a whole
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADPATIENT_Q10
Variable:	Question 10 of QOL - Person with Dementia
Definition:	10. Ability to do chores around the house
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADPATIENT_Q11
Variable:	Question 11 of QOL - Person with Dementia
Definition:	11. Ability to do things for fun
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADPATIENT_Q12
Variable:	Question 12 of QOL - Person with Dementia
Definition:	12. Money
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADPATIENT_Q13

Variable:	Question 13 of QOL - Person with Dementia
Definition:	13. Life as a whole
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent

Variable ID:	QOLADRELATIVE_Q01
Variable:	Question 1 of QOL - Family Member or Caregiver
Definition:	When you think about your relative's life, there are different aspects, some of which are listed below. Please think about each item, and rate your relative's current quality of life in each area using one of four words: poor, fair, good, or excellent. Please rate these items based on your relative's life at the present time (e.g. within the past few weeks). If you have questions about any item, please ask the person who gave you this form for assistance.
	1. Physical Health
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent

Variable ID:	QOLADRELATIVE_Q02
Variable:	Question 2 of QOL - Family Member or Caregiver
Definition:	2. Energy
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent

Variable ID:	QOLADRELATIVE_Q03
Variable:	Question 3 of QOL - Family Member or Caregiver
Definition:	3. Mood
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent

Variable ID:	QOLADRELATIVE_Q04
Variable:	Question 4 of QOL - Family Member or Caregiver
Definition:	4. Living situation
Supporting Definition:	N/A

Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADRELATIVE_Q05
Variable:	Question 5 of QOL - Family Member or Caregiver
Definition:	5. Memory
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADRELATIVE_Q06
Variable:	Question 6 of QOL - Family Member or Caregiver
Definition:	6. Family
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADRELATIVE_Q07
Variable:	Question 7 of QOL - Family Member or Caregiver
Definition:	7. Marriage
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADRELATIVE_Q08
Variable:	Question 8 of QOL - Family Member or Caregiver
Definition:	8. Friends
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADRELATIVE_Q09

Variable:	Question 9 of QOL - Family Member or Caregiver
Definition:	9. Self a whole
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADRELATIVE_Q10
Variable:	Question 10 of QOL - Family Member or Caregiver
Definition:	10. Ability to do chores around the house
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADRELATIVE_Q11
Variable:	Question 11 of QOL - Family Member or Caregiver
Definition:	11. Ability to do things for fun
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADRELATIVE_Q12
Variable:	Question 12 of QOL - Family Member or Caregiver
Definition:	12. Money
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair
	3=Good
	4=Excellent
Variable ID:	QOLADRELATIVE_Q13
Variable:	Question 13 of QOL - Family Member or Caregiver
Definition:	13. Life as a whole
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and 6 monthly
Data Source:	Relative-reported
Type:	Single answer
Response Options:	1=Poor
	2=Fair

3=Good

4=Excellent

Carer Quality of Life

Variable ID:	CARERQOL
Variable:	Carer quality of life
Definition:	Carer-reported health related QOL (Tracked via the EuroQol-5D)
Supporting Definition:	5L (but 3L can be used and cross walked to 5L score)
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver-self-reported
Type:	Multiple answer
Response Options:	5 digit code for EQ-5D-5L (eg 12132)
	EQ-VAS (0-100)

Variable ID:	EQ5D_Q01
Variable:	Mobility
Definition:	By selecting an option in each group below, please indicate which statements best describe your own health state today.
	Mobility
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = I have no problems in walking about
	2 = I have some problems in walking about
	3 = I am confined to bed

Variable ID:	EQ5D_Q02
Variable:	Selfcare
Definition:	Self-care
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = I have no problems with self-care
	2 = I have some problems washing or dressing myself
	3 = I am unable to wash or dress myself

Variable ID:	EQ5D_Q03
Variable:	Activity
Definition:	Usual activities (For example work, study, housework, family, or leisure activities)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = I have no problems with performing my usual activities
	2 = I have some problems with performing my usual activities
	3 = I am unable to perform my usual activities

Variable ID:	EQ5D_Q04
Variable:	Pain
Definition:	Pain/discomfort
Supporting Definition:	N/A

Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = I have no pain or discomfort
	2 = I have moderate pain or discomfort
	3 = I have extreme pain or discomfort

Variable ID:	EQ5D_Q05
Variable:	Anxiety
Definition:	Anxiety/depression
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = I am not anxious or depressed
	2 = I am moderately anxious or depressed
	3 = I am extremely anxious or depressed

Variable ID:	EQ5D_Q06
Variable:	EQ_VAS
Definition:	To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.
	We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Visual scale
Response Options:	Refer to visual analogue scale in sample questionnaire

Health-Related Quality of Life

Variable ID:	GH1
Variable:	Question 1 of VR-12
Definition:	In general, would you say your health is:
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = Excellent
	2 = Very good
	3 = Good
	4 = Fair
	5 = Poor

Variable ID:	PF2
Variable:	Question 2a of VR-12
Definition:	The following items are about activities you might do during a typical day. Does our health now limit you in these activities? If so, how much?
	a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = Yes, limited a lot
	2 = Yes, limited a little
	3 = No, not limited at all
Variable ID:	PF4
Variable:	Question 2b of VR-12
Definition:	b. Climbing several flights of stairs
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = Yes, limited a lot
	2 = Yes, limited a little
	3 = No, not limited at all
Variable ID:	VRP2
Variable:	Question 3a of VR-12
Definition:	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?
	a. Accomplished less than you would like
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = No, none of the time
	2 = Yes, a little of the time
	3 = Yes, some of the time
	4 = Yes, most of the time
	5 = Yes, all of the time
Variable ID:	VRP3
Variable:	Question 3b of VR-12
Definition:	b. Were limited in the kind of work or other activities
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = No, none of the time
	2 = Yes, a little of the time
	3 = Yes, some of the time
	4 = Yes, most of the time
	5 = Yes, all of the time
Variable ID:	VRE2
Variable:	Question 4a of VR-12
Definition:	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?
	a. Accomplished less than you would like

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = No, none of the time
	2 = Yes, a little of the time
	3 = Yes, some of the time
	4 = Yes, most of the time
	5 = Yes, all of the time

Variable ID:	VRE3
Variable:	Question 4b of VR-12
Definition:	b. Didn't do work or other activities as carefully as usual
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = No, none of the time
	2 = Yes, a little of the time
	3 = Yes, some of the time
	4 = Yes, most of the time
	5 = Yes, all of the time

Variable ID:	BP2
Variable:	Question 5 of VR-12
Definition:	During the past 4 weeks, how much did pain interfere with you normal work (including both work outside the home and housework)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = Not at all
	2 = A little bit
	3 = Moderately
	4 = Quite a bit
	5 = Extremely

Variable ID:	MH3
Variable:	Question 6a of VR-12
Definition:	These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.
	How much of the time during the past 4 weeks:
	a. Have you felt calm and peaceful?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = All of the time
	2 = Most of the time
	3 = A good bit of the time
	4 = Some of the time

	5 = A little of the time
	6 = None of the time

Variable ID:	VT2
Variable:	Question 6b of VR-12
Definition:	b. Did you have a lot of energy?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = All of the time
	2 = Most of the time
	3 = A good bit of the time
	4 = Some of the time
	5 = A little of the time
	6 = None of the time

Variable ID:	MH4
Variable:	Question 6c of VR-12
Definition:	c. Have you felt downhearted and blue?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = All of the time
	2 = Most of the time
	3 = A good bit of the time
	4 = Some of the time
	5 = A little of the time
	6 = None of the time

Variable ID:	SF2
Variable:	Question 7 of VR-12
Definition:	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = All of the time
	2 = Most of the time
	3 = Some of the time
	4 = A little of the time
	5 = None of the time

Variable ID:	VR12_Q08
Variable:	Question 8 of VR-12
Definition:	Now, we'd like to ask you some questions about how your health may have changed.
	Compared to one year ago, how would you rate your physical health in general now?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline

	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = Much better
	2 = Slightly better
	3 = About the same
	4 = Slightly worse
	5 = Much worse
Variable ID:	VR12_Q09
Variable:	Question 9 of VR-12
Definition:	Compared to one year ago, how would you rate your emotional health (such as feeling anxious, depressed, or irritable) in general now?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported (carer)
Type:	Single answer
Response Options:	1 = Much better
	2 = Slightly better
	3 = About the same
	4 = Slightly worse
	5 = Much worse

Variable ID:	OVERQOLWB
Variable:	Overall quality of life and wellbeing
Definition:	General health-related QOL and wellbeing (tracked via the Quality of Wellbeing Scale-Self-Administered)
Supporting Definition:	QWB-SA
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient/caregiver reported
Type:	Numerical
Response Options:	0.0-1.0
Variable ID:	QWB_SA_1A
Variable:	Question 1A QWB_SA - Acute and Chronic Symptoms
Definition:	Please indicate whether you currently experience each of the following health symptoms or problems. Do you have...
	1a. Blindness or severely impaired vision in both eyes?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	QWB_SA_1B
Variable:	Question 1B QWB_SA - Acute and Chronic Symptoms
Definition:	1b. Speech problems such as stuttering, or being unable to speak clearly?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported

Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	QWB_SA_1C
Variable:	Question 1C QWB_SA - Acute and Chronic Symptoms
Definition:	1c. Missing or paralyzed hands, feet, arms, or legs?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	QWB_SA_1D
Variable:	Question 1D QWB_SA - Acute and Chronic Symptoms
Definition:	1d. Any deformity of the face, fingers, hand or arm,
	foot or leg, or back (e.g. severe scoliosis)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	QWB_SA_1E
Variable:	Question 1E QWB_SA - Acute and Chronic Symptoms
Definition:	1e. General fatigue, tiredness. or weakness?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	QWB_SA_1F
Variable:	Question 1F QWB_SA - Acute and Chronic Symptoms
Definition:	1f. A problem with unwanted weight gain
	or weight loss?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	QWB_SA_1G
Variable:	Question 1G QWB_SA - Acute and Chronic Symptoms
Definition:	1g. A problem with being under or over weight?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported

Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	QWB_SA_1H
Variable:	Question 1H QWB_SA - Acute and Chronic Symptoms
Definition:	1h. Problems chewing your food adequately?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	QWB_SA_1I
Variable:	Question 1I QWB_SA - Acute and Chronic Symptoms
Definition:	1i. Any hearing loss or deafness?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	QWB_SA_1J
Variable:	Question 1J QWB_SA - Acute and Chronic Symptoms
Definition:	1j. Any noticeable skin problems, such as bad acne or large burns or scars on face, body, arms, or legs?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	QWB_SA_1K
Variable:	Question 1K QWB_SA - Acute and Chronic Symptoms
Definition:	1k. Eczema or burning/itching rash?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	QWB_SA_A
Variable:	Question A QWB_SA - Acute and Chronic Symptoms
Definition:	Which of the following health aides do you use/have? Dentures?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported

Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	QWB_SA_B
Variable:	Question B QWB_SA - Acute and Chronic Symptoms
Definition:	Oxygen tank?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	QWB_SA_C
Variable:	Question B QWB_SA - Acute and Chronic Symptoms
Definition:	Prosthesis?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	QWB_SA_D
Variable:	Question C QWB_SA - Acute and Chronic Symptoms
Definition:	Eye glasses or contact lenses?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	QWB_SA_E
Variable:	Question E QWB_SA - Acute and Chronic Symptoms
Definition:	Hearing aide?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	QWB_SA_F
Variable:	Question F QWB_SA - Acute and Chronic Symptoms
Definition:	Magnifying glass?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No

	1=Yes
Variable ID:	QWB_SA_G
Variable:	Question G QWB_SA - Acute and Chronic Symptoms
Definition:	Neck, back, or leg brace?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	QWB_SA_2A
Variable:	Question 2A QWB_SA - Acute and Chronic Symptoms
Definition:	For the following list of problems Indicate which days (If any) over the past 3 days, not Including today, you had the problem. If you have not had the symptom In the past 3 days, do not leave the question blank, please fill In "no days." If you have experienced the symptom In the past 3 days, please check which of the days you had It; If you experienced It on more than one of the days, fill In all days that apply.
	2a. Any problems with your vision not corrected with glasses or contact lenses (such as double vision, distorted vision, flashes, or floaters)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2B
Variable:	Question 2B QWB_SA - Acute and Chronic Symptoms
Definition:	2b. Any eye pa1n, irritation , discharge, or excessive sensitivity to light?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2C
Variable:	Question 2C QWB_SA - Acute and Chronic Symptoms
Definition:	2c. A headache?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer

Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2D
Variable:	Question 2D QWB_SA - Acute and Chronic Symptoms
Definition:	2d. Dizziness. earache, or ringing in your ears?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2E
Variable:	Question 2E QWB_SA - Acute and Chronic Symptoms
Definition:	2e. Difficulty hearing, or discharge, or bleeding from an ear?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2F
Variable:	Question 2F QWB_SA - Acute and Chronic Symptoms
Definition:	2f. Stuffy or runny nose, or bleeding from the nose?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2G
Variable:	Question 2G QWB_SA - Acute and Chronic Symptoms
Definition:	2g. A sore throat, difficulty swallowing, or hoarse voice?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2H

Variable:	Question 2H QWB_SA - Acute and Chronic Symptoms
Definition:	2h. A tooth ache or jaw pain?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2I
Variable:	Question 2I QWB_SA - Acute and Chronic Symptoms
Definition:	2i. Sore or bleeding lips, tongue, or gums?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2J
Variable:	Question 2J QWB_SA - Acute and Chronic Symptoms
Definition:	2j. Coughing or wheezing?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2K
Variable:	Question 2K QWB_SA - Acute and Chronic Symptoms
Definition:	2k. Shortness of breath or difficulty breathing?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2L
Variable:	Question 2L QWB_SA - Acute and Chronic Symptoms
Definition:	2l. Chest pain, pressure, palpitations, fast or skipped heart beat, or other discomfort in the chest?
Supporting Definition:	N/A
Inclusion Criteria:	All patients

Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2M
Variable:	Question 2M QWB_SA - Acute and Chronic Symptoms
Definition:	2m. An upset stomach. abdominal pain, nausea, heartburn, or vomiting?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2N
Variable:	Question 2N QWB_SA - Acute and Chronic Symptoms
Definition:	2n. Difficulty with bowel movements, diarrhea, constipation, rectal bleeding, black tar-like stools, or any pain or discomfort in the rectal area?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2O
Variable:	Question 2O QWB_SA - Acute and Chronic Symptoms
Definition:	2o. Pain, burn1ng, or blood in urine?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2P
Variable:	Question 2P QWB_SA - Acute and Chronic Symptoms
Definition:	2p.Lloss of bladder control, frequent night-time urination, or difficulty with urination?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline

	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2Q
Variable:	Question 2Q QWB_SA - Acute and Chronic Symptoms
Definition:	2q. Genital pain, itching, burning! or abnormal discharge, or pelvic cramping or abnormal bleeding? (does not Include normal menstruation)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2R
Variable:	Question 2R QWB_SA - Acute and Chronic Symptoms
Definition:	2r. A broken arm, wrist, foot, leg, or any other broken bone (other than in the back)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2S
Variable:	Question 2S QWB_SA - Acute and Chronic Symptoms
Definition:	2s. Pain, stiffness, cramps, weakness, or numbness m the neck or back?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2T
Variable:	Question 2T QWB_SA - Acute and Chronic Symptoms
Definition:	2t. Pain, stiffness, cramps, weakness, or numbness m the hips or sides?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline

	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2U
Variable:	Question 2U QWB_SA - Acute and Chronic Symptoms
Definition:	2u. Pain, stiffness, cramps, weakness, or numbness in any of the joints or muscles of the hand, feet, arms, or legs?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2V
Variable:	Question 2V QWB_SA - Acute and Chronic Symptoms
Definition:	2v. Swelling of ankles, hands, feet or abdomen?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2W
Variable:	Question 2W QWB_SA - Acute and Chronic Symptoms
Definition:	2w. Fever, chills, or sweats?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_2X
Variable:	Question 2X QWB_SA - Acute and Chronic Symptoms
Definition:	2x. Loss of consciousness, fainting, or seizures?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days

	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_2Y
Variable:	Question 2Y QWB_SA - Acute and Chronic Symptoms
Definition:	2y. Difficulty with your balance, standing, or walking?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3A
Variable:	Question 3A QWB_SA - Acute and Chronic Symptoms
Definition:	The following symptoms are about your feelings, thoughts, and behaviors. Please fill In which days (It any) over the past 3 days, not Including today, you have had …
	3a. Trouble falling asleep or staying asleep?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3B
Variable:	Question 3B QWB_SA - Acute and Chronic Symptoms
Definition:	3b. Spells of feeling nervous or shaky?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3C
Variable:	Question 3C QWB_SA - Acute and Chronic Symptoms
Definition:	3c. Spells of feeling upset, downhearted, or blue?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday

	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3D
Variable:	Question 3D QWB_SA - Acute and Chronic Symptoms
Definition:	3d. Excessive worry or anxiety?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3E
Variable:	Question 3E QWB_SA - Acute and Chronic Symptoms
Definition:	3e. Feelings that you had tittle or no control over events in your fife?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3F
Variable:	Question 3F QWB_SA - Acute and Chronic Symptoms
Definition:	3f. Feelings of being lonely or isolated?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3G
Variable:	Question 3G QWB_SA - Acute and Chronic Symptoms
Definition:	3g. Feelings of frustration, irritation, or close to losing your temper?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3H

Variable:	Question 3H QWB_SA - Acute and Chronic Symptoms
Definition:	3h. A hangover?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3I
Variable:	Question 3I QWB_SA - Acute and Chronic Symptoms
Definition:	3i. Any decrease of sexual interest or performance?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3J
Variable:	Question 3J QWB_SA - Acute and Chronic Symptoms
Definition:	3J. Confusion, difficulty understanding the written or spoken word, or significant memory loss?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3K
Variable:	Question 3K QWB_SA - Acute and Chronic Symptoms
Definition:	3k. Thoughts or images you could not get out of your mind?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_3L
Variable:	Question 3L QWB_SA - Acute and Chronic Symptoms
Definition:	3l. To take any medication including over-the-counter remedies (aspirin/tylenol, allergy medications, insulin, hormones, estrogen, thyroid, prednisone)?

