ICHOM

International Consortium for
Health Outcomes Measurement

OLDER PERSON
REFERENCE GUIDE

Version 1.0.3

Revised: April 10, 2017

Measuring
results
that matter

Mobility

Older Person

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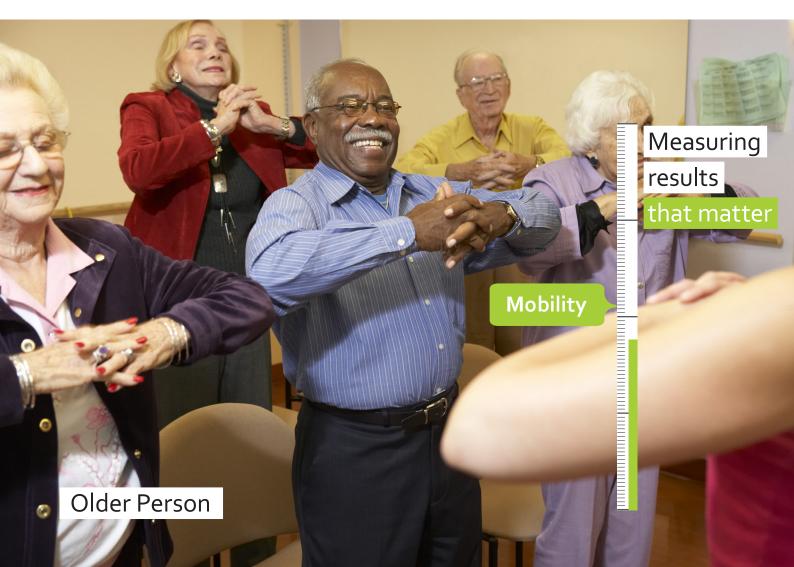
We are thrilled that you are interested in measuring outcomes for your older patients according to ICHOM standards. It is our hope that this Reference Guide will facilitate the process of implementing our Standard Set and ensure collection of comparable data for global benchmarking and learning.

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. A comprehensive data dictionary is included in the appendix.

Working Group Members for Older Person

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Older Persons in partnership with ICHOM, under the leadership of Dr. Jay Banerjee, Consultant in Emergency Medicine, University UK Hospitals of Leicester NHS Trust.

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Supporting Organizations

The Older Person Standard Set is made possible through the support of NHS England.

Thank you.

Treatment Approaches Covered for Older Persons

For Older Persons, the following treatment approaches are covered by our Standard Set.

Treatment Approaches	Treatment approaches have not been defined due to the wide range of management options and interventions for an older population. A number of potentially inappropriate medications have been listed as 'medication variables'

Scope

This is set is recommended for an older population, however there is no globally agreed definition on what age this population is.

As a guideline, the Working Group recommend measuring these outcomes for a population which, on average, is in the last 10 years of life based on average life expectancy at age 60 (Global AgeWatch Index 2014) :

For example:

UK: age 84 to ≥74
South Africa: age 76 to ≥66

ICHOM Standard Set for Older Person
Case-Mix Variables

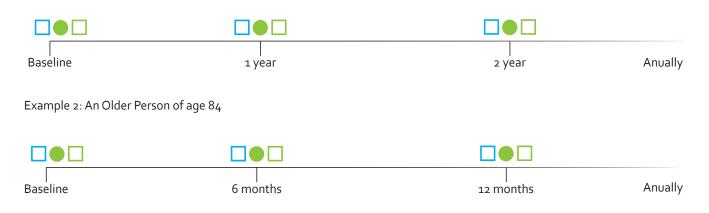| Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Demographic Factors				
All patients	Age	Date of birth	Baseline	Administrative data
	Sex	Sex at birth		
	Ethnicity	Varies by country and should be determined by country (not for cross country comparison)		
	Level of education	Highest level of schooling completed	Baseline and annually	Patient reported
	Living status and location	Most recent living arrangements		
	Smoking status	Smoking status (cigarettes, cigars or tobacco)		
	Alcohol use	How much alcohol is consumed regularly		
	Body mass index	Body mass index		Clinical data
Baseline Clinical Factors				
All patients	Frailty stage	Tracked via the Canadian Study on Health & Aging Clinical Frailty Scale	Baseline and annually	Clinical data
	Inappropriate medication use	Whether any antipsychotics, benzodiazepines, tricyclic antidepressants, opioids, 1st generation antihistamines, vasodilators or antispasmodics have been prescribed in the previous 12 months		
	Cognitive impairment	Whether any cognitive impairment exists		
	Comorbidities	Comorbidities include heart disease, high blood pressure, lung disease, diabetes, kidney disease, liver disease, disease of the nervous system, cancer (within the past 5 years), depression, substance abuse, high cholesterol		Patient reported
	Activities of daily living function	Tracked via the Barthel Index		
	Total number of medications prescribed	What is the total number of (non-topical, and not over-the-counter) regular (daily or weekly) medications the patient has been prescribed		
	Hearing or vision impairment	Whether any hearing or vision impairment exists		
	Level of care received	Whether the patient receives 24hr/daily/weekly support at home		

