

CHRONIC KIDNEY DISEASE **DATA COLLECTION REFERENCE GUIDE**

Version 1.0.0 Revised: October 25th, 2017





We are thrilled that you are interested in measuring outcomes for your chronic kidney disease 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.

© 2017 ICHOM. All rights reserved. When using this set of outcomes, or quoting therefrom, in any way, we solely require that you always make a reference to ICHOM as the source so that this organization can continue its work to define more standard outcome sets.

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, as well as scoring guides for patient-reported outcomes is included in the appendix.

Working Group Members for Chronic Kidney Disease

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Chronic Kidney Disease in partnership with ICHOM, under the leadership of Dr. Willem Jan Bos, Nephrologist at St. Antonius Hospital, Netherlands.

Belgium Andrea Stopper Wim van Biesen Germany Markus Ketteler Mexico Guillermo Garcia-	Netherlands Hans Bart Kitty Jager Marc Hemmelder Türkan Terkivatan Willem Jan Bos Wouter Verberne	Spain Eduardo Parra Moncasi Taiwan Chih-Wei Yang United Arab Emirates Muhamed Al Rohani	United Kingdom Charlotte Roberts David Wheeler Elizabeth Gibbons Zofia Das-Gupta United States Andrew Allegretti Katherine Tuttle
Garcia			Laurie Konowitz

Supporting Organizations

The Chronic Kidney DIsease Standard Set is made possible only through the support of the following organizations.

Thank you.









Conditions and Treatment Approaches Covered for Chronic Kidney Disease

For Chronic Kidney Disease, the following conditions and treatment approaches (or interventions) are covered by our Standard Set.

Conditions	Chronic Kidney Disease Stage G ₃ a/A ₃ Chronic Kidney Disease Stage G ₃ b/A ₂ /A ₃ Chronic Kidney Disease Stage G ₅
Treatment Approaches	Pre-RRT = Pre-Renal Replacement Therapy HD = Haemodialysis PD = Peritoneal Dialysis Tx = Renal Transplantation CC = Conservative Care

		Persistent albuminuria categories, description and range				
Prognosis of CKD by GFR			A1	A2	А3	
and albuminuria categories: KDIGO 2012		Normal to mildly increased	Moderately increased	Severely increased		
		<30 mg/g <3 mg/mmol	30–300 mg/g 3–30 mg/mmol	>300 mg/g >30 mg/mmol		
²),	G1	Normal or high	≥90			
/1.73 m nge	G2	Mildly decreased	60–89			
sategories (ml/min/1.73 description and range	G3a	Mildly to moderately decreased	45–59			
gories (cription	G3b	Moderately to severely decreased	30–44			
GFR categories (ml/min/1.73 m²), description and range	G4	Severely decreased	15–29			
5	G5	Kidney failure	<15			

Permission obtained from KDIGO - bit.ly/KDIGOGuide

ICHOM Standard Set for Chronic Kidney Disease Overview

Case-Mix Variables

Patient Population	Measure	Supporting Information	Timing	Data Source
Demographic Factor	rs			
	Age	N/A		
All patients	Sex	Sex at birth	Baseline	Patient-reported
	Education level	Highest attained education		
Baseline Clinical Sta	tus			
	Comorbidities	_		Clinical
	BMI	_		Cillical
All patients	Smoking	_		Patient-reported
All patients				Clinical or
	Primary renal disease			Administrative
				data
Pre-RRT & CC	Renal function			Administrative
patients	Renarionction		Baseline	data
HD patients	Vascular access type			Clinical or
Tx patients	Tue se and a set to se a	− N/A		Administrative
	Transplant type			data
	Kidney allograft	_		
	function			Administrative
Pre-RRT, CC & Tx patients	Albuminuria	_		data
	Albuminuria	_		
HD, PD, CC & Tx patients	Previous graft			Clinical or
	Dues de coe es el el las			Administrative
	Previous modality			data

Outcomes overview

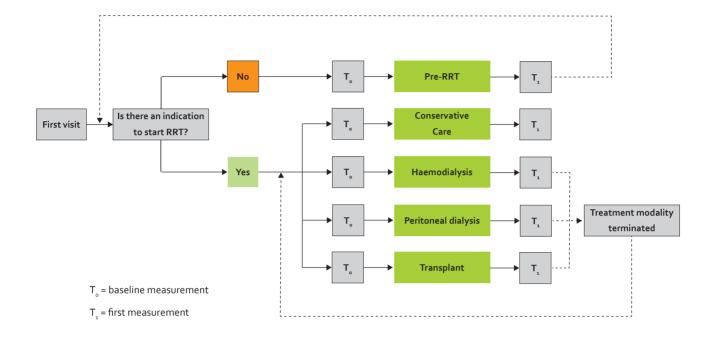
Patient Population	Measure	Supporting Information	Timing	Data Source
Survival		11 3		
All patients	Survival	Date & cause of death	Ongoing	Clinical or Administrative data
Burden of Care				
20.40.0.0.0.0.0	Hospitalisation	Number of admissions and days in hospital	Annually	Administrative data
All patients	Cardiovascular events	Tracked with additional questions		Clinical or Administrative data
Patient-Reported He				
HD, PD & CC patients	Health-Related Quality of Life, Pain, Fatigue, Physical Function, Depression, Daily Activity	Tracked with PROMIS-29 + PROMIS Global Health, or RAND-36 or SF-36	6-monthly	Patient-reported
Pre-RRT & Tx patients	Health-Related Quality of Life, Pain, Fatigue, Physical Function, Depression, Daily Activity	Tracked with PROMIS-29 + PROMIS Global Health, or RAND-36 or SF-36	Annually	Patient-reported
Treatment-Specific				
Pre-RRT & CC patients	Renal function	Tracked with eGFR and/or Serum Creatinine 6-monthly	C manufalla	Administrative data
	Kidney allograft function		6-montnly	
Tx patients	Kidney allograft survival	Tracked with status of transplant	,	
	Malignancies	Solid tumour, skin cancer, haematological malignancies		Clinical or
PD patients	PD modality survival	Tracked with status of PD modality survival	_	Administrative data
HD patients	Vascular access survival	Tracked with status of vascular access	6-monthly	

Tier 2 Implementation – Important outcomes

Patient Population	Measure	Supporting Information	Timing	Data Source
Treatment-Specific				
HD, PD & Tx patients	Bacteraemia	Tracked with positive blood culture with clinical signs	6-monthly	Clinical
Pre-RRT, CC & Tx patients	Albuminuria	Tracked with uACR or uPCR	Annually	Administrative data
PD patients	Peritonitis	Clinically suspected and/or culture-proven peritonitis	6-monthly	
Tx patients	Acute rejection	Clinically-suspected or biopsy- proven	6-monthly for the first year, then annually	Clinical

Treatment Pathway

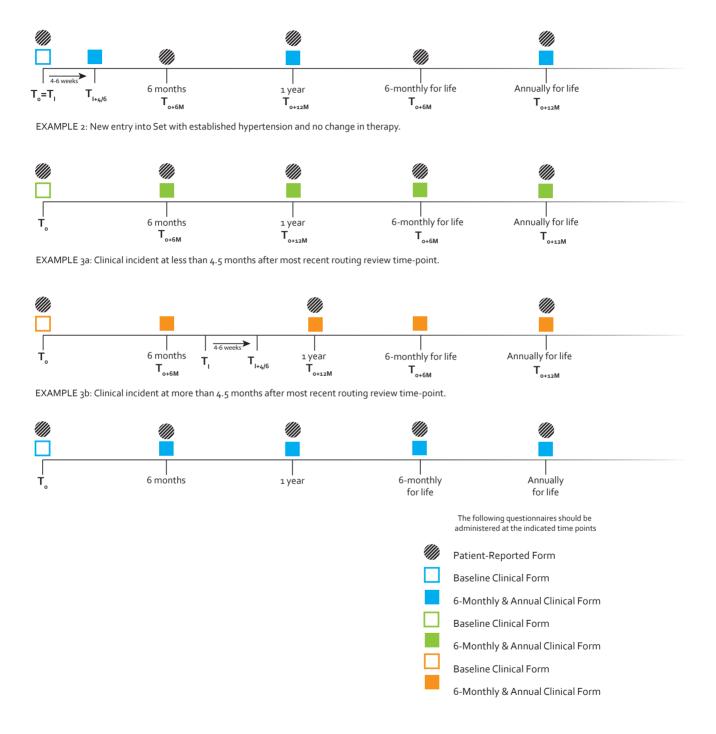
The following map illustrates how the patient in each modality will be transferred between treatment modalities, where necessary.



