



ICHOM

International Consortium for
Health Outcomes Measurement

CHRONIC KIDNEY DISEASE DATA COLLECTION REFERENCE GUIDE

Version 4.0.0
Revised: January 24th, 2022



Measuring

results

that matter

Chronic Kidney
Disease



We are thrilled that you are interested in measuring outcomes for your chronic kidney disease patients. It is our hope that this Reference Guide will facilitate the process of implementing this Set of Patient-Centered Outcome Measures and ensure collection of comparable data for global benchmarking and learning.

© 2022 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 Sets of Patient-Centered Outcome Measures.

Introducing ICHOM and the Reference Guide

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

Each 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 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.

Our aim is to make these Sets freely accessible to healthcare institutions worldwide to begin measuring, and ultimately benchmark the outcomes they achieve. In order to have a guide from which we can benchmark outcomes, we require feedback from initial implementation efforts. As such, this Reference Guide may undergo revisions on a regular basis. If you have any suggestions or would like to provide feedback, please contact info@ichom.org

Working Group Members for Chronic Kidney Disease

The following individuals dedicated both time and expertise to develop the ICHOM 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	Netherlands Hans Bart Kitty Jager Marc Hemmelder Turkan Terkivatan Willem Jan Bos Wouter Verberne	Spain Eduardo Parra Moncasi	United Kingdom Charlotte Roberts David Wheeler Elizabeth Gibbons Zofia Das-Gupta
Germany Markus Ketteler		Taiwan Chih-Wei Yang	
Mexico Guillermo Garcia-Garcia		United Arab Emirates Muhammed Al Rohani	United States Andrew Allegretti Katherine Tuttle Laurie Konowitz

Supporting Organizations

The Chronic Kidney Disease Set is made possible only through the support of the following organizations.
Thank you.



ACI NSW Agency
for Clinical
Innovation



PROVIDENCE
Health & Services



ERCPA



santeon



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 Set.

Conditions	Chronic Kidney Disease Stage G3a/A3 Chronic Kidney Disease Stage G3b/A2/A3 Chronic Kidney Disease Stage G4 Chronic Kidney Disease Stage G5
Treatment Approaches	Pre-RRT = Pre-Renal Replacement Therapy HD = Haemodialysis PD = Peritoneal Dialysis Tx = Renal Transplantation CC = Conservative Care

Prognosis of CKD by GFR and albuminuria categories: KDIGO 2012

				Persistent albuminuria categories, description and range		
				A1	A2	A3
				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
GFR categories (ml/min/1.73 m ²), description and range	G1	Normal or high	≥90			
	G2	Mildly decreased	60–89			
	G3a	Mildly to moderately decreased	45–59			
	G3b	Moderately to severely decreased	30–44			
	G4	Severely decreased	15–29			
	G5	Kidney failure	<15			

Permission obtained from KDIGO - bit.ly/KDIGOGuide

ICHOM Set of Patient-Centered Outcome Measures for Chronic Kidney Disease Overview

Case-Mix Variables

Variable	Measure	Timing	Data Source
Demographic Factors			
All patients	Year of birth	Baseline	Clinical
	Sex		Patient-reported
	Education level		Patient-reported
Baseline Clinical Factors			
All patients	Comorbidities	Baseline	Patient-reported
	BMI		Clinical
	Smoking		Patient-reported
Pre-RRT & CC patients	Primary renal disease	Baseline	Clinical
HD patients	Renal function		
Tx patients	Vascular access type		
Pre-RRT & CC patients	Transplant type	Baseline	Clinical
	Kidney allograft function		
Pre-RRT, CC & Tx patients	Albuminuria	Baseline	Clinical
HD, PD, CC & Tx patients	Previous graft		
	Previous modality		

Outcomes overview

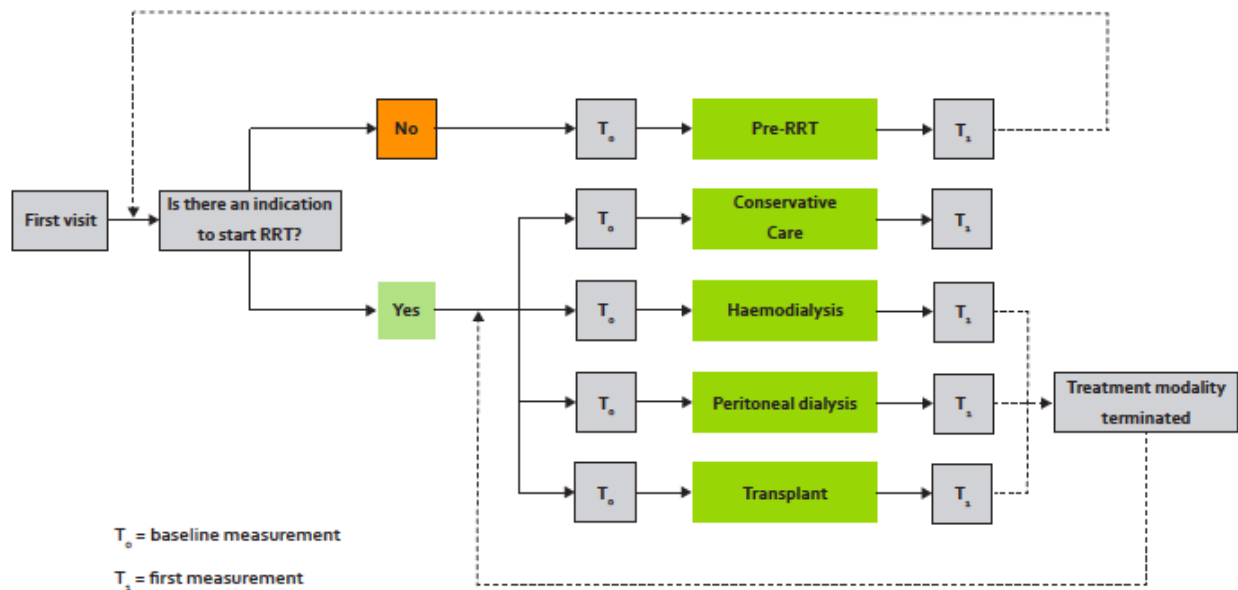
Patient Population	Measure	Timing	Data Source
Survival			
All patients	Survival	Ongoing	Clinical
Burden of Care			
All patients	Hospitalisation Cardiovascular events	Annually	Clinical
Patient-Reported Health & Wellbeing			
HD, PD & CC patients	Health-Related Quality of Life, Pain, Fatigue, Physical Function, Depression, Daily Activity	Baseline and 6-monthly	Patient-reported
Pre-RRT & Tx patients		Baseline and annually	
Treatment-Specific			
Pre-RRT & CC patients	Renal function Kidney allograft function	6-monthly	Clinical
Tx patients	Kidney allograft survival	Annually	
	Malignancies		
PD patients	PD modality survival		
HD patients	Vascular access survival	6-monthly	

Tier 2 Implementation- Important outcomes

Patient Population	Measure	Timing	Data Source
Treatment-Specific			
HD, PD & Tx patients	Bacteraemia	6-monthly	Clinical
Pre-RRT, CC & Tx patients	Albuminuria	Annually	
PD patients	Peritonitis	6-monthly	
Tx patients	Acute rejection	6-monthly for the first year, then annually	