Outcomes

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Disutility of care				
All patients	Polypharmacy	Includes the total number of prescribed medications, adverse drug events and whether medications make the patient unwell	Baseline and annually	Clinical and patient reported
	Falls	How many falls has the patient sustained in the last 12 months and how many falls have resulted in a fracture, need for any professional medical attention and hospitalization		
Symptoms, functioning and quality of life				
All patients	Loneliness and isolation	Tracked via the UCLA- 3-item scale	Baseline and annually	Patient reported
	Activities of daily living	Includes mobility and limitations to activities of daily living and tracked via the SF-36 and gait speed		Clinical data and patient reported
	Pain	Tracked via the SF-36		Patient reported
	Mood and emotional health			
	Autonomy and control	How much control the patient has over their daily life tracked via the Adult Social Care Outcomes Toolkit		
Carer				
All patients	Carer burden	Carer reported burden tracked via the 4-item screening Zarit Burden Interview	Baseline and annually	Carer reported
Healthcare responsiveness				
All patients	Participation in decision making	Includes confidence in; ability to cope with own health, role as participant in care (involved in discussions, planning) and healthcare professionals. Also includes the experience of having been treated with dignity and respect, coordination of care and discharge to place of choice.	Baseline and annually	Patient reported
Clinical status				
All patients	Frailty	Tracked via the Canadian Study on Health & Aging Clinical Frailty Scale	Baseline and annually	Clinical data
	Time spent in hospital	Number of hospital admissions, readmissions and total time spent in hospital over a year		Administrative data
	Overall survival	All-cause survival		Administrative data
Quality of death				
All patients	Place of death	Whether a preferred place to die has been expressed, the patient died in their usual place of residence and whether they died in their preferred place of death (if previously expressed)	Baseline and annually	Patient reported, clinical data and carer-reported

Follow-Up Timeline and Sample Questionnaires

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

Example 1: An Older Person of age 69 who is not admitted to hospital within 1 year

☐●☐   ☐●☐   ☐●☐
Baseline   1 year   2 year   Anually

Example 2: An Older Person of age 84

☐●☐   ☐●☐   ☐●☐
Baseline   6 months   12 months   Anually

Example 3: An Older Person who is admitted to hospital multiple times during a year

☐●☐   ●☐   ●☐
Baseline   Health   Within 30 days of   Health   Within 30 days of   Anually
              encounter,   discharge from   encounter,   discharge from
              e.g. hospital health encounter   e.g. hospital health encounter
              admission   admission

☐ Carer-reported data **(link)**
● Patient-reported data **(link)**
☐ Clinician-reported data **(link)**

Collecting Patient-Reported Outcome Measures

Survey(s) Used	Licensing Information	Scoring Guide
Medical Outcomes Study: 36-Item Short Form Survey Instrument Version 1 (SF-36)	RAND owns the copyright. All of the surveys and tools from RAND Health are public documents, available without charge. No further written permission is needed for use of this Health Survey. Please visit the following link for more information: http://www.rand.org/health/surveys_tools/mos/mos_core_36item_survey.html	See link to the left
ASCOT Toolkit	© PSSRU at the University of Kent. These materials have been developed by the Personal Social Services Research Unit at the University of Kent with funding from HM Government and are the sole property of the University of Kent. Whilst they encourage its non-commercial use, they request that all parties contact the ASCOT team (ascot@kent.ac.uk) to discuss this and enable tracking of authorised non-commercial use. Please visit the following link for more information: http://www.pssru.ac.uk/ascot/copyright.php	See link to the left
UCLA 3-Item Loneliness Scale	Hughes ME, Waite LJ, Hawkley LC, Cacioppo JT (2004) A short scale for measuring loneliness in large surveys: Results from two population-based studies. Res Aging 26(6):655–672.	
Barthel Index	The Maryland State Medical Society holds the copyright for the Barthel Index. It may be used freely for non- commercial purposes with the following citation: Mahoney FI, Barthel D. "Functional evaluation: the Barthel Index." Maryland State Med Journal 1965;14:56-61. Used with permission. Permission is required to modify the Barthel Index or to use it for commercial purposes.	

