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ORIGINAL ARTICLE

The Icelandic Heart Failure Registry—A nationwide assessment tool for HF care and intervention in HF treatment

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Abstract

Introduction The incidence of heart failure (HF) is increasing, largely because populations are both ageing and growing. Most clinical HF treatment trials are conducted on selected cohorts, only a few of which include elderly patients, among whom HF is common. HF registries can include all HF patients, independent of age or comorbidity profile, and thus reflect reality in healthcare management.

Methods The Icelandic Heart Failure Registry (IHFR) was created in the autumn of 2019 and has operated since 1 January 2020. Based on the Swedish Heart Failure Registry (SwedeHF), it quickly acquired several extensions. All patients admitted for HF to the Department of Cardiology (DC) at Landspítali – The National University Hospital of Iceland are included. Several variables are collected, including the aetiology of HF, comorbidities, clinical assessment at admission, blood tests, imaging results, treatment given and medical therapy at discharge.

Results During the 3 years from 2020 to 2022, the DC admitted 1890 patients. As some were readmitted during the study period, the true total was 2384 admissions. Because the IHFR 2023 edition includes 327 variables, automation of many of them is imperative for data collection.

Conclusion HF is a heterogenous disease with numerous underlying factors. HF management differs among HF phenotypes. A registry can serve as an unbiased indicator of care quality and has the potential to be studied in the future to assess the long-term effects of HF treatment. A registry like the IHFR, therefore, can impact the treatment of all patients recorded in it, reduce the rate of readmissions and even optimize HF management costs.

Keywords heart failure outcomes; heart failure phenotypes; quality of care; registry

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Introduction

In developed countries, the prevalence of heart failure (HF) is generally reported as 1%–2% in adults, but it is likely even higher because of underreporting in older persons.[1–4] The prevalence among individuals who are ≥70 years old is approximately 10%, but HF is much less common (1%) in patients younger than 55.[5–7] Age-adjusted HF incidence has been falling in developed countries, probably reflecting the more efficient care of patients with cardiovascular disease (CVD), which protects them from severe myocardial damage and its subsequent reduced ejection fraction (EF). Nevertheless, the number of new patients with HF continues to increase because of population ageing and growth.[8–10] Acute HF (AHF) is the leading cause of hospitalization among individuals over 65 years of age; these patients have high readmission rates and high mortality rates.[11]

More than half of HF patients have HF with preserved ejection fraction (HFpEF), and over half of all HF hospital admissions have been shown to involve HFpEF patients.[5,12] This proportion has been rising due to increased obesity-related disorders, for example, hypertension and diabetes, in the

general population.[13,14] HFpEF is projected to become the most dominant HF phenotype, affecting 1 in 10 adults during their lifetime.[15]

Clinical HF treatment trials are conducted on selected cohorts, only a few of which include elderly patients (as they are often excluded due to increased comorbidities), among whom HF is more common than in younger patients. Clinical registries can offer inclusion of every patient reported with HF, independent of the patient's age or comorbidity profile. A registry can work as an indicator of the quality of care and impact the treatment of all included patients. This can reduce both the morbidity and mortality of patients, reduce the rate of readmissions and optimize the costs of HF management.[16]

The Icelandic Heart Failure Registry (IHFR) was founded in 2019 by Dr. Ingimarsdóttir, an Icelandic HF specialist and alumna of the Postgraduate Course in Heart Failure (PCHF) at the University of Zürich, to map the epidemiology of HF in Iceland. It has been operational since 1 January 2020. All highly symptomatic HF cases [New York Heart Association (NYHA) classes III–IV] in Iceland (population 387 758 on 1 January 2023)[17] are referred to the Department of Cardiology (DC) at Landspítali University Hospital in the capital, Reykjavík. The coverage of AHF cases is thus very high but does not extend to chronic HF cases in primary care or admitted to internal medicine and geriatric departments.

