ICHOM International Consortium for Health Outcomes Measurement

ATRIAL FIBRILLATION DATA COLLECTION REFERENCE GUIDE

Version 5.0.1
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ICHOM ATRIAL FIBRILLATION

We are thrilled that you are interested in measuring outcomes for Atrial Fibrillation. It is our hope that this Reference Guide will facilitate the process of implementing our Set of Patient-Centered Outcome Measures, thereby ensuring the collection of comparable data for global benchmarking and learning.

© 2023 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

ICHOM Cardiometabolic Family of Sets - Updates

As ICHOM strives to keep our Sets up to date with clinical advancements, implementation requirements, and relevant to patient interests, we have begun an initiative to review and update all our Sets routinely every three years.

The Cardiometabolic Family of Sets represents the first group of Sets to be revised and updated as a group simultaneously. This marks an important milestone in ICHOM's journey to promote value-based healthcare from an evidence-based and patient-centered perspective. For this process, we have worked with a Steering Committee, a group of experts from the original Working Groups involved in the development of these Sets, implementers from around the world, and patient representatives, to make necessary changes to the Sets in order to ensure that they are clinically up to date and harmonized in line with ICHOM standards.

These changes include:

- Set specific updates (specific updates to Sets individually, based on feedback and in order to keep in line with clinical advancements)
- Cross-Set updates (updates made across all Cardiometabolic Sets, with the aim to harmonize standardized variables throughout different Sets in order to facilitate simultaneous implementation)

A full list of changes specific to the Atrial Fibrillation Set can be seen in the Appendix.

Working Group Members for the Atrial Fibrillation Set of Patient-Centered Outcome Measures

The following individuals dedicated both time and expertise to develop the ICHOM Set for Atrial Fibrillation Chair. The work was supported by William Seligman, ICHOM Research Fellow, Zofia Das-Gupta and Adedayo O. Jobi-Odeneye, ICHOM.

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Mike Collins
William Lewis
Kate Koplan
Christopher McLeod
Spencer Moseley
Benjamin Steinberg
Mellanie True Hills

Steering Committee Members who contributed to the update of the Cardiometabolic Family of Sets

The following individuals dedicated both time and expertise to update the ICHOM CardioMetabolic Family of Sets. The work was supported by ICHOM Project Managers Paula Blancarte Jaber and Spencer Connell, ICHOM Director of Outcomes Research Zofia Das-Gupta, and ICHOM Research Associate Isabel Miller.

Elena Arbelo
Menno Huisman
Andreas Bollman
Benjamin Steinberg
John Beltrame
Tom Lumbers
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Magdalena Walbaum
Erik (F.A.) Klok
Albertino Damasceno
Camila de Menezes Succi
Jana Nano
Kevin Veen
Cindy de Jong
Tim Benson

Supporting Organizations

The Atrial Fibrillation Set is made possible only through the support of the following organizations.

The Cardiometabolic Family Set Updates would not have been possible without the support of the following sponsor:

Thank you.

Scope of Atrial Fibrillation Set of Patient-Centered Outcome Measures

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

Conditions	An adult (≥ 18 years) diagnosed with atrial fibrillation Including: asymptomatic patients Excluding: patients diagnosed with cardiotoxic acute atrial fibrillation
Treatment Approaches	Management of cardiovascular risk factors and institution of preventive therapy | Pharmacological management | Non-pharmacological management

ICHOM Patient-Centered Outcome Measures for Atrial Fibrillation

Case-Mix Variables

Patient Population	Measure	Timing	Reporting Source
Demographic Factors			
All patients	Year of birth	Baseline	Clinical
	Sex		
	Gender		Patient-reported
	Level of education		
	Ethnicity		
	Race		
Lifestyle Interventions			
All patients	Smoking status	Baseline and annually	Patient-reported
	Alcohol intake		
	Physical activity		
	BMI		Clinical
Health Status			
All patients	Comorbidities	Baseline	Clinical
	Cognitive functioning	Baseline and annually	
	Diagnosis		
	Disease duration		
	Pharmacological treatment		
	Non-pharmacological treatment		
	Cardiovascular Procedural Treatments		

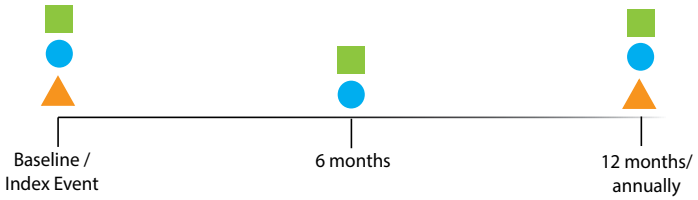
Outcomes overview

Patient Population	Measure	Timing	Reporting Source
Long-term consequences of disease			
All patients	Vital status	Ongoing	Clinical
	Ischaemic stroke, systemic embolism, unclassified stroke		
	Heart failure		
	Cardiovascular hospitalization		
	Freedom from fast atrial arrhythmia post-treatment		
	Anticoagulation management	Baseline	
	Cognitive functioning		
Complications of treatment			
All patients	Haemorrhagic stroke	Ongoing	Clinical
	Life-threatening/ major bleeding		
	Serious adverse events post-intervention		
	Medication side effects	Baseline	Patient-reported and clinical
Patient-reported outcomes			
All patients	Health-related quality of life	Baseline and 6-monthly	Patient-reported
	Physical functioning		
	Emotional functioning		
	Cognitive functioning		
	Symptom severity		
	Exercise tolerance		
	Ability to work		

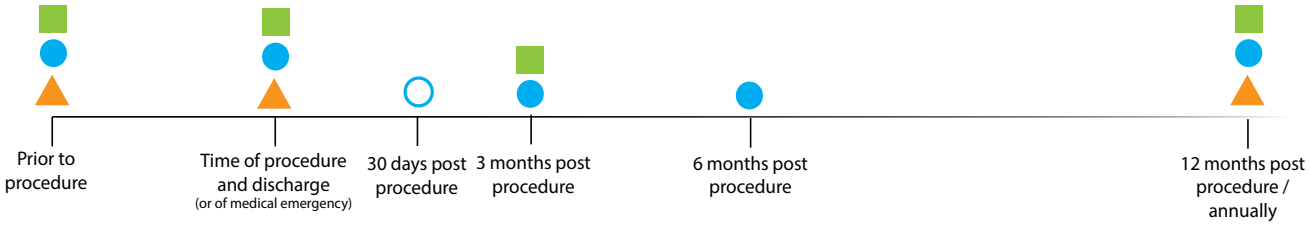
Follow-Up Timeline

The following algorithm illustrates when the Set variables should be collected from patients and clinicians.