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 Older Person Standard Set 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
Reporting Source:	Administrative or clinical
Type:	Numerical
Response Options:	According to institution
Variable ID:	PROXY
Variable:	Patient/proxy reporting
Definition:	Indicate whether a proxy or carer filled in patient reported items on behalf of the patient
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	On all forms
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	0=Patient reported
	1=Proxy reported

Demographic Factors

Variable ID:	AGE
Variable:	Age
Definition:	Date of birth
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Administrative data

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
Reporting Source:	Administrative data
Type:	Single answer
Response Options:	0=Male
	1=Female
Variable ID:	ETHNIC
Variable:	Ethnicity
Definition:	Varies by country and should be determined by country (not for cross country comparison)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Administrative data
Type:	Single answer
Response Options:	N/A
Variable ID:	LEVEDC
Variable:	Level of education
Definition:	What is the highest level of schooling the patient 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
Reporting Source:	Patient 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 patient'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
Reporting Source:	Patient reported
Type:	Single answer
Response Options:	0=Lives alone in own residence
	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
Reporting Source:	Patient 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
Reporting 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 patient?
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
Reporting Source:	Patient 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
Variable ID:	FRALEVEL
Variable:	Frailty stage
Definition:	Frailty stage using the Canadian Study on Health & Aging Clinical Frailty Scale
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Clinical
Type:	Single answer
Response Options:	0=Very fit
	1=Well
	2=Managing well
	3=Vulnerable
	4=Mildy frail
	5=Moderately frail
	6= Severely frail
	7=Very severely frail
	8=Terminally ill
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
Reporting Source:	Patient-reported
Type:	Multiple answers
Response Options:	0=The patient 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
	10=High cholesterol (sometimes referred to as hyperlipidemia)
	11=Problems caused by stroke
	12=Osteoarthritis, or degenerative arthritis
	13=Back pain
	14=Rheumatoid arthritis
Variable ID:	OPAPPROPMED
Variable:	Inappropriate medication use
Definition:	Have any antipsychotics, benzodiazepines, tricyclic antidepressants, opioids, 1st generation antihistamines, vasodilators or antispasmodics have been prescribed in the previous 12 months
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical data
Type:	Multiple answers
Response Options:	0=None of the below
	1=antipsychotics
	2=benzodiazepines
	3=tricyclic antidepressants
	4=opiods
	5=1st generation antihistamines
	6=vasodilators
	7=antispasmodics
Variable ID:	OPMEDTOT
Variable:	Total number of medications prescribed
Definition:	What is the total number of (non-topical, and not over-the-counter) prescribed medications the patient takes regularly (daily/weekly)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical data
Type:	Numerical value
Response Options:	Numerical value of body mass index in kg/m2

Variable ID:	OPADL
Variable:	Activities of daily living function
Definition:	ADL using the Barthel Index
Supporting Definition:	Total score
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Numerical value
Response Options:	0-20

Variable ID:	OPADL_Q01
Variable:	Activities of daily living function
Definition:	ADL using the Barthel Index
Supporting Definition:	Bowels
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Single answer
Response Options:	0=incontinent (or needs to be given enemata)
	1=occasional accident (once/week)
	2=continent

Variable ID:	OPADL_Q02
Variable:	Activities of daily living function
Definition:	ADL using the Barthel Index
Supporting Definition:	Bladder
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Single answer
Response Options:	0=incontinent, or catheterized and unable to manage
	1=occasional accident (max. once per 24 hours)
	2=continent (for over 7 days)

Variable ID:	OPADL_Q03
Variable:	Activities of daily living function
Definition:	ADL using the Barthel Index
Supporting Definition:	Grooming
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Single answer
Response Options:	0=needs help with personal care
	1=independent face/hair/teeth/shaving (implements provided)

Variable ID:	OPADL_Q04
Variable:	Activities of daily living function
Definition:	ADL using the Barthel Index
Supporting Definition:	Toilet use
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Single answer
Response Options:	0=dependent
	1=needs some help, but can do something alone

	2=independent (on and off, dressing, wiping)
Variable ID:	OPADL_Q05
Variable:	Activities of daily living function
Definition:	ADL using the Barthel Index
Supporting Definition:	Feeding
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Single answer
Response Options:	0=unable
	1=needs help cutting, spreading butter, etc
	2=independent (food provided within reach)
Variable ID:	OPADL_Q06
Variable:	Activities of daily living function
Definition:	ADL using the Barthel Index
Supporting Definition:	Transfer
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Single answer
Response Options:	0=unable - no sitting balance
	1=major help (one or two people, physical), can sit
	2=minor help (verbal or phsyical)
	3=independent
Variable ID:	OPADL_Q07
Variable:	Activities of daily living function
Definition:	ADL using the Barthel Index
Supporting Definition:	Mobility
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Single answer
Response Options:	0=immobile
	1=wheelchair independent, including corners, etc
	2=walks with help of one person (verbal or physical)
	3=independent (but may use any aid, e.g., stick)
Variable ID:	OPADL_Q08
Variable:	Activities of daily living function
Definition:	ADL using the Barthel Index
Supporting Definition:	Dressing
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Single answer
Response Options:	0=dependent
	1=needs help, but can do about half unaided
	2=independent (including buttons, zips, laces, etc)
Variable ID:	OPADL_Q09
Variable:	Activities of daily living function
Definition:	ADL using the Barthel Index
Supporting Definition:	Stairs
Inclusion Criteria:	All patients

Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Single answer
Response Options:	0=unable
	1=needs help (verbal, physical, carrying aid)
	2=independent up and down

