ICHOM

International Consortium for Health Outcomes Measurement

HYPERTENSION IN LOW- AND MIDDLE-INCOME COUNTRIES DATA COLLECTION REFERENCE GUIDE

Version 1.0.0
Revised: November 3rd, 2017

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

Introducing ICHOM and the Reference Guide

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

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

Our Standard Sets include initial conditions and risk factors to enable meaningful case-mix adjustment globally, ensuring that comparisons of outcomes will take into account the differences in patient populations across not only providers, but also countries and regions. A comprehensive Data Dictionary, as well as scoring guides for patient-reported outcomes are included in the appendix.

Working Group Members for Hypertension in LMIC

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Hypertension in Low- and Middle- Income Countries (LMIC) in partnership with ICHOM, under the leadership of Professor Peter Lamptey, Professor at the London School of Tropical Hygiene and Medicine, UK and President Emeritus FHI 360, Ghana.

Belarus
Vladislav Podpalov

Brazil
Otavio Berwanger
Celso Amodeo

Cameroon
Anastase Dzudie
Tamdja

Canada
Norm Campbell
Ernesto Schiffrin

Ghana
Peter Lamptey

India
Raghupathy Anchala

Malaysia
Yook-Chin Chia

Mozambique
Albertino Damasceno

Portugal
Manuela Fiuza
António Vaz Carneiro

Switzerland
Fareed Mirza

United Kingdom
Dorothea Nitsch

United States of America
Gbenga Ogedegbe

Vietnam
Nam Phuong Do Thi

We would also like to thank the following individuals for their valuable contributions to the project:

- Dr. Kolo Philip Manma from the University of Ilorin, Nigeria
- Dr. Prajjwal Pyakurel from the B.P. Koirala Institute of Health Sciences, Nepal

Supporting Organizations

The Hypertension in Low- and Middle-Income Countries Standard Set is made possible through the generous support of the Novartis Foundation.

Thank you.

Scope of the Hypertension in LMIC Standard Set

The following condition and treatment approaches (or interventions) are covered by our Standard Set.

Condition	Hypertension (ICD-10: I10)
Treatment Approaches	Pharmacological and Non-Pharmacological

ICHOM Standard Set for Hypertension Overview

Case-Mix Variables

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Demographic Factors				
All patients	Age	Date of birth	Baseline	Clinician-reported
	Sex	Sex at birth		
	Education Level	The level of schooling is defined in each country as per ISCED [International Standard Classification]		Patient-reported
Baseline Clinical Factors				
All patients	Diabetes	N/A	Baseline and annually until positive diagnosis of diabetes	Clinician-reported
	Smoking status	N/A	Baseline and annually	Patient-reported
	Family history of cardiovascular disease	N/A	Baseline	Patient-reported or clinician-reported
	BMI			Clinician-reported
	Physical activity	Tracked via the International Physical Activity Questionnaire (IPAQ)-Short Form	Annually	Patient-reported
	Sodium intake	Tracked via the WHO STEPS Instrument	Baseline and annually	

Treatment Variables

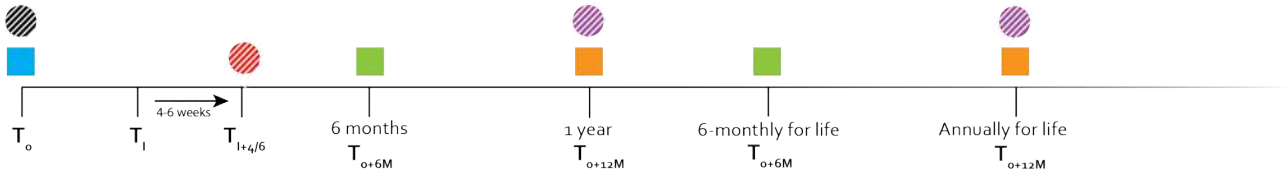
Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
All patients	Treatment approach	Assesses non-pharmacological versus pharmacological management	Baseline and annually	Clinician-reported
	Antihypertensive drug class	N/A		

Outcomes

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Survival, Disease Control and Cardiovascular Complications				
All patients	Blood pressure	N/A	Minimum annually	Clinician-reported
	Overall survival and cardiovascular survival	N/A	Annually	
	Medication side-effects and adverse events	N/A	Annually and 4-6 weeks after initiation of change of treatment	
	Ischaemic heart disease	N/A	Annually	
	Cerebrovascular disease			
	Atrial fibrillation			
	Heart failure			
	Peripheral artery disease			
	Chronic renal disease	Assessed based on proteinuria	Baseline and annually	
	Hypertensive urgency and hypertensive emergency	N/A	Annually	
Burden of Care				
All patients	Access to care	N/A	Annually	Patient-reported
	Access to medication	N/A		
	Pill burden	Number of pills or tablets taken daily		
Patient-Reported Health Status				
All patients	Quality of life	Tracked via the EQ-5D-3L (see main body of Reference Guide for alternatives)	Annually	Patient-reported
	Patient satisfaction	N/A		
Male patients	Erectile dysfunction	Tracked via PROMIS single question on erectile dysfunction		
Health Literacy and Treatment Adherence				
All patients	Beliefs about medication	Tracked via the BMQ-Specific	Annually	Patient-reported
	Medication adherence	Tracked via Hill-Bone Compliance to High Blood Pressure Therapy Scale – South Africa Version		

Follow-Up Timeline

The following timeline illustrates when Standard Set variables should be collected from patients, clinicians, and administrative sources. The Working Group recognizes that the potential burden of presenting all questions to patients at once. For this reason, the questions for patients are split into two groups and presented at alternating 6-monthly intervals.