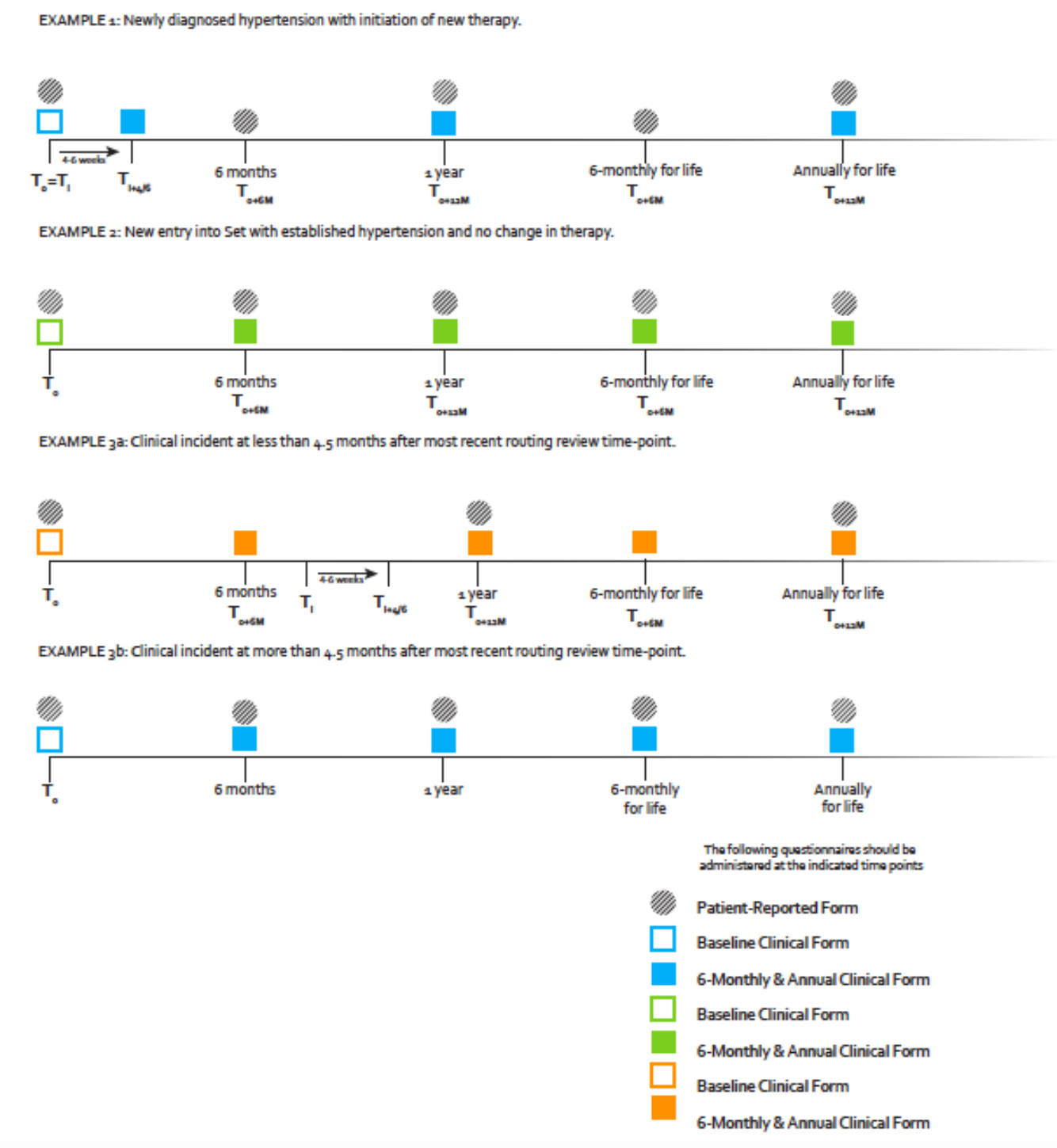
Treatment Pathway

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



Follow-Up Timeline

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



Collecting Patient-Reported Outcome and Clinical Measures

Because of varying costs and licensing requirement 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.

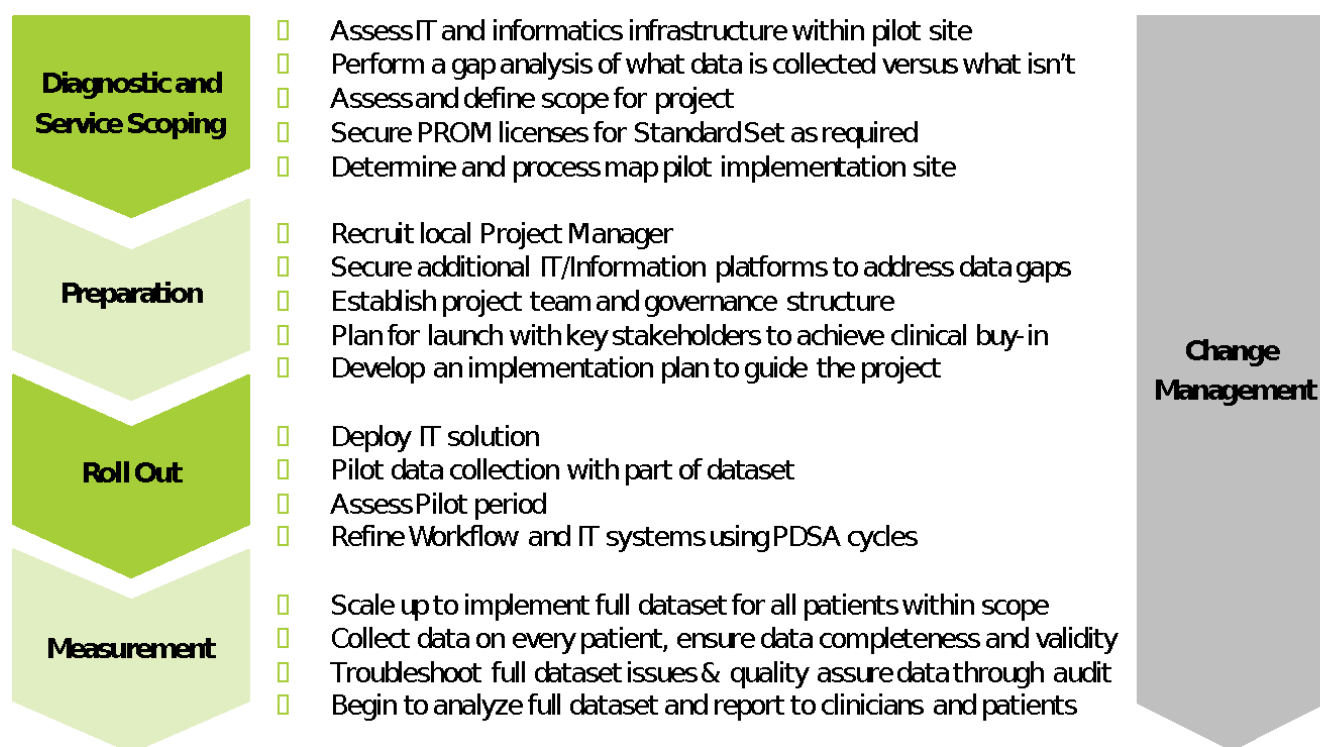
Chronic Kidney Disease Survey Used	Licensing Information	Scoring Information
Modified Self-Administered Comorbidity Questionnaire (SCQ)	The SCQ is not copyrighted and a license is not needed. It may be found at: Sangha et al (2003) The self-administered comorbidity questionnaire: A new method to assess comorbidity for clinical and health services research. <i>Arthritis Care & Research</i> 49(2): 156-163	Sangha et al (2003) The self-administered comorbidity questionnaire: A new method to assess comorbidity for clinical and health services research. <i>Arthritis Care & Research</i> 49(2): 156-163
The Optum™ SF-36v2® Health Survey	The SF-36v2 Health Survey requires a license agreement prior to the use or reproduction of the tool. Information on how to obtain a license can be found here: https://www.qualitymetric.com/	The scoring guide for the SF36v2 is only available upon a license agreement being made
PROMIS-Global Health	Free to use for non-commercial purposes and in clinical practice without a license. Information about available translations can be found here: https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures	The scoring guide for the PROMIS-Global Health can be found at: https://www.healthmeasures.net/index.php?option=com_instruments&view=measure&id=778&Itemid=992
PROMIS-29		The scoring guide for the PROMIS-29 can be found at: https://www.healthmeasures.net/index.php?option=com_instruments&view=measure&id=849&Itemid=992
RAND 36-Item Short-Form Questionnaire (SF-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-care/surveys_tools/mos/36-item-short-form.html	The scoring guide for the RAND- 36 can be found at: https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form/scoring.html
PROsetta Stone®	Developed and applied methods to link the Patient-Reported Outcome 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. https://www.prosettastone.org/	

The Growing ICHOM Community

There is a growing community of healthcare providers implementing the Set. To support your organization in implementing the set and the measurement of outcomes data, we have outlined a framework to guide the implementation and reporting of patient-centered outcomes. All materials can be downloaded for free from ICHOM Connect, for further information or to enquire about implementation support offered by ICHOM Partners, please contact us: info@ichom.org.

Implementation framework:

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



Implementation Study:

We are keen to find out if you have implemented or are implementing our ICHOM our Sets. Please fill in this survey: bit.ly/InitialImp or contact info@ichom.org for more information.

Translating the Set Tools:

PROMs 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, if permitted by its license, 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 Finalization	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 Process for Patient-Reported Outcome 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.