Variable ID:	OPADL_Q10
Variable:	Activities of daily living function
Definition:	ADL using the Barthel Index
Supporting Definition:	Bathing
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Single answer
Response Options:	0=dependent
	1=independent (or in shower)

Variable ID:	OPCOG
Variable:	Cognitive impairment
Definition:	Indicate if the patient has evidence of cognitive impairment
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Clinical
Type:	Single answer
Response Options:	0=No cognitive impairment present
	1=Yes, cognitive impairment present, but not previously diagosed with dementia
	2=Yes, dementia diagnosed

Variable ID:	OPHEAR
Variable:	Hearing impairment
Definition:	Indicate if the patient has a hearing impairment and whether this is corrected (eg with hearing aid)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Clinical
Type:	Single answer
Response Options:	0=No impairment present
	1=Yes impairment present, uncorrected
	2=Yes impairment present, corrected

Variable ID:	OPVIS
Variable:	Vision impairment
Definition:	Indicate if the patient has a vision impairment and whether this is corrected (e.g. with glasses)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Clinical
Type:	Single answer
Response Options:	0=No impairment present
	1=Yes impairment present, uncorrected
	2=Yes impairment present, corrected

Variable ID:	OPLEVCARE
Variable:	Level of care received
Definition:	Indicate what level of care the patient routinely receives
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported data
Type:	Single answer
Response Options:	0=No care required
	1=Weekly care required
	2=Daily care required
	3=Multiple times a day care required
	4=24 hour care required

Outcomes

Disutility of care

Variable ID:	POLYPHARMADV
Variable:	Polypharmacy
Definition:	Has the patient has experienced an adverse outcome due to their prescribed medication use in the last year?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Clinical
Type:	Single answer
Response Options:	0=None
	1=Hospitalization due to an adverse drug reaction
	2=Fall
	3= Mortality
	4=Other
	999=unknown

Variable ID:	POLYPHARMNO
Variable:	Polypharmacy
Definition:	What is the total number of prescribed medications regularly (on a daily/weekly basis) taken? (Please do not include over-the-counter medications, creams, lotions or ointments)
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported
Type:	Numerical
Response Options:	N/A

Variable ID:	POLYPHARMILL
Variable:	Polypharmacy
Definition:	Do you think any of your medications are making you unwell?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient reported
Type:	Single answer
Response Options:	0=Yes
	1=No
	2=Maybe
	3=Unknown

Variable ID:	FALLSTOTNO
Variable:	Falls
Definition:	How many falls have you had in the last 12 months?
Supporting Definition:	Using the WHO (2007) definition of a 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
Reporting Source:	Patient reported
Type:	Numerical
Response Options:	N/A
Variable ID:	FALLSFRACT

Variable:	Falls
Definition:	How many falls has the patient had in the last 12 months that have resulted in (any type of) fracture?
Supporting Definition:	Using the WHO (2007) definition of a 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:	Patients scoring 1 or more for the total number of falls
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Numerical
Response Options:	N/A
Variable ID:	FALLSMEDATT
Variable:	Falls
Definition:	How many falls has the patient had in the last 12 months that have resulted in the need for any professional medical attention excluding hospitalization requiring an overnight stay?
Supporting Definition:	Using the WHO (2007) definition of a 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:	Patients scoring 1 or more for the total number of falls
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Numerical
Response Options:	N/A
Variable ID:	FALLSHOSP
Variable:	Falls
Definition:	How many falls has the patient had in the last 12 months that have resulted in the need for hospitalization requiring an overnight stay?
Supporting Definition:	Using the WHO (2007) definition of a 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:	Patients scoring 1 or more for the total number of falls
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Numerical
Response Options:	N/A

Symptoms, functioning and quality of life

Variable ID:	LONELIISOL_Q01
Variable:	Question 1 of the UCLA 3-item Loneliness Scale
Definition:	How often do you feel that you lack companionship?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Numerical
Response Options:	1=Hardly ever 2=Some of the time 3=Often
Variable ID:	LONELIISOL_Q02
Variable:	Question 2 of the UCLA 3-item Loneliness Scale
Definition:	How often do you feel left out?

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Hardly ever
	2=Some of the time
	3=Often

Variable ID:	LONELIISOL_Q03
Variable:	Question 3 of the UCLA 3-item Loneliness Scale
Definition:	How often do you feel isolated from others?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Hardly ever
	2=Some of the time
	3=Often

Variable ID:	LONELIISOL_Q04
Variable:	Single loneliness question
Definition:	How often do you feel lonely?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Clinical
Type:	Single answer
Response Options:	1=Hardly ever
	2=Some of the time
	3=Often

Variable ID:	ADLMOB
Variable:	Gait speed
Definition:	4-metre timed walk (or other short course: 4m-10m) at usual walking speed. (Patients are allowed to use assistive devices if needed. Patient should repeat this walk twice, with the best time used for scoring.)
Supporting Definition:	Metres per second (m/s)
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Numerical value in meters per second
Response Options:	N/A