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.





DATA COLLECTION REFERENCE GUIDE CHRONIC KIDNEY DISEASE | 7

Collecting Patient-Reported Outcome Measures

Because of varying costs and licensing requirements of tools, the ICHOM chronic kidney disease working group recommends using one of the following options to measure health-related quality of life, fatigue, pain, physical function, depression and daily activity:

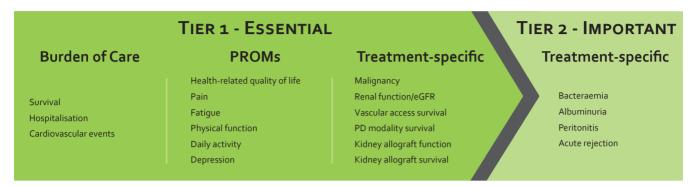
- The Optum™ SF-36v2® Health Survey **OR**
- PROMIS-Global Health AND PROMIS-29 OR
- RAND-36

For cost and licensing information, please refer to the table below. For instructions on comparing scores between these tools, please refer to the PROsetta Stone® information below.

Chronic Kidney DIsease Survey Used	Licensing Information	Scoring Guide
The Optum™ SF-36v2® Health Survey	The SF-36v2 Health Survey requires a license agreement prior to the use or reprodution of the tool. Information on how to obtain a license can be found here: bit.ly/SF36LIC	The scoring guide for the SF36v2 is only available upon a license agreement being made
PROMIS-Global Health	Free for use in clinical practice and a license is not required. Information about available translations can be	The scoring guide for the PROMIS- Global Health can be found at: bit. ly/PROMISGLOBALSCORE
PROMIS-29	found here: http://www. nihpromis.org/measures/ translations	The scoring guide for the PROMIS-29 can be found at: bit.ly/ PROMIS29SCORE
RAND-36	Free for use in clinical practice and a license is not required. The RAND-36 is available in English and Arabic. Both versions can be found here: https://www.rand.org/health/surveys_tools/mos/36-item-short-form.html	The scoring guide for the RAND- 36 can be found at: bit.ly/ RAND36SCORE
PROsetta Stone®	Developed and applied methods to link the Patient-Reported Outcomes Measurement Information System (PROMIS) with other related instruments (e.g., SF-36) to expand the range of PRO assessment options within a common, standardized metric. It provides equivalent scores for different scales that measure the same health outcome. http://www.prosettastone.org/Pages/default.aspx	

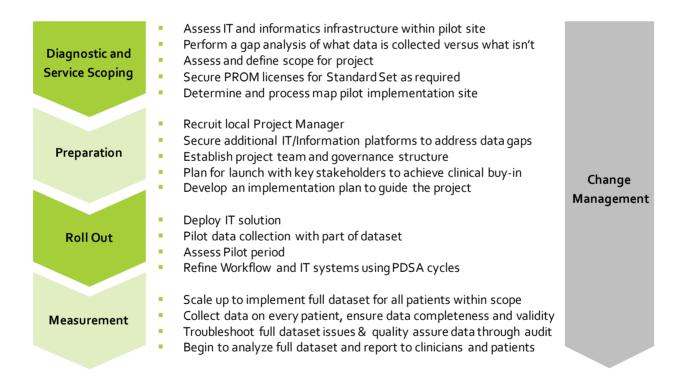
The Growing ICHOM Community

There is a growing community of healthcare providers implementing the ICHOM Standard Sets. To support your organisation in implementing the set and the measurement of outcomes data, we have outlined a framework to guide the implementation and reporting of patient-centred outcomes.



Implementation framework:

The framework below outlines the structured process to guide the implementation of an ICHOM Standard Set at your organisation. Typically, an implementation project takes 9 months to complete.



Translating the Set Tools:

PROM tools within the ICHOM Sets are available in a number of languages. To check the availability of translations, we advise contacting the Tool authors directly to obtain and translate the PROM surveys into your desired language. To independently translate PROM surveys, we recommend following the 10 steps outlined below:*1

Step 1	Preparation	Initial work carried out before the translation work begins
Step 2	Forward Translation	Translation of the original language, also called source, version of the instrument into another language, often called the target language
Step 3	Reconciliation	Comparing and merging more than one forward translation into a single forward translation
Step 4	Back Translation	Translation of the new language version back into the original language
Step 5	Back Translation Review	Comparison of the back-translated versions of the instrument with the original to highlight and investigate discrepancies between the original and the reconciled translation, which is then revised in the process of resolving the issues
Step 6	Harmonization	Comparison of back translations of multiple language versions with each other and the original instrument to highlight discrepancies between the original and its derivative translations, as well as to achieve a consistent approach to translation problems
Step 7	Cognitive Debriefing	Testing the instrument on a small group of relevant patients or lay people in order to test alternative wording and to check understandability, interpretation, and cultural relevance of the translation
Step 8	Review of Cognitive Debriefing Results and Finalisation	Comparison of the patients' or lay persons' interpretation of the translation with the original version to highlight and amend discrepancies
Step 9	Proofreading	Final review of the translation to highlight and correct any typographic, grammatical or other errors
Step 10	Final Report	Report written at the end of the process documenting the development of each translation

^{*}These ten steps follow the ISPOR Principles of Good Practice:The Cross-Cultural Adaptation Proccess for Patient-Reported Outcomes Measures ^{1 Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., et al. (2005). Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. Value in Health, 8(2), 94–104. doi:10.1111/j.1524-4733.2005.04054.x.}

For any questions about implementation please contact us at: implement@ichom.org

Appendix

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Chronic Kidney Disease 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

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

Administrative or clinical Data Source:

> Type: Numerical

Response Options: According to institution

Demographic Factors

Variable ID: AGE Variable: Age

Definition: Indicate the patient's age Supporting Definition: Recorded as year of birth

Inclusion Criteria: All patients

Timing: Baseline Data Source: Patient-reported

Type: Date by YYYY

Response Options: YYYY

Variable ID: SEX

Variable: Sex at birth

Definition: Indicate the patient's sex at birth

Supporting Definition: N/A

> Inclusion Criteria: All patients Timing: Baseline

> > Data Source: Patient-reported Single answer Type:

1 = Male

Response Options: 2 = Female

999 = Unknown

Variable ID: SOCIO

Variable: Education level

Definition: Highest attained education

Level of schooling defined in each country according to the International Standard **Supporting Definition:**