T_o = Baseline entry into Set

T_{o+6M} = 6 month review

T_{o+12M} = 12 month review

T_I = Time of clinical incident - this is the occurence of a new diagnosis of any of the clinical end points (excluding death or BP control) or the initiation of/change in pharmacological therapy

$T_{I+4/6}$ = Review after clinical incident at 4-6 weeks

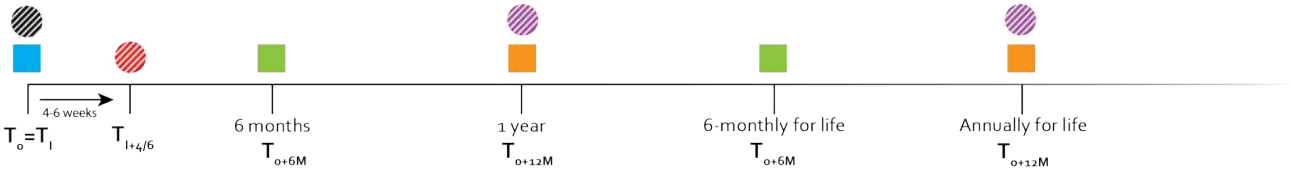
The following questionnaires should be administered at the indicated time points*:

- Clinical Form = All case-mix variables and treatment variables; Baseline survival and disease control variables
- Clinical Form = Clinical factors and treatment variables; Survival and disease control variables
- Clinical Form = Blood pressure; Medication side effects and adverse events
- Patient Form = Patient-reported case-mix variables (IPAQ, WHO STEPS, smoking status and educational level); Baseline patient-reported health status
- Patient Form = Burden of care questions; Health literacy and treatment adherence (BMQ, Hill-Bone)
- Patient Form = Patient-reported case-mix variable (IPAQ, WHO STEPS, smoking status); Patient-reported health status

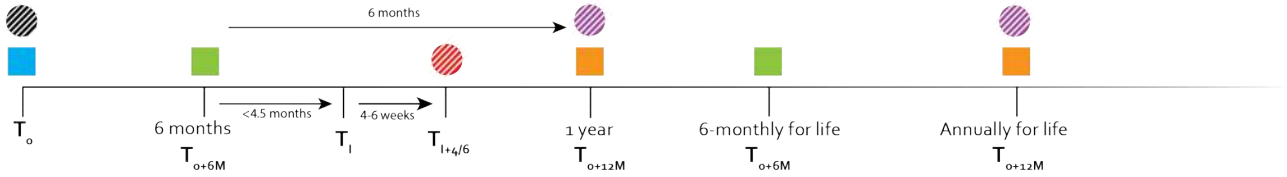
**For practical reasons, if $T_{I+4/6}$ and the next routing review period (T_{o+6M} or T_{o+12M}) fall into overlapping windows, the data can be collected at the same time.*

EXAMPLE 1: New entry into Set with established hypertension and no change in therapy.

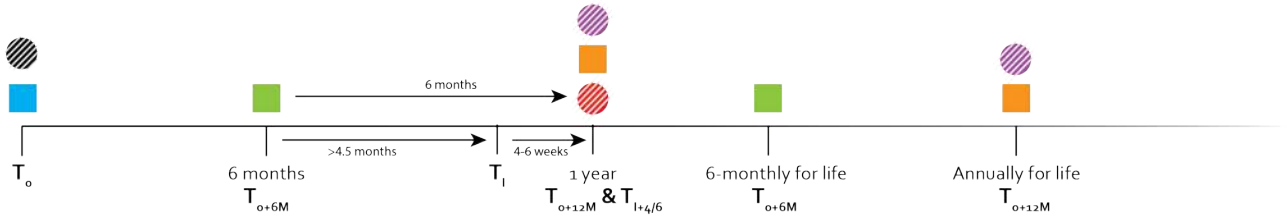
EXAMPLE 2: Newly diagnosed hypertension with initiation of new therapy.



EXAMPLE 3a: Clinical incident at less than 4.5 months after routine review time-point.



EXAMPLE 3b: Clinical incident at more than 4.5 months after routine review time-point.



Collecting Patient-Reported Outcome Measures

The ICHOM Hypertension in Low- and Middle-Income Countries Working Group recommends using the following tools to capture patient-reported outcomes including health-related quality of life, erectile dysfunction, beliefs about medications, physical activity, and medication adherence:

Survey Used	Licensing Information	Scoring Guide
EuroQoL-5D-3L (EQ-5D-3L)	Use of the EQ-5D-3L requires a licence. Please contact the EuroQol Office through the following link: https://euroqol.org/support/how-to-obtain-eq-5d/	The scoring guide can be found here: https://euroqol.org/eq-5d-instruments/eq-5d-3l-about/
PROMIS Single Question on Erectile Dysfunction	Free for use in clinical practice and a license is not required. Information about available translations can be found here: http://www.nihpromis.org/measures/translations	The scoring guide for the PROMIS Single Question on Erectile Dysfunction can be found at: http://www.healthmeasures.net/score-and-interpret/calculate-scores
Beliefs about Medication Questionnaire (BMQ)-Specific	Copyrighted, permission to use the scale can be obtained from Professor Rob Horne's research team (see citation on the right for contact information)	The scoring guide can be found in the original validation article: Horne et al. (1999) The beliefs about medicines questionnaire: The development and evaluation of a new method for assessing the cognitive representation of medication. *Psychology & Health*, 14:1.
Hill-Bone Compliance to High Blood Pressure Therapy Scale - South Africa Version	Permission to use the scale can be obtained from Estelle V. Lambert's research team (see citation on the right for contact information)	The scoring guide can be found in the original validation article: Lambert, E.V. et al. (2006) Cross-Cultural Validation of the Hill-Bone Compliance To High Blood Pressure Therapy Scale in a South African, Primary Healthcare Setting. *Ethnicity and Disease*, 16.
WHO STEPS Instrument	Free for use in clinical practice and a license is not required. Further information can be found here: http://www.who.int/chp/steps/instrument/en/	See link at left
International Physical Activity Questionnaire (IPAQ)-Short Form	Publically available, open access, and no permissions are required to use it. Further information can be found here: https://sites.google.com/site/theipaq/	See link at left

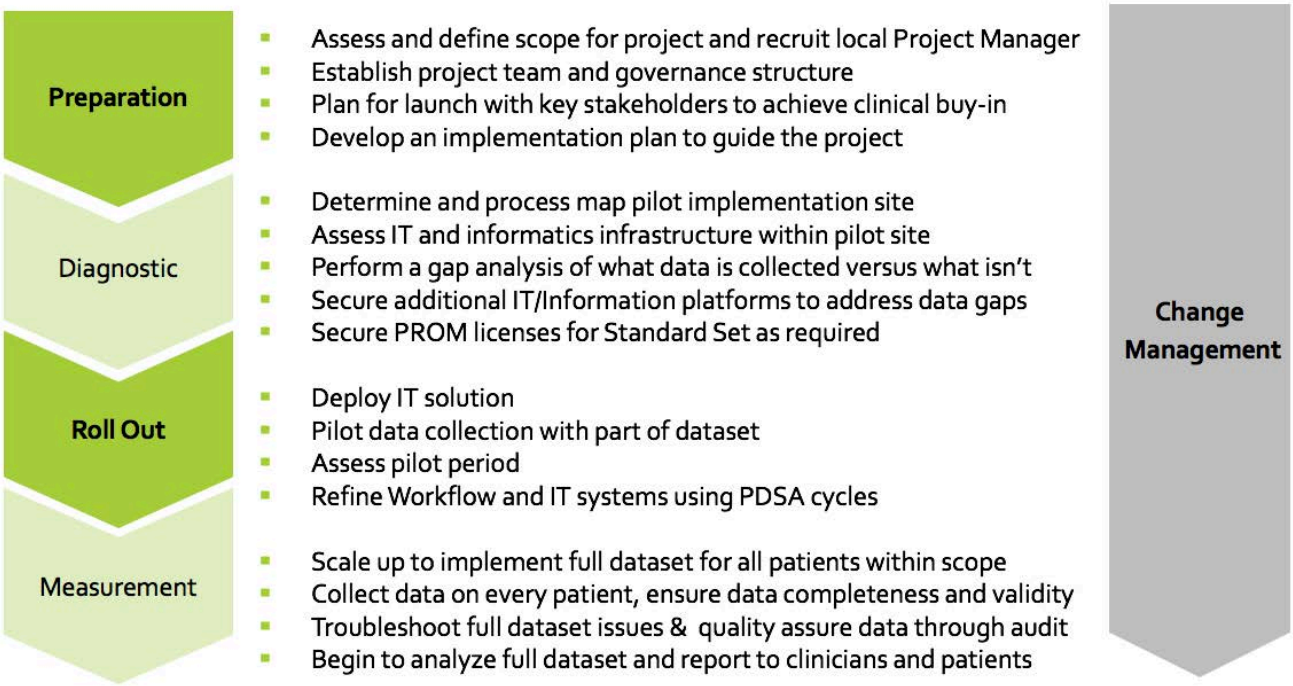
The Working Group understands that some organisations may prefer to use alternative tools to the EQ-5D to assess Health-Related Quality of Life. The following tools are also acceptable for use: PROMIS Global 10, VR-12 or SF-12. Please see below for additional information regarding these tools:

Alternative Quality of Life Surveys	Licensing Information	Scoring Guide
PROMIS Global-10	Free for use in clinical practice and a license is not required. Information about available translations can be found here: http://www.nihpromis.org/measures/translations	The scoring guide for the PROMIS Global Health Questionnaire can be found at: http://bit.ly/PROMISGLOBALSCORE
Veteran's Rand 12-Item Health Survey (VR-12)	Free for all health care organizations, license required and can be requested at: http://bit.ly/2ir84sG	See link at left
12-Item Short Form Survey (SF-12)	Optum owns the copyright and use of this questionnaire requires a license. Please visit the following link for more information: http://bit.ly/2AcNLrme	See link at left

The Growing ICHOM Community

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

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



Translating the Set Tools:

PROMs within the ICHOM Sets are available in a number of languages. We advise contacting the tool developers directly to check for availability of translations or to translate the PROM into your desired language.