Variable ID:	SF36ADLQOL_Q01
Variable:	Question 1 of the 36-Item Health Survey 1.0
Definition:	In general, would you say your health is:
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Excellent
	2=Very good
	3=Good
	4=Fair
	5=Poor

Variable ID:	SF36ADLQOL_Q02
Variable:	Question 2 of the 36-Item Health Survey 1.0

Definition:	Compared to one year ago, how would your rate your health in general now?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Much better now than one year ago
	2=Somewhat better now than one year ago
	3=About the same
	4=Somewhat worse now than one year ago
	5=Much worse now than one year ago

Variable ID:	SF36ADLQOL_Q03
Variable:	Question 3 of the 36-Item Health Survey 1.1
Definition:	The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
Supporting Definition:	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, limited a lot
	2=Yes, limited a little
	3=No, not limited at all

Variable ID:	SF36ADLQOL_Q04
Variable:	Question 4 of the 36-Item Health Survey 1.2
Definition:	The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
Supporting Definition:	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, limited a lot
	2=Yes, limited a little
	3=No, not limited at all

Variable ID:	SF36ADLQOL_Q05
Variable:	Question 5 of the 36-Item Health Survey 1.3
Definition:	The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
Supporting Definition:	Lifting or carrying groceries
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, limited a lot
	2=Yes, limited a little
	3=No, not limited at all

Variable ID:	SF36ADLQOL_Q06
Variable:	Question 6 of the 36-Item Health Survey 1.4
Definition:	The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
Supporting Definition:	Climbing several flights of stairs
Inclusion Criteria:	All patients

Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, limited a lot
	2=Yes, limited a little
	3=No, not limited at all

Variable ID:	SF36ADLQOL_Q07
Variable:	Question 7 of the 36-Item Health Survey 1.5
Definition:	The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
Supporting Definition:	Climbing one flight of stairs
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, limited a lot
	2=Yes, limited a little
	3=No, not limited at all

Variable ID:	SF36ADLQOL_Q08
Variable:	Question 8 of the 36-Item Health Survey 1.5
Definition:	The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
Supporting Definition:	Bending, kneeling, or stooping
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, limited a lot
	2=Yes, limited a little
	3=No, not limited at all

Variable ID:	SF36ADLQOL_Q09
Variable:	Question 9 of the 36-Item Health Survey 1.6
Definition:	The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
Supporting Definition:	Walking more than a mile
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, limited a lot
	2=Yes, limited a little
	3=No, not limited at all

Variable ID:	SF36ADLQOL_Q10
Variable:	Question 10 of the 36-Item Health Survey 1.6
Definition:	The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
Supporting Definition:	Walking several blocks
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, limited a lot
	2=Yes, limited a little
	3=No, not limited at all

Variable ID:	SF36ADLQOL_Q11
Variable:	Question 11 of the 36-Item Health Survey 1.7
Definition:	The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
Supporting Definition:	Walking one block
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, limited a lot
	2=Yes, limited a little
	3=No, not limited at all

Variable ID:	SF36ADLQOL_Q12
Variable:	Question 12 of the 36-Item Health Survey 1.7
Definition:	The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
Supporting Definition:	Bathing or dressing yourself
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, limited a lot
	2=Yes, limited a little
	3=No, not limited at all

Variable ID:	SF36ADLQOL_Q13
Variable:	Question 13 of the 36-Item Health Survey 1.8
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?
Supporting Definition:	Cut down the amount of time you spent on work or other activities
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes
	2=No

Variable ID:	SF36ADLQOL_Q14
Variable:	Question 14 of the 36-Item Health Survey 1.8
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?
Supporting Definition:	Accomplished less than you would like
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes
	2=No

Variable ID:	SF36ADLQOL_Q15
Variable:	Question 15 of the 36-Item Health Survey 1.9
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?
Supporting Definition:	Were limited in the kind of work or other activities
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes

	2=No
Variable ID:	SF36ADLQOL_Q16
Variable:	Question 16 of the 36-Item Health Survey 1.9
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?
Supporting Definition:	Had difficulty performing the work or other activities (for example, it took extra effort)
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes
	2=No

Variable ID:	SF36ADLQOL_Q17
Variable:	Question 17 of the 36-Item Health Survey 1.10
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)?
Supporting Definition:	Cut down the amount of time you spent on work or other activities
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes
	2=No

Variable ID:	SF36ADLQOL_Q18
Variable:	Question 18 of the 36-Item Health Survey 1.10
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)?
Supporting Definition:	Accomplished less than you would like
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes
	2=No

Variable ID:	SF36ADLQOL_Q19
Variable:	Question 19 of the 36-Item Health Survey 1.11
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)?
Supporting Definition:	Didn't do work or other activities as carefully as usual
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes
	2=No

