



ICHOM

International Consortium for
Health Outcomes Measurement

**HEART FAILURE
DATA COLLECTION
REFERENCE GUIDE**

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Measuring
results
that matter

Physical
Exertion

Heart Failure





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

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

Introducing ICHOM and the Reference Guide

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

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

Our Standard Sets include baseline 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. We also include high-level treatment variables to allow stratification of outcomes by major treatment types. A comprehensive data dictionary, as well as scoring guides for patient-reported outcomes, is included in the appendix.

Working Group Members for Heart Failure

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Heart Failure in partnership with ICHOM, under the leadership of Dr. Theresa McDonagh, Professor of Heart Failure at Kings College Hospital in London and Clinical Lead for the National Heart Failure Audit in the United Kingdom.

Australia

John Beltrame
Tom Marwick
Christopher Reid

Brazil

Sabrina Bernardez
Salvador Paiva

Canada

Daniel Burns

England

Suzanna Hardman
Tina Kinsella
Mike Knapton
Theresa McDonagh
Hugh McIntyre
Richard Mindham
Vicky Parker

Greece

Gerasimos Filippatos

Netherlands

Arno Hoes
Luuk Otterspoor

Singapore

Carolyn Lam Su Ping

South Africa

Karen Sliwa

Spain

Marisa Crespo-Leiro

Sweden

Hans Persson

United States

Mariell Jessup
Frederick Masoudi
Lynne Stevenson

Wales

Stephen Hutchison

Supporting Organizations

The Heart Failure Standard Set is made possible only through the support of the following organizations:

Thank you.



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd
Aneurin Bevan
Health Board



**American
Heart
Association®**

life is why™



**British Heart
Foundation**



**HEART FAILURE
ASSOCIATION
OF THE ESC**



**EUROPEAN
SOCIETY OF
CARDIOLOGY®**

Treatment Approaches Covered for Heart Failure

For Heart Failure, the following treatment approaches (or interventions) are covered by our Standard Set:

**Treatment
Approaches**

Pharmacotherapy | Invasive Therapy | Rehabilitation

ICHOM Standard Set for Heart Failure

Case-Mix Variables

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Demographic Factors				
All patients	Age	Date of birth	At index event* for HF	Administrative data
	Sex	Sex at birth		
	Ethnicity	Note that regulations on reporting ethnicity may differ per country		
Baseline health status				
All patients	Hypertension	Yes/No	At index event and tracked ongoing	Clinician-reported
	Diabetes			
	Renal dysfunction	Need for dialysis		
	Smoking status (current or in past year)			
	Alcohol use (>1 drink a day)	Yes/No		
	Prior MI			
	Atrial fibrillation			
	Chronic lung disease	Oxygen dependency		
	Body mass index	Height and weight		
	Ejection Fraction	Determined by echocardiogram		
Diagnostic categories	N/A			

Treatment Variables

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
All patients	Medications initiated	Medication list		
Patients receiving device	Device procedure type	Device type (ICD or CRT)	Tracked ongoing	Clinician-reported
Patients receiving cardiac surgery	Cardiac surgery procedure type	CABG, CABG+valve, CABG/valve+Other		
Patients receiving rehabilitation	Measure initiated	Rehabilitation		

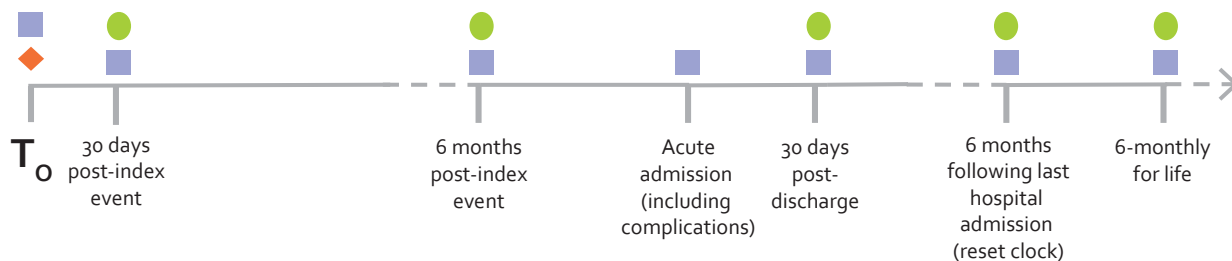
*The index event represents the entry into the set. This could be either after diagnosis in an outpatient setting, or after discharge from hospital if the initial presentation was severe enough to require admission.