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_3M
Variable:	Question 3M QWB_SA - Acute and Chronic Symptoms
Definition:	3m. To stay on a medically prescribed diet for health reasons?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_3N
Variable:	Question 3N QWB_SA - Acute and Chronic Symptoms
Definition:	3n. A loss of appetite or over-eating?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_4
Variable:	Question 4 QWB_SA - Acute and Chronic Symptoms
Definition:	4. In the last 3 days did you have any symptoms, health complaints, or pains that have not been mentioned?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	QWB_SA_4
Variable:	Question 4 QWB_SA - Acute and Chronic Symptoms
Definition:	II Yes, what were they and on which days did you have them?
	A.
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported

Type:	Free text
Response Options:	Symptoms Days
	A.
	B.

Variable ID:	QWB_SA_5A
Variable:	Question 5A QWB_SA - Self Care
Definition:	Over the last 3 days ... (please fill In all days that apply)
	5a. Did you spend any part of the day or night as a patient in a hospital, nursing home, or rehabilitation center?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_5B
Variable:	Question 5B QWB_SA - Self Care
Definition:	5b. Because of any impairment or health problem, did you need help w1th your personal care needs, such as eating, dressing, bathing, or getting around your home?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_6A
Variable:	Question 6A QWB_SA - Self Care
Definition:	Over the last 3 days ... (please fill In all days that apply)
	6a. Which days did you drive a motor vehicle?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_6B
Variable:	Question 6B QWB_SA - Self Care
Definition:	6b. Which days did you use public transportation such as a bus, subway, Medi-van, train, or airplane?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported

Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_6C
Variable:	Question 6C QWB_SA - Self Care
Definition:	6c. Which days did you either not drive a motor vehicle or not use public transportation because of your health, or need help from another person to use?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_7A
Variable:	Question 7A QWB_SA - Physical Activity
Definition:	Over the last 3 days did you ... (please fill In all days that apply)
	7a. Have trouble climbing stairs or inclines or walking off the curb?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_7B
Variable:	Question 7B QWB_SA - Physical Activity
Definition:	7b. Avoid walking, have trouble walking, or walk more slowly than other people your age?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_7C
Variable:	Question 7C QWB_SA - Physical Activity
Definition:	7c. Limp or use a cane, crutches, or walker?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days

	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_7D
Variable:	Question 7D QWB_SA - Physical Activity
Definition:	7d. Avoid or have trouble bending over, stooping, or kneeling?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_7E
Variable:	Question 7E QWB_SA - Physical Activity
Definition:	7e. Have any trouble lifting or carrying everyday objects such as books, a briefcase, or groceries?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_7F
Variable:	Question 7F QWB_SA - Physical Activity
Definition:	7f. Have any other limitations in physical movements?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_7G
Variable:	Question 7G QWB_SA - Physical Activity
Definition:	7g. Spend all or most of the day in a bed, chair, or couch because of health reasons?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_7H
Variable:	Question 7H QWB_SA - Physical Activity
Definition:	7h. Spend all or most of the day in a wheelchair?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_7I
Variable:	Question 7I QWB_SA - Physical Activity
Definition:	If In a wheelchair, on which days did someone else control its movement?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_8A
Variable:	Question 8A QWB_SA - Usual Activity
Definition:	Over the lest 3 days … (please fill in all days that apply)
	8a. Because of any physical or emotional health reasons, on which days d1d you avoid, need help with, or were limited In do1ng some of your usual activities, such as work, school or housekeeping?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_8B
Variable:	Question 8B QWB_SA - Usual Activity
Definition:	8b. Because of any physical or emotional health reasons, on which days d1d you avoid or feel limited in doing some of your usual activities, such as visiting family or friends, hobbies, shopping, recreational, or religious activities?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago

Variable ID:	QWB_SA_8C
Variable:	Question 8C QWB_SA - Usual Activity
Definition:	8c. On which days did you have to change any of your plans or activities because of your health? (Consider only ~activities that you did not report in the last 2 questions.)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=No Days
	1=Yesterday
	2=2 days ago
	3=3 days ago
Variable ID:	QWB_SA_8D
Variable:	Question 8D QWB_SA - Usual Activity
Definition:	If limited, please describe:
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Free text
Response Options:	N/A
Variable ID:	QWB_SA_9A
Variable:	Question 9A QWB_SA - Usual Activity
Definition:	9a. Would you say that your health is:
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Excellent
	1=Very Good
	2=Good
	3=Fair
	4=Poor
Variable ID:	QWB_SA_9B
Variable:	Question 9B QWB_SA - Usual Activity
Definition:	9b. Compared to a year ago, how would you rate your health in general now:
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Much better than a year ago
	1=Somewhat better than one year ago
	2=About the same as a year ago
	3=Somewhat worse than a year ago
	4=Much worse than a year ago
Variable ID:	QWB_SA_9C
Variable:	Question 9C QWB_SA - Usual Activity
Definition:	9c. Think about a scale of 0 to 1 00, with zero being the least

desirable state of health that you could imagine and 1 oo being perfect health. What number, from o to 1 oo would you g1ve to the state of your health. on average, over the last 3 days?

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=10
	1=10
	2=20
	3=30
	4=40
	5=50
	6=60
	7=70
	8=80
	9=90
	10=100

Variable ID:	QWB_SA_10
Variable:	Question 10 QWB_SA - Usual Activity
Definition:	10. Please complete the following questions:
	Sex:
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	o=Male
	1=Female

Variable ID:	QWB_SA_10I
Variable:	Question 10I QWB_SA - Usual Activity
Definition:	Age:
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Free text
Response Options:	N/A

Variable ID:	QWB_SA_10II
Variable:	Question 10II QWB_SA - Usual Activity
Definition:	What is your ethnicity?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	o=African American
	1=Asian/Pacific Islander
	2=Caucasian - Non Hispanic
	3=Hispanic
	4=Native American

	5=Other
Variable ID:	QWB_SA_10III
Variable:	Question 1OIII QWB_SA - Usual Activity
Definition:	Which of the following best describes your educational background?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=8th Grade Graduate 1=High School Graduate 2=Some College 3=College Graduate (B.S. or B.A. degree) 4=Some Graduate School 5=Completed Post-Graduate (M.A., M.D., Ph.D.)

Neuropsychiatric

Variable ID:	NEUROPSYCH
Variable:	Neuropsychiatric
Definition:	Includes anxiety and depression, apathy, delusions and hallucinations, agitation/aggression, nighttime behavior disturbances, appetite and eating abnormalities (tracked via the Neuropsychiatric Inventory-Clinician rating scale NPI-C)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Response Options:	Delusions (0-24) Hallucinations (0-21) Agitation (0-39) Aggression (0-24) Dysphoria (0-39) Anxiety (0-42) Apathy (0-36) Sleep (0-24) Appetite (0-27)
Variable ID:	NPI_C_D
Variable:	Question 0 of NPI_C - Delusions
Definition:	Does (S) have beliefs that you know are not true? For example, insisting that other people are trying to harm him/her or steal from him/her? Has he/she said that family members or staff are not who they say they are or that the house is not their home? I'm not asking about mere suspicions. I'm interested in whether (S) is convinced that these things are happening to him/her.
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	0=No 1=Yes
Variable ID:	NPI_C_D1
Variable:	Question 1 of NPI_C - Delusions

Definition:	1. Does (S) believe that he/she is in danger, that other are planning to hurt him/her or have been hurting him/her?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_D2
Variable:	Question 2 of NPI_C - Delusions
Definition:	2. Does (S) believe that others are stealing from him or her?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_D3
Variable:	Question 3 of NPI_C - Delusions
Definition:	3. Does (S) believe that his/her is having an affair?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_D4
Variable:	Question 4 of NPI_C - Delusions
Definition:	4. Does (S) believe that unwelcome guests are living in his/her house?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_D5
Variable:	Question 5 of NPI_C - Delusions

Definition:	5. Does (S) believe that his/her family, staff members or others are not who they claim to be or that they are imposters?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_D6
Variable:	Question 6 of NPI_C - Delusions
Definition:	6. Does (S) believe that his/her house is not his/her home?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_D7
Variable:	Question 7 of NPI_C - Delusions
Definition:	7. Does (S) believe that family members plan to abandon him/her?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_D8
Variable:	Question 8 of NPI_C - Delusions
Definition:	8. Does (S) believe that television or magazine figures are actually present in the room? Does he/she try to talk or interact with them?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_H

Variable:	Question 0 of NPI_C - Hallucinations
Definition:	Does (S) have hallucinations such as false visions or voices? Does (S) seem to see, hear or experience things that are not present? By this question we do not mean just mistaken beliefs such as stating that someone who has died is still alive; rather we are asking if (S) actually has abnormal experiences of sounds or visions?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	NPI_C_H1
Variable:	Question 1 of NPI_C - Hallucinations
Definition:	1. Does (S) describe hearing voices or acts if he/she hears voices?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_H2
Variable:	Question 2 of NPI_C - Hallucinations
Definition:	2. Does (S) talk to people who are not there?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_H3
Variable:	Question 3 of NPI_C - Hallucinations
Definition:	3. Does (S) describe seeing things that are not present or acts like he/she sees things that are not present (people, animals, lights, etc.)?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_H4