Variable ID:	SF36ADLQOL_Q20
Variable:	Question 20 of the 36-Item Health Survey 1.11
Definition:	During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
Supporting Definition:	N/A
Inclusion Criteria:	All patients

Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Not at all
	2=Slightly
	3=Moderately
	4=Quite a bit
	5=Extremely

Variable ID:	SF36ADLQOL_Q21
Variable:	Question 21 of the 36-Item Health Survey 1.11
Definition:	How much bodily pain have you had during the past 4 weeks?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=None
	2=Very mild
	3=Mild
	4=Moderate
	5=Severe
	6=Very severe

Variable ID:	SF36ADLQOL_Q22
Variable:	Question 22 of the 36-Item Health Survey 1.11
Definition:	During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Not at all
	2=Slightly
	3=Moderately
	4=Quite a bit
	5=Extremely

Variable ID:	SF36ADLQOL_Q23
Variable:	Question 23 of the 36-Item Health Survey 1.12
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 . . .
Supporting Definition:	Did you feel full of pep?
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
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:	SF36ADLQOL_Q24
Variable:	Question 24 of the 36-Item Health Survey 1.13
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 . . .

Supporting Definition:	Have you been a very nervous person?
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
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:	SF36ADLQOL_Q25
Variable:	Question 25 of the 36-Item Health Survey 1.14
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 . . .
Supporting Definition:	Have you felt so down in the dumps that nothing could cheer you up?
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
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:	SF36ADLQOL_Q26
Variable:	Question 26 of the 36-Item Health Survey 1.15
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 . . .
Supporting Definition:	Have you felt calm and peaceful?
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
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:	SF36ADLQOL_Q27
Variable:	Question 27 of the 36-Item Health Survey 1.16
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 . . .
Supporting Definition:	Did you have a lot of energy?
Inclusion Criteria:	All patients

Timing:	Baseline and annually
Reporting Source:	Patient-reported
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:	SF36ADLQOL_Q28
Variable:	Question 28 of the 36-Item Health Survey 1.17
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 . . .
Supporting Definition:	Have you felt downhearted and blue?
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
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:	SF36ADLQOL_Q29
Variable:	Question 29 of the 36-Item Health Survey 1.18
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 . . .
Supporting Definition:	Did you feel worn out?
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
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:	SF36ADLQOL_Q30
Variable:	Question 30 of the 36-Item Health Survey 1.19
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 . . .
Supporting Definition:	Have you been a happy person?
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
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:	SF36ADLQOL_Q31
Variable:	Question 31 of the 36-Item Health Survey 1.20
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 . . .
Supporting Definition:	Did you feel tired?
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
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:	SF36ADLQOL_Q32
Variable:	Question 32 of the 36-Item Health Survey 1.21
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 and annually
Reporting Source:	Patient-reported
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:	SF36ADLQOL_Q33
Variable:	Question 33 of the 36-Item Health Survey 1.22
Definition:	How TRUE or FALSE is each of the following statements for you.
Supporting Definition:	I seem to get sick a little easier than other people
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Definitely true
	2=Mostly true
	3=Don't know
	4=Mostly false
	5=Definitely false

Variable ID:	SF36ADLQOL_Q34
Variable:	Question 34 of the 36-Item Health Survey 1.23
Definition:	How TRUE or FALSE is each of the following statements for you.
Supporting Definition:	I am as healthy as anybody I know
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported

Type:	Single answer
Response Options:	1=Definitely true
	2=Mostly true
	3=Don't know
	4=Mostly false
	5=Definitely false

Variable ID:	SF36ADLQOL_Q35
Variable:	Question 35 of the 36-Item Health Survey 1.24
Definition:	How TRUE or FALSE is each of the following statements for you.
Supporting Definition:	I expect my health to get worse
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Definitely true
	2=Mostly true
	3=Don't know
	4=Mostly false
	5=Definitely false

Variable ID:	SF36ADLQOL_Q36
Variable:	Question 36 of the 36-Item Health Survey 1.25
Definition:	How TRUE or FALSE is each of the following statements for you.
Supporting Definition:	My health is excellent
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Definitely true
	2=Mostly true
	3=Don't know
	4=Mostly false
	5=Definitely false

Variable ID:	AUTONCON
Variable:	Question from the Adult Social Care Outcomes Toolkit
Definition:	Which of the following statements best describes how much control you have over your daily life? (By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want.
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Caregiver-reported
Type:	Single answer
Response Options:	1=I have as much control over my daily life as I want
	2=I have adequate control over my daily life
	3=I have some control over my daily life, but not enough
	4=I have no control over my daily life

Carer burden

Variable ID:	CARERBUR_Q01
Variable:	Question 1 of the 4-item Zarit Burden Interview
Definition:	Do you feel that because of your relative that you don't have enough time for yourself?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Caregiver-reported

Type:	Single answer
Response Options:	1=Never
	2=Rarely
	3=Sometime
	4=Quite frequently
	5=Nearly always