All patients with Atrial Fibrillation, regardless of treatment



All patients with Atrial Fibrillation who have undergone a procedure



The following questionnairs should be administered at the indicated time points:

- Patient-Reported Outcome Measures (PROMs)
- Clinical-Reported Outcome Measures (CROMS)
- CROMs: Vital Status and Warning Signs
- Case-Mix Variables

The timeline is not reset in the case of hospitalization or medical emergency

Collecting Patient-Reported Outcome Measures

Survey(s) Used	Licensing Information	Scoring Guide
Montreal Cognitive Assessment (MoCA)	Free to use in clinical practice without permission following the completion of mandatory training and certification. Written permission and a Licensing Agreement is additionally required if funded by commercial entity or pharma. For more information and the permission form, please visit: https://www.mocatest.org/permission/	See link at left
The Optum™ SF-12 Health Survey	The SF-12 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 at: https://bit.ly/2CpDuul	The scoring guide for the SF-12 is only available upon a license agreement being made.
PROMIS GH-10 v1.2	Free access. PROMIS measures are copyrighted. All English and Spanish version of PROMIS are publicly available for use in one's individual research, clinical practice, educational assessment, or other application without licensing or royalty fees. Commercial users must seek permission to use, reproduce, or distribute measures. Integration into proprietary technology requires written permission. Please read the PROMIS Terms and Conditions of Use for more information. https://www.healthmeasures.net/images/PROMIS/Terms_of_Use_HM_approved_1-12-17_-_Updated_Copyright_Notices.pdf	The scoring guide for the PROMIS Global Health is available at: https://bit.ly/2Fm7Y2n
EQ-5D-3L	Use of the EQ-5D-3L requires a license. It may be found at https://registration.euroqol.org/?_gl=1*1o6eln5*_up*MQ..*_ga*MTUzNjk2OTE1NS4xNjcyODUzNTU0*_	See link at left
WHO Disability Assessment Schedule (WHODAS v2.0)	A license is needed to use the WHODAS 2.0 in systems for data capturing or electronic records, available at https://www.who.int/about/policies/publishing/permissions	See link at left
VR-12	Requires permission for use. Access can be requested at: https://www.bu.edu/sph/about/departments/health-law-policy-and-management/research/vr-36-vr-12-and-vr-6d/request-access/	See link at left
Patient Health Questionnaire-2 (PHQ-2)	The PHQ-2 is free to use, and a license is not needed. It may be found at: https://doi.org/10.1097/01.mlr.0000093487.78664.3c	See Link at Left

PROMIS Cognitive Function	Free to use for non-commercial purposes and in clinical practice without a license. Information on available translations can be found at: https://bit.ly/29aOZu9	The scoring guide for the PROMIS Cognitive Function is available at: https://bit.ly/2HFOhnW
Atrial Fibrillation Effect on Quality-of-Life Questionnaire (AFEQT)	The AFEQT requires a license agreement and one-time fee of $500 prior to use. The license agreement may be found at: http://www.afeqt.org/	See link at left
University of Toronto Atrial Fibrillation Severity Scale (AFSS)	The AFSS is free to use for students, physicians, academic users, and in clinical practice. Healthcare organizations, commercial users, and IT companies must submit a request, and fees may apply to use the measure. More information can be found at: https://eprovide.mapi-trust.org/instruments/atrial-fibrillation-severity-scale	The scoring guide for the AFSS is only available upon a license agreement being made.
Work Productivity and Activity Impairment Questionnaire: General Health V2.0 (WPAI:GH)	Free for use and a license is not required. It may be found at: http://www.reillyassociates.net/WPAI_GH.html	See link at left
Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia (ASTA)	The ASTA questionnaire is free to use, whether it is for individual use or for a project. To access the questionnaire, you must fill out a form which can be found through the following link: https://asta.walraf.se/en/inuseanda-asta/	https://asta.walraf.se/en/inuseanda-asta/

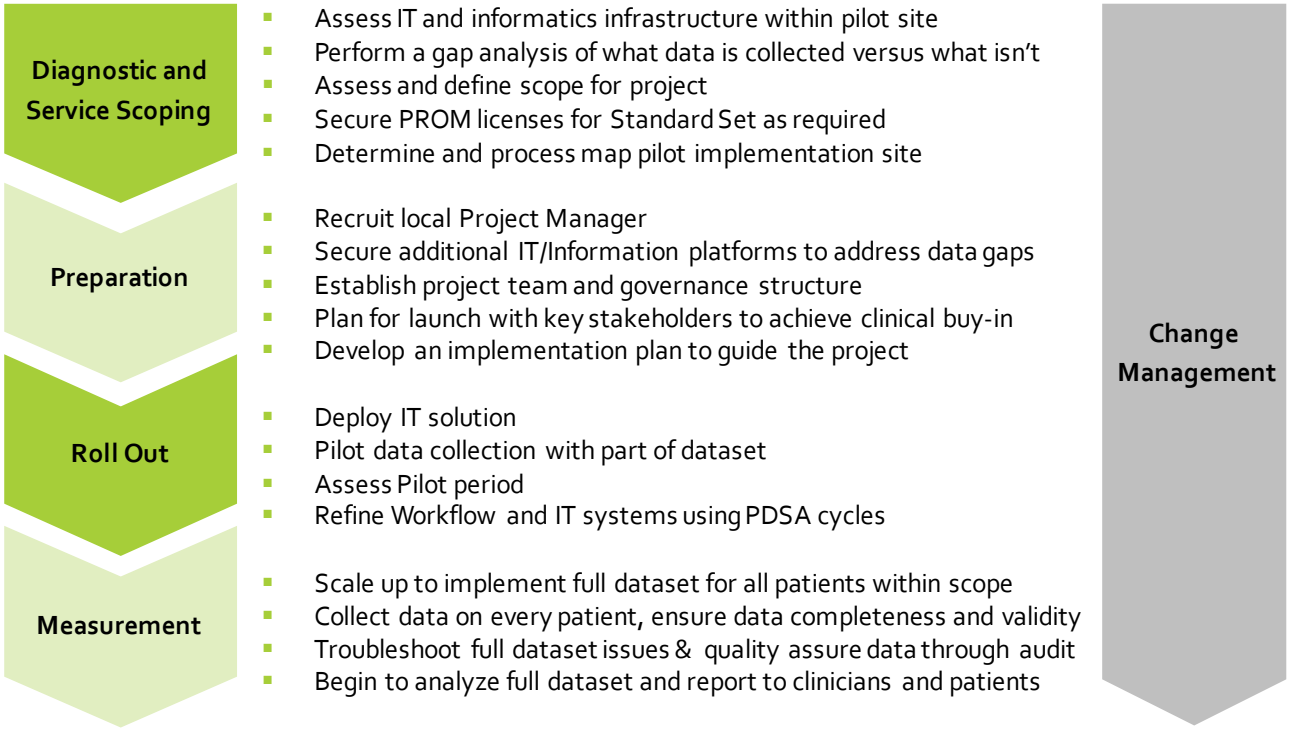
ICHOM

International Consortium for
Health Outcomes Measurement

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 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 Outcomes Measures [1] Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., et al. (2005). Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. Value in Health, 8(2), 94–104. doi:10.1111/j.1524-4733.2005.04054.