Outcomes

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Functional				
All patients	Maximum level of physical exertion	Tracked with KCCQ-12 and NYHA	Tracked ongoing except at acute admissions	Patient and clinician-reported
	Symptom control: SOB			
	Symptom control: Fatigue and tiredness	Tracked with PROMIS Physical Function and KCCQ-12		Patient-reported
	Living independently/self-care			
	Employment			
Peripheral oedema	Tracked with KCCQ-12			
Symptom control: Disturbed sleep				
Psychosocial				
All patients	Health-related Quality of Life	Tracked with KCCQ-12	Tracked ongoing except at acute admissions	Patient-reported
	Depression and anxiety	Tracked with PHQ-2		
	Confidence/self-esteem	Tracked with KCCQ-12		
Burden of care				
All patients	Medication side-effects	Yes/No	Tracked ongoing except at acute admissions	Clinician-reported
	Financial burden	Due to device, medication and/or hospitalization		
	Complications of treatment			
	Number of hospital appointments			N/A
	Number of hospital readmissions			
Length of stay	Date of admission and discharge			
Survival				
All patients	Mortality	N/A	Tracked ongoing	Administrative data

Measurement Timeline and Sample Questionnaires

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



Index event* for Heart Failure (first clinical encounter since entry to the the Set or new

T_0 Diagnosis)

◆ Baseline characteristics ([link](#))

● PROMs (patient reported outcome measures) ([link](#))

■ Clinician reported outcomes ([link](#))

*The index event represents the entry into the set. This could either be after diagnosis/first encounter in an outpatient setting, or at discharge from hospital if the initial presentation was severe enough to require admission.

Collecting Patient-Reported Outcome Measures

Heart Failure Survey Used	Licensing Information	Scoring Guide
KCCQ-12 – Kansas City Cardiomyopathy Questionnaire-Short Version	You can obtain a license to use this instrument at your institution by visiting http://cvoutcomes.org/licenses	See link on the left
NYHA – New York Heart Association Functional Classification	The NYHA is free for all health care organizations, and a license is not needed.	
PROMIS Physical Function Short Form 4a – Patient-Reported Outcome Measurement Information System	PROMIS Physical Function is free for all health care organizations, and a license is not needed. For more information, please visit http://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures	See link on the left
Patient Health Questionnaire (PHQ-2)	The PHQ-2 is free for all health care organizations, and a license is not needed.	The scoring guide may be found at http://www.phqscreeners.com/instructions/instructions.pdf

The Growing ICHOM Community

By implementing the ICHOM Standard Sets, you become part of an expanding, international community of innovative health care providers dedicated to improving value for patients. To learn more about how ICHOM can assist your organization in implementing outcome measurement, contact us at implement@ichom.org, or visit <http://www.ichom.org/measure>.

Appendix

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Heart Failure Standard Set as consistently as possible with the Working Group recommendation. ICHOM is actively preparing for benchmarking efforts based on this data, and all data submitted for comparisons will need to be transformed into the following data structure if not already structured as such. **We are happy to provide an Excel version of this data dictionary for technical use.**

Please timestamp all variables. Some Standard Set variables are collected at multiple timepoints, and we will ask you to submit these variables in a concatenated VARIABLEID_TIMESTAMP form for future analyses. For example, VARIABLEID_BASE (baseline); VARIABLEID_6MO (6 month follow-up); VARIABLEID_1YR (1 year follow-up), etc.

Case-Mix Variables

Variable ID:	N/A
Variable:	Patient ID
Definition:	Indicate the patient's medical record number
Supporting Definition:	This number will not be shared with ICHOM. In the case patient-level data is submitted to ICHOM for benchmarking or research purposes, a separate ICHOM Patient Identifier will be created and cross-linking between the ICHOM Patient Identifier and the medical record number will only be known at the treating institution
Inclusion Criteria:	All patients
Timing:	At index event for HF
Reporting Source:	Administrative data
Type:	Numerical
Response Options:	According to institution

Demographic Factors

Variable ID:	AGE
Variable:	Age
Definition:	Please provide the patient's date of birth
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	At index event for HF
Reporting Source:	Administrative data
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY

Variable ID:	SEX
Variable:	Sex
Definition:	Please provide the patient's sex at birth
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	At index event for HF
Reporting Source:	Administrative data
Type:	Single answer
Response Options:	1 = Male 2 = Female

Variable ID:	ETNIC
Variable:	Ethnicity
Definition:	Varies by country and should be determined by country (not for cross country

comparison)

This response option is based upon the U.S. Standards for the Classification of Federal Data on Race and Ethnicity, and reflects standards in the U.S. Please adapt questions according to your country's guidelines.