Few studies on HF have been carried out in Iceland. In 2017, Einarsson *et al*. used the Age Gene/Environment Susceptibility (AGES) material from the Icelandic Heart Association (IHA) and found that the incidence of HF among the elderly (66–98 years old) was 16.5 per 1000 individuals.[18] Before the implementation of the IHFR, no routine recording of HF had been carried out in Iceland. Only International Classification of Diseases Version 10 (ICD-10) codes from medical institutions involving HF diagnosis have been available to assess the scope of the HF burden, but no such study has been carried out to date. In the Heart Failure Association Atlas, no data on the incidence and prevalence of HF in Iceland are available, only the average length of stay, which is 11.1 days and is among the longest in Europe.[19]

The original framework of the IHFR was based on the structure of the Swedish Heart Failure Registry (SwedeHF, or RiksSvikt in Swedish).[20] The main reason for choosing this model for the IHFR was that SwedeHF has been shown to be a valuable tool to improve the management of HF patients, and both countries have similar healthcare systems with equal access for all inhabitants. However, several extensions were added from the very beginning, as both imaging and genetic mapping have offered great possibilities for diagnosing the underlying causes of HF in more detail. In Iceland, as in other Nordic countries, each inhabitant has a unique personal identification number. This facilitates follow-up and makes the registry more reliable. The primary aim of the IHFR was to map the epidemiology of HF in Iceland, with the secondary aim of creating an assessment tool for the quality of care of hospitalized HF patients. The IHFR underlines the goal of creating conditions for research on HF in Iceland, and the aim is to fill a big gap in evidence concerning AHF assessment, care and prognosis in Iceland. The proactive registration of admitted HF patients makes it possible to enhance HF management by interacting with the treating medical teams while patients are still admitted and during their subsequent outpatient visits. Thus, the quality of care assessment primarily focuses on the only national university hospital but may in the future also include smaller healthcare facilities that may join the IHFR, for example, general practice and smaller district hospitals. A possible aim for the future is to participate in international randomized clinical trials that use the registry to provide pragmatic answers to relevant clinical questions.

Methods

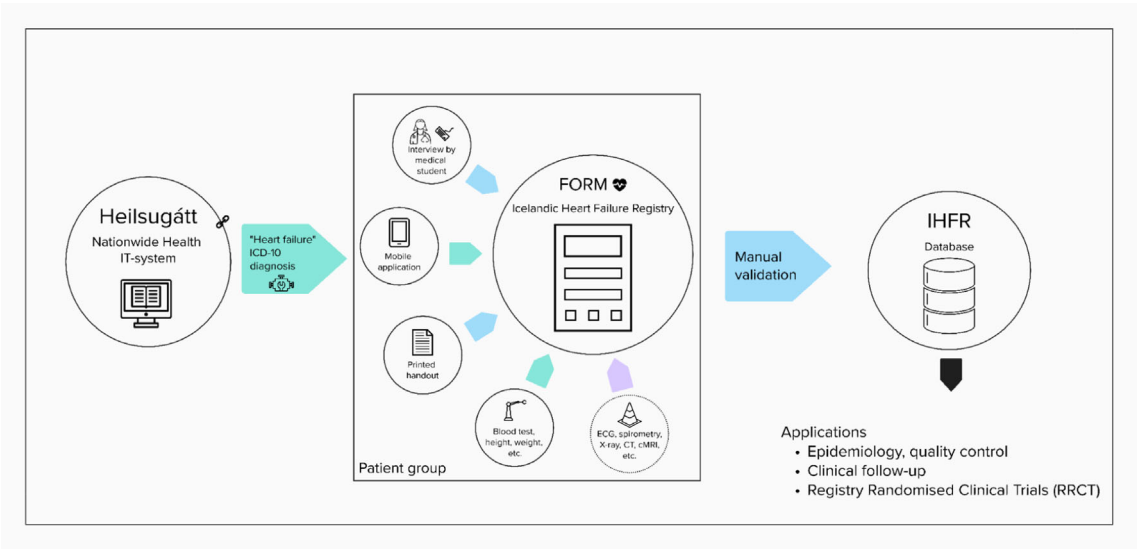
The IHFR was implemented in the Nationwide Heilsugátt Health IT System, which covers the electronic health records (EHRs) for all patients in Iceland and operates according to the ISO/IEC 27001:2013 standard. The inclusion criteria are that patients should be at least 18 years old, clinically assessed as having HF and admitted to the DC at Landspítali University Hospital. Patients are recorded in the registry by means of a rule engine, which adds any patient whose admission record includes the term 'heart failure' or has any of the following ICD-10 diagnoses, which cover HF: I50.0, I50.1, I50.9, I11.0, I13.0, I13.2, I42.0, I42.6, I42.7 and I42.9 (Figure 1).[21]