Appendix

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Atrial Fibrillation 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 months 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 case the 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
Reporting Source:	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
Reporting 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 non-binary 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
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = Male 2 = Female 3 = Other 999 = Undisclosed
Variable ID:	Gender_CVD
Variable:	Gender identity
Definition:	The patient's gender identity
Supporting Definition:	This measure should be recorded if appropriate and legal based on local standards in the particular geographic region, and should be self-reported by the patient. This is an optional question but ICHOM encourages that this information is collected. This data will help to support combating health disparities based on gender identity but all patient data regarding gender identity will be kept confidential. The patient's response will then be coded based on LOINC's standards. All patients may choose not to answer as well.
Displayed Value	Do you think of yourself as … ?
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Boy/Man 2 = Girl/Woman 3 = Non-Binary 4 = Trans man/Transgender Man/FTM 5= Trans woman/Transgender woman/MTF 6 = None of these describe me 999 = Prefer not to answer
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
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0 = None 1 = Primary 2 = Secondary 3 = Tertiary
Variable ID:	Race
Variable:	Race
Definition:	The biological race of the person

Supporting Definition:	This measure should be recorded based on local standards in the particular geographic region and should be self-reported by the patient. This is an optional question but ICHOM encourages that this information is collected and is as racially and ethnically inclusive as possible. This data will help to support combating health disparities based on race but all patient data regarding race and ethnicity will be kept confidential. The patient's response will then be coded based on LOINC's standards. All patients may choose not to answer as well.
Displayed Value	Please indicate the biological race that you identify with
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	Please report your race based on your geographic region's local standards.
Variable ID:	Ethnicity
Variable:	Ethnicity
Definition:	The cultural ethnicity of the person that they most closely identify with
Supporting Definition:	This measure should be recorded based on local standards in the particular geographic region and should be self-reported by the patient. This is an optional question but ICHOM encourages that this information is collected and is as racially and ethnically inclusive as possible. This data will help to support combating health disparities based on ethnicity but all patient data regarding race and ethnicity will be kept confidential. The patient's response will then be coded based on LOINC's standards. All patients may choose not to answer as well.
Displayed Value	Please indicate the ethnicity that you identify with
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	Please report your ethnicity based on your geographic region's local standards.

Lifestyle Interventions

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 Annually
Reporting 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:	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 Annually
Reporting 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 Annually
Reporting Source:	Clinical
Type:	Numerical value
Value Domain:	code
Response Options:	1 = kilograms 2 = lbs

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 Annually
Reporting 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 Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = centimeters 2 = inches
Variable ID:	BMIValue
Variable:	Body mass index
Definition:	Body mass index
Supporting Definition:	Height and weight are used to calculate BMI. BMI calculated as kg/m2.
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	quantity
Response Options:	none
Variable ID:	AlcoholAmount
Variable:	Alcohol intake amount
Definition:	A person's self-reported usual number of alcohol-containing standard drinks on a typical week.
Supporting Definition:	Alcohol consumption measured as standard drinks. The standard drink reference measure used in ICHOM is 10 grams of pure alcohol, which is equivalent to 12.5 milliliters of alcohol, or roughly 1 small glass of wine/25cl of regular beer (5% alcohol). The size of a standard drink can be localized to suit your local circumstances, but will need to be mapped back to the ICHOM reference.
Displayed Value	How many standard alcoholic drinks do you drink per week? One standard drink is equal to 12.5ml of pure alcohol, or roughly 1 small glass of wine/25cl of regular beer (5% alcohol).
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Patient- reported
Type:	Single answer
Value Domain:	quantity
Response Options:	None

Variable ID:	PAVSDAY
Variable:	The Physical Activity Q1
Definition:	On average, how many days per week do you engage in moderate to strenuous exercise (like a brisk walk, slow biking, general gardening)?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Patient- reported
Type:	Numerical value
Value Domain:	quantity
Response Options:	Numerical value of days per week
Variable ID:	PAVSTIME
Variable:	The Physical Activity Q2
Definition:	On average, how many minutes do you engage in exercise at this level?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Patient- reported
Type:	Numerical value
Value Domain:	quantity
Response Options:	Numerical value of minutes per week
Variable ID:	PAVSUM
Variable:	The Physical Activity Q3
Definition:	Total minutes per week of physical activity (multiply PAVSDAY by PAVSTIME)
Supporting Definition:	Average minutes per week of moderate intensity physical activity performed by patient
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= 0 minutes 1 = 1 - 150 minutes 2 = >150 minutes

Baseline Health Status

Variable ID:	CVDComorbidities
Variable:	Cardiovascular Comorbidities
Definition:	Indicate which comorbidities the patient is living with. Select all that apply.
Supporting Definition:	Include ALL conditions that apply at every annual follow-up.
Displayed Value	Indicate which comorbidities the patient is living with. Select all that apply.
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Multiple answer
Value Domain:	Code
Response Options:	0 = no other diseases 1 = Heart Disease (Angina, heart attack, or HF) 2 = High Blood Pressure 3 = Atrial Fibrillation or Flutter 4 = Chronic Pulmonary Disease (Asthma, Chronic Bronchitis, COPD, Emphysema) 5 = Diabetes 6 = Peripheral Artery Disease 7 = Myocardial Infarction

	8 = Obesity 9 = Stroke 10 = Ulcer or stomach disease 11 = Renal Insufficiency 12 = Liver Disease 13 = Anemia or other blood disease 14 = Cancer/Other Cancer in last 5 years 15 = AIDS/Immunodeficiency 16 = Presence/History of Depression 17 = Anxiety or Neuroses 18 = Presence/History of Psychotic Mental Illness (e.g., Schizophrenia) 19 = Substance Abuse 20 = Osteoarthritis, degenerative arthritis 21 = Rheumatoid Arthritis 22 = Periodontal Disease 888 = Other Medical Problems
Variable ID:	IntracranialHaemorrhage
Variable:	Intracranial haemorrhage
Definition:	Indicate whether the patient has ever been diagnosed with an intracranial haemorrhage
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline at time of atrial fibrillation diagnosis
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	VASCDIS
Variable:	Vascular diseases e.g. coronary disease, arterial disease
Definition:	Indicate whether the patient has a documented history or is currently diagnosed with Vascular diseases
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline at time of atrial fibrillation diagnosis
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes 999 = Unknown
Variable ID:	HYPERTHYR
Variable:	Hyperthyroidism
Definition:	Indicate whether the patient has a documented history or is currently diagnosed with Hyperthyroidism
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline at time of atrial fibrillation diagnosis
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes 999 = Unknown
Variable ID:	OSA
Variable:	Obstructive sleep apnea