Variable ID:	CARERBUR_Q02
Variable:	Question 2 of the 4-item Zarit Burden Interview
Definition:	Do you feel stressed between caring for your relative and trying to meet other responsibilities (work, home)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Caregiver-reported
Type:	Single answer
Response Options:	1=Never
	2=Rarely
	3=Sometime
	4=Quite frequently
	5=Nearly always

Variable ID:	CARERBUR_Q03
Variable:	Question 3 of the 4-item Zarit Burden Interview
Definition:	Do you feel strained when you are around your relative?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Caregiver-reported
Type:	Single answer
Response Options:	1=Never
	2=Rarely
	3=Sometime
	4=Quite frequently
	5=Nearly always

Variable ID:	CARERBUR_Q04
Variable:	Question 4 of the 4-item Zarit Burden Interview
Definition:	Do you feel uncertain about what to do about your relative?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Never
	2=Rarely
	3=Sometime
	4=Quite frequently
	5=Nearly always

Participation and decision making

Variable ID:	PARTANDDEC_Q01
Variable:	Discharge to place of choice
Definition:	After an admission or readmission to hospital, were you discharged to your place of choice? (if there have been multiple admissions, please refer to the most recent admission)
Supporting Definition:	N/A
Inclusion Criteria:	Patients who have had any hospital admission
Timing:	Baseline

	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes
	2=No
	3=Don't know

Variable ID:	PARTANDDEC_Q02
Variable:	Involved in discharge planning
Definition:	Do you agree with the following statement?
Supporting Definition:	Regarding discharge planning, I was as involved in discussions and decisions about my care, support and treatment as I wanted to be
Inclusion Criteria:	Patients who have had any hospital admission
Timing:	Baseline
	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, definitely
	2=Yes, to some extent
	3=No

Variable ID:	PARTANDDEC_Q03
Variable:	Confidence in ability to cope with own health problems Question 1
Definition:	Do you agree with the following statement?
Supporting Definition:	I was given enough information about my condition or treatment
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not enough
	2 = The right amount
	3 =Too much

Variable ID:	PARTANDDEC_Q04
Variable:	Confidence in ability to cope with own health problems Question 2
Definition:	Do you agree with the following statement?
Supporting Definition:	Staff gave my family or someone close to me all the information they needed to help care for me
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Yes, definitely
	2 = Yes, to some extent
	3 =No, I did not want or need them to

Variable ID:	PARTANDDEC_Q05
Variable:	Confidence in role as participant in care (involved in discussions, decision making and care planning) Question 1
Definition:	During the delivery of your healthcare, were you able to participate in decision-making about your care?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, definitely

2=Yes, to some extent

3=No

Variable ID:	PARTANDDEC_Q06
Variable:	Confidence in role as participant in care (involved in discussions, decision making and care planning) Question 2
Definition:	Do you agree with the following statement?
Supporting Definition:	I was as involved in discussions and decisions about my care, support and treatment as I wanted to be
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, definitely
	2=Yes, to some extent
	3=No

Variable ID:	PARTANDDEC_Q07
Variable:	Confidence in role as participant in care (involved in discussions, decision making and care planning) Question 3
Definition:	Do you agree with the following statement?
Supporting Definition:	My family or carer was also involved in these decisions as much as I wanted them to be
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes, definitely
	2=Yes, to some extent
	3=No
	4=There was no family or carer available to be involved
	5=I did not want my family or carer to be involved

Variable ID:	PARTANDDEC_Q08
Variable:	Confidence in healthcare professionals
Definition:	Did you have confidence and trust in the healthcare staff treating or supporting you?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	2 = Yes, always
	2 = Yes, sometimes
	3 = No

Variable ID:	PARTANDDEC_Q09
Variable:	Experience of having been treated with dignity and respect
Definition:	Do you agree with the following statement?
Supporting Definition:	Overall, I felt I was treated with respect and dignity while I was receiving my care from this service
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	2 = Yes, always

	2 = Yes, sometimes
	3 = No
Variable ID:	PARTANDDEC_Q10
Variable:	Coordination of care Question 1
Definition:	Do you agree with the following statement?
Supporting Definition:	The staff that cared for me had been given all the necessary information about my condition or illness from the person who referred me
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes
	2=No
	3=Don't know
Variable ID:	PARTANDDEC_Q11
Variable:	Coordination of care Question 2
Definition:	Do you agree with the following statement?
Supporting Definition:	I always know who was coordinating my care
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Clinical
Type:	Single answer
Response Options:	1=Yes
	2=No - I co-ordinate my own care and support
	3=Don't know
	4=Not sure

Frailty

Variable ID:	FRALEVEL
Variable:	Frailty stage
Definition:	Frailty stage using the Canadian Study on Health & Aging Clinical Frailty Scale
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Administrative
Type:	Single answer
Response Options:	0=Very fit
	1=Well
	2=Managing well
	3=Vulnerable
	4=Mildly frail
	5=Moderately frail
	6= Severely frail
	7=Very severely frail
	8=Terminally ill