All patients admitted to the DC are reviewed daily, and if the rule engine has not identified a particular HF patient, that patient is manually added to the IHFR. The criteria for aiding the identification process of these HF patients are mainly an elevation in the N-terminal pro-brain natriuretic peptide (NT-proBNP) above the individual patient's baseline and if the admitting physician writes 'heart failure' on the summary of the daily list of admissions to the DC. If this is present, an assessment that the patient is truly suffering from HF is made by an HF specialist. Patients identified by the rule engine are scrutinized during their registration; if they were admitted due to causes other than HF, no registration is made, and they are excluded. A new form in the IHFR is completed for every admission, so a single patient can have several forms in the registry. Therefore, it is possible to see all HF readmissions of all individual patients over time.

Variables

The only demographic variables registered are the patient identification number, date of birth and gender. For those

Figure 1 Overview of the data collection process for the Icelandic Heart Failure Registry (IHFR). cMRI, cardiac magnetic resonance imaging; CT, computed tomography; ECG, electrocardiogram; ICD-10, International Classification of Diseases Version 10.



patients who answer the quality of life (QoL) questionnaires, there is information on education level, marital status and smoking status as well.

QoL assessment

To assess HF patients' QoL, the IHFR adopted two questionnaires from SwedeHF: the EuroQol-5 Dimension (EQ 5D) and the Kansas City Cardiomyopathy Questionnaire-12 (KCCQ-12).[22,23] The General Anxiety Disorder 7 Questionnaire (GAD-7) and the Patient Health Questionnaire-9 (PHQ-9) were added to screen for anxiety and depression, respectively.[24,25] All of these are tick-box handouts—two medical students interview visually impaired patients. Since May 2023, an inpatient mobile device application has been available that sends the QoL questionnaires directly to the mobile device of each patient. Upon completion, the answers are transferred into the patient's medical chart, covering the current (or recent) admission (Figure 1). Many patients do not have smartphones, which makes this process difficult.

The aetiology of HF and the possible precipitating trigger

The IHFR's detailed recording of underlying causes (aetiology), with 51 unique causes documented, provides a comprehensive overview of the diversity across phenotypes (see Appendix S1). An HF specialist goes through all recorded patients and determines the aetiology of HF for each individual patient. In some instances, it can be difficult to ascertain the main underlying cause because there is more than one significant contributing factor. Therefore, the ability to record a second underlying cause or possible precipitating trigger has been added. An HF patient with reduced ejection fraction (HFrEF) caused by ischaemic heart disease (IHD) with regional abnormality may become decompensated due to ventricular tachycardia, making IHD the aetiology and 'arrhythmia – ventricular tachycardia' the second underlying cause or precipitating factor. To take another example, a patient with cardiac amyloidosis (CA) might present with atrioventricular conduction delay and extreme bradycardia, making CA the aetiology and 'arrhythmia – bradycardia' the trigger.

Previous medical history

The registry records comorbidities, for example, IHD and whether the patient has undergone certain cardiac procedures (Table 1). The baseline kidney function is assessed by taking a 3 month average of the estimated glomerular filtration rate (eGFR) of the last available eGFR measurements, assuming that they are not older than 1 year. This definition was recommended by nephrologists at Landspítali – The National University Hospital of Iceland. If prior measurements are not available or exceed 1 year, the baseline eGFR is recorded as 'unknown'.

Clinical assessment

To assess the clinical extent of HF at admission, that is, the effect on general physical capacity, the IHFR, like the SwedeHF,

Table 1 Type of previous cardiac intervention and comorbidity variables reported in the registry.