Classification of Education

Inclusion Criteria: All patients

Timing: Baseline and ongoing

Data Source: Patient-reported

Type: Single answer

Response Options: o = None

1 = Primary 2 = Secondary 3 = Tertiary

Baseline Characteristics

Variable ID: TREATMENTTYPE
Variable: Treatment pathway

Definition: Indicate which treatment pathway the patient is following

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Baseline

Data Source: Administrative or clinical

Type: Single answer

Response Options: 1 = Pre-Renal Replacement Therapy

2 = Conservative care3 = Haemodialysis4 = Peritoneal Dialysis

5 = Functioning kidney transplant

Variable ID: PREVTREAT

Variable: Previous modality treatment(s)

Definition: Indicate the patient's previous modality treatment(s)

Supporting Definition: N/A

Inclusion Criteria: Tx, HD, PD, CC

Timing: Baseline

Data Source: Administrative or clinical

Type: Multiple answer

Response Options: o = None

1 = Haemodialysis 2 = Peritoneal dialysis 3 = Kidney transplant 999 = Unknown

Variable ID: SMOKING
Variable: Smoking status

Definition: Indicate the patient's category

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Baseline

Data Source: Patient-reported **Type:** Single answer

Response Options: o = Never

1 = Former 2 = Current

Variable ID: HEIGHT Variable: Height

Definition: Indicate the patient's height

Supporting Definition: Height and weight are used to calculate BMI

Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical

Type: Numerical value

Response Options: Numerical value of height in centimeters or inches

Variable ID: HEIGHTUNIT Variable: Height units

Definition: Indicate units of height

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Baseline

Timing: Baseline **Data Source:** Clinical

Type: Single answer **Response Options:** 1 = centimeters

2 = inches

Variable ID: WEIGHT
Variable: Weight

Definition: Indicate the patient's weight

Supporting Definition: Height and weight are used to calculate BMI

Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical

Type: Numerical value

Response Options: Numerical value of weight in kilograms or pounds

Variable ID: WEIGHTUNIT Variable: Weight units

Definition: Indicate units of weight

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical

Type: Single answer **Response Options:** 1 = kilograms

2 = pounds

Baseline Condition Factors

Variable ID: PRIMRENDIS

Variable: Primary renal disease

Definition: Indicate the patient's primary renal disease

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Baseline

Data Source: Administrative or clinical

Type: Single answer

Response Options: 1 = Uncertain aetiology

2 = Diabetes mellitus3 = Glomerulonephritis4 = Hypertension

5 = Polycystic kidney disease

6 = Pyelonephritis

7 = Renal vascular disease

8 = Other

Variable ID: BASEGRAFT

Variable: Previous kidney allografts

Definition: How many kidney allografts has the patient previously received (excluding current

allograft)?

Supporting Definition: N/A

Inclusion Criteria: Tx, HD, PD, CC

Timing: Baseline

Data Source: Administrative or clinical

Type: Numerical

Response Options: N/A

Variable ID: BASEHDTYPE
Variable: Vascular access type

Definition: Indicate the most recent type of vascular access

Supporting Definition: N/A
Inclusion Criteria: HD
Timing: Baseline

Data Source: Administrative or clinical

Type: Single answer

Response Options: 1 = AV graft

2 = AV fistula 3 = Catheter

Variable ID: BASETRANSTYPE Variable: Transplant type

Definition: Indicate the type of the most recent transplant

Supporting Definition: N/A
Inclusion Criteria: Tx
Timing: Baseline

Data Source: Administrative or clinical

Type: Single answer

Response Options: 1 = Deceased donor 2 = Living donor

Variable ID: BASERFUNC

Variable: Renal/kidney allograft function

Definition: Indicate how the patient's baseline renal/kidney allograft function was measured

Supporting Definition: N/A

Inclusion Criteria: Pre-RRT, CC, Tx

Timing: Baseline

Data Source: Administrative data **Type:** Single answer

Response Options: o = No measurement taken

1 = Serum Creatinine

2 = eGFR

3 = Serum Creatinine + eGFR

999 = Unknown

Variable ID: BASERFUNCDATE

Variable: Renal function/kidney allograft measurement date

Definition: Provide the date of baseline renal/kidney allograft function measurement

Supporting Definition: N/A

Inclusion Criteria: If "1 = Serum Creatinine", "2 = eGFR" or "3 = Serum Creatinine + eGFR" to

BASERFUNC

Timing: Baseline

Data Source: Administrative data **Type:** Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: BASERFUNCSCUNIT Variable: Serum Creatinine unit

Definition: Indicate the units used for serum creatinine measurement

Supporting Definition: N/A

Inclusion Criteria: If "1 = Serum Creatinine" or "3 = Serum Creatinine + eGFR" to BASERFUNC

Timing: Baseline

Data Source: Administrative data **Type:** Single answer

Response Options: 1 = umol/l

2 = mg/dl

Variable ID: BASERFUNCCAL

Variable: Serum Creatinine callibration

Definition: Indicate which serum creatinine assay is used

Supporting Definition: N/A

Inclusion Criteria: If "1 = Serum Creatinine" or "3 = Serum Creatinine + eGFR" to BASERFUNC

Timing: Baseline

Data Source: Administrative data

Type: Single answer

Response Options: 1 = Jaffe

2 = Enzymatic 999 = Unknown

Variable ID: BASEIDMSCAL

Variable: Isotope dilution mass spectrometry (IDMS) callibration **Definition:** Indicate if isotope dilution mass spectrometry is used

Supporting Definition: N/A

Inclusion Criteria: If "1 = Serum Creatinine" or "3 = Serum Creatinine + eGFR" to BASERFUNC

Timing: Baseline

Data Source: Administrative data **Type:** Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: BASERFUNCSC Variable: Serum Creatinine

Definition: Provide the serum creatinine value

Supporting Definition: N/A

Inclusion Criteria: If "1 = Serum Creatinine" or "3 = Serum Creatinine + eGFR" to BASERFUNC

Timing: Baseline

Data Source: Administrative data

Type: Numerical

Response Options: N/A

Variable ID: BASERFUNCEGFRMEAS

Variable: eGFR equation

Definition: Provide the eGFR equation

Supporting Definition: N/A

Inclusion Criteria: If "2 = eGFR" or "3 = Serum Creatinine + eGFR" to BASERFUNC

Timing: Baseline

Data Source: Administrative data

Type: Single answer

Response Options: 1 = CKD-EPI Serum Creatinine

2 = MDRD-4 3 = MDRD-6 4 = Cockcroft-Gault

5 = Other

Variable ID: BASERFUNCEGFR

Variable: eGFR value

Definition: Provide the eGFR value

Supporting Definition: N/A

Inclusion Criteria: If "2 = eGFR" or "3 = Serum Creatinine + eGFR" to BASERFUNC

Timing: Baseline

Data Source: Administrative data

Type: Numerical

Response Options: N/A

Variable ID: BASEALB
Variable: Albuminuria

Definition: Indicate whether albuminuria was measured

Supporting Definition: Urine albumin/creatinine ratio in spot urine (preferred), or urine protein/creatinine

ratio (alternative)

Inclusion Criteria: Pre-RRT, CC, Tx

Timing: Baseline

Data Source: Administrative data

Type: Single answer

Response Options: o = No

1 = Urine albumin/creatinine ratio in spot urine2 = Urine protein/creatinine ratio in spot urine

999 = Unknown

Variable ID: BASEALBUNIT

Variable: Units of albuminuria measurement

Definition: Indicate the units used for albuminuria measurement

Supporting Definition: N/A

Inclusion Criteria: If "1 = Urine albumin/creatinine ratio in spot urine" or "2 = Urine protein/creatinine

ratio in spot urine" to BASEALB

Timing: Baseline

Data Source: Administrative data

Type: Single answer

Response Options: 1 = mg/g

2 = mg/mmol

Variable ID: BASEALBCAL

Variable: Albuminuria callibration

Definition: Indicate which albuminuria assay is used

Supporting Definition: N/A

Inclusion Criteria: If "1 = Urine albumin/creatinine ratio in spot urine" or "2 = Urine protein/creatinine

ratio in spot urine" to BASEALB

Timing: Baseline

Data Source: Administrative data

Type: Single answer

Response Options: 1 = Immunoassay

2 = Dipstick 999 = Unknown

Variable ID: BASEALBMEASURE1

Variable: Urine ACR

Definition: Provide urine ACR in spot urine(mg/g, mg/mmol)