Supporting Definition: This is based upon the U.S. Standards for the Classification of Federal Data on Race and Ethnicity, and reflects standards in the U.S. Please adapt questions according to your country's guidelines

Inclusion Criteria: All patients

Timing: At index event for HF

Reporting Source: Clinician-reported

Type: Single answer

Response Options: 0 = American Indian or Alaska Native

1 = Asian

2 = Black or African American

3 = Hispanic or Latino

4 = Native Hawaiian or Other Pacific Islander

5 = White

6 = Other

999 = Unknown

Baseline Health Status

Variable ID: AFIB

Variable: Atrial fibrillation

Definition: Have you ever been told by your doctor that you have atrial fibrillation?

Supporting Definition: Item is phrased as a patient reported measure. However, if the patient is unable to answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

Timing: At index event for HF and if "0 = No" or "999 = Unknown" to AFIB, tracked ongoing

Reporting Source: Clinician-reported, patient-reported, or administrative

Type: Single answer

Response Options: 0 = No

1 = Yes

999 = Unknown

Variable ID: PRIORMI

Variable: Prior MI

Definition: Have you ever been told by your doctor that you've had a heart attack (this is sometimes called a myocardial infarction, or MI)?

Supporting Definition: Item is phrased as a patient reported measure. However, if the patient is unable to answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

Timing: At index event for HF and if "0 = No" or "999 = Unknown" to PRIORMI, tracked ongoing

Reporting Source: Clinician-reported, patient-reported, or administrative

Type: Single answer

Response Options: 0 = No

1 = Yes

999 = Unknown

Variable ID: SMOKE

Variable: Smoking status

Definition: Do you currently smoke, or have you smoked cigarettes or tobacco over the past year?

Supporting Definition: Smoking status (of cigarettes or tobacco). Item is phrased as a patient reported measure. However, if the patient is unable to answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

Timing: At index event for HF and tracked ongoing

Reporting Source:	Clinician-reported, patient-reported, or administrative
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	ALCOHOL
Variable:	Alcohol use
Definition:	Do you drink more than one alcoholic drink a day?
Supporting Definition:	One standard alcoholic drink is: 12 ounces of regular beer (about 5% alcohol) 5 ounces of wine (about 12% alcohol) 1.5 ounces of distilled spirits (about 40% alcohol) Item is phrased as a patient reported measure. However, if the patient is unable to answer, this information can be abstracted from the medical records.
Inclusion Criteria:	All patients
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported, patient-reported, or administrative
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	HYPERTEN
Variable:	Past medical history: Hypertension
Definition:	Indicate whether the patient has a documented history of hypertension, diagnosed and treated with medication and/or diet and/or exercise
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	At index event for HF and if "0 = No" or "999 = Unknown" to HYPERTEN, tracked ongoing
Reporting Source:	Clinician-reported, patient-reported, or administrative
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	HEIGHT
Variable:	Height
Definition:	Please indicate the height of the patient
Supporting Definition:	Height and weight are used to calculate BMI
Inclusion Criteria:	All patients
Timing:	At index event for HF
Reporting Source:	Clinician-reported or administrative
Type:	Numeric value
Response Options:	Numeric value of height in metric or imperial system
Variable ID:	HEIGHTUNIT
Variable:	Height units
Definition:	Units
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	At index event for HF
Reporting Source:	Clinician-reported or administrative
Type:	Single answer
Response Options:	1 = cm 2 = in
Variable ID:	WEIGHT
Variable:	Weight
Definition:	Please indicate the weight of the patient

Supporting Definition:	Height and weight are used to calculate BMI
Inclusion Criteria:	All patients
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported or administrative
Type:	Numeric value
Response Options:	Numeric value of weight in metric or imperial system
Variable ID:	WEIGHTUNIT
Variable:	Weight units
Definition:	Units
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported or administrative
Type:	Single answer
Response Options:	1 = kg 2 = lbs
Variable ID:	DIAB
Variable:	Diabetes mellitus
Definition:	Have you ever been told by your doctor that you have diabetes?
Supporting Definition:	Item is phrased as a patient reported measure. However, if the patient is unable to answer, this information can be abstracted from the medical records.
Inclusion Criteria:	All patients
Timing:	At index event for HF and if "0 = No" or "999 = Unknown" to DIAB, tracked ongoing
Reporting Source:	Clinician-reported, patient-reported, or administrative
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	CHRONLD
Variable:	Past medical history: Chronic lung disease
Definition:	Indicate whether the patient has a chronic lung disease
Supporting Definition:	Including but not limited to COPD and asthma
Inclusion Criteria:	All patients
Timing:	At index event for HF and if "0 = No" or "999 = Unknown" to CHFRONLD, tracked ongoing
Reporting Source:	Clinician-reported, patient-reported, or administrative
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	RENDYS
Variable:	Renal dysfunction
Definition:	Indicate whether the patient has a diagnosis of renal dysfunction
Supporting Definition:	Renal dysfunction is the documented history of AKI or Increase in serum creatinine by ≥ 0.3 mg/dl (≥ 26.5 l mol/l) within 48 hours; or increase in serum creatinine to ≥ 1.5 times baseline, which is known or presumed to have occurred within the prior 7 days; or urine volume < 0.5 ml/kg/h for 6 hours; or new requirement for dialysis
Inclusion Criteria:	All patients
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported, patient-reported, or administrative
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	ECHOPERF
Variable:	Echocardiogram performed