Time spent in hospital

Variable ID:	ADMISSIONS
Variable:	Admissions
Definition:	How many times has the patient been admitted (requiring an overnight stay) to a hospital or acute care facility in the last 12 months (unplanned, all-cause)
Supporting Definition:	N/A

Timing:	Baseline
	Annually
Reporting Source:	Administrative
Type:	Numerical value
Response Options:	N/A
Variable ID:	READMISSIONS
Variable:	Readmissions
Definition:	How many times has the older person been readmitted to a hospital or acute care facility within 30 days of a previous admission (unplanned, all cause) in the last 12 months
Supporting Definition:	N/A
Inclusion Criteria:	All patients who have had a hospital admission
Timing:	Baseline
	Annually
Reporting Source:	Administrative
Type:	Numerical value
Response Options:	N/A
Variable ID:	LENGTHOFST
Variable:	Total length of stay in hospital within 12 month
Definition:	Indicate the total length (in days)of all admissions to hospital in the last 12 months
Supporting Definition:	N/A
Inclusion Criteria:	All patients who have had a hospital admission
Timing:	Baseline
	Annually
Reporting Source:	Clinical
Type:	Numerical value
Response Options:	N/A
Variable ID:	DISCHARGELOC
Variable:	Place of discharge
Definition:	Was the patient discharged to their usual place of residence (this is where the patient resided prior to their admission)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients who have had a hospital admission
Timing:	Baseline
	Annually
Reporting Source:	Administrative
Type:	Single answer
Response Options:	1=Yes
	2=No
	3=Unknown

Overall survival

Variable ID:	OVERALLSURV
Variable:	Overall survival
Definition:	Indicate whether the patient has died
Supporting Definition:	All cause mortality
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Administrative (e.g. death registry)
Type:	Single answer
Response Options:	0=No
	1=Yes
Variable ID:	DEATHDATE
Variable:	Date of death
Definition:	Indicate the date of death

Supporting Definition:	N/A
Inclusion Criteria:	All patients who have died
Timing:	Baseline
	Annually
Reporting Source:	Administrative
Type:	Date
Response Options:	DD/MM/YYYY

Place of death

Variable ID:	EXPREDEA
Variable:	Desire to express preferred place of death
Definition:	Please indicate whether you would like to express a preferred place to die?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1=Yes
	2=No, would prefer not to say
	3=Unknown

Variable ID:	PREFPOD
Variable:	Preferred place of death
Definition:	Please indicate where you would prefer to die?
Supporting Definition:	N/A
Inclusion Criteria:	Patient who would like to express a preferred place of death
Timing:	Baseline
	Annually
Reporting Source:	Carer-reported
Type:	Single answer
Response Options:	1=Acute hospital
	2=Community hospitals
	3=Own residence
	4=Care/nursing home
	5=Hospice
	6=Other residence (e.g. carer/family)
	7=Other
	8=Unknown

Variable ID:	PREPODCAR
Variable:	Whether the patient died in their preferred place
Definition:	Please indicate whether you believe your relative died in their place of preference?
Supporting Definition:	N/A
Inclusion Criteria:	Carers whose patient has died
Timing:	Baseline
	Annually
Reporting Source:	Clinical
Type:	Single answer
Response Options:	1=Yes
	2=No
	3=Unknown

Variable ID:	POD
Variable:	Place of death
Definition:	Indicate where the patient died as indicated on certificate of death
Supporting Definition:	N/A
Inclusion Criteria:	All patients who have died
Timing:	Baseline

	Annually
Reporting Source:	Administrative
Type:	Single answer
Response Options:	1=Acute hospital
	2=Community hospitals
	3=Own residence
	4=Care/nursing home
	5=Hospice
	6=Other residence (e.g. carer/family)
	7=Other
	8=Unknown
Variable ID:	PODUSUAL
Variable:	Place of death as usual place of residence
Definition:	Indicate whether the patient died in their usual place of residence
Supporting Definition:	N/A
Inclusion Criteria:	All patients who have died
Timing:	Baseline
	Annually
Reporting Source:	Clinical
Type:	Single answer
Response Options:	1=Yes
	2=No
	3=Unknown
Variable ID:	PODPERF
Variable:	Place of death as preferred
Definition:	Indicate whether the patient died in their place of preference
Supporting Definition:	This is informed by the patient's previous expressed preferred place of death
Inclusion Criteria:	All patients who have died
Timing:	Baseline
	Annually
Reporting Source:	Clinical
Type:	Single answer
Response Options:	1=Yes
	2=No
	3=Unknown

ICHOM Contact Information

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Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
1.0.1	Outcomes Table	Modification to Participation in Decision Making supporting information
1.0.2	Data Dictionary	Removed DATEOFDEATH from Disutility of Care outcomes
1.0.3	Contact Information	Removed inactive email address: ichomteam@ichom.org

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