Appendix

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Chronic Kidney Disease 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. **For technical use an Excel version of this data dictionary is also available for download on ICHOM Connect. Excel data dictionary is the most up-to-date version and it is the recommended document to plan data collection.**

Please timestamp all variables. Some 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
Displayed Value:	N/A
Inclusion Criteria:	All patients
Timing:	On all forms
Data Source:	Administrative or clinical
Type:	Numerical
Value Domain:	N/A
Response Options:	According to institution

Demographic Factors

Variable ID:	YearOfBirth
Variable:	Year of Birth
Definition:	Year of birth
Supporting Definition:	None
Displayed Value:	In what year were you born?
Inclusion Criteria:	All patients
Timing:	Baseline
Data Source:	Clinical
Type:	Date by YYYY
Value Domain:	Date
Response Options:	YYYY

Variable ID:	Sex
Variable:	Sex
Definition:	The patient's sex at birth
Supporting Definition:	For statistical purposes, the following category codes, labels and definitions are preferred: CODE 1 Male: Persons who have male or predominantly masculine biological characteristics, or male sex assigned at birth. CODE 2 Female: Persons

who have female or predominantly feminine biological characteristics, or female sex assigned at birth. CODE 3 Other: Persons who have mixed or non-binary biological characteristics (if known), or a nonbinary sex assigned at birth. The value meaning of 'Other' has been assigned to Code 3 for this value domain, which replaces 'Intersex or indeterminate' for the superseded value domain Sex code N. Terms such as 'indeterminate', 'intersex', 'non-binary', and 'unspecified' are variously used to describe the 'Other' category of sex. The label 'Other' is used because a more descriptive term has not been widely agreed within the general community. Sex refers to the chromosomal, gonadal and anatomical characteristics associated with biological sex. Where there is an inconsistency between anatomical and chromosomal characteristics, sex is based on anatomical characteristics.

Displayed Value: Please indicate your sex at birth
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 1= Male
 2= Female
 3= Other
 999= Undisclosed

Variable ID: EducationLevel

Variable: Level of Education

Definition: Highest level of education completed based on local standard definitions of education levels

Supporting Definition: This measure may vary based on local standards for education levels so please consult the International Standard Classification to select what level most closely relates to your education experience. Please follow this link here:
<http://uis.unesco.org/sites/default/files/documents/international-standard-classification-of-education-isced-2011-en.pdf>

Displayed Value: Please indicate your highest level of schooling.

Inclusion Criteria: All patients

Timing: Baseline and ongoing

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= 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: None

Displayed Value: None

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 1 = Pre-Renal Replacement Therapy
2 = Conservative care
3 = Haemodialysis
4 = Peritoneal Dialysis
5 = Functioning kidney transplant

Variable ID: PREVTEAT

Variable: Previous modality treatment(s)

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

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: Tx, HD, PD, CC

Timing: Baseline

Data Source: Clinical

Type: Multiple answer

Value Domain: Code

Response Options: 0 = None
1 = Haemodialysis
2 = Peritoneal dialysis
3 = Kidney transplant
999 = Unknown

Variable ID: SmokingStatus

Variable: Smoking status

Definition: A person's current and past smoking behavior

Supporting Definition: Daily smoker: A person who smokes daily

Weekly smoker: A person who smokes at least weekly but not daily

Former smoker: A person who does not smoke at all now, but has smoked at least 100 cigarettes or a similar amount of other tobacco products in his/her lifetime

Never-smoker: A person who does not smoke now and has smoked fewer than 100 cigarettes or similar amount of other tobacco products in his/her lifetime

Displayed Value: Please indicate your smoking behavior. More detailed definitions are as follows:

Daily smoker: A person who smokes daily

Weekly smoker: A person who smokes at least weekly but not daily

Former smoker: A person who does not smoke at all now, but has smoked at least 100 cigarettes or a similar amount of other tobacco products in his/her lifetime

Never-smoker: A person who does not smoke now and has smoked fewer than 100 cigarettes or similar amount of other tobacco products in his/her lifetime

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Current every day smoker
1 = Current weekly smoker
2 = Former smoker
3 = Never smoker
4 = Others
999 = Unknown if ever smoked

Variable ID: HeightValue

Variable: Body height

Definition: The height of a person, measured in the indicated units

Supporting Definition: The measurement protocol described below are those recommended by the International Society for the Advancement of Kinanthropometry as described by Norton et al. (1996), and the World Health Organization (WHO Expert Committee 1995), which was adapted from Lohman et al. (1988).

Measurement protocol:

Height measurements can be based on recumbent length or standing height. In general, length measurements are recommended for children under 2 years of age and height measurements for others.

The measurement of height requires a vertical metric rule, a horizontal headboard, and a non-compressible flat even surface on which the subject stands. The equipment may be fixed or portable, and should be described and reported.

The graduations on the metric rule should be at 0.1 cm intervals, and the metric rule should have the capacity to measure up to at least 210 cm.

Measurement intervals and labels should be clearly readable under all conditions of use of the instrument.

Apparatus that allows height to be measured while the subject stands on a platform scale is not recommended.

Adults and children who can stand:

The subject should be measured without shoes (i.e. is barefoot or wears thin socks) and wears little clothing so that the positioning of the body can be seen. Anything that may affect or interfere with the measurement should be noted on the data collection form (e.g. hairstyles and accessories, or physical problems). The subject stands with weight distributed evenly on both feet, heels together, and the head positioned so that the line of vision is at right angles to the body. The correct position for the head is in the Frankfort horizontal plan (Norton et al. 1996). The arms hang freely by the sides. The head, back, buttocks and heels are positioned vertically so that the buttocks and the heels are in contact with the vertical board. To obtain a consistent measure, the subject is asked to inhale deeply and stretch to their fullest height. The measurer applies gentle upward pressure through the mastoid processes to maintain a fully erect position when the measurement is taken. Ensure that the head remains positioned so that the line of vision is at right angles to the body, and the heels remain in contact with the base board.

The movable headboard is brought onto the top of the head with sufficient pressure to compress the hair.

The measurement is recorded to the nearest 0.1 cm. Take a repeat measurement.

If the two measurements disagree by more than 0.5 cm, then take a third measurement. All raw measurements should be recorded on the data collection form. If practical, it is preferable to enter the raw data into the database as this enables intra-observer and, where relevant, inter-observer errors to be assessed. The subject's measured height is subsequently calculated as the mean of the two observations, or the mean of the two closest measurements if a third is taken, and recorded on the form. If only a mean value is entered into the database then the data collection forms should be retained.

It may be necessary to round the mean value to the nearest 0.1 cm. If so, rounding should be to the nearest even digit to reduce systematic over reporting (Armitage & Berry 1994). For example, a mean value of 172.25 cm would be rounded to 172.2 cm, while a mean value of 172.35 cm would be rounded to 172.4 cm.

Infants:

For the measurement of supine length of children up to and including 2 years of age, two observers are required. One observer positions the head correctly while the other ensures the remaining position is correct and brings the measuring board in contact with the feet. The subject lies in a supine position on a recumbent length table or measuring board. The crown of the head must touch the stationary, vertical headboard. The subject's head is held with the line of vision aligned perpendicular to the plane of the measuring surface. The shoulders and buttocks must be flat against the table top, with the shoulders and hips aligned at right angles to the long axis of the body. The legs must be extended at the hips and knees and lie flat against the table top and the arms rest against the sides of the

trunk. The measurer must ensure that the legs remain flat on the table and must shift the movable board against the heels. In infants care has to be taken to extend the legs gently. In some older children two observers may also be required. In general, length or height is measured and reported to the nearest 0.1 cm. For any child, the length measurement is approximately 0.5–1.5 cm greater than the height measurement. It is therefore recommended that when a length measurement is applied to a height-based reference for children over 24 months of age (or over 85 cm if age is not known), 1.0 cm be subtracted before the length measurement is compared with the reference. It is also recommended that as a matter of procedure and data recording accuracy, the date be recorded when the change is made from supine to standing height measure.

Validation and quality control measures:

All equipment, whether fixed or portable should be checked prior to each measurement session to ensure that both the headboard and floor (or footboard) are at 90 degrees to the vertical rule. With some types of portable anthropometer it is necessary to check the correct alignment of the headboard, during each measurement, by means of a spirit level. Within- and, if relevant, between-observer variability should be reported. They can be assessed by the same (within-) or different (between-) observers repeating the measurement of height, on the same subjects, under standard conditions after a short time interval. The standard deviation of replicate measurements (technical error of measurement (Pederson & Gore 1996)) between observers should not exceed 5 mm and be less than 5 mm within observers.

Extreme values at the lower and upper end of the distribution of measured height should be checked both during data collection and after data entry. Individuals should not be excluded on the basis of true biological difference. Last digit preference, and preference or avoidance of certain values, should be analysed in the total sample and (if relevant) by observer, survey site and over time if the survey period is long.

Displayed Value: Please indicate your body height.

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Numerical value

Value Domain: Quantity

Response Options: Numerical value of height

Variable ID: HeightUnit

Variable: Body height units

Definition: Units of body height

Supporting Definition: None

Displayed Value: Please indicate what units of measurement (centimeters or inches) that you recorded your height in.

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 1 = centimeters
2 = inches

Variable ID: WeightValue

Variable: Body weight

Definition: The body weight of a person, measured in the indicated units

Supporting Definition: The collection of anthropometric measurements, particularly in those who are overweight or obese or who are concerned about their weight, should be

performed with great sensitivity and without drawing attention to an individual's weight.