Variable:	Question 4 of NPI_C - Hallucinations
Definition:	4. Does (S) report smelling odors not smelled by others?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_H5
Variable:	Question 5 of NPI_C - Hallucinations
Definition:	5. Does (S) describe feeling things on his/her skin or otherwise appear to be feeling things crawling on or touching him/her?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_H6
Variable:	Question 6 of NPI_C - Hallucinations
Definition:	6. Does (S) say or act like he/she tastes things that are not present?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_H7
Variable:	Question 7 of NPI_C - Hallucinations
Definition:	7. Does (S) describe any other unusual sensory experiences?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_AGI

Variable:	Question 0 of NPI_C - Agitation
Definition:	Is (S) hard to handle or uncooperative or resistive to care?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	NPI_C_AGI1
Variable:	Question 1 of NPI_C - Agitation
Definition:	1. Does (S) get upset when people are trying to care for him/her or resist activities such as changing clothes?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGI2
Variable:	Question 2 of NPI_C - Agitation
Definition:	2. Is (S) stubborn, having to have things his/her way?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGI3
Variable:	Question 3 of NPI_C - Agitation
Definition:	3. Is (S) uncooperative or resistive to help from others?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGI4
Variable:	Question 5 of NPI_C - Agitation
Definition:	4. Does (S) ask repetitive questions or make repetitive statements?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress

	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_AGI5
Variable:	Question 6 of NPI_C - Agitation
Definition:	5. Does (S) seem restless in general?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_AGI6
Variable:	Question 7 of NPI_C - Agitation
Definition:	6. Is (S) unable to sit still or does he/she fidget constantly?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_AGI7
Variable:	Question 8 of NPI_C - Agitation
Definition:	7. Does (S) ask or complain about his or her health often, even though it is unjustified?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_AGI8
Variable:	Question 9 of NPI_C - Agitation
Definition:	8. Does (S) refuse to take medications?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress

	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGI9
Variable:	Question 10 of NPI_C - Agitation
Definition:	9. Does (S) pace nervously or angrily, in a way that differs from general wandering?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGI10
Variable:	Question 11 of NPI_C - Agitation
Definition:	10. Does (S) aggressively try to leave the residence or get to a different place (e.g., room)?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGI11
Variable:	Question 12 of NPI_C - Agitation
Definition:	11. Does (S) attempt to inappropriately use the phone in an attempt to get help from others?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGI12
Variable:	Question 13 of NPI_C - Agitation
Definition:	12. Does (S) hoard object?

Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_AGI13
Variable:	Question 14 of NPI_C - Agitation
Definition:	13. Does (S) hide objects?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_AGG
Variable:	Question 0 of NPI_C - Aggression
Definition:	Does (S) shout angrily, slam doors, or attempt to hit or hurt others? Does (S) intentionally fall or try to harm him/herself?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	NPI_C_AGG1
Variable:	Question 1 of NPI_C - Aggression
Definition:	1. Does (S) shout or curse angrily?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_AGG2
Variable:	Question 2 of NPI_C - Aggression
Definition:	2. Does (S) slam doors, kick furniture, and throw things?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity

Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGG3
Variable:	Question 3 of NPI_C - Aggression
Definition:	3. Does (S) attempt to hurt or hit others?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGG4
Variable:	Question 5 of NPI_C - Aggression
Definition:	4. Does (S) grab, push or scratch others?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGG5
Variable:	Question 6 of NPI_C - Aggression
Definition:	5. Is (S) unreasonably or uncharacteristically argumentative?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGG6
Variable:	Question 7 of NPI_C - Aggression
Definition:	6. Is (S) intrusive, such as taking others' possessions or entering another's room inappropriately?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity

Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGG7
Variable:	Question 8 of NPI_C - Aggression
Definition:	7. Is (S) in covert or open conflict with staff or others?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_AGG8
Variable:	Question 9 of NPI_C - Aggression
Definition:	8. Does (S) try to do things that are dangerous, such as lighting a match or climbing out a window?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS
Variable:	Question 0 of NPI_C - Dysphoria
Definition:	Does (S) seem sad or depressed? Does (S) say that he/she feels sad or depressed?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	NPI_C_DYS1
Variable:	Question 1 of NPI_C - Dysphoria
Definition:	1. Does (S) have periods of tearfulness or sobbing that seem to indicate sadness?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually

Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS2
Variable:	Question 2 of NPI_C - Dysphoria
Definition:	2. Does (S) say he/she is sad or in low spirits or acts as if he/she is sad or in low spirits?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS3
Variable:	Question 3 of NPI_C - Dysphoria
Definition:	3. Does (S) put him/herself down or say that he/she feels like a failure?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS4
Variable:	Question 4 of NPI_C - Dysphoria
Definition:	4. Does (S) seem very discouraged or say he/she has no future?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS5
Variable:	Question 5 of NPI_C - Dysphoria
Definition:	5. Does (S) say he/she is a burden to the family and that the family would be better off without him/her?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline

	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS6
Variable:	Question 6 of NPI_C - Dysphoria
Definition:	6. Does (S) express a wish for death or talk about killing him/herself?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS7
Variable:	Question 7 of NPI_C - Dysphoria
Definition:	7. Does (S) say that he/she is a bad person and deserves to be punished?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS8
Variable:	Question 9 of NPI_C - Dysphoria
Definition:	8. Does (S) have a worried or pained expression?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS9
Variable:	Question 10 of NPI_C - Dysphoria
Definition:	9. Is (S) pessimistic or overly negative, expecting the worst?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually

Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS10
Variable:	Question 11 of NPI_C - Dysphoria
Definition:	10. Is (S) suddenly irritable or easily annoyed?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS11
Variable:	Question 12 of NPI_C - Dysphoria
Definition:	11. Has (S) changed in his/her eating habits, such as eating more/less or more/less often than usual?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS12
Variable:	Question 13 of NPI_C - Dysphoria
Definition:	12. Does (S) talk about feeling guilty for things that for which he/she had no control over?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_DYS13
Variable:	Question 14 of NPI_C - Dysphoria
Definition:	13. Does (S) seem to no longer enjoy previously enjoyable activities?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline

	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_ANX
Variable:	Question 0 of NPI_C - Anxiety
Definition:	Is (S) very nervous, worried, or frightened for no apparent reason? Does (S) seem very tense or fidgety? Is (S) afraid to be apart from you or from others that he/she trusts?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	NPI_C_ANX1
Variable:	Question 1 of NPI_C - Anxiety
Definition:	1. Does (S) say that he/she is worried about planned events such as appointments or family visits?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_ANX2
Variable:	Question 2 of NPI_C - Anxiety
Definition:	2. Does (S) have periods of feeling shaky, unable to relax, or feeling very tense?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_ANX3
Variable:	Question 3 of NPI_C - Anxiety
Definition:	3. Does (S) have periods of [or complain of] shortness of breath, gasping or sighing for no reason other than being nervous?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline

	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_ANX4
Variable:	Question 4 of NPI_C - Anxiety
Definition:	4. Does (S) complain of butterflies in his/her stomach, or of racing or pounding of the heart because of being nervous [Symptoms not explained by ill health]?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_ANX5
Variable:	Question 5 of NPI_C - Anxiety
Definition:	5. Does (S) avoid certain places or situations that make him/her more nervous such as meeting with friends or participating in ward activities?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_ANX6
Variable:	Question 6 of NPI_C - Anxiety
Definition:	6. Does (S) become upset when separated from you? Does he/she cling to you to keep from being separated?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)
Variable ID:	NPI_C_ANX7
Variable:	Question 7 of NPI_C - Anxiety
Definition:	7. Does (S) talk about feeling threatened or act as if he/she is frightened?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity

Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_ANX8
Variable:	Question 8 of NPI_C - Anxiety
Definition:	8. Does (S) have a worried expression?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_ANX9
Variable:	Question 9 of NPI_C - Anxiety
Definition:	9. Does (S) make repeated statements or comments about something bad that is going to happen?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_ANX10
Variable:	Question 10 of NPI_C - Anxiety
Definition:	10. Does (S) express worry or concern over his/her health or body functions, worries that are not justified?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_ANX11
Variable:	Question 11 of NPI_C - Anxiety
Definition:	11. Does (S) become tearful from worry?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency

	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_ANX12
Variable:	Question 12 of NPI_C - Anxiety
Definition:	12. Does (S) have unrealistic fears about being alone or being abandoned?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_ANX13
Variable:	Question 13 of NPI_C - Anxiety
Definition:	13. Does (S) ask repeated questions about what he/she should be doing or where he/she should be going?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_ANX14
Variable:	Question 14 of NPI_C - Anxiety
Definition:	14. Does (S) seem overly focused or concerned with tasks or activities and is not easily distracted or deterred?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND
Variable:	Question 0 of NPI_C - Apathy/Indifference
Definition:	Has (S) lost interest in the world around him/her? Has (S) lost interest in doing things or lack motivation for starting new activities? Is (S) more difficult to engage

	in conversation or in doing chores? Is (S) apathetic or indifferent?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	NPI_C_APA_IND1
Variable:	Question 1 of NPI_C - Apathy/Indifference
Definition:	1. Does (S) seem less spontaneous and active than usual?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Numeric answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND2
Variable:	Question 2 of NPI_C - Apathy/Indifference
Definition:	2. Is (S) less likely to initiate a conversation?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND3
Variable:	Question 3 of NPI_C - Apathy/Indifference
Definition:	3. Is (S) less affectionate or lacking in emotions when compared to his/her usual self?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND4
Variable:	Question 4 of NPI_C - Apathy/Indifference
Definition:	4. Does (S) contribute less to household chores?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency

	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND5
Variable:	Question 5 of NPI_C - Apathy/Indifference
Definition:	5. Does (S) seem less spontaneous and active than usual?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND6
Variable:	Question 6 of NPI_C - Apathy/Indifference
Definition:	6. Does (S) seem less interested in the activities and plans of others?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND7
Variable:	Question 7 of NPI_C - Apathy/Indifference
Definition:	7. Has (S) lost interest in friends and family members?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND8
Variable:	Question 8 of NPI_C - Apathy/Indifference
Definition:	8. Is (S) less enthusiastic about his/her usual interests?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity

Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND9
Variable:	Question 9 of NPI_C - Apathy/Indifference
Definition:	9. Does (S) sit quietly without paying attention to things going on around him/her?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND10
Variable:	Question 10 of NPI_C - Apathy/Indifference
Definition:	10. Has (S) reduced participation in social activities even when stimulated?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND11
Variable:	Question 11 of NPI_C - Apathy/Indifference
Definition:	11. Is (S) less interested in or curious about routine or new events in his/her environment?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APA_IND12
Variable:	Question 12 of NPI_C - Apathy/Indifference
Definition:	12. Does (S) express less emotion in response to positive or negative or events?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity

Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_SLEEPDIS
Variable:	Question 0 of NPI_C - Sleep Disorders
Definition:	Does (S) have difficulty sleeping (do not count present if (S) simply gets up once or twice per night to go to the bathroom and falls back asleep immediately). Is (S) up at night? Does (S) wander at night, get dressed, go into others' rooms?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	NPI_C_SLEEPDIS1
Variable:	Question 1 of NPI_C - Sleep Disorders
Definition:	1. Does (S) have difficulty falling asleep?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_SLEEPDIS2
Variable:	Question 2 of NPI_C - Sleep Disorders
Definition:	2. Does (S) get up during the night? [do not count if (S) gets up once or twice per night only to go to the bathroom and falls back asleep immediately]?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
	Baseline
Timing:	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_SLEEPDIS3
Variable:	Question 3 of NPI_C - Sleep Disorders
Definition:	3. Does (S) wander, pace or get involved in inappropriate activities at night?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients

Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_SLEEPDIS4
Variable:	Question 4 of NPI_C - Sleep Disorders
Definition:	4. Does (S) awaken you during the night or disturb others?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_SLEEPDIS5
Variable:	Question 5 of NPI_C - Sleep Disorders
Definition:	5. Does (S) awaken at night, dress, and plan to go out, thinking that it is morning and time to start the day?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_SLEEPDIS6
Variable:	Question 6 of NPI_C - Sleep Disorders
Definition:	6. Does (S) sleep excessively during the day?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_SLEEPDIS7
Variable:	Question 7 of NPI_C - Sleep Disorders
Definition:	7. Does (S) awaken too early in the morning (before other (S)s)?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients

Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_SLEEPDIS8
Variable:	Question 9 of NPI_C - Sleep Disorders
Definition:	8. Is (S) agitated or concerned about sleeping at night? Does he/she worry about being able to fall asleep or about awakening at night?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APP_ EAT_DIS
Variable:	Question 0 of NPI_C - Appetite and Eating Disorders
Definition:	Has (S) had any change in appetite, weight, or eating habits? (Count as NA if (S) is incapacitated and has to be fed.) Has there been any change in type of food he/she prefers?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	NPI_C_APP_ EAT_DIS1
Variable:	Question 1 of NPI_C - Appetite and Eating Disorders
Definition:	1. Has (S) had a loss of appetite?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APP_ EAT_DIS2
Variable:	Question 2 of NPI_C - Appetite and Eating Disorders
Definition:	2. Has (S) had an increase of appetite?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline

	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APP_ EAT_DIS3
Variable:	Question 3 of NPI_C - Appetite and Eating Disorders
Definition:	3. Has (S) had a loss of weight?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APP_ EAT_DIS4
Variable:	Question 4 of NPI_C - Appetite and Eating Disorders
Definition:	4. Has (S) had a gain of weight?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APP_ EAT_DIS5
Variable:	Question 5 of NPI_C - Appetite and Eating Disorders
Definition:	5. Has (S) had a change in eating behavior such as putting too much food in his/her mouth at once?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APP_ EAT_DIS6
Variable:	Question 6 of NPI_C - Appetite and Eating Disorders
Definition:	6. Has (S) had a change in the kind of food he/she likes, such as eating too many sweets or other specific types of food?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients

Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APP_ EAT_DIS7
Variable:	Question 7 of NPI_C - Appetite and Eating Disorders
Definition:	7. Has (S) developed eating behaviors such as eating exactly the same types of food each day or eating the food in exactly the same order?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APP_ EAT_DIS8
Variable:	Question 9 of NPI_C - Appetite and Eating Disorders
Definition:	8. Does (S) eat or drink inappropriate substances or non-food items?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Variable ID:	NPI_C_APP_ EAT_DIS9
Variable:	Question 10 of NPI_C - Appetite and Eating Disorders
Definition:	9. Does (S) frequently demand food and/or drinks, even if he/she has just eaten/drank something?
Supporting Definition:	Caregiver to respond to Frequency, Severity, and Distress
	Patient to respond to Frequency
	Clinician to respond to Severity
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver, Patient, or Clinical Impression
Type:	Single answer
Response Options:	Frequency (0-4)
	Severity (0-3)
	Distress (0-5)

Clinical Dementia Rating

Variable ID:	CDR_INFOR_MEM1
Variable:	Questions 1 of CDR_Memory Questions for Informant
Definition:	1. Does he/she have a problem with his/her memory or thinking?

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	CDR_INFOR_MEM1A
Variable:	Questions 1A of CDR_Memory Questions for Informant
Definition:	1a. If yes, is this a consistent problem (as opposed to inconsistent)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	CDR_INFOR_MEM2
Variable:	Questions 2 of CDR_Memory Questions for Informant
Definition:	2. Can he/she recall recent events?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	CDR_INFOR_MEM3
Variable:	Questions 3 of CDR_Memory Questions for Informant
Definition:	3. Can he/she remember a short list of items (shopping)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	CDR_INFOR_MEM4
Variable:	Questions 4 of CDR_Memory Questions for Informant
Definition:	4. Has there been some decline in memory during the past year?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	CDR_INFOR_MEM5
Variable:	Questions 5 of CDR_Memory Questions for Informant
Definition:	5. Is his/her memory impaired to such a degree that it would have interfered with his/her activities of daily life a few years ago (or pre-retirement activities)? (collateral source's opinion)

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	CDR_INFOR_MEM6
Variable:	Questions 6 of CDR_Memory Questions for Informant
Definition:	6. Does he/she completely forget a major event (e.g. a trip, a party, a family wedding) within a few weeks of the event?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	CDR_INFOR_MEM7
Variable:	Questions 7 of CDR_Memory Questions for Informant
Definition:	7. Does he/she forget pertinent details about the major event?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	CDR_INFOR_MEM8
Variable:	Questions 8 of CDR_Memory Questions for Informant
Definition:	8. Does he/she completely forget important information of the distant past (e.g. date of birth, wedding date, place of employment)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	CDR_INFOR_MEM9
Variable:	Questions 9 of CDR_Memory Questions for Informant
Definition:	9. Tell me about some recent event in his/her life she should remember. (For later testing, obtain details such as location of the event, time of day, participants, how long the event was, when it ended and how the patient or other participants got there)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	Within 1 week:
	Within 1 month:

Variable ID:	CDR_INFOR_MEM10
Variable:	Questions 10 of CDR_Memory Questions for Informant
Definition:	10. When was he/she born?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	N/A
Variable ID:	CDR_INFOR_MEM11
Variable:	Questions 11 of CDR_Memory Questions for Informant
Definition:	11. Where was he/she born?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	N/A
Variable ID:	CDR_INFOR_MEM12
Variable:	Questions 12 of CDR_Memory Questions for Informant
Definition:	12. What was the last school he/she attended?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	Name:
	Place:
	Grade:
Variable ID:	CDR_INFOR_MEM13
Variable:	Questions 13 of CDR_Memory Questions for Informant
Definition:	13. What was his/her main occupation/job (or spouse's job if patient was not employed)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	N/A
Variable ID:	CDR_INFOR_MEM14
Variable:	Questions 14 of CDR_Memory Questions for Informant
Definition:	14. What was his/her major job (or spouse's job if patient was not employed)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	N/A
Variable ID:	CDR_INFOR_MEM15
Variable:	Questions 15 of CDR_Memory Questions for Informant
Definition:	15. When did he/she (or spouse) retire and why?
Supporting Definition:	N/A

Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	N/A

Variable ID:	CDR_INFOR_ORIENT1
Variable:	Question 1 of CDR_Orientation Questions for information
Definition:	How often does he/she know the exact:
	1. Date of the Month?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Usually
	1=Sometimes
	2=Rarely
	3=Don't Know

Variable ID:	CDR_INFOR_ORIENT2
Variable:	Question 2 of CDR_Orientation Questions for information
Definition:	2. Month?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Usually
	1=Sometimes
	2=Rarely
	3=Don't Know

Variable ID:	CDR_INFOR_ORIENT3
Variable:	Question 3 of CDR_Orientation Questions for information
Definition:	3. Year?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Usually
	1=Sometimes
	2=Rarely
	3=Don't Know