Supporting Definition: N/A

Inclusion Criteria: If "1 = Urine albumin/creatinine ratio in spot urine" to BASEALB

Timing: Baseline

Data Source: Administrative data

Type: Numerical

Response Options: Numerical value

Variable ID: BASEALBMEASURE2

Variable: Urine PCR

Definition: Provide urine PCR in spot urine(mg/g, mg/mmol)

Supporting Definition: N/A

Inclusion Criteria: If "2 = Urine protein/creatinine ratio in spot urine" to BASEALB

Timing: Baseline

Data Source: Administrative data

Type: Numerical

Response Options: Numerical value

Variable ID: BASEALBDATE

Variable: Albuminuria measurement

Definition: Provide the date of the most recent albuminuria measurement

Supporting Definition: N/A

Inclusion Criteria: If "1 = Urine albumin/creatinine ratio in spot urine" or "2 = Urine protein/creatinine

ratio in spot urine" to BASEALB

Timing: Baseline

Data Source: Administrative data

Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: BASEHBP

Variable: High blood pressure

Definition: Indicate whether the patient has hypertension and/or uses antihypertensive

medication at baseline

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Baseline **Data Source:** Clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: BASEDM

Variable: Diabetes mellitus

Definition: Indicate whether the patient has baseline diabetes mellitus

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical

Type: Single answer

Response Options: o = No

1 = Diabetes mellitus type 12 = Diabetes mellitus type 2

999 = Unknown

Variable ID: BASECLD

Variable: Chronic lung disease

Definition: Indicate whether the patient has baseline chronic lung disease

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Baseline **Data Source:** Clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: BASELIVD
Variable: Liver disease

Definition: Indicate whether the patient has baseline chronic liver disease

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Baseline

Timing: Baseline **Data Source:** Clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: BASECVE

Variable: Cardiovascular events

Definition: Indicate whether the patient has had any baseline cardiovascular events

Supporting Definition: Cardiovascular events of interest are acute myocardial infarction, stroke (excluding

transient ischemic attacks), and limb amputation (excluding traumatic injury)

Inclusion Criteria: All patients

Timing: Baseline **Data Source:** Clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: BASEAMI

Variable: Myocardial infarction

Definition: Indicate whether the patient has had a myocardial infarction

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to BASECVE

Timing: Baseline **Data Source:** Clinical

Type: Single answer

Response Options: o = No

ı = Yes

999 = Unknown

Variable ID: BASESTR

Variable: Stroke (excluding transient ischemic attacks)

Definition: Indicate whether the patient has had a stroke (excluding transient ischemic

attacks)

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to BASECVE

Timing: Baseline **Data Source:** Clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: BASELIMB

Variable: Limb amputation (not due to traumatic injury)

Definition: Indicate whether the patient has had a limb amputation (not due to traumatic

injury)

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to BASECVE

Timing: Baseline

Data Source: Clinical

Time: Single angue

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: BASEMALIG Variable: Malignancies

Definition: Indicate whether the patient has any malignancies

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable: BASEMALIGTYPE1
Variable: Malignancies type 1

Definition: Indicate whether the malignancy is a solid tumour

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to BASEMALIG

> Timing: Baseline Data Source: Clinical

> > Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: BASEMALIGTYPE₂ Variable: Malignancies type 2

Definition: Indicate whether the malignancy is skin cancer

Supporting Definition:

Inclusion Criteria: If "1 = yes" to BASEMALIG

Baseline Timina: Data Source: Clinical Type: Single answer

o = No **Response Options:**

1 = Yes

999 = Unknown

Variable ID: BASEMALIGTYPE3 Variable: Malignancies type 3

Definition: Indicate whether the malignancy is a haematological malignancy

Supporting Definition:

Inclusion Criteria: If "1 = yes" to BASEMALIG

> Timing: Baseline Data Source: Clinical

Type: Single answer

Response Options: o = No 1 = Yes Outcomes

999 = Unknown

Survival

Variable ID: DEATH Variable: Death

Definition: Indicate whether the patient died

Supporting Definition:

Inclusion Criteria: All patients Timing: Ongoing

> Administrative or clinical Data Source:

> > Single answer Type:

Response Options: o = No

1 = Yes

DEATHDATE Variable ID: Date of death Variable:

Definition: Indicate the date of death

Supporting Definition: N/A

> If "1 = yes" to DEATH **Inclusion Criteria:**

> > Timing: Ongoing

Data Source: Administrative or clinical Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: **DEATHCAUSE** Cause of death Variable:

Definition: Indicate the cause of death **Supporting Definition:** Use SMARRT categories **Inclusion Criteria:** If "1 = yes" to DEATH

> Timing: Ongoing

Data Source: Clinical

Type: Single answer

Response Options: 1 = Cardiovascular

2 = Infection

3 = Renal Replacement Therapy Complication

4 = Malignancy

5 = Treatment Withdrawal

6 = Other 999 = Unknown

Burden of Care

Variable ID: HOSPADMALL

Variable: All admission to hospitals

Definition: How many times has the patient been admitted (requiring at least an overnight

stay) to a hospital/acute care facility in the last 12 months?

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Annually

Data Source: Administrative data

Type: Numerical

Response Options: Numerical value

Variable ID: HOSPADMTOTAL

Variable: Total number of days hospitalised

Definition: In total, how many days has the patient been hospitalised (requiring at least an

overnight stay) at a hospital/acute care facility in the last 12 months?

Supporting Definition: N/A

Inclusion Criteria: If ≥1 to HOSPADMALL

Timing: Annually

Data Source: Administrative data

Type: Numerical

Response Options: Numerical value

Variable ID: CARDIOEV

Variable: Cardiovascular events

Definition: Indicate if the patient was diagnosed with a cardiovascular event

Supporting Definition: Cardiovascular events of interest are acute myocardial infarction, stroke (excluding

transient ischemic attacks), and limb amputation (excluding traumatic injury)

Inclusion Criteria: All patients

Timing: Annually

Data Source: Administrative or clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: CARDIOAMI

Variable: Acute Myocardial Infarction

Definition: Indicate if the patient was diagnosed with an acute myocardial infarction

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to CARDIOEV

Timing: Annually

Data Source: Administrative or clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: AMIDATE

Variable: Date of acute myocardial infarction

Definition: Indicate the date of acute myocardial infarction diagnosis

Supporting Definition: Multiple dates possible **Inclusion Criteria:** If "1 = yes" to CARDIOAMI

Timing: Annually

Data Source: Administrative or clinical **Type:** Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: CARDIOSTR

Variable: Stroke (excluding transient ischemic attacks)

Definition: Indicate if the patient was diagnosed with a stroke

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to CARDIOEV

Timing: Annually

Data Source: Administrative or clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: STRDATE
Variable: Date of stroke

Definition: Indicate the date of stroke diagnosis

Supporting Definition: Multiple dates possible **Inclusion Criteria:** If "1 = yes" to CARDIOSTR

Timing: Annually

Data Source: Administrative or clinical **Type:** Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: CARDIOLIMB

Variable: Limb amputation (not due to traumatic injury)