Displayed Value: Please indicate your body weight.

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Numerical value

Value Domain: Quantity

Response Options: Numerical value of weight

Variable ID: WeightUnit

Variable: Body weight units

Definition: Units of body weight

Supporting Definition: None

Displayed Value: Please indicate what units of measurement (kilograms or pounds) that you recorded your weight in.

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 1 = kilograms
2 = lbs

Baseline Condition Factors

Variable ID: PRIMRENDIS

Variable: Primary renal disease

Definition: Indicate the patient's primary renal disease

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 1 = Uncertain aetiology
2 = Diabetes mellitus
3 = Glomerulonephritis
4 = 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: None

Displayed Value: None

Inclusion Criteria: Tx, HD, PD, CC

Timing: Baseline

Data Source: Clinical

Type: Numerical

Value Domain: Quantity

Response Options:	None
Variable ID:	BASEHDTYPE
Variable:	Vascular access type
Definition:	Indicate the most recent type of vascular access
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	HD
Timing:	Baseline
Data Source:	Clinical
Type:	Single answer
Value Domain:	Code
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:	None
Displayed Value:	None
Inclusion Criteria:	Tx
Timing:	Baseline
Data Source:	Clinical
Type:	Single answer
Value Domain:	Code
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:	None
Displayed Value:	None
Inclusion Criteria:	Pre-RRT, CC, Tx
Timing:	Baseline
Data Source:	Clinical
Type:	Single answer
Value Domain:	Code
Response Options:	0 = 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:	None
Displayed Value:	None
Inclusion Criteria:	If "1 = Serum Creatinine", "2 = eGFR" or "3 = Serum Creatinine + eGFR" to BASERFUNC
Timing:	Baseline
Data Source:	Clinical
Type:	Date by DD/MM/YYYY
Value Domain:	Date
Response Options:	DD/MM/YYYY
Variable ID:	CreatinineUnit

Variable: Serum Creatinine units
Definition: Indicate the units used for serum creatinine measurement
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = Serum Creatinine" or "3 = Serum Creatinine + eGFR" to BASERFUNC
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 1 = $\mu\text{mol/l}$
2 = mg/dl

Variable ID: BASERFUNCCAL
Variable: Serum Creatinine callibration
Definition: Indicate which serum creatinine assay is used
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = Serum Creatinine" or "3 = Serum Creatinine + eGFR" to BASERFUNC
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
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: None
Displayed Value: None
Inclusion Criteria: If "1 = Serum Creatinine" or "3 = Serum Creatinine + eGFR" to BASERFUNC
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: CreatinineValue
Variable: Serum Creatinine
Definition: Provide the serum creatinine value in the indicated units
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = Serum Creatinine" or "3 = Serum Creatinine + eGFR" to BASERFUNC
Timing: Baseline
Data Source: Clinical
Type: Numerical
Value Domain: Quantity
Response Options: None

Variable ID: BASERFUNCEGFRMEAS
Variable: eGFR equation
Definition: Provide the eGFR equation
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "2 = eGFR" or "3 = Serum Creatinine + eGFR" to BASERFUNC

Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 1 = CKD-EPI Serum Creatinine
2 = MDRD-4
3 = MDRD-6
4 = Cockcroft-Gault
5 = Other

Variable ID: BASERFUNGFR
Variable: eGFR value
Definition: Provide the eGFR value
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "2 = eGFR" or "3 = Serum Creatinine + eGFR" to BASERFUNGFR
Timing: Baseline
Data Source: Clinical
Type: Numerical
Value Domain: Quantity
Response Options: None

Variable ID: AlbuminuriaMethod
Variable: Method of albuminuria measurement
Definition: Indicate the method of albuminuria measurement
Supporting Definition: Urine albumin/creatinine ratio in spot urine (preferred), or urine protein/creatinine ratio (alternative)
Displayed Value: None
Inclusion Criteria: Pre-RRT, CC, Tx
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = Albuminuria not assessed
1 = Urine albumin/creatinine ratio in spot urine
2 = Urine protein/creatinine ratio in spot urine
999 = Unknown

Variable ID: AlbuminuriaUnit
Variable: Units of albuminuria measurement
Definition: Indicate the units used for albuminuria measurement
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = Urine albumin/creatinine ratio in spot urine" or "2 = Urine protein/creatinine ratio in spot urine" to AlbuminuriaMethod
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 1 = mg/g
2 = mg/mmol

Variable ID: BASEALBCAL
Variable: Albuminuria callibration
Definition: Indicate which albuminuria assay is used
Supporting Definition: None
Displayed Value: None

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

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 1 = Immunoassay
2 = Dipstick
999 = Unknown

Variable ID: AlbuminuriaACR

Variable: Results of urine ACR

Definition: Provide urine ACR in spot urine in indicated unit

Supporting Definition: None

Displayed Value: None

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

Timing: Baseline

Data Source: Clinical

Type: Numerical

Value Domain: Quantity

Response Options: None

Variable ID: AlbuminuriaPCR

Variable: Urine PCR

Definition: Provide urine PCR in spot urine in indicated unit

Supporting Definition: None

Displayed Value: None

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

Timing: Baseline

Data Source: Clinical

Type: Numerical

Value Domain: Quantity

Response Options: None

Variable ID: AlbuminuriaDate

Variable: Date of albuminuria measurement

Definition: Provide the date of albuminuria measurement

Supporting Definition: None

Displayed Value: None

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

Timing: Baseline

Data Source: Clinical

Type: Date by DD/MM/YYYY

Value Domain: Date

Response Options: Date

Variable ID: ComorbiditiesSACQ

Variable: SACQ Comorbidities

Definition: Indicate whether the patient has a documented history of any of the following comorbidities

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Have you been told by a doctor that you have any of the following?

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Patient-reported

Type: Multiple answer Separate multiple entries with ";"

Value Domain: Code

Response Options: 0 = I have no other diseases
 1 = Heart disease (For example, angina, heart attack, or heart failure)
 2 = High blood pressure
 3 = Lung disease (For example, asthma, chronic bronchitis, or emphysema)
 4 = Diabetes
 5 = Ulcer or stomach disease
 6 = Kidney disease
 7 = Liver disease
 8 = Anemia or other blood disease
 9 = Cancer/Other cancer (within the last 5 years)
 10 = Depression
 11 = Osteoarthritis, degenerative arthritis
 12 = Back pain
 13 = Rheumatoid arthritis
 14 = Other medical problems

Variable ID: ComorbiditiesSACQ_HeartDiseaseFU1

Variable: SACQ comorbidities: Heart Disease: Follow-Up Question 1

Definition: Please indicate if the patient receives treatment for Heart disease (For example, angina, heart attack, or heart failure)

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Do you receive treatment for heart disease (For example, angina, heart failure, or heart attack)?

Inclusion Criteria: If answered 1= Heart disease to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = No
 1 = Yes

Variable ID: ComorbiditiesSACQ_HeartDiseaseFU2

Variable: SACQ comorbidities: Heart Disease: Follow-Up Question 2

Definition: Please indicate if the patient's heart disease limits their function

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Does your heart disease limit your activities?

Inclusion Criteria: If answered 1= Heart disease to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = No
 1 = Yes

Variable ID: ComorbiditiesSACQ_HighBloodPressureFU1

Variable: SACQ comorbidities: High Blood Pressure: Follow-Up Question 1

Definition: Please indicate if the patient receives treatment for high blood pressure

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Do you receive treatment for high blood pressure?

Inclusion Criteria: If answered 2= High blood pressure to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_HighBloodPressureFU2
Variable: SACQ comorbidities: High Blood Pressure: Follow-Up Question 2
Definition: Please indicate if the patient's high blood pressure limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your high blood pressure limit your activities?
Inclusion Criteria: If answered 2= High blood pressure to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_LungDiseaseFU1
Variable: SACQ comorbidities: Lung Disease: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for lung disease
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Do you receive treatment for lung disease?
Inclusion Criteria: If answered 3= Lung disease to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_LungDiseaseFU2
Variable: SACQ comorbidities: Lung Disease: Follow-Up Question 2
Definition: Please indicate if the patient's lung disease limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your lung disease limit your activities?
Inclusion Criteria: If answered 3= Lung disease to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_DiabetesFU1
Variable: SACQ comorbidities: Diabetes: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for diabetes

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Do you receive treatment for diabetes?

Inclusion Criteria: If answered 4= Diabetes to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_DiabetesFU2

Variable: SACQ comorbidities: Diabetes: Follow-Up Question 2

Definition: Please indicate if the patient's diabetes limits their function

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Does your diabetes limit your activities?

Inclusion Criteria: If answered 4= Diabetes to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_StomachDiseaseFU1

Variable: SACQ comorbidities: Stomach Disease: Follow-Up Question 1

Definition: Please indicate if the patient receives treatment for an ulcer or stomach disease

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Do you receive treatment for an ulcer or stomach disease?