Variable ID:	CDR_INFOR_ORIENT4
Variable:	Question 4 of CDR_Orientation Questions for information
Definition:	4. Day of the Week?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually

Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Usually
	1=Sometimes
	2=Rarely
	3=Don't Know

Variable ID:	CDR_INFOR_ORIENT5
Variable:	Question 5 of CDR_Orientation Questions
	for information
Definition:	5. Does he/she have difficulty with time relationships (when events happened in relation to
	each other)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Usually
	1=Sometimes
	2=Rarely
	3=Don't Know

Variable ID:	CDR_INFOR_ORIENT6
Variable:	Question 6 of CDR_Orientation Questions
	for information
Definition:	6. Can he/she find his/her way around familiar streets?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Usually
	1=Sometimes
	2=Rarely
	3=Don't Know

Variable ID:	CDR_INFOR_ORIENT7
Variable:	Question 7 of CDR_Orientation Questions
	for information
Definition:	7. How often does he/she know how to get from one place to another outside his/her
	neighborhood?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Usually
	1=Sometimes
	2=Rarely
	3=Don't Know

Variable ID:	CDR_INFOR_ORIENT8
Variable:	Question 8 of CDR_Orientation Questions
	for information
Definition:	8. How often can he/she find his/her way around indoors?
Supporting Definition:	N/A

Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Usually
	1=Sometimes
	2=Rarely
	3=Don't Know
Variable ID:	CDR_INFOR_JUDGE_PROB1
Variable:	Question B1 of CDR_Judgement and Problem Solving Questions for Informant
Definition:	1. In general, if you had to rate his/her abilities to solve problems at the present time, would
	you consider them:
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=As good as they have ever been
	1=Good, but not as good as before
	2=Fair
	3=Poor
	4=No ability at all
Variable ID:	CDR_INFOR_JUDGE_PROB2
Variable:	Question B2 of CDR_Judgement and Problem Solving Questions for Informant
Definition:	2. Rate his/her ability to cope with small sums of money (e.g. calculate change,
	leave a small tip):
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No loss
	1=Some loss
	2=Severe loss
Variable ID:	CDR_INFOR_JUDGE_PROB3
Variable:	Question B3 of CDR_Judgement and Problem Solving Questions for Informant
Definition:	3. Rate his/her ability to handle complicated financial or business transactions (e.g.
	balance check book, pay bills):
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No loss
	1=Some loss
	2=Severe loss
Variable ID:	CDR_INFOR_JUDGE_PROB4
Variable:	Question B4 of CDR_Judgement and Problem Solving Questions for Informant
Definition:	4. Can he/she handle a household emergency (e.g. plumbing leak, small fire)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline

	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=As well as before
	1=Worse than before because of trouble thinking
	2=Worse than before, another reason (why)

Variable ID:	CDR_INFOR_JUDGE_PROB5
Variable:	Question B5 of CDR_Judgement and Problem Solving Questions for Informant
Definition:	5. Can he/she understand situations or explanations?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Usually
	1=Sometimes
	2=Rarely
	3=Don't Know

Variable ID:	CDR_INFOR_JUDGE_PROB6
Variable:	Question B6 of CDR_Judgement and Problem Solving Questions for Informant
Definition:	6. Does he/she behave* appropriately (i.e. in his/her usual (premorbid) manner) in social situations and interactions with other people?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Usually
	1=Sometimes
	2=Rarely
	3=Don't Know

Variable ID:	CDR_INFOR_COMMAFF
Variable:	Question 0 of CDR_Community Affairs Questions for Informant
Definition:	Occupational
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes
	2=N/A

Variable ID:	CDR_INFOR_COMMAFF1
Variable:	Question 1 of CDR_Community Affairs Questions for Informant
Definition:	1. Is the patient still working?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	If not applicable, proceed to item 4
	If yes, proceed to item 3
	If no, proceed to item 2

Variable ID:	CDR_INFOR_COMMAFF2
Variable:	Question 2 of CDR_Community Affairs Questions for Informant
Definition:	2. Did memory or thinking problems contribute to the patient's decision to retire? (Question 4 is next)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No 1=Yes 2=D/K

Variable ID:	CDR_INFOR_COMMAFF3
Variable:	Question 3 of CDR_Community Affairs Questions for Informant
Definition:	3. Does the patient have significant difficulty in his/her job because of problems with memory or thinking?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Rarely or Never 1=Sometimes 2=Usually 3=Don't Know

Variable ID:	CDR_INFOR_COMMAFF4
Variable:	Question 4 of CDR_Community Affairs Questions for Informant
Definition:	4. Did he/she ever drive a car?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No 1=Yes

Variable ID:	CDR_INFOR_COMMAFF4A
Variable:	Question 4A of CDR_Community Affairs Questions for Informant
Definition:	Does the patient drive a car now?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No 1=Yes

Variable ID:	CDR_INFOR_COMMAFF4B
Variable:	Question 4B of CDR_Community Affairs Questions for Informant
Definition:	If no, is this because of memory or thinking problems?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Caregiver or Clinical Impression

Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	CDR_INFOR_COMMAFF5
Variable:	Question 5 of CDR_Community Affairs Questions for Informant
Definition:	5. If he/she is still driving, are there problems or risks because of poor thinking?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	CDR_INFOR_COMMAFF6
Variable:	Question 6 of CDR_Community Affairs Questions for Informant
Definition:	6. *Is he/she able to independently shop for needs?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0 Rarely or Never (Needs to be accompanied on any shopping trip)
	1 Sometimes (Shops for limited number of items: buys duplicate items or forgets needed items)
	2 Usually
	3 Don't Know

Variable ID:	CDR_INFOR_COMMAFF7
Variable:	Question 7 of CDR_Community Affairs Questions for Informant
Definition:	7. Is he/she able to carry out activities independently outside the home?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0 Rarely or Never ((Generally unable to perform Activities without help)
	1 Sometimes (Limited and/or routine e.g. superficial participation In church or meetings; trips to beauty salons)
	2 Usually (Meaningful participation in activities e.g. voting)
	3 Don't Know

Variable ID:	CDR_INFOR_COMMAFF8
Variable:	Question 8 of CDR_Community Affairs Questions for Informant
Definition:	8. Is he/she taken to social functions outside the family home?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	CDRI_INFOR_COMMAFF8A
Variable:	Question 8A of CDR_Community Affairs Questions for Informant
Definition:	If no, why not
Supporting Definition:	N/A

Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	CDR_INFOR_COMMAFF9
Variable:	Question 9 of CDR_Community Affairs Questions for Informant
Definition:	9. Would a casual observer of the patient's behavior think the patient was ill?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	CDR_INFOR_COMMAFF10
Variable:	Question 10 of CDR_Community Affairs Questions for Informant
Definition:	10. If in a nursing home, does he/she participate well in social functions (thinking)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No
	1=Yes

Variable ID:	CDR_INFOR_COMMAFF10_1A
Variable:	Question 10_1A of CDR_Community Affairs Questions for Informant
Definition:	1a. What changes have occurred in his/her abilities to perform household tasks?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	N/A

Variable ID:	CDR_INFOR_COMMAFF10_1B
Variable:	Question 10_1B of CDR_Community Affairs Questions for Informant
Definition:	1b. What can he/she still do well?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	N/A

Variable ID:	CDR_INFOR_COMMAFF10_2A
Variable:	Question 10_2A of CDR_Community Affairs Questions for Informant
Definition:	2a. What changes have occurred in his/her abilities to perform hobbies?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression

Type:	Free text
Response Options:	N/A
Variable ID:	CDR_INFOR_COMMAFF10_2B
Variable:	Question 10_2B of CDR_Community Affairs Questions for Informant
Definition:	2b. What can he/she still do well?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	N/A
Variable ID:	CDR_INFOR_COMMAFF10_3
Variable:	Question 10_3 of CDR_Community Affairs Questions for Informant
Definition:	3. If in a nursing home, what can he/she no longer do well (Home and Hobbies)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	N/A
Variable ID:	CDR_INFOR_COMMAFF10_4
Variable:	Question 10_4 of CDR_Community Affairs Questions for Informant
Definition:	4. Ability to perform household tasks
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=0 No Loss
	1=0.5
	2=1 Severe Loss
Variable ID:	CDR_INFOR_COMMAFF10_4A
Variable:	Question 10_4A of CDR_Community Affairs Questions for Informant
Definition:	Please describe
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	N/A
Variable ID:	CDR_INFOR_COMMAFF10_5
Variable:	Question 10_5 of CDR_Community Affairs Questions for Informant
Definition:	5. Is he/she able to perform household tasks at the level of:
	(Pick one. The informant does not need to be asked directly)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=No meaningful function
	(Performs simple activities, such as making a bed, only with much supervision)
	1=Functions in limited activities only

(With some supervision, washed dishes with acceptable cleanliness; sets table)
2=Functions independently in some activities
(Operates appliances, such as a vacuum cleaner; prepares simple meals)
3=Functions in usual activities but not at usual level
4=Normal function in usual activities

Variable ID:	CDR_INFOR_COMMAFF10_6
Variable:	Question 10_6 of CDR_Community Affairs Questions for Informant
Definition:	*What is your estimate of his/her mental ability in the following areas:
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Free text
Response Options:	N/A