Definition: Indicate if the patient was diagnosed with a limb amputation

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to CARDIOEV

Timing: Annually

Data Source: Administrative or clinical

Type: Single answer

Response Options: o = No

1 = Yes

Variable ID: LIMBDATE

Variable: Date of limb amputation

Definition: Indicate the date of limb amputation diagnosis (not due to traumatic injury)

Supporting Definition: Multiple dates possible **Inclusion Criteria:** If "1 = yes" to CARDIOLIMB

Timing: Annually

Data Source: Administrative or clinical **Type:** Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Patient-Reported Health & Wellbeing

Variable ID: PROMCHOICE

Variable: Which Patient-Reported Outcome Measure(s) are you using? **Definition:** Which Patient-Reported Outcome Measure(s) are you using?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = PROMIS-Global Health & PROMIS-29

2 = RAND-363 = SF-36v2.0

Variable ID: PROMIS-29_Qo1 Variable: PROMIS-29 - PFA11

Definition: Are you able to do chores such as vacuuming or yard work?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported **Type:** Single answer

Response Options: 5 = Without any difficulty

4 = With a little difficulty 3 = With some difficulty 2 = With much difficulty

1 = Unable to do

Variable ID: PROMIS-29_Qo2 Variable: PROMIS-29 - PFA21

Definition: Are you able to go up and down stairs at a normal pace?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Without any difficulty

4 = With a little difficulty 3 = With some difficulty 2 = With much difficulty

1 = Unable to do

Variable ID: PROMIS-29_Qo3
Variable: PROMIS-29 - PFA23

Definition: Are you able to go for a walk of at least 15 minutes?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Without any difficulty

4 = With a little difficulty3 = With some difficulty2 = With much difficulty

1 = Unable to do

Variable ID: PROMIS-29_Qo4 Variable: PROMIS-29 - PFA53

Definition: Are you able to run errands and shop?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported **Type:** Single answer

Response Options: 5 = Without any difficulty

4 = With a little difficulty 3 = With some difficulty 2 = With much difficulty

1 = Unable to do

Variable ID: PROMIS-29_Q05
Variable: PROMIS-29 - EDANX01
Definition: In the past 7 days...

I felt fearful

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Never

2 = Rarely3 = Sometimes4 = Often5 = Always

Variable ID: PROMIS-29_Q06
Variable: PROMIS-29 - EDANX40
Definition: In the past 7 days...

I found it hard to focus on anything other than my anxiety

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Never

2 = Rarely3 = Sometimes4 = Often5 = Always

Variable ID: PROMIS-29_Qo7
Variable: PROMIS-29 - EDANX41
Definition: In the past 7 days...

My worries overwhelmed me

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Never

2 = Rarely3 = Sometimes4 = Often5 = Always

Variable ID: PROMIS-29_Qo8
Variable: PROMIS-29 - EDA

Variable: PROMIS-29 - EDANX53 **Definition:** In the past 7 days...

I felt uneasy

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Never

2 = Rarely 3 = Sometimes 4 = Often 5 = Always

Variable ID: PROMIS-29_Q09
Variable: PROMIS-29 - EDDEP04

Definition: In the past 7 days...

I felt worthless

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Never

2 = Rarely 3 = Sometimes 4 = Often 5 = Always

Variable ID: PROMIS-29_Q10

Variable: PROMIS-29 - EDDEPo6 **Definition:** In the past 7 days...

I felt helpless

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Never

2 = Rarely 3 = Sometimes 4 = Often 5 = Always

Variable ID: PROMIS-29_Q11
Variable: PROMIS-29 - EDDEP29
Definition: In the past 7 days...

I felt depressed

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Never

2 = Rarely 3 = Sometimes 4 = Often 5 = Always

Variable ID: PROMIS-29_Q12
Variable: PROMIS-29 - EDDEP41
Definition: In the past 7 days...

I felt hopeless

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Never

2 = Rarely 3 = Sometimes 4 = Often 5 = Always

Variable ID: PROMIS-29_Q13
Variable: PROMIS-29 - Hi7
Definition: During the past 7 days...

I feel fatiqued

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Not at all

2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

Variable ID: PROMIS-29_Q14
Variable: PROMIS-29 - AN3
Definition: During the past 7 days...

I have troube starting things because I am tired

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer **Response Options:** 1 = Not at all

2 = A little bit 3 = Somewhat 4 = Quite a bit

4 = Quite a bit 5 = Very much

Variable ID: PROMIS-29_Q15
Variable: PROMIS-29 - FATEXP41
Definition: In the past 7 days...

How run-down did you feel on average?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer **Response Options:** 1 = Not at all

2 = A little bit 3 = Somewhat 4 = Quite a bit

5 = Very much PROMIS-29 Q16 Variable ID: Variable: PROMIS-29 - FATEXP40 **Definition:** In the past 7 days... How fatigued were you on average? **Supporting Definition:** If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE **Inclusion Criteria:** Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually Data Source: Patient-reported Type: Single answer **Response Options:** 1 = Not at all 2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much PROMIS-29_Q17 Variable ID: Variable: PROMIS-29 - Sleep109 **Definition:** In the past 7 days... My sleep quality was... **Supporting Definition:** N/A **Inclusion Criteria:** If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually Data Source: Patient-reported Single answer Type: **Response Options:** 5 = Very poor 4 = Poor 3 = Fair 2 = Good 1 = Very good Variable ID: PROMIS-29_Q18 Variable: PROMIS-29 - Sleep116 **Definition:** In the past 7 days... My sleep was refreshing... **Supporting Definition:** If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE **Inclusion Criteria:** Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually Data Source: Patient-reported Type: Single answer **Response Options:** 5 = Not at all 4 = A little bit 3 = Somewhat 2 = Quite a bit 1 = Very much Variable ID: PROMIS-29_Q19 Variable: PROMIS-29 - Sleep20 **Definition:** In the past 7 days... I had a problem with my sleep... **Supporting Definition: Inclusion Criteria:** If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually Data Source: Patient-reported

Type:

Single answer

Response Options: 5 = Not at all

4 = A little bit 3 = Somewhat 2 = Quite a bit 1 = Very much

Variable ID: PROMIS-29_Q20
Variable: PROMIS-29 - Sleep44
Definition: In the past 7 days...

I had difficulty falling asleep

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Not at all

4 = A little bit 3 = Somewhat 2 = Quite a bit 1 = Very much

Variable ID: PROMIS-29_Q21

Variable: PROMIS-29 - SRPPER11_CaPS

Definition: I have trouble doing all of my regular leisure activities with others

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Never

4 = Rarely 3 = Sometimes 2 = Usually 1 = Always

Variable ID: PROMIS-29_Q22

Variable: PROMIS-29 - SRPPER18_CaPS

Definition: I have trouble doing all of the family activities that I want to do

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Never

4 = Rarely 3 = Sometimes 2 = Usually 1 = Always

Variable ID: PROMIS-29_Q23

Variable: PROMIS-29 - SRPPER23_CaPS

Definition: I have trouble doing all of my usual work (include work at home)

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Never

4 = Rarely 3 = Sometimes 2 = Usually 1 = Always

Variable ID: PROMIS-29_Q24

Variable: PROMIS-29 - SRPPER46_CaPS

Definition: I have trouble doing all of the activities with friends that I want to do

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Never

4 = Rarely 3 = Sometimes 2 = Usually 1 = Always

Variable ID: PROMIS-29_Q25
Variable: PROMIS-29 - PAININ9
Definition: In the past 7 days...

How much did pain interfere with your day to day activities?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Not at all

2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

Variable ID: PROMIS-29_Q26
Variable: PROMIS-29 - PAININ22
Definition: In the past 7 days...