Inclusion Criteria: If answered 5= Ulcer or stomach disease to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_StomachDiseaseFU2

Variable: SACQ comorbidities: Stomach Disease: Follow-Up Question 2

Definition: Please indicate if the patient's ulcer or stomach disease limits their function

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Does your ulcer or stomach disease limit your activities?

Inclusion Criteria: If answered 5= Ulcer or stomach disease to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_KidneyDiseaseFU1

Variable:	SACQ comorbidities: Kidney Disease: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for kidney disease
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for kidney disease?
Inclusion Criteria:	If answered 6= Kidney disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
<hr/>	
Variable ID:	ComorbiditiesSACQ_KidneyDiseaseFU2
Variable:	SACQ comorbidities: Kidney Disease: Follow-Up Question 2
Definition:	Please indicate if the patient's kidney disease limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your kidney disease limit your activities?
Inclusion Criteria:	If answered 6= Kidney disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
<hr/>	
Variable ID:	ComorbiditiesSACQ_LiverDiseaseFU1
Variable:	SACQ comorbidities: Liver Disease: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for liver disease
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for liver disease?
Inclusion Criteria:	If answered 7= Liver disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
<hr/>	
Variable ID:	ComorbiditiesSACQ_LiverDiseaseFU2
Variable:	SACQ comorbidities: Liver Disease: Follow-Up Question 2
Definition:	Please indicate if the patient's liver disease limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your liver disease limit your activities?
Inclusion Criteria:	If answered 7= Liver disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No

1= Yes

Variable ID:	ComorbiditiesSACQ_BloodDiseaseFU1
Variable:	SACQ comorbidities: Blood Disease: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for anemia or other blood disease
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for anemia or other blood disease?
Inclusion Criteria:	If answered 8= Anemia or other blood disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes

Variable ID:	ComorbiditiesSACQ_BloodDiseaseFU2
Variable:	SACQ comorbidities: Blood Disease: Follow-Up Question 2
Definition:	Please indicate if the patient's anemia or other blood disease limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your anemia or other blood disease limit your activities?
Inclusion Criteria:	If answered 8= Anemia or other blood disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes

Variable ID:	ComorbiditiesSACQ_CancerFU1
Variable:	SACQ comorbidities: Cancer: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for cancer/another cancer
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for cancer/another cancer?
Inclusion Criteria:	If answered 9= Cancer/Other cancer to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes

Variable ID:	ComorbiditiesSACQ_CancerFU2
Variable:	SACQ comorbidities: Cancer: Follow-Up Question 2
Definition:	Please indicate if the patient's cancer/other cancer limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your cancer/other cancer limit your activities?
Inclusion Criteria:	If answered 9= Cancer/Other cancer to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer

Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_DepressionFU1
Variable: SACQ comorbidities: Depression: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for depression
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Do you receive treatment for depression?
Inclusion Criteria: If answered 10= Depression to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_DepressionFU2
Variable: SACQ comorbidities: Depression: Follow-Up Question 2
Definition: Please indicate if the patient's depression limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your depression limit your activities?
Inclusion Criteria: If answered 10= Depression to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_OsteoarthritisFU1
Variable: SACQ comorbidities: Osteoarthritis: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for osteoarthritis/degenerative arthritis
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Do you receive treatment for osteoarthritis/degenerative arthritis?
Inclusion Criteria: If answered 11= Osteoarthritis, degenerative arthritis to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_OsteoarthritisFU2
Variable: SACQ comorbidities: Osteoarthritis: Follow-Up Question 2
Definition: Please indicate if the patient's osteoarthritis/degenerative arthritis limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your osteoarthritis/degenerative arthritis limit your activities?

Inclusion Criteria: If answered 11= Osteoarthritis, degenerative arthritis to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_BackPainFU1
Variable: SACQ comorbidities: Back Pain: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for back pain
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Do you receive treatment for back pain?
Inclusion Criteria: If answered 12= Back pain to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_BackPainFU2
Variable: SACQ comorbidities: Back Pain: Follow-Up Question 2
Definition: Please indicate if the patient's back pain limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your back pain limit your activities?
Inclusion Criteria: If answered 12= Back pain to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_RheumatoidArthritisFU1
Variable: SACQ comorbidities: Rheumatoid Arthritis: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for rheumatoid arthritis
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Do you receive treatment for rheumatoid arthritis?
Inclusion Criteria: If answered 13= Rheumatoid arthritis to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_RheumatoidArthritisFU2
Variable: SACQ comorbidities: Rheumatoid Arthritis: Follow-Up Question 2
Definition: Please indicate if the patient's rheumatoid arthritis limits their function

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Does your rheumatoid arthritis limit your activities?

Inclusion Criteria: If answered 13= Rheumatoid arthritis to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_Other

Variable: SACQ comorbidities: Other Medical Problems

Definition: Please indicate what other medical problems the patient is experiencing

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: What other medical problems are you experiencing?

Inclusion Criteria: If answered 14= Other medical problems to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: String

Response Options: None

Variable ID: ComorbiditiesSACQ_Score

Variable: Score of the SACQ comorbidities questionnaire

Definition: Please indicate the summed score for all of the patient's comorbidities

Supporting Definition: An individual can receive a max of 3 points for each medical condition: 1 point for the presence of the problem, another point if he/she receives treatment for it, and an additional point if the problem causes a limitation in function. The Max score a patient can receive is 45 points

Displayed Value: What is the total summed score of the patient's SACQ responses?

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Numerical value

Value Domain: Quantity

Response Options: Total summed score

Variable ID: CardiovascularEvent

Variable: Cardiovascular event

Definition: Has the patient been diagnosed with any cardiovascular event?

Supporting Definition: Cardiovascular events of interest are acute myocardial infarction, stroke (excluding transient ischemic attacks), and limb amputation (excluding traumatic injury)

Displayed Value: None

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: MyocardialInfarction

Variable: Myocardial infarction

Definition: Indicate whether the patient has a documented history of myocardial infarction.

Supporting Definition: 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.

Displayed Value: Have you ever been told by your doctor that you've had a heart attack or a myocardial infarction?

Inclusion Criteria: If "1 = yes" to CardiovascularEvent

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: StrokeExclTIA

Variable: Stroke (excluding transient ischemic attacks)

Definition: Indicate whether the patient was ever diagnosed with a stroke (excluding transient ischemic attacks)

Supporting Definition: Stroke is defined as any confirmed neurological deficit of abrupt onset caused by a disturbance in blood supply to the brain that did not resolve within 24 hours

Displayed Value: Have you ever been told by a doctor that you have had a stroke?

Inclusion Criteria: If "1 = yes" to CardiovascularEvent

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = 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: None

Displayed Value: None

Inclusion Criteria: If "1 = yes" to CardiovascularEvent

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: AnyMalignancies

Variable: Malignancies

Definition: Indicate whether the patient has any malignancies

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: MalignSolid
Variable: Solid malignancy
Definition: Indicate whether the malignancy is a solid tumour
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = yes" to AnyMalignancies
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: MalignSkin
Variable: Skin malignancy
Definition: Indicate whether the malignancy is skin cancer
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = yes" to AnyMalignancies
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: MalignHematological
Variable: Haematological malignancy
Definition: Indicate whether the malignancy is a haematological malignancy
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = yes" to AnyMalignancies
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Unknown

Outcomes

Survival

Variable ID: VitalStatus
Variable: Vital status
Definition: Indicate if the person has deceased, regardless of cause
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: All patients
Timing: Ongoing

Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: DeceasedDate
Variable: Date of death
Definition: The date of death of the person
Supporting Definition: It is recommended that in cases where all components of the date of death are not known or where an estimate is arrived at from age, a valid date be used together with a flag to indicate that it is an estimate.

For record identification and/or the derivation of other metadata items that require accurate date of death information, estimated dates of death should be identified by a date accuracy indicator to prevent inappropriate use of date of death data. The linking of client records from diverse sources, the sharing of patient data, and data analysis for research and planning all rely heavily on the accuracy and integrity of the collected data. In order to maintain data integrity and the greatest possible accuracy an indication of the accuracy of the date collected is critical. The collection of Date accuracy indicator may be essential in confirming or refuting the positive identification of a person. For this reason it is strongly recommended that the data element Date accuracy indicator also be recorded at the time of record creation to flag the accuracy of the data.