Previous cardiac intervention
Percutaneous coronary intervention (PCI)
Coronary artery bypass graft (CABG)
Open-heart valve surgery
Transcatheter aortic valve implantation (TAVI)
MitraClip implantation
Transcatheter tricuspid repair
Interatrial shunt device placement
Hypertension
Sleep apnoea
Atrial fibrillation
Stroke
Haemorrhagic
Thrombotic
Transient ischaemic attack (TIA)
Minor stroke
Major stroke
Diabetes
Type 1
Type 2
Unknown
Chronic obstructive pulmonary disease (COPD)
Heart valve disease
Peripheral artery disease
Cancer
Type
Stage
Baseline kidney function

uses the NYHA functional class and Killip classification.[26,27] The Killip classification was originally used for patients who had suffered an acute myocardial infarction; it takes physical examination into account as well as the development of HF, but it is not suitable for all HF patients. To provide extra information, other clinical signs of HF were added to the registry, including raised jugular venous pressure, ascites, sacral oedema, liver enlargement (hepatomegaly) and leg oedema grades 1–4.[28]

Laboratory results

On the admission day and 24 h later, certain blood tests are measured (Table 2). The registry automatically calculates iron saturation. The highest troponin T value during admission is recorded. Forty-eight hours after admission, a rule engine checks which blood tests have been measured, flagging any of the tests in Table 2 that have not been ordered. New requests for these tests are sent to the central laboratory responsible for performing the measurements.

Investigation results at admission

The electrocardiogram (ECG) results are recorded in three sections: atrial rhythm, ventricular rhythm and QRS duration, which is recorded in milliseconds (see Appendix S1).

Table 2 Laboratory results measured in the registry.

Haemoglobin	Admission and 24 h later
Sodium	Admission and 24 h later
Potassium	Admission and 24 h later
Creatinine	Admission and 24 h later
eGFR	Admission and 24 h later
NT-proBNP (if available)	Admission and discharge
Iron	During hospitalization
Iron-binding capacity	During hospitalization
Ferritin	During hospitalization
HbA1c	During hospitalization
Troponin T	During hospitalization

Abbreviations: eGFR, estimated glomerular filtration rate; HbA1c, glycated haemoglobin; NT-proBNP, N-terminal pro-brain natriuretic peptide.

The left ventricular ejection fraction (LVEF) is recorded, and its determination method—transthoracic echocardiography (TTE), trans-oesophageal echocardiography (TOE), myocardial scintigraphy or cardiac magnetic resonance imaging (cMRI)—is specified. All patients undergoing a TTE have multiple echo variables recorded (see Appendix S1). The LVEF is divided into preserved EF (≥50%, HFpEF), mildly reduced EF (41%–49%, HFmrEF), reduced EF (≤40%, HFrEF), unknown EF and improved EF (HFimpEF).[29] In the IHFR, HFimpEF is defined as a normalization of EF, that is, EF ≥ 50% after treatment for a patient originally diagnosed with HFrEF. In the European Society of Cardiology (ESC) HF Guidelines from 2021, it is mentioned that patients with a history of reduced LVEF ≤ 40% (HFrEF) who later present with LVEF > 50% should be considered to have recovered HFrEF or 'HF with improved LVEF' (rather than HFpEF).[29] It was therefore decided to call this group HFimpEF in the IHFR. In the same year, 2021, the Heart Failure Society of America, the Heart Failure Association of the ESC, the Japanese Heart Failure Society and the Writing Committee of the Universal Definition of Heart Failure published a position paper on the universal definition and classification of HF. According to them, 'HFimpEF' is defined as HF with a baseline LVEF ≤ 40%, a ≥10 point increase from baseline LVEF and a second measurement of LVEF > 40%.[30] The IHFR has been operational since 1 January 2020, and it was decided from the very beginning to use a full recovery of EF to describe this group. In light of Bozkurt *et al.*'s study,[30] a more suitable name for this group in the IHFR could be 'recovered' LVEF, or HFrecEF.

A chest X-ray is recorded as not performed, normal, pulmonary venous congestion and/or cardiomegaly. The spirometry results of the ratio of the forced expiratory volume in the first 1 s to the forced vital capacity (FEV1/FVC ratio) and (if available) the value of the diffusing capacity of the lungs for carbon monoxide (DLCO) are recorded. The type of in-hospital device implantation is recorded (see Appendix S1). Icelandic HF patients needing left ventricular assist device (LVAD) implantation or heart transplantation are sent to Gothenburg, Sweden, for those procedures. These registration options are only available in the 2024 version of the registry and are tick-box options (yes/no).