How much did pain interfere with work around the home?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer **Response Options:** 1 = Not at all

Response Options. 1-Not at an

2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

Variable ID: PROMIS-29_Q27
Variable: PROMIS-29 - PAININ31
Definition: In the past 7 days...

How much did pain interfere with your ability to participate in social activities?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Not at all

2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

Variable ID: PROMIS-29_Q28

Variable: PROMIS-29 - PAININ34 **Definition:** In the past 7 days...

How much did pain interfere with your household chores?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Not at all

2 = A little bit 3 = Somewhat 4 = Quite a bit 5 = Very much

Variable ID: PROMIS-29_Q29
Variable: PROMIS-29 - Globalo7
Definition: In the past 7 days...

How would you rate your pain on average?

Supporting Definition: Indicate pain level on a scale of 1-10, where o = No pain, and 10 = Worst imaginable

pain

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: Numerical value between 1 and 10

Variable ID: PROMIS-G_Qo1

Variable: Globalo1 - Patient reported general health status

Definition: In general, would you say your health is:

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer stions: 5 = Excellent

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-G_Qo2

Variable: Globalo2 - Global patient reported health-related QOL

Definition: In general, would you say your quality of life is:

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-G_Qo3

Variable: Globalo3 - Patient reported general health status **Definition:** In general, how would you rate your physical health?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer **Response Options:** 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-G_Q04

Variable: Globalo4 - Mood, global cognitive function

Definition: In general, how would you rate your mental health, including your mood and your

ability to think?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-G_Qo5

Variable: Globalo5 - Social participation

Definition: In general, how would you rate your satisfaction with your social activities and

relationships?

Supporting Definition: N/A

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-G_Qo6

Variable: Globalog - Social participation

Definition: In general, please rate how well you carry out your usual social activities and roles.

(This includes activities at home, at work and in your community, and

responsibilities as a parent, child, spouse, employee, friend, etc.)

Supporting Definition: N/A

> **Inclusion Criteria:** If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

> > Timing: HD, PD & CC= Baseline and 6-monthly

> > > Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

> Single answer Type:

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-G Q07 Variable: Globalo6 - Mobility

Definition: To what extent are you able to carry out your everyday physical activities such as

walking, climbing stairs, carrying groceries, or moving a chair?

Supporting Definition:

If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE **Inclusion Criteria:**

> Timing: HD, PD & CC= Baseline and 6-monthly

> > Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Completely

> 4 = Mostly 3 = Moderately 2 = A little 1 = Not at all

PROMIS-G Qo8 Variable ID: Variable: Global10 - Mood

Definition: In the past 7 days, how often have you been bothered by emotional problems such

as feeling anxious, depressed or irritable?

Supporting Definition:

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Patient-reported

Data Source: Type: Single answer **Response Options:** 1 = Never

2 = Rarely 3 = Sometimes 4 = Often

5 = Always Variable ID: PROMIS-G_Qo9 Variable: Globalo8 - Fatique

Definition: In the past 7 days, how would you rate your fatigue on average?

Supporting Definition:

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

> HD, PD & CC= Baseline and 6-monthly Timing: Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

> Type: Single answer

1 = None **Response Options:**

2 = Mild 3 = Moderate 4 = Severe 5 = Very severe Variable ID: PROMIS-G_Q10

Variable: Globalo7 - Pain and other unpleasant sensations

Definition: In the past 7 days, how would you rate your pain on average?

Supporting Definition: Indicate pain level on a scale of 1-10, where o = No pain, and 10 = Worst imaginable

pain

Inclusion Criteria: If "1 = PROMIS-Global Health & PROMIS-29" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported **Type:** Single answer

Response Options: Numerical value between 1 and 10

Variable ID: RAND-36_Qo1 Variable: RAND-36_Qo1

Definition: In general, would you say your health is:

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer
Response Options: 1 = Excellent

2 = Very good 3 = Good 4 = Fair 5 = Poor

Variable ID: RAND-36_Q02 Variable: RAND-36_Q02

Definition: Compared to one year ago, how would you rate your health in general now?

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Qo3 Variable: RAND-36_Qo3

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?:

Vigorous activities, such as running, lifting heavy objects, participating in

strenuous sports

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q04 Variable: RAND-36_Q04 **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?:

Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or

playing golf

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Qo5 Variable: RAND-36_Qo5

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: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q06 Variable: RAND-36_Q06

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?:

Climbing several flights of stairs

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q07 Variable: RAND-36_Q07

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?:

Climbing one flight of stairs

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Qo8 Variable: RAND-36_Qo8 **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?:

Bending, kneeling, or stooping

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Qo9 Variable: RAND-36_Qo9

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?:

Walking more than a mile

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q10 Variable: RAND-36_Q10

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?:

Walking several blocks

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q11 Variable: RAND-36_Q11

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?:

Walking one block

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q12 Variable: RAND-36_Q12 **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?:

Bathing or dressing yourself

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q13 Variable: RAND-36_Q13

Definition: Dring 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?: Cut down the amount of time you spent on work or other activities

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Yes

2 = No

Variable ID: RAND-36_Q14 Variable: RAND-36_Q14

Definition: Dring 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?:

Accomplished less than you would like

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Yes

2 = No

Variable ID: RAND-36_Q15 Variable: RAND-36_Q15

Definition: Dring 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?:

Were limited in the kind of work or other activities

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Yes

2 = No

Variable ID: RAND-36_Q16 Variable: RAND-36_Q16

Definition: Dring 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?:

Had difficulty performing the work or other activities (for example, it took extra

effort)

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported **Type:** Single answer

Response Options: 1 = Yes

2 = No

Variable ID: RAND-36_Q17 Variable: RAND-36_Q17

Definition: Dring 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)?:

Cut down the amount of time you spent on work or other activities

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported **Type:** Single answer

Response Options: 1 = Yes

2 = No

Variable ID: RAND-36_Q18 Variable: RAND-36_Q18

Definition: Dring 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)?:

Accomplished less than you would like

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Yes

2 = No

Variable ID: RAND-36_Q19 Variable: RAND-36_Q19

Definition: Dring 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)?:

Didn't do work or other activities as carefully as usual

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Yes

2 = No

Variable ID: RAND-36_Q20 Variable: RAND-36_Q20

Definition: Dring 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: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Not at all

2 = A little bit 3 = Moderately 4 = Quite a bit 5 = Extremely

Variable ID: RAND-36_Q21
Variable: RAND-36_Q21

Definition: How much bodily pain have you had during the past 4 weeks?

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = None

2 = Very mild3 = Mild4 = Moderate5 = Severe6 = Very severe

Variable: RAND-36_Q22 Variable: RAND-36_Q22

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: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Not at all

2 = A little bit3 = Moderately4 = Quite a bit5 = Extremely

Variable ID: RAND-36_Q23 Variable: RAND-36_Q23

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...

Did you feel full of pep?

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q24 Variable: RAND-36_Q24

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...

Have you been a very nervous person?

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q25 Variable: RAND-36_Q25

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...

Have you felt so down in the dumps that nothing could cheer you up?

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q26 Variable: RAND-36_Q26

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...

Have you felt calm and peaceful?

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q27 Variable: RAND-36_Q27

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...

Did you have a lot of energy?

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q28 Variable: RAND-36_Q28

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...

Have you felt downhearted and blue?

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q29 Variable: RAND-36_Q29

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...

Did you feel worn out?

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q30 Variable: RAND-36_Q30

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...

Have you been a happy person?

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q31 Variable: RAND-36_Q31

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...

Did you feel tired?