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

Appendix

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Hypertension in LMIC Standard Set in line with the Working Group recommendation. **We are happy to provide an Excel version of this data dictionary for technical use.**

Case-Mix Variables

Demographic Factors

Variable ID:	N/A
Variable:	Patient ID
Definition:	Indicate the patient's medical record number
Supporting Definition:	This number will not be shared with ICHOM. In the case patient-level data is submitted to ICHOM for benchmarking or research purposes, a separate ICHOM Patient Identifier will be created and cross-linking between the ICHOM Patient Identifier and the medical record number will only be known at the treating institution
Inclusion Criteria:	All patients
Timing:	On all forms
Reporting Source:	Administratively-reported or clinician-reported
Type:	Numerical
Response Options:	According to institution
Variable ID:	AGE
Variable:	Age
Definition:	Indicate the patient's date of birth
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Administratively-reported or clinician-reported
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY
Variable ID:	SEX
Variable:	Sex
Definition:	Indicate the patient's sex at birth
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Administratively-reported or clinician-reported
Type:	Single answer
Response Options:	1 = Male 2 = Female 999 = Undisclosed

Variable ID:	EDUC
Variable:	Education level
Definition:	Please indicate highest level of schooling completed
Supporting Definition:	The level of schooling is defined in each country as per ISCED [International Standard Classification]
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	0 = None 1 = Primary 2 = Secondary 3 = Tertiary 999 = Unknown

Clinical Factors

Variable ID:	DIAB
Variable:	Past medical history: Diabetes
Definition:	Indicate if the patient has a documented history of diabetes mellitus (regardless of duration of disease or need for anti-diabetic agents). If newly diagnosed, the diagnosis should meet the following criteria: Fasting plasma glucose >= 7.0mmol/L (126 mg/dL) or 2-hour plasma glucose >= 11.1 mmol/L (200mg/dL) [2 hours post 75g glucose load]
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually until positive diagnosis of diabetes
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	FPG
Variable:	Fasting plasma glucose
Definition:	For newly diagnosed diabetics indicate fasting plasma glucose if available
Supporting Definition:	Fasting plasma glucose value in mg/dL or mmol/L
Inclusion Criteria:	Optional
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Numerical
Response Options:	N/A
Variable ID:	FPGUNITS
Variable:	Units of fasting plasma glucose
Definition:	Units of fasting plasma glucose
Supporting Definition:	N/A
Inclusion Criteria:	If fasting plasma glucose value is provided
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = mg/dL 2 = mmol/L
Variable ID:	SMOKE
Variable:	Smoking status
Definition:	Do you smoke?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported

Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	SMOKECESS
Variable:	Smoking cessation
Definition:	How long ago did you give up smoking?
Supporting Definition:	N/A
Inclusion Criteria:	If answered 'no' to smoking status (SMOKE)
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never smoked 1 = Less than 1 year 2 = 1-5 years 3 = 5-10 years 4 = >10 years 999 = Undisclosed
Variable ID:	FAMHX
Variable:	Family history of CVD
Definition:	Is there a history of cardiovascular disease in a parent or sibling?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Patient-reported or clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	HEIGHT
Variable:	Height
Definition:	Indicate the patient's height in centimeters or inches
Supporting Definition:	Height and weight are used to calculate BMI
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Clinician-reported
Type:	Numerical
Response Options:	Numerical value
Variable ID:	HEIGHTUNIT
Variable:	Height units
Definition:	Indicate units of height
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = Centimeters 2 = Inches
Variable ID:	WEIGHT
Variable:	Weight
Definition:	Indicate the patient's weight in kilograms or pounds
Supporting Definition:	Height and weight are used to calculate BMI
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Numerical
Response Options:	Numerical value

Variable ID:	WEIGHTUNIT
Variable:	Weight units
Definition:	Indicate units of weight
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = Kilograms 2 = Pounds
Variable ID:	LIPIDLOW
Variable:	Lipid lowering therapy
Definition:	Indicate if the patient is on lipid lowering therapy
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	LIPIDMED
Variable:	Lipid lowering medication
Definition:	Specify lipid lowering therapy
Supporting Definition:	N/A
Inclusion Criteria:	If answered 1 to LIPIDLOW
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = Statin 2 = Ezetimibe 3 = Fibrates 4 = Other 999 = Unknown
Variable ID:	CREADONE
Variable:	Optional creatinine reading
Definition:	Has the patient had a creatinine test?
Supporting Definition:	N/A
Inclusion Criteria:	Optional
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = No 1 = Yes 999 = Unknown/ not done
Variable ID:	CKDCREA
Variable:	Creatinine
Definition:	Provide the patient's serum creatinine reading
Supporting Definition:	Please provide the most recent value
Inclusion Criteria:	If responded "yes" to CREADONE
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Numerical, enter "ooo" if unknown
Response Options:	Numerical value
Variable ID:	CKDCREAUNITS
Variable:	Creatinine units
Definition:	What are the units of creatinine?