Definition:	Indicate whether an echocardiogram was performed to assess ejection fraction
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	At index event for HF
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown

Variable ID:	EJECFRAC
Variable:	Ejection Fraction
Definition:	If "1 = yes" to ECHOPERF, please state range of patient's ejection fraction:
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to ECHOPERF
Timing:	At index event for HF
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = <30% 2 = 30-39% 3 = 40-50% 4 = >50%

Variable ID:	DIAGCAT
Variable:	Diagnostic categories
Definition:	Please indicate diagnostic categories:
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	At index event for HF
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	1 = Ischaemic 2 = Hypertensive 3 = Valvular 4 = Familial 5 = Peripartum 6 = Myocarditis/Inflammatory 7 = Infiltrative 8 = Stress/Takotsubo 9 = Chagas Disease 10 = Idiopathic/Other 999 = Unknown

Treatment Variables

Treatment Variables

Variable ID:	PHARMACOTHERAPY
Variable:	Medications initiated
Definition:	Indicate whether the patient is currently being prescribed medication for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown

Variable ID:	PHARMATYPE1
Variable:	Angiotensin Converting Enzyme (ACE) Inhibitors

Definition:	Indicate whether ACE inhibitors are currently prescribed for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to PHARMACOTHERAPY
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown

Variable ID:	PHARMATYPE2
Variable:	Angiotensin Receptor II Blocker
Definition:	Indicate whether Angiotensin Receptor II Blockers are currently prescribed for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to PHARMACOTHERAPY
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown

Variable ID:	PHARMATYPE3
Variable:	Angiotensin Receptor Blocker/Nepriylsin Inhibitor combination
Definition:	Indicate whether an Angiotensin Receptor Blocker/Nepriylsin Inhibitor combination is currently prescribed for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to PHARMACOTHERAPY
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown

Variable ID:	PHARMATYPE4
Variable:	Beta Blocker
Definition:	Indicate whether Beta Blockers are currently prescribed for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to PHARMACOTHERAPY
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown

Variable ID:	PHARMATYPE5
Variable:	Calcium Channel Blocker
Definition:	Indicate whether Calcium Channel Blockers are currently prescribed for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to PHARMACOTHERAPY
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown

Variable ID:	PHARMATYPE6
Variable:	Digoxin
Definition:	Indicate whether Digoxin is currently prescribed for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to PHARMACOTHERAPY
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PHARMATYPE7
Variable:	Diuretics
Definition:	Indicate whether Diuretics are currently prescribed for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to PHARMACOTHERAPY
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PHARMATYPE8
Variable:	Hydralazine and Isosorbide Dinitrate
Definition:	Indicate whether Hydralazine and Isosorbide Dinitrate are currently prescribed for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to PHARMACOTHERAPY
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PHARMATYPE9
Variable:	Ivabradine
Definition:	Indicate whether Ivabradine is currently prescribed for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to PHARMACOTHERAPY
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PHARMATYPE10
Variable:	Mineralocorticoid Receptor Antagonists
Definition:	Indicate whether Mineralocorticoid Receptor Antagonists are currently prescribed for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to PHARMACOTHERAPY
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes

	999 = Unknown
Variable ID:	PHARMATYPE11
Variable:	Other
Definition:	Indicate whether other medications are currently prescribed for heart failure
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to PHARMACOTHERAPY
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	DEVPROCEDURE
Variable:	Cardiac device fitted
Definition:	Did the patient receive a cardiac device to treat heart failure?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	DEVPROCEDURETYPE
Variable:	Device procedure type
Definition:	Indicate the device type
Supporting Definition:	ICD = Implantable Cardioverter Defibrillator CRT = Cardiac Resynchronisation Therapy
Inclusion Criteria:	If "1 = Yes" to DEVPROCEDURE
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = ICD 2 = CRT 3 = ICD + CRT 4 = Other 999 = Unknown
Variable ID:	DEVPROCEDUREDATE
Variable:	Date of device procedure
Definition:	Indicate the date of DEVPROCEDURE
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to DEVPROCEDURE
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY
Variable ID:	CARDSURG
Variable:	Cardiac surgery undergone
Definition:	Did the patient undergo cardiac surgery?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes

	999 = Unknown
Variable ID:	CARDSURGTYPE
Variable:	Cardiac surgery type
Definition:	Indicate the cardiac surgery type
Supporting Definition:	CABG = Cardiac surgery for heart failure
Inclusion Criteria:	if "1 = Yes" to CARDSURG
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = CABG only 2 = Valve 3 = CABG + valve 4 = Other 999 = Unknown
Variable ID:	CARDSURGDATE
Variable:	Date of cardiac surgery
Definition:	Indicate the date of CARDSURG
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to CARDSURG
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY
Variable ID:	REHAB
Variable:	Cardiac rehabilitation
Definition:	Has cardiac rehabilitation been initiated?
Supporting Definition:	Cardiac rehabilitation is a medically-supervised programme that involves adopting heart-healthy lifestyle changes to address risk factors for cardiovascular disease. This programme includes exercise training, education on heart-healthy living, and counseling to reduce stress and helps patients return to an active life.
Inclusion Criteria:	All patients
Timing:	At index event for HF and tracked ongoing
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown

Outcomes

Degree of Health

Variable ID:	KCCQ12_Q01a
Variable:	Question 1a of KCCQ-12
Definition:	Heart failure affects different people in different ways. Some feel shortness of breath while others feel fatigue. Please indicate how much you are limited by heart failure (shortness of breath or fatigue) in your ability to do the following activities over the past 2 weeks... a. Showering/bathing
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Tracked ongoing
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Extremely limited 2 = Quite a bit limited 3 = Moderately limited 4 = Slightly limited 5 = Not at all limited

6 = Limited for other reasons or did not do the activity

Variable ID: KCCQ12_Q01b

Variable: Question 1b of KCCQ-12

Definition: Heart failure affects different people in different ways. Some feel shortness of breath while others feel fatigue. Please indicate how much you are limited by heart failure (shortness of breath or fatigue) in your ability to do the following activities over the past 2 weeks...

b. Walking 1 block on level ground

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Tracked ongoing

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = Extremely limited

2 = Quite a bit limited

3 = Moderately limited

4 = Slightly limited

5 = Not at all limited

6 = Limited for other reasons or did not do the activity

Variable ID: KCCQ12_Q01c

Variable: Question 1c of KCCQ-12

Definition: Heart failure affects different people in different ways. Some feel shortness of breath while others feel fatigue. Please indicate how much you are limited by heart failure (shortness of breath or fatigue) in your ability to do the following activities over the past 2 weeks...

c. Hurrying or jogging (as if to catch a bus)

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Tracked ongoing

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = Extremely limited

2 = Quite a bit limited

3 = Moderately limited

4 = Slightly limited

5 = Not at all limited

6 = Limited for other reasons or did not do the activity

Variable ID: KCCQ12_Q02

Variable: Question 2 of KCCQ-12

Definition: Over the past 2 weeks, how many times did you have swelling in your feet, ankles or legs when you woke up in the morning?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Tracked ongoing

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = Every morning

2 = 3 or more times per week but not every day

3 = 1-2 times per week

4 = Less than once a week

5 = Never over the past 2 weeks

Variable ID: KCCQ12_Q03

Variable: Question 3 of KCCQ-12

Definition: Over the past 2 weeks, on average, how many times has fatigue limited your ability to do what you want?

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Tracked ongoing
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = All of the time
2 = Several times per day
3 = At least once a day
4 = 3 or more times per week but not every day
5 = 1-2 times per week
6 = Less than once a week
7 = Never over the past 2 weeks

Variable ID: KCCQ12_Qo4
Variable: Question 4 of KCCQ-12
Definition: Over the past 2 weeks, on average, how many times has shortness of breath limited your ability to do what you wanted?

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Tracked ongoing
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = All of the time
2 = Several times per day
3 = At least once a day
4 = 3 or more times per week but not every day
5 = 1-2 times per week
6 = Less than once a week
7 = Never over the past 2 weeks

Variable ID: KCCQ12_Qo5
Variable: Question 5 of KCCQ-12
Definition: Over the past 2 weeks, on average, how many times have you been forced to sleep sitting up in a chair or with at least 3 pillows to prop you up because of shortness of breath?

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Tracked ongoing
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = Every night
2 = 3 or more times per week but not every day
3 = 1-2 times per week
4 = Less than once a week
5 = Never over the past 2 weeks

Variable ID: KCCQ12_Qo6
Variable: Question 6 of KCCQ-12
Definition: Over the past 2 weeks, how much has your heart failure limited your enjoyment of life?