Definition:	Indicate whether the patient has a documented history or is currently diagnosed with Obstructive sleep apnea
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline at time of atrial fibrillation diagnosis
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes 999 = Unknown
Variable ID:	MOCA
Variable:	Montreal Cognitive Assessment
Definition:	Montreal Cognitive Assessment for cognitive function
Supporting Definition:	The MOCA assesses several cognitive domains. The test is a one-page 30-point test administered in approximately 10 minutes. The test and administration instructions are available for clinicians online
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	quantity
Response Options:	Value of of 30

Health Status Measured at Baseline and Annually

Variable ID:	AFIB
Variable:	Type of atrial fibrillation
Definition:	What is the type of atrial fibrillation that the patient has been diagnosed with?
Supporting Definition:	- Paroxysmal (episode of AF that terminates spontaneously or with intervention in less than seven days) - Persistent (AF that lasts for more than seven days and requires intervention in order for cardioversion to occur) - Long-standing persistent (episodes of AF extending greater than 12 months) - Permanent (AF that will not be cardioverted or has failed cardioversion)
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = Paroxysmal atrial fibrillation 2 = Persistent atrial fibrillation 3 = Long-standing persistent atrial fibrillation 4 = Permanent atrial fibrillation 999 = Unknown
Variable ID:	DISDUR_AFIB
Variable:	Disease duration
Definition:	Indicate the year of atrial fibrillation diagnosis
Supporting Definition:	- Recent (less than a year) date unknown - Diagnosed at DD/MM/YYYY - Unknown
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Single answer

Value Domain:	code
Response Options:	0= Recent, data unknown 999 = Unknown Date of diagnosis (DD/MM/YYYY)
Variable ID:	CVDNonPharmTx
Variable:	Cardiovascular Non-Pharmacological Treatment
Definition:	Please indicate which of the following non-pharmacological treatments the patient is receiving.
Supporting Definition:	Lifestyle modifications includes physical activity and other behavioural changes, e.g. smoking cessation.
Displayed Value	Please indicate which of the following non-pharmacological treatments the patient is receiving.
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Multiple answer
Value Domain:	Code
Response Options:	1= Disease Education 2= Comorbidity Education 3= Vaccination Education 4= Dietary Advice 5= Lifestyle modifications
Variable ID:	CVDPharmaTx
Variable:	Cardiovascular Pharmacological Treatment
Definition:	Please indicate if the patient is currently receiving any pharmacological treatment?
Supporting Definition:	None
Displayed Value	Please indicate if the patient is currently receiving any pharmacological treatment?
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	Code
Response Options:	0 = No 1= Yes 999= Unknown
Variable ID:	CVDPharmaTx_Drug
Variable:	Cardiovascular Pharmacological Treatment Drug
Definition:	Please indicate which of the following pharmacological treatments the patient is receiving.
Supporting Definition:	None
Displayed Value	Please indicate which of the following pharmacological treatments the patient is receiving.
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Multiple answer
Value Domain:	Code
Response Options:	1= Insulin therapy 2= Statins (e.g. atorvastatin, rosuvastatin, etc.) 3= SGLT2 Inhibitors 4= Metformin 5= Sulfonylurea 6= GLP1 Agonists 7= Antilplatelet agents (e.g. ASA, Clopidogrel, Prasugrel, Ticagrelor, etc.) 8= Novel oral anticoagulant (NOAC) (e.g. rivaroxaban, dabigatran, etc.) 9= Isosorbide Dinitrate 10= Angiotensin Receptor

	Blocker/Neprilysin Inhibitor Combination 11= Beta-blockers (e.g. metoprolol, bisoprolol, propranolol, etc.) 12= Vitamin K Antagonists (e.g. warfarin) 13= Mineralocorticoid Receptor Antagonists (e.g spironolactone) 14= Angiotensin II Receptor Antagonist (e.g. losartan, irbesartan, candesartan, etc.) 15= ACE Inhibitors (e.g. enalapril, captopril, etc.) 16= Loop diuretics (e.g. furosemide) 888= Other
Variable ID:	PHARMATYPE1_AFIB
Variable:	NDHP calcium channel blockers
Definition:	Indicate whether NDHP calcium channel blocker e.g. diltiazem is currently prescribed for atrial fibrillation
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to PHARMACOTHERAPY_AFIB
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes 999 = Unknown
Variable ID:	PHARMATYPE2_AFIB
Variable:	Cardiac glycosides
Definition:	Indicate whether Cardiac glycosides e.g. digoxin are currently prescribed for atrial fibrillation
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to PHARMACOTHERAPY_AFIB
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes 999 = Unknown
Variable ID:	PHARMATYPE3_AFIB
Variable:	Sodium channel blockers
Definition:	Indicate whether Sodium channel blockers e.g. flecainide, quinidine, disopryamide are currently prescribed for atrial fibrillation
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to PHARMACOTHERAPY_AFIB
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes 999 = Unknown
Variable ID:	PHARMATYPE4a_AFIB
Variable:	Potassium channel blockers

Definition:	Indicate whether Potassium channel blockers e.g. sotalol, dofetilide are currently prescribed for atrial fibrillation
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to PHARMACOTHERAPY_AFIB
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes 999 = Unknown
Variable ID:	PHARMATYPE4b_AFIB
Variable:	Multichannel blockers
Definition:	Indicate whether Multichannel blockers e.g. amiodarone are currently prescribed for atrial fibrillation
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to PHARMACOTHERAPY_AFIB
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes 999 = Unknown
Variable ID:	CVDProcedTx
Variable:	Cardiovascular Procedural Treatment
Definition:	Please indicate if the patient has previously undergone cardiac procedure.
Supporting Definition:	None
Displayed Value	Please indicate if the patient has previously undergone cardiac procedure.
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Clinical
Type:	Multiple answer
Value Domain:	Code
Response Options:	0= None 1=CABG 2=Valve surgery 3=Any cardiac surgery 4=prior percutaneous coronary procedure 5=prior percutaneous valve procedure 6= Another percutaneous intervention (e.g. catheter ablation)

Outcomes

Long-Term Consequences of Disease

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
Reporting 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:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to VitalStatus
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Date by DD/MM/YYYY
Value Domain:	date
Response Options:	none
Variable ID:	DEATHCAUSE_AFIB
Variable:	Cause of death
Definition:	The cause of cardiovascular death of the person
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to VitalStatus
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = an acute myocardial infarction 2 = sudden cardiac death 3 = heart failure 4 = stroke 5 = cardiovascular procedure 6 = cardiovascular haemorrhage 7 = other cardiovascular causes e.g. peripheral arterial disease 8 = Other cause of death (not cardiovascular) 999 = Unknown
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:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	EVENTTYPE
Variable:	Cardiovascular event type
Definition:	Indicate the type of cardiovascular event that occurred
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to CardiovascularEvent
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = an ischaemic stroke 2 = a systemic embolism 3 = an unclassified stroke 4 = none of above