Displayed Value: None
Inclusion Criteria: If "1 = yes" to VitalStatus
Timing: Ongoing
Data Source: Clinical
Type: Date by DD/MM/YYYY
Value Domain: Date
Response Options: None

Variable ID: DEATHCAUSE_CKD
Variable: Cause of death
Definition: The cause of death of the person
Supporting Definition: Use SMARRT categories
Displayed Value: None
Inclusion Criteria: If "1 = yes" to VitalStatus
Timing: Ongoing
Data Source: Clinical
Type: Single answer
Value Domain: Code
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:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	Quantity
Response Options:	Numerical value
Variable ID:	DaysHospitalised12Months
Variable:	Total number of days spent in hospital over past 12 months
Definition:	The total length (in days) of all admissions to hospital or acute care facility in the last 12 months
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If ≥1 to HOSPADMALL
Timing:	Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	Quantity
Response Options:	None
Variable ID:	CardiovascularEvent
Variable:	Cardiovascular event
Definition:	Has the patient been diagnosed with any cardiovascular event?
Supporting Definition:	Cardiovascular events of interest are acute myocardial infarction, stroke (excluding transient ischemic attacks), and limb amputation (excluding traumatic injury)
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	Code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	MyocardialInfarction
Variable:	Myocardial infarction
Definition:	Indicate whether the patient has a documented history of myocardial infarction.
Supporting Definition:	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.
Displayed Value:	Have you ever been told by your doctor that you've had a heart attack or a myocardial infarction?
Inclusion Criteria:	If "1 = yes" to CardiovascularEvent
Timing:	Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	Code
Response Options:	0 = 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
Displayed Value:	None

Inclusion Criteria: If "1 = yes" to MyocardialInfarction

Timing: Annually

Data Source: Clinical

Type: Date by DD/MM/YYYY

Value Domain: Date

Response Options: DD/MM/YYYY

Variable ID: StrokeExclTIA

Variable: Stroke (excluding transient ischemic attacks)

Definition: Indicate whether the patient was ever diagnosed with a stroke (excluding transient ischemic attacks)

Supporting Definition: Stroke is defined as any confirmed neurological deficit of abrupt onset caused by a disturbance in blood supply to the brain that did not resolve within 24 hours

Displayed Value: Have you ever been told by a doctor that you have had a stroke?

Inclusion Criteria: If "1 = yes" to CardiovascularEvent

Timing: Annually

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: STRDATE

Variable: Date of stroke

Definition: Indicate the date of stroke diagnosis

Supporting Definition: Multiple dates possible

Displayed Value: None

Inclusion Criteria: If "1 = yes" to StrokeExclTIA

Timing: Annually

Data Source: Clinical

Type: Date by DD/MM/YYYY

Value Domain: Date

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: None

Displayed Value: None

Inclusion Criteria: If "1 = yes" to CardiovascularEvent

Timing: Annually

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = 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

Displayed Value: None

Inclusion Criteria: If "1 = yes" to CARDIOLIMB

Timing: Annually

Data Source: Clinical

Type: Date by DD/MM/YYYY

Value Domain: Date

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:	None
Displayed Value:	None
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
Value Domain:	Code
Response Options:	1 = PROMIS-Global Health & PROMIS-29 2 = RAND-36 3 = SF-36v2.0
Variable ID:	PROMIS-29_Q01
Variable:	PROMIS-29 - PFA11
Definition:	Are you able to do chores such as vacuuming or yard work?
Supporting Definition:	None
Displayed Value:	Are you able to do chores such as vacuuming or yard work?
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
Value Domain:	Code
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_Q02
Variable:	PROMIS-29 - PFA21
Definition:	Are you able to go up and down stairs at a normal pace?
Supporting Definition:	None
Displayed Value:	Are you able to go up and down stairs at a normal pace?
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
Value Domain:	Code
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_Q03
Variable:	PROMIS-29 - PFA23
Definition:	Are you able to go for a walk of at least 15 minutes?
Supporting Definition:	None
Displayed Value:	Are you able to go for a walk of at least 15 minutes?

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
Value Domain: Code
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_Q04
Variable: PROMIS-29 - PFA53
Definition: Are you able to run errands and shop?
Supporting Definition: None
Displayed Value: Are you able to run errands and shop?
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
Value Domain: Code
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: None
Displayed Value: In the past 7 days...
I felt fearful
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
Value Domain: Code
Response Options: 1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = 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: None
Displayed Value: In the past 7 days...
I found it hard to focus on anything other than my anxiety
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
Value Domain: Code
Response Options: 1 = Never
 2 = Rarely
 3 = Sometimes
 4 = Often
 5 = Always

Variable ID: PROMIS-29_Q07
Variable: PROMIS-29 - EDANX41
Definition: In the past 7 days...
 My worries overwhelmed me

Supporting Definition: None
Displayed Value: In the past 7 days...
 My worries overwhelmed me
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
Value Domain: Code
Response Options: 1 = Never
 2 = Rarely
 3 = Sometimes
 4 = Often
 5 = Always

Variable ID: PROMIS-29_Q08
Variable: PROMIS-29 - EDANX53
Definition: In the past 7 days...
 I felt uneasy

Supporting Definition: None
Displayed Value: In the past 7 days...
 I felt uneasy
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
Value Domain: Code
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: None
Displayed Value: In the past 7 days...
 I felt worthless
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

Value Domain: Code

Response Options: 1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always

Variable ID: PROMIS-29_Q10

Variable: PROMIS-29 - EDDEP06

Definition: In the past 7 days...
I felt helpless

Supporting Definition: None

Displayed Value: In the past 7 days...
I felt helpless

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

Value Domain: Code

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: None

Displayed Value: In the past 7 days...
I felt depressed

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

Value Domain: Code

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: None

Displayed Value: In the past 7 days...
I felt hopeless

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
Value Domain: Code
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 fatigued

Supporting Definition: None

Displayed Value: During the past 7 days...
 I feel fatigued

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

Value Domain: Code

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 trouble starting things because I am tired

Supporting Definition: None

Displayed Value: During the past 7 days...
 I have trouble starting things because I am tired

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

Value Domain: Code

Response Options: 1 = Not at all
 2 = A little bit
 3 = Somewhat
 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: None

Displayed Value: In the past 7 days...
 How run-down did you feel on average?

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
Value Domain: Code
Response Options: 1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

Variable ID: PROMIS-29_Q16
Variable: PROMIS-29 - FATEXP40
Definition: In the past 7 days...
How fatigued were you on average?
Supporting Definition: None
Displayed Value: In the past 7 days...
How fatigued were you on average?
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
Value Domain: Code
Response Options: 1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

Variable ID: PROMIS-29_Q17
Variable: PROMIS-29 - Sleep109
Definition: In the past 7 days...
My sleep quality was...
Supporting Definition: None
Displayed Value: In the past 7 days...
My sleep quality was...
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
Value Domain: Code
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: None
Displayed Value: In the past 7 days...
My sleep was refreshing...
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

Value Domain: Code

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: None

Displayed Value: In the past 7 days...
I had a problem with my sleep...

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

Value Domain: Code

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: None

Displayed Value: In the past 7 days...
I had difficulty falling asleep

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

Value Domain: Code

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: None

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

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
Value Domain: Code
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: None
Displayed Value: I have trouble doing all of the family activities that I want to do
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
Value Domain: Code
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: None
Displayed Value: I have trouble doing all of my usual work (include work at home)
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
Value Domain: Code
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: None
Displayed Value: I have trouble doing all of the activities with friends that I want to do
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
Value Domain: Code
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:	None
Displayed Value:	In the past 7 days... How much did pain interfere with your day to day activities?
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
Value Domain:	Code
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:	None
Displayed Value:	In the past 7 days... How much did pain interfere with work around the home?
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
Value Domain:	Code
Response Options:	1 = Not at all 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:	None
Displayed Value:	In the past 7 days... How much did pain interfere with your ability to participate in social activities?
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
Value Domain:	Code
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 - PAININ ₃₄
Definition:	In the past 7 days... How much did pain interfere with your household chores?
Supporting Definition:	None
Displayed Value:	In the past 7 days... How much did pain interfere with your household chores?
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
Value Domain:	Code
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 - Globalo ₇
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 0 = No pain, and 10 = Worst imaginable pain
Displayed Value:	In the past 7 days... How would you rate your pain on average?
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
Value Domain:	Quantity
Response Options:	Numerical value between 1 and 10

Variable ID:	PROMIS-G_Q01
Variable:	Globalo₁ - Patient reported general health status
Definition:	In general, would you say your health is:
Supporting Definition:	None
Displayed Value:	In general, would you say your health is:
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
Value Domain:	Code
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID:	PROMIS-G_Q02
Variable:	Globalo ₂ - Global patient reported health-related QOL
Definition:	In general, would you say your quality of life is:

Supporting Definition: None

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

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

Value Domain: Code

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: None

Displayed Value: In general, how would you rate your physical health?

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

Value Domain: Code

Response Options: 5 = Excellent
4 = Very good
3 = Good
2 = Fair
1 = Poor

Variable ID: PROMIS-G_Qo4

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: None

Displayed Value: In general, how would you rate your mental health, including your mood and your ability to think?