Medications and doses

The admission procedure includes recording whether the patient needed diuretic treatment and/or received an iron infusion. It is also recorded whether the patient received vasoactive treatment (Table 3). On discharge, certain medications are recorded, including the total dosage per 24 h. The record further includes information on whether the patient uses multi-dose dispensing. If the patient is not discharged with a certain type of medication, the reason for inadequate treatment is recorded: adverse reaction, discomfort, chronic kidney disease, hypotension, hyperkalaemia, bradycardia, unable to take tablets (reduced consciousness or swallowing problems), refusal to take the medication, unknown, palliative care or not indicated. Medications of patients at admission are not recorded specifically in the registry, but such information is available in the EHRs of the hospital.

Planned follow-up

The death of any patient during the current admission is recorded. When a living patient is discharged, the record states whether the patient is followed up in the HF outpatient clinic, sees a cardiologist in a private clinic or is managed by their general practitioner (GP). When a patient is readmitted or comes to the HF outpatient clinic, the data from the last admission can be easily retrieved from the registry, and the attending physician can get a quick, comprehensive, up-to-date overview of the patient being treated.

The data collection process

Figure 1 shows the IHFR data collection process. The green arrows show automatic processes. The most important of these are blood test results, height, weight, blood pressure and heart rate. The blue arrows show processes that require manual entry into the data form. An arrow for manual inclusion is not shown in the figure. The purple arrow shows the processes currently under development. These are, first, hotkeys to incorporate the PDF reports of ECG, spirometry and imaging results directly into the registration form, saving manual entry time. Second, the IT department will research the acquisition of electronic data—the medication at discharge (with exact dosage) and cardiac echocardiography variables—from other computer systems for direct importation into the registration form. Currently, it is possible to retrieve epidemiology data from the registry that can be used to answer various research questions. Real-time registration makes it possible to give feedback to the cardiology ward if treatment is inadequate—for example, if the admitted patient is not on guideline-mediated therapy. Lastly, the data can be used to select patients for clinical trials based on inclu-

Table 3 Overview of the drugs that are recorded during admission and upon discharge.

During admission
Furosemide i.v. or p.o.
Iron i.v.—type and dose
Vasoactive treatment
Dobutamine
Dopamine
Isoprenaline
Levosimendan
Milrinone
Epinephrine
Norepinephrine
Nitroglycerin
Upon discharge
Angiotensin-converting enzyme inhibitors (ACEIs)
Angiotensin receptor blockers (ARBs)
Beta-blockers (BBs)
Mineralocorticoid receptor antagonists (MRAs)
Angiotensin receptor neprilysin inhibitors (ARNIs)
Sinus node inhibitors
Loop diuretics
Bumetanide
Furosemide
Torasemide
Non-loop diuretics
Bendroflumethiazide
Hydrochlorothiazide
Metolazone
Indapamide
Digoxin
Amiodarone, including the day of initiation; the most current thyroid-stimulating hormone level is then registered
Medication for cardiac amyloidosis
Tafamidis or other
Cholesterol-lowering drugs
Statins
Ezetimibe
Fibrates
PCSK9 inhibitors
Nitrates—short or long acting
Acetylsalicylic acid
P2Y12 inhibitors
Clopidogrel
Prasugrel
Ticagrelor
Anticoagulation
Warfarin
Dabigatran
Rivaroxaban
Apixaban
Edoxaban
Other
Vericiguat
Omecamtiv mecarbil
Sodium-glucose cotransporter-2 (SGLT2) inhibitors
Dapagliflozin
Canagliflozin
Empagliflozin
Ertugliflozin
Sotagliflozin
Oral/subcutaneous hypoglycaemic agents
Insulin
Metformin
Glucagon-like peptide-1 analogues
Dipeptidyl peptidase-4 inhibitors
Sulfonylurea
Repaglinide
Thiazolidinedione
Alpha-glucosidase inhibitors

Abbreviations: P2Y12, purinergic receptor type Y, subtype 12; PCSK9, proprotein convertase subtilisin/kexin type 9.

sion and exclusion criteria found in the registry. When a patient is readmitted and a new form is established, past answers can automatically be imported into the new form, although each variable must be confirmed with a mouse click before registration in the new form. Within the coming years, it is planned to start a biobank with the blood of all patients (not only HF patients) admitted to the DC at Landspítali University Hospital. This will open up numerous research opportunities, including examining genetic associations with HF. Discussions are ongoing concerning the available blood samples that will be in the future biobank, their quantities, accessibility and terms of use for prospective researchers.