Variable ID:	EVENTDATE
Variable:	Date of Cardiovascular event
Definition:	Provide the date of which the Cardiovascular event occurred
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1, 2, or 3" to EVENTTYPE
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	HeartFailure
Variable:	Heart failure
Definition:	Person has been clinically diagnosed with heart failure at any point in time
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	HFDATE
Variable:	Date of Heart failure diagnosis
Definition:	Provide the date of Heart failure diagnosis
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1 = Yes" to HeartFailure
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	LVEF
Variable:	Left ventricular ejection fraction
Definition:	Indicate if left ventricular ejection fraction (LVEF) was measured
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to HeartFailure
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = Yes 2 = No
Variable ID:	LeftVentricularEjectionFraction
Variable:	Left ventricular ejection fraction
Definition:	Please state range of patient's ejection fraction:
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If '1 = Yes' to LVEF
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = <30% 2 = 30-39% 3 = 40-50% 4 = >50%

	999 = Unknown
Variable ID:	LVEFDATE
Variable:	Date of Left ventricular ejection fraction
Definition:	Provide date of LVEF measurement
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to LVEF
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	LVEFVALUE
Variable:	Value of LVEF measurement
Definition:	Provide a value of LVEF measurement
Supporting Definition:	N/A
Displayed Value	
Inclusion Criteria:	If "1=Yes to LVEF"
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Numerical value
Value Domain:	
Response Options:	LVEF measurement value
Variable ID:	CVHOSPADM
Variable:	Cardiovascular hospital admission
Definition:	Indicate if the patient was admitted* due to an unplanned cardiovascular cause**
Supporting Definition:	*admission= at least one overnight stay at a hospital or acute care facility from first atrial fibrillation diagnosis ** Cardiovascular causes for admission are ones in which the principal admitting diagnosis relates to the cardiovascular system: myocardial infarction/ ischaemic heart disease, heart failure, stroke/TIA, peripheral arterial disease, AF, venous thromboembolism/PE, etc.
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes
Variable ID:	CVHOSPTYPE
Variable:	Type of cardiovascular cause hospital admission
Definition:	Indicate type of cardiovascular cause
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to CVHOSPADM
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = myocardial infarction / ischaemic heart disease 2 = heart failure 3 = stroke/TIA 4 = peripheral arterial disease 5 = venous thromboembolism/PE 6 = atrial fibrillation 7 = other cardiovascular cause
Variable ID:	FAA
Variable:	Fast Atrial Arhythmia
Definition:	Was a fast atrial arrhythmia detected?
Supporting Definition:	None

Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes
Variable ID:	FAADATE
Variable:	Date of fast atrial arrhythmia detection
Definition:	Provide the date when fast atrial arrhythmia was detected
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to FAA
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	FAATREATMENT
Variable:	Type of treatment
Definition:	Indicate type of treatment
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to FAA
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = Rate control drugs 2 = Pharmacological cardioversion 3 = Electrical cardioversion 4 = Atrial ablation 5 = AVN/His bundle ablation. 6 = Surgical atrial ablation 7 = Pacemaker 8 = Other
Variable ID:	FAATREATMONITOR
Variable:	Fast atrial arrhythmia post treatment monitoring
Definition:	If the patient received the treatment, indicate the type of monitoring performed post-treatment
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to FAA
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = 12-lead ECG 2 = Ambulatory monitoring 3 = Implantable devices 4 = Wearable devices/smartphones
Variable ID:	FAATREATMONITORDATE
Variable:	Date when each treatment started to be monitored
Definition:	Provide the date when each treatment started to be monitored
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to FAA
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer

Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	FFFAA
Variable:	Free from fast atrial arrhythmia at the time of post-treatment monitoring
Definition:	Was the patient free from fast atrial arrhythmia at the time of the post-treatment monitoring (i.e. in sinus rhythm or rate-controlled atrial fibrillation?)
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to FAA
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes
Variable ID:	ANTICOAG
Variable:	Anticoagulation therapy
Definition:	Was the patient prescribed anticoagulation therapy?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes
Variable ID:	ANTICOAGDATE
Variable:	Date when anticoagulation therapy started
Definition:	Provide date when the treatment began
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to ANTICOAG
Timing:	Baseline
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	NOANTICOAG
Variable:	Patient not presdribed anticoagulation therapy
Definition:	If the patient was not prescribed anticoagulation therapy, please provide reason
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "0= No" to ANTICOAG
Timing:	Baseline
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = Not recommended by current guidelines. Anticoagulants are not appropriate for beneficial reasons e.g. young patient with no underlying heart conditions 2 = Not recommended by current guidelines. Anticoagulants inappropriate for harmful reason or due to harm reasons e.g. patients with serious bleeding events 3 = Patient refusal 4 = Medication and / or monitoring / follow-up unavailable 5 = Cognitive dysfunction 6 = Short life expectancy 7 = High costs (including health insurance issue) 8 = Other (specify)
Variable ID:	LAAOD
Variable:	Left atrial appendage occlusion device, closure or excision of the left atrial appendage

Definition:	Did the patient receive a left atrial appendage occlusion device, closure or excision of the left atrial appendage?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes
Variable ID:	LAAODDATE
Variable:	Date of Left atrial appendage occlusion device, closure or excision of the left atrial appendage
Definition:	Please provide the date when the patient received a left atrial appendage occlusion device, closure or excision of the left atrial appendage
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to LAAOD
Timing:	Baseline
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	ANTICOAGCHANGE
Variable:	Change in anticoagulation therapy status
Definition:	Did patient anticoagulation therapy status change?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to ANTICOAG
Timing:	6 months
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes, the patient started taking the therapy 2 = Yes, the patient stopped taking the therapy
Variable ID:	ANTICOAGFU
Variable:	Anticoagulation therapy follow up
Definition:	Provide date when the anticoagulation therapy began
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to ANTICOAGCHANGE
Timing:	6 months
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	NOANTICOAGFU
Variable:	Patient not prescribed anticoagulation therapy at follow up
Definition:	If the patient stopped anticoagulation therapy, please provide reason
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "2= Yes, the patient stopped taking the therapy" to ANTICOAGCHANGE
Timing:	6 months
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1= Not recommended by current guidelines. Anticoagulants are not appropriate for beneficial reasons e.g. young patient with no underlying heart conditions

2 = Not recommended by current guidelines. Anticoagulants inappropriate for harmful reasons or due to harm reasons e.g. patients with serious bleeding events
3 = Patient refusal
4= Medication and/or monitoring/follow-up unavailable
5= Cognitive dysfunction
6= Short life expectancy
7= High costs (including health insurance issue)
8= Other (specify)