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

Value Domain: Code

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: None

Displayed Value: In general, how would you rate your satisfaction with your social activities and relationships?

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
Value Domain: Code
Response Options: 5 = Excellent
4 = Very good
3 = Good
2 = Fair
1 = Poor

Variable ID: PROMIS-G_Qogr
Variable: Globalogr - 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: None
Displayed Value: 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.)

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
Value Domain: Code
Response Options: 5 = Excellent
4 = Very good
3 = Good
2 = Fair
1 = Poor

Variable ID: PROMIS-G_Qo6
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: None
Displayed Value: To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

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
Value Domain: Code
Response Options: 5 = Completely
4 = Mostly
3 = Moderately
2 = A little
1 = Not at all

Variable ID: PROMIS-G_Q10r
Variable: Global10r - 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: None

Displayed Value: In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?

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

Value Domain: Code

Response Options: 1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always

Variable ID: PROMIS-G_Qo8r

Variable: Globalo8r - Fatigue

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

Supporting Definition: None

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

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

Value Domain: Code

Response Options: 1 = None
2 = Mild
3 = Moderate
4 = Severe
5 = Very severe

Variable ID: PROMIS-G_Qo7r

Variable: Globalo7r - 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 0 = No pain, and 10 = Worst imaginable pain

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

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

Value Domain: Quantity

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: None

Displayed Value: In general, would you say your health is:

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

Value Domain: Code

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: None

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

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

Value Domain: Code

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_Q03

Variable: RAND-36_Q03

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: None

Displayed Value: 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

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

Value Domain: Code

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: None

Displayed Value: 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

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

Value Domain: Code

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?: Lifting or carrying groceries

Supporting Definition: None

Displayed Value: 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?: Lifting or carrying groceries

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

Value Domain: Code

Response Options: 1 = Yes, limited a lot
2 = Yes, limited a little
3 = No, not limited at all

Variable ID: RAND-36_Qo6

Variable: RAND-36_Qo6

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: None

Displayed Value: 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

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

Value Domain: Code

Response Options: 1 = Yes, limited a lot
2 = Yes, limited a little
3 = No, not limited at all

Variable ID: RAND-36_Qo7

Variable: RAND-36_Qo7

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: None

Displayed Value: 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

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

Value Domain: Code

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: None

Displayed Value: 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

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

Value Domain: Code

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: None

Displayed Value: 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

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

Value Domain: Code

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: None

Displayed Value: 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

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

Value Domain: Code

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: None

Displayed Value: 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

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

Value Domain: Code

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: None

Displayed Value: 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

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

Value Domain: Code

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

Supporting Definition: None

Displayed Value: 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?:
Cut down the amount of time you spent on work or other activities

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

Value Domain: Code

Response Options: 1 = Yes
2 = No

Variable ID: RAND-36_Q14

Variable: RAND-36_Q14

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?:
Accomplished less than you would like

Supporting Definition: None

Displayed Value: 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?:
Accomplished less than you would like

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

Value Domain: Code

Response Options: 1 = Yes
2 = No

Variable ID: RAND-36_Q15

Variable: RAND-36_Q15

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?:
Were limited in the kind of work or other activities

Supporting Definition: None

Displayed Value: 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?:
Were limited in the kind of work or other activities

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

Value Domain: Code

Response Options: 1 = Yes
2 = No

Variable ID: RAND-36_Q16

Variable: RAND-36_Q16

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?:
Had difficulty performing the work or other activities (for example, it took extra effort)

Supporting Definition: None

Displayed Value: 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?:
Had difficulty performing the work or other activities (for example, it took extra effort)

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
Value Domain: Code
Response Options: 1 = Yes
2 = No

Variable ID: RAND-36_Q17

Variable: RAND-36_Q17

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

Supporting Definition: None

Displayed Value: 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)?:
Cut down the amount of time you spent on work or other activities

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

Value Domain: Code

Response Options: 1 = Yes
2 = No

Variable ID: RAND-36_Q18

Variable: RAND-36_Q18

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)?:
Accomplished less than you would like

Supporting Definition: None

Displayed Value: 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)?:
Accomplished less than you would like

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

Value Domain: Code

Response Options: 1 = Yes
2 = No

Variable ID: RAND-36_Q19

Variable: RAND-36_Q19

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)?:
Didn't work or other activities as carefully as usual

Supporting Definition: None

Displayed Value: 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)?:
 Didn't do work or other activities as carefully as usual
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
Value Domain: Code
Response Options: 1 = Yes
 2 = No

Variable ID: RAND-36_Q20

Variable: RAND-36_Q20

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: None

Displayed Value: 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?

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

Value Domain: Code

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: None

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

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

Value Domain: Code

Response Options: 1 = None
 2 = Very mild
 3 = Mild
 4 = Moderate
 5 = Severe
 6 = Very severe

Variable ID: 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: None

Displayed Value: During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

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
Value Domain: Code
Response Options: 1 = Not at all
2 = A little bit
3 = Moderately
4 = Quite a bit
5 = 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: None

Displayed Value: 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?

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
Value Domain: Code
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: None

Displayed Value: 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?

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

Value Domain: Code
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: None
Displayed Value: 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?
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
Value Domain: Code
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: None
Displayed Value: 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?
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
Value Domain: Code
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: None

Displayed Value: 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?

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

Value Domain: Code

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: None

Displayed Value: 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?

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

Value Domain: Code

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:	None
Displayed Value:	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?
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
Value Domain:	Code
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
<hr/>	
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:	None
Displayed Value:	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?
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
Value Domain:	Code
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
<hr/>	
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:	None
Displayed Value:	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?
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
Value Domain:	Code
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:	None
Displayed Value:	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.)?
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
Value Domain:	Code
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:	RAND-36_Q33
Variable:	RAND-36_Q33
Definition:	How TRUE or FALSE is each of the following statements for you. I seem to get sick a little easier than other people
Supporting Definition:	None
Displayed Value:	How TRUE or FALSE is each of the following statements for you. I seem to get sick a little easier than other people
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
Value Domain:	Code

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: None

Displayed Value: How TRUE or FALSE is each of the following statements for you.
I am as healthy as anybody I know

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

Value Domain: Code

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: None

Displayed Value: How TRUE or FALSE is each of the following statements for you.
I expect my health to get worse

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

Value Domain: Code

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: None

Displayed Value: How TRUE or FALSE is each of the following statements for you.
My health is excellent

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

Value Domain: Code

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

Displayed Value: None

Inclusion Criteria: Pre-RRT, CC, Tx

Timing: 6-monthly

Data Source: Clinical

Type: Single answer

Value Domains: Code

Response Options: 0 = No measurement taken
1 = CKD-EPI Serum Creatinine
2 = eGFR
3 = Serum Creatinine + eGFR
999 = Unknown

Variable ID: CreatinineUnit

Variable: Serum Creatinine units

Definition: Indicate the units used for serum creatinine measurement

Supporting Definition: None

Displayed Value: None

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

Timing: 6-monthly

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 1 = $\mu\text{mol/l}$
2 = mg/dl

Variable ID: CreatinineValue

Variable: Serum Creatinine

Definition: Provide the serum creatinine value in the indicated units

Supporting Definition: None

Displayed Value: None

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

Timing: 6-monthly

Data Source: Clinical

Type: Numerical

Value Domain: Quantity

Response Options: None

Variable ID: RFUNCEGFRMEAS

Variable: eGFR equation

Definition: Provide the eGFR equation

Supporting Definition: None

Displayed Value: None

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

Timing: 6-monthly

Data Source: Clinical

Type: Single answer
Value Domain: Code
Response Options: 1 = CKD-EPI Serum Creatinine
2 = MDRD-4
3 = MDRD-6
4 = Cockcroft-Gault
5 = Other

Variable ID: eGFR
Variable: Estimated glomerular filtration rate
Definition: The persons estimated glomerular filtration rate (eGFR)
Supporting Definition: eGFR as measured in milliliter per minute
Displayed Value: None
Inclusion Criteria: If "2 = eGFR" or "3 = Serum Creatinine + eGFR" to BASERFUNC
Timing: 6-monthly
Data Source: Clinical
Type: Numerical
Value Domain: Quantity
Response Options: None

Variable ID: RFUNCDATE
Variable: Renal function measurement date
Definition: Provide the date of renal function measurement
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = Serum Creatinine", "2 = eGFR" or "3 = Serum Creatinine + eGFR" to RFUNC
Timing: 6-monthly
Data Source: Clinical
Type: Date by DD/MM/YYYY
Value Domain: Date
Response Options: DD/MM/YYYY