Variable ID:	CDR_INFOR_COMMAFF10_6A
Variable:	Question 10_6A of CDR_Community Affairs Questions for Informant
Definition:	A. Dressing (The Dementia Scale of Blessed)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Unaided
	1=Occasionally misplaced buttons etc.
	2=Wrong sequence commonly forgotten items
	3=Unable to dress

Variable ID:	CDR_INFOR_COMMAFF10_6B
Variable:	Question 10_6B of CDR_Community Affairs Questions for Informant
Definition:	B. Washing, grooming
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Unaided
	1=Needs prompting
	2=Sometimes needs help
	3=Always or nearly always needs help

Variable ID:	CDR_INFOR_COMMAFF10_6C
Variable:	Question 10_6C of CDR_Community Affairs Questions for Informant
Definition:	C. Eating habits
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Cleanly; proper utensils
	1=Messily; spoon
	2=Simple solids
	3=Has to be fed completely

Variable ID:	CDR_INFOR_COMMAFF10_6D
Variable:	Question 10_6D of CDR_Community Affairs Questions for Informant
Definition:	D. Sphincter control (The Dementia Scale of Blessed)

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Caregiver or Clinical Impression
Type:	Single answer
Response Options:	0=Normal complete control
	1=Occasionally wets bed
	2=Frequently wets bed
	3=Doubly incontinent

Variable ID:	CDR_PAT_MEM1
Variable:	Question 1 of CDR_Memory Questions for Patient
Definition:	1. Do you have problems with memory or thinking?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= No
	1=Yes

Variable ID:	CDR_PAT_MEM2
Variable:	Question 2 of CDR_Memory Questions for Patient
Definition:	2. A few moments ago your (spouse etc) told me a few recent experiences you had. Will you tell me something about those? (Prompt for details if needed, such as location of the event, time of day, participants, how long the event was, when it ended and how the patient or other participants got there.)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Free text
Response Options:	Within 1 week
	1.0 – Largely correct
	0.5
	0.0 – Largely incorrect
	Within 1 month
	1.0 – Largely correct
	0.5
	0.0 – Largely incorrect

Variable ID:	CDR_PAT_MEM3				
Variable:	Question 3 of CDR_Memory Questions for Patient				
Definition:	3. I will give you a name and address to remember for a few minutes. Repeat this name and address after me: (Repeat until the phrase is correctly repeated or to a maximum of three attempts)				
Supporting Definition:	Elements (Underline elements repeated correctly in each attempt)				
	1	2	3	4	5
	John	Brown	42	Market St	Sydney
	John	Brown	42	Market St	Sydney
	John	Brown	42	Market St	Sydney
Inclusion Criteria:	All patients				
Timing:	Baseline				
	Annually				
Data Source:	Patient-reported				
Type:	Free text				

Response Options:	Elements (Underline elements repeated correctly in each attempt)

1	2	3	4	5
John	Brown	42	Market St	Sydney
John	Brown	42	Market St	Sydney
John	Brown	42	Market St	Sydney

Variable ID:	CDR_PAT_MEM4
Variable:	Question 4 of CDR_Memory Questions for Patient
Definition:	4. When were you born?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Free text
Response Options:	N/A

Variable ID:	CDR_PAT_MEM5
Variable:	Question 5 of CDR_Memory Questions for Patient
Definition:	5. Where were you born?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Free text
Response Options:	

Variable ID:	CDR_PAT_MEM6
Variable:	Question 6 of CDR_Memory Questions for Patient
Definition:	6. What was the last school you attended?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Free text
Response Options:	Name
	Place
	Grade

Variable ID:	CDR_PAT_MEM7
Variable:	Question 7 of CDR_Memory Questions for Patient
Definition:	7. What was your main occupation/job (or spouse's if not employed)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Free text
Response Options:	N/A

Variable ID:	CDR_PAT_MEM8
Variable:	Question 8 of CDR_Memory Questions for Patient
Definition:	8. What was your last major job (or spouse's if not employed)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Free text
Response Options:	N/A

Variable ID:	CDR_PAT_MEM9
Variable:	Question 9 of CDR_Memory Questions for Patient
Definition:	9. When did you (or your spouse) retire and why?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Free text
Response Options:	N/A

Variable ID:	CDR_PAT_MEM10
Variable:	Question 10 of CDR_Memory Questions for Patient
Definition:	10. Repeat the name and address I asked you to remember:
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Free text
Response Options:	Elements (Underline elements repeated correctly in each attempt)

1	2	3	4	5
John	Brown	42	Market St	Sydney

Variable ID:	CDR_PAT_ORIENT1
Variable:	Question 1 CDR_Orientation Questions for Patient
Definition:	Record the patient's answer verbatim for each question
	1. What is the date today?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Correct
	1=Incorrect

Variable ID:	CDR_PAT_ORIENT2
Variable:	Question 2 CDR_Orientation Questions for Patient
Definition:	2. What day of the week is it?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Correct
	1=Incorrect

Variable ID:	CDR_PAT_ORIENT3
Variable:	Question 3 CDR_Orientation Questions for Patient
Definition:	3. What is the month?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Correct
	1=Incorrect

Variable ID:	CDR_PAT_ORIENT4
Variable:	Question 4 CDR_Orientation Questions for Patient
Definition:	4. What is the year?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Correct
	1=Incorrect
Variable ID:	CDR_PAT_ORIENT5
Variable:	Question 5 CDR_Orientation Questions for Patient
Definition:	5. What is the name of this place?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Correct
	1=Incorrect
Variable ID:	CDR_PAT_ORIENT6
Variable:	Question 6 CDR_Orientation Questions for Patient
Definition:	6. What town or city are we in?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Correct
	1=Incorrect
Variable ID:	CDR_PAT_ORIENT7
Variable:	Question 7 CDR_Orientation Questions for Patient
Definition:	7. What time is it?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Correct
	1=Incorrect
Variable ID:	CDR_PAT_ORIENT8
Variable:	Question 8 CDR_Orientation Questions for Patient
Definition:	8. Does the patient who the informant is (in your judgment)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Correct
	1=Incorrect
Variable ID:	CDR_PAT__JUDGE_PROBL_SOLV1
Variable:	Question 1 CDR_Judgement and Problem Solving Questions for the Patient

Definition:	Instructions: If initial response by subject does not merit a grade 0, press the matter to identify the patient's best understanding of the problem. Circle the nearest response.
	Similarities:
	1. turnip..............cauliflower
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = vegetables
	1 = edible foods, living things, can be cooked, etc
	2 = answers not pertinent; differences; buy them
Variable ID:	CDR_PAT__JUDGE_PROBL_SOLV2
Variable:	Question 2 CDR_Judgement and Problem Solving Questions for the Patient
Definition:	Similarities:
	2. desk...............bookcase
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = furniture, office furniture; both hold books
	1 = wooden, legs
	2 = not pertinent, differences
Variable ID:	CDR_PAT__JUDGE_PROBL_SOLV3
Variable:	Question 3 CDR_Judgement and Problem Solving Questions for the Patient
Definition:	Differences
	3. lie...................mistake
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = one deliberate, one unintentional
	1 = one bad, the other good – or explains only one
	2 = anything else, similarities
Variable ID:	CDR_PAT__JUDGE_PROBL_SOLV4
Variable:	Question 4 CDR_Judgement and Problem Solving Questions for the Patient
Definition:	Differences
	4. river................canal
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = natural – artificial
	2 = anything else
Variable ID:	CDR_PAT__JUDGE_PROBL_SOLV5
Variable:	Question 5 CDR_Judgement and Problem Solving Questions for the Patient
Definition:	Calculations:
	5. How many five cent pieces in a dollar?

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Correct
	1=Incorrect

Variable ID:	CDR_PAT__JUDGE_PROBL_SOLV6
Variable:	Question 6 CDR_Judgement and Problem Solving Questions for the Patient
Definition:	Calculations:
	6. How many 20 cent pieces in $5.40?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Correct
	1=Incorrect

Variable ID:	CDR_PAT__JUDGE_PROBL_SOLV7
Variable:	Question 7 CDR_Judgement and Problem Solving Questions for the Patient
Definition:	Calculations
	7. Subtract 3 from 20 and keep subtracting 3 from each new number all the way down.
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Correct
	1=Incorrect

Variable ID:	CDR_PAT__JUDGE_PROBL_SOLV8
Variable:	Question 8 CDR_Judgement and Problem Solving Questions for the Patient
Definition:	Judgment:
	8. Upon arriving in a strange city, how would you locate a friend that you wished to see?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = try the telephone book, city directory, go to the courthouse for a directory; call a mutual friend
	1 = call the police, call the operator usually will not give address
	2 = no clear response

Variable ID:	CDR_PAT__JUDGE_PROBL_SOLV9
Variable:	Question 9 CDR_Judgement and Problem Solving Questions for the Patient
Definition:	Judgment:
	9. Patient's assessment of disability and station in life and understanding of why he/she is present at the examination (may have covered, but rate here):
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually

Data Source:	Patient-reported
Type:	Single answer
Response Options:	0=Good Insight
	1=Partial Insight
	2=Little Insight

Daily Living

Variable ID:	DAILYLIV
Variable:	Daily living
Definition:	Includes activities of daily living such as sleeping, eating and financial resource. Tracked via the Bristol Activity Daily Living Scale
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Clinical
Type:	Numerical
Response Options:	0-60