Complications of Treatment

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 Annually
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	IntracranialHaemorrhage
Variable:	Intracranial haemorrhage
Definition:	Indicate whether the patient has ever been diagnosed with an intracranial haemorrhage
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to CardiovascularEvent
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	HSTROKEDATE
Variable:	Date of haemorrhagic stroke
Definition:	Please provide date of Haemorrhagic stroke
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to IntracranialHaemorrhage
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	FBLEED
Variable:	Fatal bleeding
Definition:	Indicate whether the patient had fatal bleeding
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code

Response Options:	0= No 1 = Yes
Variable ID:	FBLEEDDATE
Variable:	Date of fatal bleeding
Definition:	Provide date of fatal bleeding event
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to FBLEED
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	CRITICALBLEED
Variable:	Symptomatic bleeding in a critical area or organ
Definition:	Indicate whether the patient had symptomatic bleeding in a critical area or organ e.g. intracranial, intraspinal, intraocular, retroperitoneal, intra-articular, or pericardial, or intramuscular with compartment syndrome
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes
Variable ID:	CRITICALBLEEDDATE
Variable:	Date of symptomatic bleeding in a critcal area or organ
Definition:	Provide date of symptomatic bleeding in a critical area or organ e.g. intracranial, intraspinal, intraocular, retroperitoneal, intra-artiular, or poricardial, or intramuscular with compartment syndrome
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to CRITICALBLEED
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	BLEEDOUTCOME
Variable:	Bleeding caused a fall in haemoglobin or transfusion
Definition:	Indicate whether the patient had bleeding causing a fall in haemoglobin > 2g/dL or transfusion of > 2 units of whole blood/red cells
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes
Variable ID:	BLEEDOUTCOMEDATE
Variable:	Date of when bleeding caused a fall in haemoglobin or transfusion
Definition:	Provide date of when patient had bleeding causing a fall in haemoglobin > 2g/dL or transfusion of > 2 units of whole blood/red cells
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to BLEEDOUTCOME
Timing:	Ongoing

Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	PROCEDURE
Variable:	Procedures
Definition:	Did the patient receive one of the listed procedures? (choose the one that applies, note the patient could have several procedures)
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single or multiple answers
Value Domain:	code
Response Options:	1= Catheter- based ablation: 1a= Pulmonary vein isolation 1b= Complex left atrial catheter ablation 1c= AV node ablation 1d= Atrial flutter ablation 2 = Surgical ablation procedure (including MAZE) 3 = Hybrid catheter and surgical ablation 4= Left atrial appendage closure/occlusion (device) 5= Left atrial appendage ligation/excision (surgical) 6= Electrical cardioversion 7= Pacemaker implantation 8= Pharmacological cardioversion 9= No, patient didn't receive any of listed procedures
Variable ID:	PROCEDUREDATE
Variable:	Date of the procedure
Definition:	Provide date of the procedure
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1-8" to PROCEDURE
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	date
Response Options:	None
Variable ID:	PROCEDURESAE
Variable:	Serious adverse event(s) due to procedure
Definition:	Did the patient experience serious adverse event(s) due to the procedure within 90 days of follow-up?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1-8" to PROCEDURE
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes
Variable ID:	SAE_AFIB
Variable:	Serious adverse event due to procedure
Definition:	Please specify serious adverse event(s)
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to PROCEDURESAE
Timing:	Ongoing
Reporting Source:	Clinical

Type:	Single/multiple answers
Value Domain:	code
Response Options:	1 = In hospital death 2 = Vascular complications 2a = Postoperative haemorrhage 2b = Postoperative haemorrhage requiring transfusion 2c = Vascular complications 2d = Pericardial tamponade 3 = Requiring open heart surgery 4 = Requiring repeat ablation procedure 5 = Ventricular arrhythmias 6 = Respiratory complications 6a = Pneumothorax 6b = Phrenic nerve palsy 6c = Pulmonary vein stenosis 6d = Other iatrogenic respiratory complications 7 = Trauma embolic complications, stroke, TIA, systemic or pulmonary embolism 8 = Postprocedure infections 9 = Atrio-esophageal fistula 10 = Other (specify)
Variable ID:	SAEDATE
Variable:	Date(s) of Serious adverse events due to procedure
Definition:	Provide date(s) of serious adverse events due to procedure
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to PROCEDURESAE
Timing:	Ongoing
Reporting Source:	Clinical
Type:	Date(s)
Value Domain:	date
Response Options:	DD/MM/YYYY
Variable ID:	MEDSEDISCONT
Variable:	Medication side effects resulting in discontinuation of atrial fibrillation medication
Definition:	Did you experience a medication side effects that resulted in discontinuing your prescribed medication for atrial fibrillation?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1 = Yes
Variable ID:	MEDSE
Variable:	Side effects resulting in discontinuation of AF medication
Definition:	Which side effects caused discontinuation of your prescribed medication for atrial fibrillation?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to MEDSEDISCONT
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Choose all that apply
Value Domain:	code
Response Options:	1= Dizziness, fainting, lightheadedness or loss of consciousness 2= Erectile dysfunstion 3= Hair loss 4= Memory problems, brain for or poor concentration 5= Mental health issues such as depression or anxiety

6= Muscle or joint pain
7= Shortness of breath
8= Stomach problems such as nausea, vomitting or diarrhea
9= Unexplained bruising or bleeding
10= Unusual weakness or tiredness
11= Weight loss
12= Other (specify)

Variable ID:	MEDCLASS
Variable:	Class of medication discontinued by patient
Definition:	Which class of medication was discontinued by the patient?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If "1= Yes" to MEDSEDISCONT
Timing:	Baseline 6-monthly
Reporting Source:	Clinical
Type:	Multiple answer
Value Domain:	code
Response Options:	1= Antithrombotic 2= Anticoagulation 3= Antiplatelet 4= Rhythym 5= Rate control 6= Other (specify) 999= Unknown

Health-Related Quality of Life

Variable ID:	HR-HSQoL
Variable:	Health-related Quality of Life/Self-Reported Health Status
Definition:	What Health-Related Quality of Life tool are you using?
Supporting Definition:	None
Displayed Value	What Health-Related Quality of Life tool are you using?
Inclusion Criteria:	All patients
Timing:	
Reporting Source:	Clinical
Type:	Multiple answer
Value Domain:	Code
Response Options:	1= EQ5D3L 2 = WHODAS V2.0-12 3 = VR-12 4 = PROMIS GH-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:	None
Displayed Value	None
Inclusion Criteria:	If answered "1 = EQ5D3"' to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	
Value Domain:	N/A
Response Options:	None

Variable ID:	WHODAS_Q01
Variable:	Question 1 of WHODAS 2.0
Definition:	This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

	Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please select only one response. In the past 30 days, how much difficulty did you have in: S1: Standing for long periods such as 30 minutes?
Supporting Definition:	None
Displayed Value	This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs. Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please select only one response. In the past 30 days, how much difficulty did you have in: S1: Standing for long periods such as 30 minutes?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild 2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	WHODAS_Q02
Variable:	Question 2 of WHODAS 2.0
Definition:	S2: Taking care of your household responsibilities?
Supporting Definition:	None
Displayed Value	S2: Taking care of your household responsibilities?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild 2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	WHODAS_Q03
Variable:	Question 3 of WHODAS 2.0
Definition:	S3: Learning a new task, for example, learning how to get to a new place?
Supporting Definition:	None
Displayed Value	S3: Learning a new task, for example, learning how to get to a new place?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild 2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	WHODAS_Q04
Variable:	Question 4 of WHODAS 2.0

Definition:	S4: How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?
Supporting Definition:	None
Displayed Value	S4: How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild 2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	WHODAS_Q05
Variable:	Question 5 of WHODAS 2.0
Definition:	S5: How much have you been emotionally affected by your health problems?
Supporting Definition:	None
Displayed Value	S5: How much have you been emotionally affected by your health problems?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild 2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	WHODAS_Q06
Variable:	Question 6 of WHODAS 2.0
Definition:	S6: Concentrating on doing something for ten minutes?
Supporting Definition:	None
Displayed Value	S6: Concentrating on doing something for ten minutes?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild 2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	WHODAS_Q07
Variable:	Question 7 of WHODAS 2.0
Definition:	S7: Walking a long distance such as a kilometer [or equivalent]?
Supporting Definition:	None
Displayed Value	S7: Walking a long distance such as a kilometer [or equivalent]?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild

	2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	WHODAS_Q08
Variable:	Question 8 of WHODAS 2.0
Definition:	S8: Washing your whole body?
Supporting Definition:	None
Displayed Value	S8: Washing your whole body?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild 2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	WHODAS_Q09
Variable:	Question 9 of WHODAS 2.0
Definition:	S9: Getting dressed?
Supporting Definition:	None
Displayed Value	S9: Getting dressed?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild 2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	WHODAS_Q10
Variable:	Question 10 of WHODAS 2.0
Definition:	S10: Dealing with people you do not know?
Supporting Definition:	None
Displayed Value	S10: Dealing with people you do not know?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild 2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	WHODAS_Q11
Variable:	Question 11 of WHODAS 2.0
Definition:	S11: Maintaining a friendship
Supporting Definition:	None
Displayed Value	S11: Maintaining a friendship
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported

Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild 2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	WHODAS_Q12
Variable:	Question 12 of WHODAS 2.0
Definition:	S12: Your day-to-day work?
Supporting Definition:	None
Displayed Value	S12: Your day-to-day work?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None 1 = Mild 2 = Moderate 3 = Severe 4 = Extreme or cannot do
Variable ID:	GH1
Variable:	Question 1 of VR-12
Definition:	In general, would you say your health is:
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 WHODAS 2.0
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	1 = Excellent 2 = Very good 3 = Good 4 = Fair 5 = Poor
Variable ID:	MH3
Variable:	Question 6a of VR-12
Definition:	These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks: a. Have you felt calm and peaceful?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Variable ID:	MH4
Variable:	Question 6c of VR-12
Definition:	c. Have you felt downhearted and blue?
Supporting Definition:	None
Displayed Value	None

Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting 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:	PF2
Variable:	Question 2a of VR-12
Definition:	The following items are about activities you might do during a typical day. Does our health now limit you in these activities? If so, how much? a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting 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:	PF4
Variable:	Question 2b of VR-12
Definition:	b. Climbing several flights of stairs
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting 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:	SF2
Variable:	Question 7 of VR-12
Definition:	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting 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:	VR12_Q08
Variable:	Question 8 of VR-12
Definition:	Now, we'd like to ask you some questions about how your health may have changed. Compared to one year ago, how would you rate your physical health in general now?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	1 = Much better 2 = Slightly better 3 = About the same 4 = Slightly worse 5 = Much worse
Variable ID:	VR12_Q09
Variable:	Question 9 of VR-12
Definition:	Compared to one year ago, how would you rate your emotional health (such as feeling anxious, depressed, or irritable) in general now?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	1 = Much better 2 = Slightly better 3 = About the same 4 = Slightly worse 5 = Much worse
Variable ID:	VRE2
Variable:	Question 4a of VR-12
Definition:	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? a. Accomplished less than you would like
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	1 = No, none of the time 2 = Yes, a little of the time 3 = Yes, some of the time 4 = Yes, most of the time 5 = Yes, all of the time
Variable ID:	VRE3
Variable:	Question 4b of VR-12
Definition:	b. Didn't do work or other activities as carefully as usual
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly

Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	1 = No, none of the time 2 = Yes, a little of the time 3 = Yes, some of the time 4 = Yes, most of the time 5 = Yes, all of the time
Variable ID:	VRP2
Variable:	Question 3a of VR-12
Definition:	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? a. Accomplished less than you would like
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	1 = No, none of the time 2 = Yes, a little of the time 3 = Yes, some of the time 4 = Yes, most of the time 5 = Yes, all of the time
Variable ID:	VRP3
Variable:	Question 3b of VR-12
Definition:	b. Were limited in the kind of work or other activities
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	1 = No, none of the time 2 = Yes, a little of the time 3 = Yes, some of the time 4 = Yes, most of the time 5 = Yes, all of the time
Variable ID:	VT2
Variable:	Question 6b of VR-12
Definition:	b. Did you have a lot of energy?
Supporting Definition:	None
Displayed Value	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting 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:	PROMIS-10_Q01
Variable:	Global01

Definition:	Please respond to each question or statement by marking one box per row: In general, would you say your health is:
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.
Displayed Value	In general, would you say your health is:
Inclusion Criteria:	If answered "4 = PROMIS GH-10" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting 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-10_Q02
Variable:	Global02
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 answered "4 = PROMIS GH-10" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor

Physical Functioning

Variable ID:	PROMIS-10_Q03
Variable:	Global03
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 answered "4 = PROMIS GH-10" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor

Cognitive Functioning

Variable ID:	PROMIS-10_Q04
Variable:	Global04
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 answered "4 = PROMIS GH-10" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting 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-10_Q05
Variable:	Global05
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 you social activities and relationships?
Inclusion Criteria:	If answered "4 = PROMIS GH-10" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor

Ability to Work

Variable ID:	PROMIS-10_Q09r
Variable:	Global09r
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, rate how well you carry out your usual social activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)
Inclusion Criteria:	If answered "4 = PROMIS GH-10" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor

Exercise Tolerance

Variable ID:	PROMIS-10_Q06
Variable:	Global06
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 answered "4 = PROMIS GH-10" to HR-HSQoL

Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5 = Completely 4 = Mostly 3 = Moderately 2 = A little 1 = Not at all