Variable ID: AlbuminuriaMethod
Variable: Method of albuminuria measurement
Definition: Indicate the method of albuminuria measurement
Supporting Definition: Urine albumin/creatinine ratio in spot urine (preferred), or urine protein/creatinine ratio (alternative)
Displayed Value: None
Inclusion Criteria: Pre-RRT, CC, Tx
Timing: Annually
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = Albuminuria not assessed
1 = Urine albumin/creatinine ratio in spot urine
2 = Urine protein/creatinine ratio in spot urine
999 = Unknown

Variable ID: AlbuminuriaUnit
Variable: Units of albuminuria measurement
Definition: Indicate the units used for albuminuria measurement
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = Urine albumin/creatinine ratio in spot urine" or "2 = Urine protein/creatinine ratio in spot urine" to AlbuminuriaMethod
Timing: Annually
Data Source: Clinical
Type: Single answer

Value Domain:	Code
Response Options:	1 = mg/g 2 = mg/mmol
Variable ID:	AlbuminuriaACR
Variable:	Results of urine ACR
Definition:	Provide urine ACR in spot urine in indicated unit
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If "1 = Urine albumin/creatinine ratio in spot urine" to AlbuminuriaMethod
Timing:	Baseline
Data Source:	Clinical
Type:	Numerical
Value Domain:	Quantity
Response Options:	None
Variable ID:	AlbuminuriaPCR
Variable:	Urine PCR
Definition:	Provide urine PCR in spot urine in indicated unit
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If "2 = Urine protein/creatinine ratio in spot urine" to AlbuminuriaMethod
Timing:	Baseline
Data Source:	Clinical
Type:	Numerical
Value Domain:	Quantity
Response Options:	None
Variable ID:	AlbuminuriaDate
Variable:	Date of albuminuria measurement
Definition:	Provide the date of albuminuria measurement
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If "1 = Urine albumin/creatinine ratio in spot urine" or "2 = Urine protein/creatinine ratio in spot urine" to AlbuminuriaMethod
Timing:	Baseline
Data Source:	Clinical
Type:	Date by DD/MM/YYYY
Value Domain:	Date
Response Options:	Date
Variable ID:	BACTER
Variable:	Bacteraemia
Definition:	Indicate if the patient was diagnosed with bacteraemia
Supporting Definition:	Positive blood culture with clinical signs and symptoms
Displayed Value:	None
Inclusion Criteria:	HD, PD, Tx
Timing:	6-monthly
Data Source:	Clinical
Type:	Single answer
Value Domain:	Code
Response Options:	0 = 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:	None

Displayed Value:	None
Inclusion Criteria:	If "1 = yes" to BACTER
Timing:	6-monthly
Data Source:	Clinical
Type:	Numerical
Value Domain:	Quantity
Response Options:	Numerical value
Variable ID:	HDSTART
Variable:	Haemodialysis start
Definition:	Indicate when haemodialysis was started
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	HD
Timing:	Baseline
Data Source:	Clinical
Type:	Date by DD/MM/YYYY
Value Domain:	Date
Response Options:	DD/MM/YYYY
Variable ID:	HDTYPE
Variable:	Vascular access type
Definition:	Indicate the type of the most recent vascular access
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	HD
Timing:	Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	Code
Response Options:	1 = AV graft 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:	None
Displayed Value:	None
Inclusion Criteria:	HD
Timing:	6-monthly
Data Source:	Clinical
Type:	Single answer
Value Domain:	Code
Response Options:	0 = 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
Displayed Value:	None
Inclusion Criteria:	If "1 = yes" to HDNEW
Timing:	6-monthly
Data Source:	Clinical
Type:	Date by DD/MM/YYYY
Value Domain:	Date

Response Options:	DD/MM/YYYY
Variable ID:	HDNEWTYPE
Variable:	New vascular access type
Definition:	Indicate the type of new vascular access
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If "1 = yes" to HDNEW
Timing:	6-monthly
Data Source:	Clinical
Type:	Single answer
Value Domain:	Code
Response Options:	1 = AV graft 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
Displayed Value:	None
Inclusion Criteria:	PD
Timing:	Baseline
Data Source:	Clinical
Type:	Date by DD/MM/YYYY
Value Domain:	Date
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
Displayed Value:	None
Inclusion Criteria:	PD
Timing:	Ongoing
Data Source:	Clinical
Type:	Single answer
Value Domain:	Code
Response Options:	0 = 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:	None
Displayed Value:	None
Inclusion Criteria:	If "1 = yes" to PDSWITCH
Timing:	Ongoing
Data Source:	Clinical
Type:	Date by DD/MM/YYYY
Value Domain:	Date
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 signs of peritoneal inflammation or peritoneal fluid leukocyte count of $> 0.1 \times 10^9/L$ with at least 50% polymorphonuclear neutrophilic cells or positive culture of peritoneal fluid

Displayed Value: None

Inclusion Criteria: PD

Timing: 6-monthly

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: PERITONPROOF

Variable: Peritonitis diagnosis

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

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: If "1 = yes" to PERITON

Timing: 6-monthly

Data Source: Clinical

Type: Single answer

Value Domain: Code

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: None

Displayed Value: None

Inclusion Criteria: If "1 = yes" to PERITON

Timing: 6-monthly

Data Source: Clinical

Type: Numerical

Value Domain: Quantity

Response Options: Numerical value

Variable ID: TRANSDATE

Variable: Date of kidney transplant

Definition: Provide the date of transplant surgery

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: Tx

Timing: Annually

Data Source: Clinical

Type: Date by DD/MM/YYYY

Value Domain: Date

Response Options: DD/MM/YYYY

Variable ID: TRANSNEW

Variable: Subsequent kidney transplant

Definition: Indicate whether there has been a subsequent kidney transplant

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: Tx

Timing: Annually
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: TRANSNEWTPE
Variable: Type of new transplant
Definition: Was the transplanted kidney from a living or deceased donor?
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = yes" to TRANSNEW
Timing: Annually
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 1 = Living donor
2 = Deceased donor
999 = Unknown

Variable ID: TRANSNEWDTE
Variable: Date of subsequent kidney transplant
Definition: Provide the date of a subsequent kidney transplant
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = yes" to TRANSNEW
Timing: Annually
Data Source: Clinical
Type: Date by DD/MM/YYYY
Value Domain: Date
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
Displayed Value: None
Inclusion Criteria: Tx
Timing: 6-monthly for the first year, then annually
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = 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: None
Displayed Value: None
Inclusion Criteria: If "1 = yes" to TRANSNEW
Timing: 6-monthly for the first year, then annually
Data Source: Clinical

Type: Single answer
Value Domain: Code
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: None
Displayed Value: None
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
Value Domain: Date
Response Options: DD/MM/YYYY

Variable ID: AnyMalignancies
Variable: Malignancies
Definition: Indicate whether the patient has any malignancies
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: Tx
Timing: Annually
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: MalignSolid
Variable: Solid malignancy
Definition: Indicate whether the malignancy is a solid tumour
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = yes" to AnyMalignancies
Timing: Annually
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: MalignSkin
Variable: Skin malignancy
Definition: Indicate whether the malignancy is skin cancer
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: If "1 = yes" to AnyMalignancies
Timing: Annually
Data Source: Clinical
Type: Single answer
Value Domain: Code

Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: MalignHematological

Variable: Haematological malignancy

Definition: Indicate whether the malignancy is a haematological malignancy

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: If "1 = yes" to AnyMalignancies

Timing: Annually

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: MALIGDATE

Variable: Date of malignancy diagnosis

Definition: Indicate the date of malignancy diagnosis

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: If "1 = yes" to AnyMalignancies

Timing: Annually

Data Source: Clinical

Type: Date by DD/MM/YYYY

Value Domain: Date

Response Options: DD/MM/YYYY

Working Group Member Conflicts of Interests

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

Name	Title	Declarations
Willem Jan Bos	Nephrologist	Roche- research support
Wouter Verbeme	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	Fresenius Medical Care- salary
Andrew Allegretti	Instructor of Medicine	Translation Medicine Group- research support
Chih-Wei Yang	Professor of Nephrology	None declared
David Wheeler	Nephrologist	None declared
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 Hemmeler	Nephrologist	None declared
Markus Ketteler	Professor of Medicine	None declared
Muhammed Al Rohani	Associate Professor of Internal Medicine	None declared
Türkan Terkivatan	Consultant Surgeon	None declared
Wim Van Biesen	Professor of Nephrology	None declared

ICHOM Contact Information

Website	http://www.ichom.org
Business Address	<div>United States Office</div> <div>399 Boylston Street 6th Floor</div> <div>Boston, MA 02116, USA</div> <div>United Kingdom Office</div> <div>1 Alfred Place</div> <div>London</div> <div>WC1E 7EB, UK</div>

Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
4.0.0	Data Dictionary, Appendix	Harmonisation updates
4.0.0	Whole Document	Wording change. Replacing 'Standard Sets' to 'Sets of Patient-Centered Outcome Measures'

www.ichom.org