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Tracked ongoing
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = It has extremely limited my enjoyment of life
2 = It has limited my enjoyment of life quite a bit
3 = It has moderately limited my enjoyment of life
4 = It has slightly limited my enjoyment of life
5 = It has not limited my enjoyment of life at all

Variable ID:	KCCQ12_Q07
Variable:	Question 7 of KCCQ-12
Definition:	If you had to spend the rest of your life with your heart failure the way it is right now, how would you feel about this?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Tracked ongoing
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all satisfied 2 = Mostly dissatisfied 3 = Somewhat satisfied 4 = Mostly satisfied 5 = Completely satisfied
Variable ID:	KCCQ12_Q08a
Variable:	Question 8a of KCCQ-12
Definition:	How much does your heart failure affect your lifestyle? Please indicate how your heart failure may have limited your participation in the following activities over the past 2 weeks. a. Hobbies, recreational activities
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Tracked ongoing
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Severely limited 2 = Limited quite a bit 3 = Moderately limited 4 = Slightly limited 5 = Did not limit at all 6 = Does not apply or did not do for other reasons
Variable ID:	KCCQ12_Q08b
Variable:	Question 8b of KCCQ-12
Definition:	How much does your heart failure affect your lifestyle? Please indicate how your heart failure may have limited your participation in the following activities over the past 2 weeks. b. Working or doing household chores
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Tracked ongoing
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Severely limited 2 = Limited quite a bit 3 = Moderately limited 4 = Slightly limited 5 = Did not limit at all 6 = Does not apply or did not do for other reasons
Variable ID:	KCCQ12_Q08c
Variable:	Question 8c of KCCQ-12
Definition:	How much does your heart failure affect your lifestyle? Please indicate how your heart failure may have limited your participation in the following activities over the past 2 weeks. c. Visiting family or friends out of your home
Supporting Definition:	N/A
Inclusion Criteria:	All patients

Timing: Tracked ongoing
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = Severely limited
 2 = Limited quite a bit
 3 = Moderately limited
 4 = Slightly limited
 5 = Did not limit at all
 6 = Does not apply or did not do for other reasons

Variable ID: NYHA_Qo1
Variable: Question 1 of NYHA
Definition: Patient symptoms
Supporting Definition: NYHA - New York Heart Association classification of heart failure (Functional Capacity)
Inclusion Criteria: All patients
Timing: Tracked ongoing
Reporting Source: Clinician-reported
Type: Single answer
Response Options: 0 = Class I: No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea (shortness of breath).
 1 = Class II: Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea (shortness of breath).
 2 = Class III: Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea.
 3 = Class IV: Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

Variable ID: NYHA_Qo2
Variable: Question 2 of NYHA
Definition: Objective assessment of patient
Supporting Definition: NYHA - New York Heart Association classification of heart failure (Objective assessment by clinician)
Inclusion Criteria: All patients
Timing: Tracked ongoing
Reporting Source: Clinician-reported
Type: Single answer
Response Options: 0 = Class A: No objective evidence of cardiovascular disease. No symptoms and no limitation in ordinary physical activity.
 1 = Class B: Objective evidence of minimal cardiovascular disease. Mild symptoms and slight limitation during ordinary activity. Comfortable at rest.
 2 = Class C: Objective evidence of moderately severe cardiovascular disease. Marked limitation in activity due to symptoms, even during less-than-ordinary activity. Comfortable only at rest.
 3 = Class D: Objective evidence of severe cardiovascular disease. Severe limitation. Experiences symptoms even while at rest.

Variable ID: PROMIS_QPFA11
Variable: Question PFA11 of PROMIS Physical Function - Short Form 4a
Definition: Are you able to do chores such as vacuuming or yard work?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: Tracked ongoing except at acute admissions
Reporting Source: Patient-reported
Type: Single answer
Response Options: 5 = Without any difficulty
 4 = With a little difficulty
 3 = With some difficulty

2 = With much difficulty
1 = Unable to do

Variable ID: PROMIS_QPFA21
Variable: Question PFA21 of PROMIS Physical Function - Short Form 4a
Definition: Are you able to go up and down stairs at a normal pace?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: Tracked ongoing except at acute admissions
Reporting Source: Patient-reported
Type: Single answer
Response Options: 5 = Without any difficulty
4 = With a little difficulty
3 = With some difficulty
2 = With much difficulty
1 = Unable to do

Variable ID: PROMIS_QPFA23
Variable: Question PFA23 of PROMIS Physical Function - Short Form 4a
Definition: Are you able to go for a walk of at least 15 minutes?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: Tracked ongoing except at acute admissions
Reporting Source: Patient-reported
Type: Single answer
Response Options: 5 = Without any difficulty
4 = With a little difficulty
3 = With some difficulty
2 = With much difficulty
1 = Unable to do