Variable ID:	BADLS_Q01
Variable:	Bristol Activities of Daily Living Scale
Definition:	1. Food
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Selects and prepared food as required
	1= Able to prepare food if ingredients set out
	2=Can prepare food if prompted step by step
	3=Unable to prepare food even with prompting and supervision
	4=Not applicable

Variable ID:	BADLS_Q02
Variable:	Bristol Activities of Daily Living Scale
Definition:	2. Eating
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Eats appropriately using correct cutlery
	1= Eats appropriately if food made manage-able and/or uses spoon
	2= Uses fingers to eat food
	3= Needs to be fed
	4= Not applicable

Variable ID:	BADLS_Q03
Variable:	Bristol Activities of Daily Living Scale
Definition:	3. Drink
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Selects and prepares drinks as required
	1= Can prepare drinks if ingredients left available

2= Can prepare drinks if prompted step by step
3= Unable to make a drink even with prompting and supervision
4= Not applicable

Variable ID:	BADLS_Q04
Variable:	Bristol Activities of Daily Living Scale
Definition:	4. Drinking
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Drinks appropriately
	1= Drinks appropriately with aids, beaker/straw etc.
	2= Does not drink appropriately even with aids but attempts to
	3= Has to have drinks administered (fed)
	4= Not applicable

Variable ID:	BADLS_Q05
Variable:	Bristol Activities of Daily Living Scale
Definition:	5. Dressing
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Selects appropriate clothing and dresses self
	1= Puts clothes on in wrong order and/or back to front and/or dirty clothing
	2= Unable to dress self but moves limbs to assist
	3= Unable to assist and requires total dressing
	4= Not applicable

Variable ID:	BADLS_Q06
Variable:	Bristol Activities of Daily Living Scale
Definition:	6. Hygiene
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Washes regularly and independently
	1= Can wash self if given soap, flannel, towel, etc.
	2= Can wash self if prompted and supervised
	3= Unable to wash self and needs full assistance
	4= Not applicable

Variable ID:	BADLS_Q07
Variable:	Bristol Activities of Daily Living Scale
Definition:	7. Teeth
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Cleans own teeth/dentures regularly and independently
	1= Cleans teeth/dentures if given appropriate items
	2= Requires some assistance, toothpaste on brush, brush to mouth, etc.

3= Full assistance given
4= Not applicable

Variable ID:	BADLS_Q08
Variable:	Bristol Activities of Daily Living Scale
Definition:	8. Bath/Shower
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Bathes regularly and independently
	1= Needs bath to be drawn/shower turned on but washes independently
	2= Needs supervision and prompting to wash
	3= Totally dependent, needs full assistance
	4= Not applicable
Variable ID:	BADLS_Q09
Variable:	Bristol Activities of Daily Living Scale
Definition:	9. Toilet/Commode
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Uses toilet appropriately when required
	1= Needs to be taken to the toilet and given assistance
	2= Incontinent of urine or feces
	3= Incontinent of urine and feces
	4= Not applicable
Variable ID:	BADLS_Q10
Variable:	Bristol Activities of Daily Living Scale
Definition:	10. Transfers
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Can get in/out of chair unaided
	1= Can get into a chair but needs help to get out
	2= Needs help getting in and out of a chair
	3= Totally dependent on being put into and lifted from chair
	4= Not applicable
Variable ID:	BADLS_Q11
Variable:	Bristol Activities of Daily Living Scale
Definition:	11. Mobility
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Walks independently
	1= Walks with assistance, i.e. furniture, arm for support
	2= Uses aids to mobilize, i.e. frame, sticks etc.
	3= Unable to walk

4= Not applicable

Variable ID:	BADLS_Q12
Variable:	Bristol Activities of Daily Living Scale
Definition:	12. Orientation—Time
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Fully orientated to time/day/date etc.
	1= Unaware of time/day etc but seems unconcerned
	2= Repeatedly asks the time/day/date
	3= Mixes up night and day
	4= Not applicable

Variable ID:	BADLS_Q13
Variable:	Bristol Activities of Daily Living Scale
Definition:	13. Orientation—Space
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Fully orientated to surroundings
	1= Orientated to familiar surroundings only
	2= Gets lost in home, needs reminding where bathroom is, etc.
	3= Does not recognize home as own and attempts to leave
	4= Not applicable

Variable ID:	BADLS_Q14
Variable:	Bristol Activities of Daily Living Scale
Definition:	14. Communication
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Able to hold appropriate conversation
	1= Shows understanding and attempts to respond verbally with gestures
	2= Can make self understood but difficulty understanding others
	3= Does not respond to or communicate with others
	4= Not applicable

Variable ID:	BADLS_Q15
Variable:	Bristol Activities of Daily Living Scale
Definition:	15. Telephone
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Uses telephone appropriately, including obtaining correct number
	1= Uses telephone if number given verbally/visually or pre-dialed
	2= Answers telephone but does not make calls
	3= Unable/unwilling to use telephone at all
	4= Not applicable

Variable ID:	BADLS_Q16
Variable:	Bristol Activities of Daily Living Scale
Definition:	16. Housework/Gardening
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Able to do housework/gardening to previous standard
	1= Able to do housework/gardening but not to previous standard
	2= Limited participation even with a lot of supervision
	3= Unwilling/unable to participate in previous activities
	4= Not applicable
Variable ID:	BADLS_Q17
Variable:	Bristol Activities of Daily Living Scale
Definition:	17. Shopping
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Shops to previous standard
	1= Only able to shop for 1 or 2 items with or without a list
	2= Unable to shop alone, but participates when accompanied
	3= Unable to participate in shopping even when accompanied
	4= Not applicable
Variable ID:	BADLS_Q18
Variable:	Bristol Activities of Daily Living Scale
Definition:	18. Finances
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Responsible for own finances at previous level
	1= Unable to write check but can sign name and recognizes money values
	2= Can sign name but unable to recognize money values
	3= Unable to sign name or recognize money values
	4= Not applicable
Variable ID:	BADLS_Q19
Variable:	Bristol Activities of Daily Living Scale
Definition:	19. Games/Hobbies
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Participates in pastimes/activities to previous standard
	1= Participates but needs instruction/supervision
	2= Reluctant to join in, very slow, needs coaxing
	3= No longer able or willing to join in
	4= Not applicable
Variable ID:	BADLS_Q20

Variable:	Bristol Activities of Daily Living Scale
Definition:	20. Transport
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0= Able to drive, cycle or use public transport independently
	1= Unable to drive but uses public transport or bike etc
	2= Unable to use public transport alone
	3= Unable/unwilling to use transport even when accompanied
	4= Not applicable

Cognitive

Variable ID:	COG
Variable:	Cognitive
Definition:	Includes memory, orientation, verbal fluency and executive function (tracked via the Montreal Cognitive Assessment)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Clinical
Type:	Numerical
Response Options:	0-30
Variable ID:	MOCA_1
Variable:	Visuospatial/Executive
Definition:	Visuospatial/Executive
Supporting Definition:	http://www.mocatest.org/wp-content/uploads/2015/tests-instructions/MoCA-Test-English_7_1.pdf
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Numerical score
Response Options:	Score 0-5
Variable ID:	MOCA_2
Variable:	Naming
Definition:	Naming
Supporting Definition:	http://www.mocatest.org/wp-content/uploads/2015/tests-instructions/MoCA-Test-English_7_1.pdf
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Numerical score
Response Options:	Score 0-3
Variable ID:	MOCA_3
Variable:	Memory
Definition:	Memory
Supporting Definition:	http://www.mocatest.org/wp-content/uploads/2015/tests-instructions/MoCA-Test-English_7_1.pdf
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported

Type:	N/A
Response Options:	N/A
Variable ID:	MOCA_4
Variable:	Attention
Definition:	Attention
Supporting Definition:	http://www.mocatest.org/wp-content/uploads/2015/tests-instructions/MoCA-Test-English_7_1.pdf
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Numerical score
Response Options:	Score 0-3
Variable ID:	MOCA_5
Variable:	Language
Definition:	Language
Supporting Definition:	http://www.mocatest.org/wp-content/uploads/2015/tests-instructions/MoCA-Test-English_7_1.pdf
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Numerical score
Response Options:	Score 0-1
Variable ID:	MOCA_6
Variable:	Abstraction
Definition:	Abstraction
Supporting Definition:	http://www.mocatest.org/wp-content/uploads/2015/tests-instructions/MoCA-Test-English_7_1.pdf
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Numerical score
Response Options:	Score 0-2
Variable ID:	MOCA_7
Variable:	Delayed Recall
Definition:	Delayed Recall
Supporting Definition:	http://www.mocatest.org/wp-content/uploads/2015/tests-instructions/MoCA-Test-English_7_1.pdf
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Numerical score
Response Options:	Score 0-5
Variable ID:	MOCA_8
Variable:	Orientation
Definition:	Orientation
Supporting Definition:	http://www.mocatest.org/wp-content/uploads/2015/tests-instructions/MoCA-Test-English_7_1.pdf
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Data Source:	Patient-reported
Type:	Numerical score

ICHOM Contact Information

Website	http://www.ichom.org

Business Address	14 Arrow Street, Suite #11 Cambridge, MA 02138

Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
1.0.1	Collecting Clinician and Patient-Reported Outcome Measures	Added VR-12 for measuring Health-Related Quality of Life

www.ichom.org