Supporting Definition:	N/A
Inclusion Criteria:	If value for creatinine is provided
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = mg/dL 2 = mmol/L
Variable ID:	CREACALIB
Variable:	Creatinine calibration
Definition:	Was the creatinine reader calibrated to IDMS (isotope dilution mass spectrometry)
Supporting Definition:	
Inclusion Criteria:	If value for creatinine is provided
Timing:	Baseline and annually
Reporting Source:	Clinician-reported/administratively-reported
Type:	Single answer
Response Options:	1 = Yes 2 = No 999 = Unknown
Variable ID:	STEPS_Q01
Variable:	STEPS dietary survey
Definition:	The next questions ask about your knowledge, attitudes and behaviour towards dietary salt. Dietary salt includes ordinary table salt, unrefined salt such as sea salt, iodized salt and salty sauces such as soya sauce or fish sauce (see showcard). The following questions are on adding salt to the food right before you eat it, on how food is prepared in your home, on eating processed foods that are high in salt such as [insert country specific examples], and questions on controlling your salt intake. Please answer the questions even if you consider yourself to eat a diet low in salt. How often do you add salt to your food before you eat it or as you are eating it?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Often 3 = Sometimes 4 = Rarely 5 = Never 999 = Don't know
Variable ID:	STEPS_Q02
Variable:	STEPS dietary survey
Definition:	How often is salt added in cooking or preparing foods in your household?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Often 3 = Sometimes 4 = Rarely 5 = Never 999 = Don't know
Variable ID:	STEPS_Q03
Variable:	STEPS dietary survey
Definition:	How often do you eat processed food high in salt, such as [add country specific examples]?

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Often 3 = Sometimes 4 = Rarely 5 = Never 999 = Don't know
Variable ID:	STEPS_Q04
Variable:	STEPS dietary survey
Definition:	How much salt do you think you consume?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Far too much 2 = Too much 3 = Just the right amount 4 = Too little 5 = Far too little 6 = Don't know
Variable ID:	IPAQ_Q01
Variable:	Physical activity IPAQ-Short Form
Definition:	During the last 7 days, on how many days did you do vigorous physical activities like heavy lifting, digging, aerobics, or fast bicycling?
Supporting Definition:	Please precede the question with the following introduction from the survey: "We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the last 7 days. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport. Think about all the vigorous activities that you did in the last 7 days. Vigorous physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time."
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = No vigorous physical activities 999 = Unknown
Variable ID:	IPAQ_Q02
Variable:	Physical activity IPAQ-Short Form
Definition:	How much time did you usually spend doing vigorous physical activities on one of those days?

Supporting Definition:	N/A
Inclusion Criteria:	If answered '1-7' to vigorous physical activity ('IPAQ_Q01')
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Numerical response
Response Options:	Numerical value between 0 and 7 (use 000 if "don't know" or "unsure")
Variable ID:	IPAQ_Q02_UNIT
Variable:	Physical activity IPAQ-Short Form
Definition:	Indicate units of time
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Hours 2 = Minutes
Variable ID:	IPAQ_Q03
Variable:	Physical activity IPAQ-Short Form
Definition:	During the last 7 days, on how many days did you do moderate physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.
Supporting Definition:	Please precede this question with the following text: "Think about all the moderate activities that you did in the last 7 days. Moderate activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time."
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = No moderate physical activities 999 = Unknown
Variable ID:	IPAQ_Q04
Variable:	Physical activity IPAQ-Short Form
Definition:	How much time did you usually spend doing moderate physical activities on one of those days?
Supporting Definition:	N/A
Inclusion Criteria:	If answered '1-7' to moderate physical activity ('IPAQ_Q04')
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Numerical response
Response Options:	Numerical value (use 000 if "don't know" or "unsure")
Variable ID:	IPAQ_Q04_UNIT
Variable:	Physical activity IPAQ-Short Form
Definition:	Indicate units of time
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer

Response Options:	1 = Hours 2 = Minutes
Variable ID:	IPAQ_Q05
Variable:	Physical activity IPAQ-Short Form
Definition:	During the last 7 days, on how many days did you walk for at least 10 minutes at a time?
Supporting Definition:	Please precede this question with the following text: " Think about the time you spent walking in the last 7 days. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure."
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = No walking 999 = Unknown
Variable ID:	IPAQ_Q06
Variable:	Physical activity IPAQ-Short Form
Definition:	How much time did you usually spend walking on one of those days?
Supporting Definition:	N/A
Inclusion Criteria:	If answered '1-7' to walking ('IPAQ_Q05')
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Numerical response
Response Options:	Numerical value (use 000 if "don't know" or "unsure")
Variable ID:	IPAQ_Q06_UNIT
Variable:	Physical activity IPAQ-Short Form
Definition:	Indicate units of time
Supporting Definition:	N/A
Inclusion Criteria:	If answered '1-7' to walking ('IPAQ_Q05')
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Hours 2 = Minutes
Variable ID:	IPAQ_Q07
Variable:	Physical activity IPAQ-Short Form
Definition:	During the last 7 days, how much time did you spend sitting on a week day?
Supporting Definition:	Please precede this question with the following text: "The last question is about the time you spent sitting on weekdays during the last 7 days. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television."
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Numerical response
Response Options:	Numerical value (use 000 if "don't know" or "unsure")
Variable ID:	IPAQ_Q07_UNIT
Variable:	Physical activity IPAQ-Short Form

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Hours 2 = Minutes

Treatment Variables

Treatment Variables

Variable ID:	TX
Variable:	Treatment approach
Definition:	What is the management approach?
Supporting Definition:	Non-pharmacological management includes lifestyle interventions, exercise, diet and other non-pharmacological approaches.
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = Non-pharmacological management only 1 = Pharmacological management (with or without non-pharmacological treatment)

Variable ID:	DRUGCLASS
Variable:	Antihypertensive drug class
Definition:	Is patient on any of the following drug classes?
Supporting Definition:	Please select all options that apply
Inclusion Criteria:	If answered '1' to treatment approach (TX)
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Multiple answer
Response Options:	1 = ACEi/ARB 2 = Alpha-blocker 3 = Beta-blocker 4 = Loop Diuretics 5 = Thiazides 6 = Calcium channel blocker 7 = Other 999 = Unknown