Variable ID: PROMIS_QPFA53
Variable: Question PFA53 of PROMIS Physical Function - Short Form 4a
Definition: Are you able to run errands and shop?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: Tracked ongoing except at acute admissions
Reporting Source: Patient-reported
Type: Single answer
Response Options: 5 = Without any difficulty
4 = With a little difficulty
3 = With some difficulty
2 = With much difficulty
1 = Unable to do

Variable ID: PHQ2_Q01
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: N/A
Inclusion Criteria: All patients
Timing: Tracked ongoing except at acute admissions
Reporting Source: Patient-reported
Type: Single answer
Response Options: 0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Variable ID: PHQ2_Q02
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: N/A

Inclusion Criteria: All patients

Timing: Tracked ongoing except at acute admissions

Reporting Source: Patient-reported

Type: Single answer

Response Options: 0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Burden of care

Variable ID: ARIDATE

Variable: Date of arrival

Definition: Indicate the date the patient was admitted

Supporting Definition: Date used to calculate total length of stay and post-procedure length of stay

Inclusion Criteria: All patients

Timing: Tracked ongoing

Reporting Source: Administrative data

Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY at arrival

Variable ID: DISDATE

Variable: Date of discharge

Definition: Indicate the date the patient was discharged

Supporting Definition: Date used to calculate total length of stay

Inclusion Criteria: All patients

Timing: Tracked ongoing

Reporting Source: Administrative data

Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY at discharge

Variable ID: COMPLDEVICE

Variable: Complication due to device

Definition: Did the patient's appointment or admission have any complications which were related to a device for Heart Failure including, but not exclusively: active bleeding requiring exploration and/or transfusion, abscess related to the device, minor infection (localized, treated with antibiotics and surgical drainage) related to the device, major infection (systemic, requiring device explant) related to the device, minor malfunction (requiring follow-up appointment/reprogramming), and/or major malfunction (requiring explant or revision)?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: At index event for HF and tracked ongoing

Reporting Source: Clinician-reported

Type: Single answer

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

Variable ID: COMPLDEVICEDATE

Variable: Date of complication due to device

Definition: Indicate the date of COMPLDEVICE

Supporting Definition: N/A

Inclusion Criteria: if "1 = Yes" to COMPLDEVICE

Timing: At index event for HF and tracked ongoing

Reporting Source: Clinician-reported

Type: Date by DD/MM/YYYY

Response Options:	DD/MM/YYYY or 999 = Unknown
Variable ID:	COMPLHOSP
Variable:	Healthcare-associated infection
Definition:	Did the patient have a major healthcare-associated infection (requiring IV antibiotics and/or prolonged hospital stay – 14 days or more) during this admission?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Tracked at index event & acute admissions due to heart failure
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	COMPLHOSPDATE
Variable:	Date of diagnosis of healthcare-associated infection
Definition:	Indicate the date of COMPLHOSP
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to COMPLHOSP
Timing:	Tracked at index event & acute admissions due to heart failure
Reporting Source:	Clinician-reported
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY or 999 = Unknown
Variable ID:	COMPLMED
Variable:	Complication due to medication
Definition:	Did the patient have a major adverse event related to Heart Failure medication during this admission, and/or as a cause of this admission?
Supporting Definition:	A major adverse event is a response to a drug which is noxious and unintended, and which occurs at doses normally used in a person for the prophylaxis, diagnosis, or therapy of disease, or for the modifications of physiological function.
Inclusion Criteria:	All patients
Timing:	Tracked at index event & acute admissions due to heart failure
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	COMPLMEDDATE
Variable:	Date of diagnosis of complication due to medication
Definition:	Indicate the date of COMPLMED
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to COMPLMED
Timing:	Tracked at index event & acute admissions due to heart failure
Reporting Source:	Clinician-reported
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY or 999 = Unknown
Variable ID:	FINBURDEN
Variable:	Financial resources
Definition:	How hard is it for you to pay for the very basics like food, housing, medical care, and heating? Choose the statement which is most relevant
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Tracked ongoing except at acute admissions
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Very hard

1 = Somewhat hard
2 = Not hard at all
999 = Unknown

Variable ID:	HOSPADM
Variable:	Hospital admissions
Definition:	How many times has the patient been hospitalised in the last 12 months due to heart failure?
Supporting Definition:	This variable is collected every 12 months from date of entry into the set.
Inclusion Criteria:	All patients
Timing:	Baseline and 12-monthly
Reporting Source:	Administrative or patient/caregiver reported
Type:	Numerical
Response Options:	Numerical value or 999 = Unknown