Supporting Definition: N/A

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q32 Variable: RAND-36_Q32

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: If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer **Response Options:** 1 = All of the time

DATA COLLECTION REFERENCE GUIDE

2 = Most of the time 3 = Some of the time4 = A little of the time 5 = None of the time

Variable ID: RAND-36_Q33 Variable: RAND-36 Q33

How TRUE or FALSE is each of the following statements for you. **Definition:**

I seem to get sick a little easier than other people

Supporting Definition: N/A

> Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE

Timina: HD, PD & CC= Baseline and 6-monthly Pre-RRT & Tx = Baseline and annually

Patient-reported

Data Source: Type: Single answer

Response Options: 1 = Definitely true

> 2 = Mostly true 3 = Don't know 4 = Mostly false 5 = Definitely false

Variable ID: RAND-36_Q34 Variable: RAND-36_Q34

Definition: How TRUE or FALSE is each of the following statements for you.

I am as healthy as anybody I know

Supporting Definition: N/A

> **Inclusion Criteria:** If "2 = RAND-36" to PROMCHOICE

Timing: HD, PD & CC= Baseline and 6-monthly

Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q35 Variable: RAND-36_Q35

Definition: How TRUE or FALSE is each of the following statements for you.

I expect my health to get worse

Supporting Definition: N/A

> If "2 = RAND-36" to PROMCHOICE **Inclusion Criteria:**

> > Timing: HD, PD & CC= Baseline and 6-monthly

> > > Pre-RRT & Tx = Baseline and annually

Data 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: RAND-36_Q36 Variable: RAND-36_Q36

Definition: How TRUE or FALSE is each of the following statements for you.

My health is excellent

Supporting Definition:

Inclusion Criteria: If "2 = RAND-36" to PROMCHOICE HD, PD & CC= Baseline and 6-monthly Timing:

Pre-RRT & Tx = Baseline and annually

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Definitely true

2 = Mostly true
3 = Don't know
4 = Mostly false
5 = Definitely false

Treatment-Specific

Variable ID: RFUNC

Variable: Renal/Kidney Allograft Function

Definition: Indicate how renal/kidney allograft function was measured

Supporting Definition: Serum creatinine and/or eGFR by CKD-EPI serum creatinine (preferred) or

alternative equation

Inclusion Criteria: Pre-RRT, CC, Tx

Timing: 6-monthly

Data Source: Administrative data

Type: Single answer

Response Options: o = No measurement taken

1 = CKD-EPI Serum Creatinine

2 = eGFR

3 = Serum Creatinine + eGFR

999 = Unknown

Variable ID: RFUNCSCUNIT

Variable: Serum Creatinine unit

Definition: Indicate the units used for serum creatinine measurement

Supporting Definition: N/A

Inclusion Criteria: If "1 = Serum Creatinine" or "3 = Serum Creatinine + eGFR" to RFUNC

Timing: 6-monthly

Data Source: Administrative data

Type: Single answer

Response Options: 1 = umol/l

2 = mg/dl

Variable ID: RFUNCSC

Variable: Serum Creatinine

Definition: Provide the serum creatinine value

Supporting Definition: N/A

Inclusion Criteria: If "1 = Serum Creatinine" or "3 = Serum Creatinine + eGFR" to RFUNC

Timing: 6-monthly

Data Source: Administrative data

Type: Numerical

Response Options: N/A

Variable: RFUNCEGFRMEAS
Variable: eGFR equation

Definition: Provide the eGFR equation

Supporting Definition: N/A

Inclusion Criteria: If "2 = eGFR" or "3 = Serum Creatinine + eGFR" to RFUNC

Timing: 6-monthly

Data Source: Administrative data

Type: Single answer

Response Options: 1 = CKD-EPI Serum Creatinine

2 = MDRD-4 3 = MDRD-6 4 = Cockcroft-Gault

5 = Other

OUTCOMES

Variable ID: RFUNCEGFR Variable: eGFR value

Definition: Provide the eGFR value

Supporting Definition: N/A

Inclusion Criteria: If "2 = eGFR" or "3 = Serum Creatinine + eGFR" to RFUNC

Timing: 6-monthly

Data Source: Administrative data

Type: Numerical

Response Options: N/A

Variable ID: RFUNCDATE

Variable: Renal function measurement date

Definition: Provide the date of renal function measurement

Supporting Definition: N/A

Inclusion Criteria: If "1 = Serum Creatinine", "2 = eGFR" or "3 = Serum Creatinine + eGFR" to RFUNC

Timing: 6-monthly

Data Source: Administrative data

Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: ALB

Variable: Albuminuria

Definition: Indicate whether albuminuria was measured

Supporting Definition: Urine albumin/creatinine ratio in spot urine (preferred), or urine protein/creatinine

ratio (alternative)

Inclusion Criteria: Pre-RRT, CC, Tx

Timing: Annually

Data Source: Administrative data

Type: Single answer

Response Options: o = No

1 = Urine albumin/creatinine ratio in spot urine2 = Urine protein/creatinine ratio in spot urine

999 = Unknown

Variable ID: ALBUNIT

Variable: Units of albuminuria measurement

Definition: Indicate the units used for albuminuria measurement

Supporting Definition: N/A

Inclusion Criteria: If "1 = Urine albumin/creatinine ratio in spot urine" or "2 = Urine protein/creatinine

ratio in spot urine" to ALB

Timing: Annually

Data Source: Administrative data

Type: Single answer

Response Options: 1 = mg/g

2 = mg/mmol

Variable ID: ALBMEASURE1

Variable: Urine ACR

Definition: Provide urine ACR in spot urine(mg/g, mg/mmol)

Supporting Definition: N/A

Inclusion Criteria: If "1 = Urine albumin/creatinine ratio in spot urine" to ALB

Timing: Annually

Data Source: Administrative data

Type: Numerical

Response Options: Numerical value

Variable ID: ALBMEASURE2
Variable: Urine PCR

Definition: Provide urine PCR in spot urine(mg/g, mg/mmol)

Supporting Definition: N/A

Inclusion Criteria: If "2 = Urine protein/creatinine ratio in spot urine" to ALB

Timing: Annually

Data Source: Administrative data

Type: Numerical

Response Options: Numerical value

Variable ID: ALBDATE

Variable: Albuminuria measurement

Definition: Provide the date of albuminuria measurement

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to ALB

Timing: Annually

Data Source: Administrative data

Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: BACTER
Variable: Bacteraemia

Definition: Indicate if the patient was diagnosed with bacteraemia **Supporting Definition:** Positive blood culture with clinical signs and symptoms

Inclusion Criteria: HD, PD, Tx
Timing: 6-monthly
Data Source: Clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: BACTEREP

Variable: Number of diagnosed bacteraemia episodes

Definition: Indicate how many episodes of bacteraemia the patient was diagnosed with

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to BACTER

Timing: 6-monthly

Data Source: Clinical

Type: Numerical

Response Options: Numerical value

Variable ID: HDSTART

Variable: Haemodialysis start

Definition: Indicate when haemodialysis was started

Supporting Definition: N/A Inclusion Criteria: HD

Timing: Baseline

Data Source: Administrative or clinical **Type:** Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: HDTYPE

Variable: Vascular access type

Definition: Indicate the type of the most recent vascular access

Supporting Definition: N/A
Inclusion Criteria: HD
Timing: Annually

Allitodity

Data Source: Administrative or clinical

Type: Single answer **Response Options:** 1 = AV graft

2 = AV fistula

2 = AV fistula 3 = Catheter

Variable ID: HDNEW

Variable: Subsequent vascular access

Definition: Indicate whether a subsequent vascular access had to be created

Supporting Definition: N/A Inclusion Criteria: HD

Timing: 6-monthly

Data Source: Administrative or clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: HDNEWDATE