Symptom Severity

Variable ID:	PROMIS-10_Q10r
Variable:	Global10r
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 answered "4 = PROMIS GH-10" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5 = Never 4 = Rarely 3 = Sometimes 2 = Often 1 = Always
Variable ID:	PROMIS-10_Q08r
Variable:	Global08r
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 answered "4 = PROMIS GH-10" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5 = None 4 = Mild 3 = Moderate 2 =Severe 1 = Very severe
Variable ID:	PROMIS-10_Q07r
Variable:	Global07r
Definition:	In the past 7 days, how would you rate your pain on average?
Supporting Definition:	Indicate pain level on a scale of 0-10, 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 answered "4 = PROMIS GH-10" to HR-HSQoL
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	Numerical value between 0 and 10

Optional Quality of Life

Variable ID:	ASTA_QoL_1
Variable:	ASTA Quality of Life Question 1
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_2
Variable:	ASTA Quality of Life Question 2
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_3
Variable:	ASTA Quality of Life Question 3
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_4
Variable:	ASTA Quality of Life Question 4
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_5
Variable:	ASTA Quality of Life Question 5

Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_6
Variable:	ASTA Quality of Life Question 6
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_7
Variable:	ASTA Quality of Life Question 7
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_8
Variable:	ASTA Quality of Life Question 8
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_9
Variable:	ASTA Quality of Life Question 9
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data

Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_10
Variable:	ASTA Quality of Life Question 10
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_11
Variable:	ASTA Quality of Life Question 11
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_12
Variable:	ASTA Quality of Life Question 12
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	N/A
Variable ID:	ASTA_QoL_13
Variable:	ASTA Quality of Life Question 13
Definition:	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Supporting Definition:	None
Displayed Value	please contact license holder for the questionnaire. ichom will provide you with the technical specifications on how to collect the data
Inclusion Criteria:	All patients
Timing:	Baseline 6-monthly
Reporting Source:	Patient-reported
Type:	Single answer

Value Domain:	Code
Response Options:	N/A

Depression

Variable ID:	phq2-q01_CVD
Variable:	question 1 of phq-2
Definition:	over the past 2 weeks how often have you been bothered by any of the following problems little interest or pleasure in doing things
Supporting Definition:	A score >3 should lead to administration of PHQ-9 or Diagnostic Interview
Displayed Value	over the past 2 weeks how often have you been bothered by any of the following problems little interest or pleasure in doing things
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = Not at all 1 = Several days 2 = More than half the days 3 = Nearly every day
Variable ID:	phq2-q02_CVD
Variable:	question 2 of phq-2
Definition:	over the past 2 weeks how often have you been bothered by any of the following problems feeling down depressed or hopeless
Supporting Definition:	A score >3 should lead to administration of PHQ-9 or Diagnostic Interview
Displayed Value	over the past 2 weeks how often have you been bothered by any of the following problems feeling down depressed or hopeless
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = Not at all 1 = Several days 2 = More than half the days 3 = Nearly every day

Working Group Member Conflicts of Interests

Name	Affiliation	Declarations
A.John Camm	St. George's University of London	Personal fees from: Allergan, Alta Thera, Astellas, Astra Zeneca, Acesion, Huya, Incarda, Merck, Menarini, Milestone, Bayer, Boehringer Ingelheim, Bristol-Myers Squibb, Daiichi Sankyo, Pfizer, Portola, Boston Scientific, Abbott, Biotronik, Medtronic, Cardiac Insight.
Elena Arbelo	Hospital Clinic de Barcelona, Universitat de Barcelona, Institut d'Investigacions Biomediques Agust Pi I Sunyer (DIBAPS)	Personal fees Biosense Webster
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Andreas Bollmann	Leipzig University, Heart Center Leipzig	None declared
Gyorgy Bathory	-	None declared
Bridget Caffery-Armstrong	-	None declared
Daniel Cehic	GenesisCare	Financial relationship with GenesisCare Boehringer Ingelheim, Abbott, Biotronik, speaker fees Boehringer Ingelheim, Amulet trail from Abbott
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Mike Collins	-	None declared
Zofia Das-Gupta	ICHOM	None declared
Gopi Dandamudi	Indiana University	None declared
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Matthew Fay	Warwick Medical School, Atrial Fibrillation Association, Thrombosis UK	Consultancy and logistics fees Bayer, Pfizer, BMS
Isabelle van Gelder	-	None declared
Shinya Goto	Tokai University	Research grant Sanofi, Ono, Pfizer, Bristol Myers Squibb, personal fees Bayer, Astra Zeneca
Christopher Granger	Duke University	Personal fees from Abbvie, Medscape, Merck, Rho, Sirtex, Verseon, Gilead Sceinces, Boston Scientific grants and personal fees from Ametheon, Janssen, Medtronic, Astra Zeneza, Novartis, Pfizer, Bayer, Boehringer Ingelheim, Daiichi Sankyo
Jeffrey Healey	McMaster University, Hamilton Health Sciences, Population Health Research Institute	Research grant and personal fees Bristol-Meyers-Squibb, Boston Scientific, research grant Medtronic, St. Jude Medical, Boehringer-Ingelheim, personal fees Servier

Jeroen Hendriks	University of Adelaide	Lecture fees Boehringer Ingelheim, Pfizer BMSServed on the Task Force Writing Committee to develop the 2016 European Society of Cardiology guidelines for the management of atrial fibrillation
Mellanie True Hills	StopAfib.org, American Foundation for Women's Health	Employee at American Foundation for Women's Health, and True Hill, Inc, both organizations receive grants, speaking and consulting fees from industry
Richard Hobbs	Nuffield Department of Primary Care Health Sciences	None declared
Menno Huisman	University of Leiden	Grants from ZonMW Dutch Healthcare Fund and Aspen, grants and personal fees from Boehringer Ingelheim,Pfizer-BMS, Bayer Health Care, Daiichi-Sankyo, outside the submitted work.
Adedayo O. Jobi-Odeneye	ICHOM	None declared
Kate Koplan	Kaiser Permanente	None declared
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William Lewis	The MetroHealth System, Case Westem Reserve University, American Heart Association Get With The Guidelines Atrial Fibrillation Module	None declared
Trudie Lobban	Arrhythmia Alliance	None declared
Christopher McLeod	Mayo Clinic	None declared
Spencer Moseley	-	None declared
William Seligman	ICHOM	None declared
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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'
5.0.1	Whole Document	Updates were made to harmonize the Atrial Fibrillation Set with other ICHOM Cardiometabolic Sets. The following changes were made: Gender_CVD, CVDNonPharmT, CVDPharmaTx, CVDPharmaTx_Drug, CVDProcedTx variables were added. All ComorbiditiesSACQ[...] variables, COPD, STROKE_TIA, PROCEDURETYPE1-PROCEDURETYPE8, PHARMATYPE8_AFIB, and Promis10_Q01 - Promis10_Q07r were removed. Updates were made to all PHARMATYPE[...]_AFIB variables. ASTA tool was included as a cost-free alternative option. The PHQ-9 was changed to the PHQ-2. The Timepoints of the Set were updated.

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