Variable ID:	HOSPAPPT
Variable:	Hospital appointments
Definition:	How many hospital appointments has the patient had in the last 12 months due to heart failure?
Supporting Definition:	This variable is collected every 12 months from date of entry into the set.
Inclusion Criteria:	All patients
Timing:	Baseline and 12-monthly
Reporting Source:	Administrative or patient/caregiver reported
Type:	Numerical
Response Options:	Numerical value or 999 = Unknown

Mortality

Variable ID:	DEATH
Variable:	Patient died, regardless of cause
Definition:	Indicate if the patient has died
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Tracked ongoing
Reporting Source:	Administrative data
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown

Variable ID:	DEATHDATE
Variable:	Date of death
Definition:	Indicate the date the patient was declared dead
Supporting Definition:	Patients who die before during a hospital admission before baseline data have been collected should also be included
Inclusion Criteria:	If "1 = Yes" to DEATH
Timing:	Tracked ongoing
Reporting Source:	Administrative data
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY or 999 = Unknown

Variable ID:	DEATHPLACE
Variable:	Location of death
Definition:	Indicate where patient died
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to DEATH
Timing:	Tracked ongoing
Reporting Source:	Administrative data
Type:	Single answer
Response Options:	1 = Hospital: acute or community hospitals/units but not psychiatric hospitals 2 = Own residence: the death occurred in the place of usual residence where this is

not a communal establishment

3 = Care home: private home or residential home or specialist nursing homes

4 = Hospices: many hospices are 'freestanding' but some are found within hospitals. Also, hospices increasingly work in the community

888 = Other

999 = Unknown

ICHOM Contact Information

Website

<http://www.ichom.org>

Business Address

14 Arrow Street, Suite #11
Cambridge, MA 02138

Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
1.0.1	Treatment Variables Table	Added REHAB variable
1.0.2	Data Dictionary	Removed PALLIATIVE variable, added HOSPADM & HOSPAPPT variables
1.0.3	Contact Information	Removed inactive email address: ichomteam@ichom.org
1.0.4	Data Dictionary	Updated response options for EJECDRAC variable
1.1.0	Outcomes Table	Changed PROMIS and KCCQ-12 to patient-reported
1.1.0	Collecting Patient-Reported Outcome Measures	Changed PROMIS tool to PROMIS Physical Function
1.1.0	Data Dictionary	Changed response options for EJECDRAC variable; changed scoring for KCCQ-12 items; changed definitions and response options for PROMIS variables; changed FINBURDEN from "clinician-reported" to "patient-reported"
1.1.1	Data Dictionary	Changed response options for CHRONLD, RENDYS, DEVPROCEDURETYPE and CABGPROCEDURETYPE variables; updated unknown codes for COMPLDEVICE, COMPLHOSP, DEATH, and DEATHDATE variables; changed data source classification for AFIB, PRIORMI, SMOKE, ALCOHOL, HYPERTEN, HEIGHT, HEIGHTUNIT, WEIGHT, WEIGHTUNIT, DIAB, CHRONLD, and RENDYS
1.1.1	Table	Corrected spelling for HOSPADM and HOSPATT; revised data source for FINBURDEN
1.1.2	Cover Image	Cover image file updated
1.1.3	Data Dictionary	Added "999 = unknown" option to Baseline Health Status variables. Added ECHOPERF variable to Baseline Health Status. Changed scoring options for DIAGCAT.

1.1.3	Data Dictionary	<p>Changed SMOKE definition. Changed timing of all Baseline Health Status variables. Changed definition of REHAB. Added DEVPROCEDURE, CABGPROCEDURE and PHARMATYPE 1-11 to Treatment Variables. PROMIS Health-Related Quality of Life questions changed, now using PROMIS Short Form 4a. Changed wording of KCCQ-12Q03 . Changed definition and supporting definition of HOSPADM. Added COMPLHOSPDATE, changed item of COMPLHOSP and deleted COMPLANTI and COMPLHOSP.</p>
1.1.4	Data Dictionary	<p>Changed definition and supporting definition for HOSPADM, CABGPROCEDURE and CABGPROCEDURETYPE. Changed response options for CABGPROCEDURETYPE. Changed REHAB supporting definition. Corrected spelling mistake for NYHA_Q01. Changed timing for COMPLHOSP, COMPLHOSPDATE, COMPLMED, COMPLMEDDATE.</p>
1.1.4	Outcomes Table	<p>Changed timing of outcome variables</p>
1.1.4	Collecting Patient-Reported Outcome Measures	<p>Changed link for the PROMIS questionnaire licensing information</p>

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