Variable: Subsequent vascular access date

Definition: Provide the date of starting haemodialysis using the subsequent vascular access

Supporting Definition: Multiple dates possible **Inclusion Criteria:** If "1 = yes" to HDNEW

Timing: 6-monthly

Data Source: Administrative or clinical **Type:** Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: HDNEWTYPE

Variable: New vascular access type

Definition: Indicate the type of new vascular access

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to HDNEW

Timing: 6-monthly

Data Source: Administrative or clinical

Type: Single answer **Response Options:** 1 = AV graft 2 = AV fistula

2 = AV fistula 3 = Catheter

Variable ID: PDSTART

Variable: Peritoneal dialysis start

Definition: Indicate when peritoneal dialysis was started

Supporting Definition: First fluid exchange with intention of causing solute or fluid clearance

Inclusion Criteria: PD
Timing: Baseline

Data Source: Administrative or clinical **Type:** Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: PDSWITCH

Variable: Treatment pathway change

Definition: Indicate whether treatment was sustainably switched (to conservative care,

haemodialysis or transplant)

Supporting Definition: Sustained switch is defined as >30 days

Inclusion Criteria: PD
Timing: Ongoing

Data Source: Administrative or clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: PDSWITCHDATE

Variable: Treatment pathway change date

Definition: Provide the date of starting conservative, haemodialysis or transplant

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to PDSWITCH

Timing: Ongoing

Data Source: Administrative or clinical

Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: PERITON
Variable: Peritonitis

Definition: Indicate if the patient was diagnosed with peritonitis **Supporting Definition:** Clinically suspected and/or culture-proven peritonitis

Episodes of peritonitis defined as clinical sings of peritoneal inflammation or

peritoneal fluid leukocyte count of > 0.1 x 10^9/L with at least 50%

polymorphonuclear neutrophilic cells or positive culture of peritoneal fluid

Inclusion Criteria: PD

Timing: 6-monthly **Data Source:** Clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: PERITONPROOF
Variable: Peritonitis diagnosis

Definition: Indicate whether peritonitis was clinically suspected and/or culture-proven

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to PERITON

Timing: 6-monthly **Data Source:** Clinical

Type: Single answer

Response Options: 1 = Clinically suspected

2 = Culture proven

3 = Clinically suspected and culture proven

Variable ID: PERITONEP

Variable: Number of peritonitis episodes diagnosed

Definition: Indicate how many episodes of peritonitis the patient was diagnosed with

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to PERITON

Timing: 6-monthly

Data Source: Clinical

Type: Numerical

Response Options: Numerical value

Variable ID: TRANSDATE

Variable: Date of kidney transplant

Definition: Provide the date of transplant surgery

Supporting Definition: N/A Inclusion Criteria: Tx

Timing: Annually

Data Source: Administrative data **Type:** Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: TRANSNEW

Variable: Subsequent kidney transplant

Definition: Indicate whether there has been a subsequent kidney transplant

Supporting Definition: N/A
Inclusion Criteria: Tx
Timing: Appl.

Timing: Annually

Data Source: Administrative data

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: TRANSNEWTYPE
Variable: Type of new transplant

Definition: Was the transplanted kidney from a living or deceased donor?

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to TRANSNEW

Timing: Annually

Data Source: Administrative data

Type: Single answer **tions:** 1 = Living donor

Response Options: 1 = Living donor 2 = Deceased donor

999 = Unknown

Variable ID: TRANSNEWDATE

Variable: Date of subsequent kidney transplant

Definition: Provide the date of a subsequent kidney transplant

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to TRANSNEW

Timing: Annually

Data Source: Administrative data **Type:** Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: TRANSREJ

Variable: Kidney transplant rejection

Definition: Indicate whether an episode of biopsy-proven and/or clinically-suspected acute

rejection of the kidney transplant was diagnosed

Supporting Definition: According to Banff classification. Category 2: acute/active antibody-mediated

rejection, category 3, category 4: acute/active T-cell mediated rejection

Inclusion Criteria: Tx

Timing: 6-monthly for the first year, then annually

Data Source: Clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: TRANSPROOF

Variable: Transplant rejection diagnosis

Definition: Indicate whether acute rejection was clinically suspected and/or biopsy-proven

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to TRANSNEW

Timing: 6-monthly for the first year, then annually

Data Source: Clinical

Type: Single answer

Response Options: 1 = Clinically suspected

2 = Biopsy proven

3 = Clinically suspected and culture proven

Variable ID: TRANSREJDATE

Variable: Kidney transplant rejection date

Definition: Provide the date of acute rejection diagnosis

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to TRANSREj

Timing: 6-monthly for the first year, then annually

Data Source: Clinical

Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: MALIG
Variable: Malignancies

Definition: Indicate whether the patient has any malignancies

Supporting Definition: N/A Inclusion Criteria: Tx

Timing: Annually

Data Source: Administrative or clinical

Type: Single answer

Response Options: o = No

ı = Yes

999 = Unknown

Variable ID: MALIGTYPE1

Variable: Malignancies type 1

Definition: Indicate whether the malignancy is a solid tumour

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to MALIG

Timing: Annually

Data Source: Administrative or clinical

Type: Single answer

Response Options: o = No

ı = Yes

999 = Unknown

Variable ID: MALIGTYPE2

Variable: Malignancies type 2

Definition: Indicate whether the malignancy is skin cancer

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to MALIG

Timing: Annually

Data Source: Administrative or clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: MALIGTYPE3

Variable: Malignancies type 3

Definition: Indicate whether the malignancy is a haematological malignancy

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to MALIG

Timing: Annually

Data Source: Administrative or clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: MALIGDATE

Variable: Date of malignancy diagnosis

Definition: Indicate the date of malignancy diagnosis

Supporting Definition: N/A

Inclusion Criteria: If "1 = yes" to MALIG

Timing: Annually

Data Source: Administrative or clinical **Type:** Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Working Group Member Conflicts of Interest

At the beginning of the Working Group process, we ask all Working Group members to declare any conflicts of interest they have. We then circulate these within the Group to ensure transparency.

Name	Title	Declarations
Willem Jan Bos	Nephrologist	Roche - research support
Wouter Verberne	Nephrology Resident	Roche - research support
Charlotte Roberts	Vice President of Standardisation	None declared
Zofia Das-Gupta	Project Leader	None declared
Andrea Stopper	Executive Vice-President	Fresensius Medical Care - salary
Andrew Allegretti	Instructor of Medicine	Translation Medicine Group - research support
Chih-Wei Yang	Professor of Nephrology	None declared
David Wheeler	Nephrologist	
Eduardo Parra Moncasi	Nephrologist	None declared
Elizabeth Gibbons	Senior Research Scientist	None declared
Guillermo Garcia-Garcia	Research Professor	Pisa Farmaceutica - personal fees
Hans Bart	Patient Representative/Director	Pharmaceutical companies - grants
Katherine Tuttle	Executive Director for Research Professor of Medicine Nephrologist	Eli Lilly and Company - consulting fees Boehringer Ingelheim - consulting fees
Kitty Jager	Professor of Medical Informatics & Kidney Epidemiology	None declared
Laurie Konowitz	Patient Representative	None declared
Marc Hemmelder	Nephrologist	None declared
Markus Ketteler	Professor of Medicine	None declared
Muhamed Al Rohani	Associate Professor of Internal Medicine	None declared
Türkan Terkivatan	Consultant Surgeon	None declared
Wim Van Biesen	Professor of Nephrology	None declared

DATA COLLECTION REFERENCE GUIDE CHRONIC KIDNEY DISEASE | 50

Reference Guide Revisions

Reference Guide Version Location within Reference Guide Content Change

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