Outcomes

Survival, Disease Control and Cardiovascular Complications

Variable ID:	BPSYS
Variable:	Systolic blood pressure
Definition:	Patient systolic blood pressure reading in mmHg
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Minimum annually
Reporting Source:	Clinician-reported
Type:	Numerical
Response Options:	Numerical value

Variable ID:	BPDIA
Variable:	Diastolic blood pressure
Definition:	Patient diastolic blood pressure reading in mmHg
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Minimum annually
Reporting Source:	Clinician-reported
Type:	Numerical
Response Options:	Numerical value
Variable ID:	DEATH
Variable:	Has the patient died?
Definition:	Has the patient died, regardless of cause?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	At time of death
Reporting Source:	Clinician-reported/administratively-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	DEATHDATE
Variable:	Date of death
Definition:	If yes, indicate date of death
Supporting Definition:	N/A
Inclusion Criteria:	If answered 'yes' to overall survival (OVERALLSURV)
Timing:	At time of death
Reporting Source:	Clinician-reported/administratively-reported
Type:	Date by DD/MM/YYYY or by MM/YYYY (in case exact day is unknown)
Response Options:	DD/MM/YYYY or MM/YYYY
Variable ID:	CAUSEDEATH
Variable:	Cause of death
Definition:	If yes, indicate cause of death, if known
Supporting Definition:	N/A
Inclusion Criteria:	If answered 'yes' to overall survival (OVERALLSURV)
Timing:	
Reporting Source:	Clinician-reported/administratively-reported
Type:	Single answer
Response Options:	1 = Acute myocardial infarction 2 = Sudden cardiac death 3 = Heart failure 4 = Stroke 5 = Cardiovascular procedures 6 = Cardiovascular haemorrhage 7 = Other cardiovascular causes 8 = Non-cardiovascular causes 9 = Cause unknown
Variable ID:	MEDEFFECTS
Variable:	Medication side effects and adverse events
Definition:	Has the patient experienced any adverse events or unwanted side effects of medication?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually and 4-6 weeks after initiation or change of treatment
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No

	1 = Yes 999 = Unknown
Variable ID:	MEDEFFECTSSPEC
Variable:	Type of medication side effects
Definition:	If yes, please specify by selecting all that apply
Supporting Definition:	Hypotension and clinical manifestations of hypotension
Inclusion Criteria:	If answered 'yes' to medication side effects ('MEDEFFECTS')
Timing:	Annually and 4-6 weeks after initiation or change of treatment
Reporting Source:	Clinician-reported
Type:	Multiple answer
Response Options:	1 = Falls 2 = Acute kidney injury 3 = Peripheral oedema 4 = Fatigue or unusual tiredness 5 = Electrolyte abnormalities 6 = Hypokalaemia 7 = Cough 8 = Erectile dysfunction 9 = Urinary frequency 10 = Other
Variable ID:	IHD
Variable:	Ischaemic heart disease
Definition:	Does the patient have ischaemic heart disease?
Supporting Definition:	Myocardial infarction (ICD10: I21) or angina (ICD10: I20) diagnosed by a clinician
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	CERVD
Variable:	Cerebrovascular disease
Definition:	Does the patient have cerebrovascular disease?
Supporting Definition:	Cerebrovascular accident (ICD10: I60 - Subarachnoid haemorrhage, I61 – Intracerebral haemorrhage, I62 – other non-traumatic intracranial haemorrhage, I63 – cerebral infarction, I64 - Stroke, not specified as haemorrhage or infarction) or transient ischaemic attack (ICD10: G45 - Transient cerebral ischaemic attacks and related syndromes) diagnosed by a clinician
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	AFIB
Variable:	Atrial fibrillation
Definition:	Does the patient have atrial fibrillation?
Supporting Definition:	Atrial fibrillation (ICD10: I48.0 paroxysmal atrial fibrillation, I48.1 – persistent atrial fibrillation, I48.2 Chronic atrial fibrillation) diagnosed by a clinician
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes

	999 = Unknown
Variable ID:	HF
Variable:	Heart failure
Definition:	Does the patient have heart failure?
Supporting Definition:	Heart failure (ICD10: I50- Heart failure, ICD:10 I11.0 – hypertensive heart disease with (congestive) heart failure) diagnosed by a clinician
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	HFCAUSE
Variable:	Cause of heart failure
Definition:	If yes, what is the underlying cause?
Supporting Definition:	N/A
Inclusion Criteria:	If answered 'yes' to heart failure ('HF')
Timing:	Annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = Valvular disease 2 = Hypertension 3 = Cardiomyopathy 4 = Ischaemic heart disease 5 = Other 6 = Unknown
Variable ID:	PAD
Variable:	Peripheral artery disease
Definition:	Does the patient have peripheral artery disease?
Supporting Definition:	Peripheral artery disease (ICD:10 I70.2 - Atherosclerosis of arteries of extremities) diagnosed by clinician
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	CKD
Variable:	Chronic renal disease
Definition:	Does the patient have chronic kidney disease as evidenced by proteinuria?
Supporting Definition:	Renal disease (ICD10: I12 Hypertensive renal disease incl. any condition in N00-N07, N18.-, N19 or N26 due to hypertension) (Please ensure that other causes of proteinuria, such as urinary tract infection, have been ruled out)
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PROTEINEVID
Variable:	Evidence of proteinuria
Definition:	How was proteinuria detected?
Supporting Definition:	N/A
Inclusion Criteria:	If "yes" to CKD

Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = Manually read urine dipstick 2 = Electronically read urine dipstick 3 = Urinary albumin/creatinine ratio
Variable ID:	URINEDIP
Variable:	Results of urine dip
Definition:	Proteinuria as provided by electronically read urine dipstick
Supporting Definition:	N/A
Inclusion Criteria:	If responded "1" or "2" to PROTEINEVID
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Single response
Response Options:	1 = + 2 = ++ 3 = +++ 4 = Unknown/results unavailable
Variable ID:	URINEACR
Variable:	Results of urine ACR if done in place of urine dip
Definition:	Evidence of proteinuria as evidenced by urinary ACR
Supporting Definition:	
Inclusion Criteria:	If responded "3" to PROTEINEVID
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Numerical
Response Options:	Numerical value
Variable ID:	URINEACRUNITS
Variable:	Units of urinary ACR
Definition:	Units of urinary ACR
Supporting Definition:	N/A
Inclusion Criteria:	If ACR value provided
Timing:	Baseline and annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = mg/g 2 = mg/mmol
Variable ID:	HTNEMERG
Variable:	Hypertensive urgency/ Hypertensive emergency
Definition:	Has the patient had a blood pressure reading above 180/120 mmHg in the past 12 months?
Supporting Definition:	Hypertensive urgency is an acute rise in BP >180/120 mmHg with no evidence of acute end-organ damage. Hypertensive emergency is an acute rise in BP > 180/120 with evidence of acute end organ damage.
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	HTNENDORG
Variable:	Acute end-organ damage
Definition:	If yes, does the patient have evidence of acute end-organ damage?
Supporting Definition:	N/A
Inclusion Criteria:	If answered 'yes' to hypertensive urgency/ hypertensive emergency ('HYPTENEMERG')

Timing:	Annually
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	HTNENDORGTYPE
Variable:	Type of acute end-organ damage
Definition:	If yes, please specify the type of acute end-organ damage:
Supporting Definition:	N/A
Inclusion Criteria:	If answered 'yes' to acute end-organ damage ('HYPTENENDORG')
Timing:	Annually
Reporting Source:	Clinician-reported
Type:	Multiple answer
Response Options:	1 = Ophthalmological 2 = Renal 3 = Cardiac 4 = Cerebrovascular 999 = Unknown

Burden of Care

Variable ID:	ACCESCARE
Variable:	Access to care
Definition:	Was there any time during the past 12 months when you really needed to consult your healthcare provider but you did not?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Yes, there was at least one occasion 2 = No, there was no occasion
Variable ID:	CAREBARRIER
Variable:	Barriers to accessing care
Definition:	If yes, why?
Supporting Definition:	N/A
Inclusion Criteria:	If answered 'yes' to access to care ('ACCESCARE')
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Multiple answer
Response Options:	1 = Could not afford to (too expensive) 2 = Waiting list 3 = Could not take time because of work, care for children or for others 4 = Too far to travel/no means of transportation 5 = Fear of doctor/hospitals/examination/treatment 6 = Wanted to wait and see if problem got better on its own 7 = Didn't know any good doctor or specialist? 8 = Other reason
Variable ID:	ACCESMEDS
Variable:	Access to medication
Definition:	Were you able to obtain the medication prescribed by your healthcare provider in the appropriate dose and formulation?
Supporting Definition:	Access to drugs is the ability to access drugs as prescribed by healthcare provider
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer

Response Options:	1 = Yes 2 = No
Variable ID:	MEDBARRIER
Variable:	Barriers to accessing medication
Definition:	If no, please specify reason:
Supporting Definition:	N/A
Inclusion Criteria:	If answered 'no' to access to medication ('ACCESMEDS')
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Medication not available 2 = Cost 3 = Other
Variable ID:	PILLBRDN
Variable:	Pill burden
Definition:	What is the total number of pills or tablets that you take daily?
Supporting Definition:	Pill burden is the number of total daily pills patient takes
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Numerical
Response Options:	Numerical value

Patient-Reported Health Status

Variable ID:	HRQOL
Variable:	Health-related Quality of Life
Definition:	What Health-related Quality of Life tool are you using?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Clinician-reported/administratively-reported
Type:	Single answer
Response Options:	1 = EQ5D3L 2 = SF-12 3 = VR-12 4 = PROMIS-10
Variable ID:	EQ5D3L
Variable:	EuroQoL-5D-3L (EQ-5D-3L)
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	The Working Group recommends the EQ-5D, but understands that some organisations may prefer to use alternative tools to assess Health-Related Quality of Life. The following tools are also acceptable for use: PROMIS Global 10, VR-12 or SF-12.
Inclusion Criteria:	If answered '1 = EQ5D3L' to Health-related Quality of Life ('HRQOL')
Timing:	Annually
Reporting Source:	Patient-reported
Variable ID:	SF12
Variable:	12-Item Short Form Survey (SF-12)
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	The Working Group recommends the EQ-5D, but understands that some organisations may prefer to use alternative tools to assess Health-Related Quality

	of Life. The following tools are also acceptable for use: PROMIS Global 10, VR-12 or SF-12.
Inclusion Criteria:	If answered '2 = SF12' to Health-related Quality of Life ('HRQOL')
Timing:	Annually
Reporting Source:	Patient-reported
Variable ID:	VR12
Variable:	Veteran's Rand 12-Item Health Survey (VR-12)
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	The Working Group recommends the EQ-5D, but understands that some organisations may prefer to use alternative tools to assess Health-Related Quality of Life. The following tools are also acceptable for use: PROMIS Global 10, VR-12 or SF-12.
Inclusion Criteria:	If answered '3 = VR12' to Health-related Quality of Life ('HRQOL')
Timing:	Annually
Reporting Source:	Patient-reported
Variable ID:	PROMIS10
Variable:	PROMIS Global-10
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	The Working Group recommends the EQ-5D, but understands that some organisations may prefer to use alternative tools to assess Health-Related Quality of Life. The following tools are also acceptable for use: PROMIS Global 10, VR-12 or SF-12.
Inclusion Criteria:	If answered '4 = PROMIS10' to Health-related Quality of Life ('HRQOL')
Timing:	Annually
Reporting Source:	Patient-reported
Variable ID:	ERECT
Variable:	PROMIS single question on erectile dysfunction (SFEFN101)
Definition:	How would you rate your ability to get and keep an erection? (If you use pills, injections, or a penis pump to help you get an erection, please answer this questions thinking about the times that you used these aids.)
Supporting Definition:	Erectile function is the frequency and quality of achieving and maintaining an erection for sexual activity.
Inclusion Criteria:	If responded "1=male" to SEX
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Have not tried to get an erection in the past 30 days 5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor
Variable ID:	PATIENTSATISF
Variable:	Patient satisfaction
Definition:	How satisfied are you with the care you have received for your hypertension over the past 12 months?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Very satisfied 2 = Satisfied

	3 = Neither satisfied nor unsatisfied 4 = Unsatisfied 5 = Very unsatisfied

Health Beliefs and Treatment Adherence

Variable ID:	BMQ
Variable:	BMQ-Specific
Definition:	BMQ-Specific Subscale
Supporting Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported
Variable ID:	HILLBONE
Variable:	Hill-Bone Compliance to High Blood Pressure Therapy Scale - South Africa Version
Definition:	N/AN/A
Supporting Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Inclusion Criteria:	All patients
Timing:	Annually
Reporting Source:	Patient-reported

Working Group Member Conflicts of Interest

At the beginning of the Working Group process, we ask all Working Group members to declare any conflicts of interest (COIs). COIs listed below include those declared at the beginning of Set development.

Working Group

Name	Affiliation	Declarations
Peter Lamptey (Chair)	FHI 360, London School of Tropical Hygiene and Medicine	None
Albertino Damasceno	Eduardo Mondlane University	Dr. Albertino Damasceno declares that he has received personal funding from Astra Zeneca and Merck for the purpose of giving a lecture at conferences, and declares no other conflicts of interest.
Anastase Dzudie Tamdja	PASCAR, University of Yaounde	None
António Vaz Carneiro	Universidade de Lisboa	None
Celso Amodeo	Brazilian Society of Cardiology	Celso Amodeo declares that he has received funding from Servier Laboratories and Merck as a member of their scientific boards, from Novartis as a writing engagement, and from ACHE Laboratories for a speaking engagement. He declares no other conflicts of interest.
Dorothea Nitsch	London School of Hygiene and Tropical Medicine	None
Ernesto Schiffrin	McGill University, Jewish General Hospital	Dr. Ernesto Schiffrin declares that he has recevie honoraria (ad boards) from Novartis and Actelion. He also declares receipt of a discovery research grant from Servier. He declares no other conflicts of interest.
Fareed Mirza	Novartis Foundation	None
Gbenga Ogedegbe	New York University Langone Medical Centre	None
Manuela Fiuza	Universidade de Lisboa	None
Nam Phuong Do Thi	Heart Institute of Ho Chi Minh City	None
Norm Campbell	University of Calgary	Dr. Norm Campbell declares that he has received funding from the Novartis Foundation as a consultant to hypertension control programs in low-resource settings and declares no other conflicts of interest.
Otavio Berwanger	Hospital do Coração	None
Raghupathy Anchala	Indian Institute of Public Health, Hyderabad - The Public Health Foundation of India	Dr. Raghupathy Anchala declares that he has received funding from the Wellcome Trust- PHFI consortium (GBP 20,000) to develop clinical decision support systems for management of hypertension in primary healthcare settings (2010-2013). He has not received any funds from pharmaceutical industry and declares no conflict of interest.
Vladislav Podpalov	Vitebsk State Medical University, Belarusian Hypertension Society	None
Yook-Chin Chia	Malaysia Hypertension Society, University of Malaya	Dr. Yook Chin Chia declares that she has received speakers' honorarium from Abbott, Bayer, BI, GSK, Novartis, Menarini, MSD, Pfizer, Sanofi, Servier, Takeda, Omron and has served on Advisory Board for Hypertension for Pfizer, Servier, Takeda and declares no other conflicts of interest.

ICHOM Team

Name	Affiliation	Declarations
Charlotte Roberts	ICHOM, Vice President of Standardisation	None
Oluwakemi Okunade	ICHOM, Project Leader	None
Rachel Zack	ICHOM, Research Fellow	None
Elizabeth Olson	ICHOM, Senior Research Associate	None

Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change

www.ichom.org