Outcomes

The IHFR can be linked to several national registers in Iceland. The Population Register can be used to calculate the incidence and mortality rates of HF. The National Patient Register can be used to assess the number of HF admissions and look at comorbidities. The Cause of Death Register can give information on vital status, date of death and whether the patient died of CVD or other causes. The Surgeon General in Iceland has a national register for all prescriptions, which is available to all physicians through the Nationwide Heilsugátt Health IT System. This can help monitor the dispensation of prescribed drugs and assess adherence to medication.

Access to the registry

Access to the registry is controlled by the director, and currently, only HF physicians and nurses in the HF outpatient clinic at Landspítali – The National University Hospital of Iceland have access to it. Patients can opt out if they do not want to answer QoL questionnaires, but all clinical variables are recorded as part of quality assurance, and patients do not sign an informed consent form because the data are pseudonymized and cannot be traced back to individuals. Only aggregated data are reported in analyses, and patient privacy and data security are managed by the strict rules that apply to the EHRs in the Heilsugátt Health IT System. Only with the approval of the Scientific Research Committee for Health Research of Landspítali – The National University Hospital of Iceland are specified healthcare professionals given access to the data. The current data access protocol aims to promote high-quality HF research. Healthcare professionals in Iceland are invited to propose new research projects that address significant questions in this field.

Validity

The IHFR has not gone through external validity. Many of the variables are from SwedeHF, and several extensions have been adopted from the European Unified Registries on Heart Care Evaluation and Randomized Trials (EuroHeart). Nevertheless, it is extremely important to validate it, and there may be opportunities to do so by collaborating with SwedeHF to ensure data accuracy and reliability, which would instil more confidence in the data's integrity. This could potentially be beneficial for both parties.

Results

From 1 January 2020 to 1 January 2023, data from a total of 1890 patients were collected, and 2384 registrations were made; some of the patients were readmitted. The data collection for the years 2020, 2021 and 2022 is complete (shown in Table 4), that is, manually validated by an HF specialist.

HF is a heterogeneous disease with many different underlying causes. Figure 2 shows that IHD is the main underlying cause of HF among patients with HFrEF and HFmrEF, while the underlying causes of those with HFpEF are more scattered. Most HFpEF patients have HF due to diastolic dysfunction (DD), IHD, hypertension, atrial fibrillation or valvular heart disease (VHD). The IHFR offers a unique opportunity to map the distribution of rare causes of HF, such as Fabry disease, post-partum cardiomyopathy (PPCM) and CA. The most common underlying causes of HFimpEF are atrial fibrillation and IHD.

Figure 3 shows the number of admissions per month and the age distribution of patients admitted with AHF to the DC at Landspítali – The University Hospital of Iceland from January 2020 to January 2023. On average, the patients were 74.9 years old. Breaking this down by gender, women averaged 78.3 years, and men averaged 72.8 years. The second plot illustrates the monthly admission rate, showing an average of 64.7 admissions per month.

Discussion

The IHFR offers a nationwide perspective on HF epidemiology in Iceland using real-world data and may, in the future, be studied in the potential assessment of the long-term effects of HF treatment for all patients. Much effort has been put into improving data quality by increasing the number of

Table 4 The Icelandic Heart Failure Registry records overview for the years 2020–2022.

	Year		
	2020	2021	2022
No. of patients	666	592	632
No. of complete registrations	837	745	802

Figure 2 Underlying causes of heart failure (HF) among different HF phenotypes. HFmrEF, HF with mildly reduced ejection fraction; HFpEF, HF with preserved ejection fraction; HFrEF, HF with reduced ejection fraction.

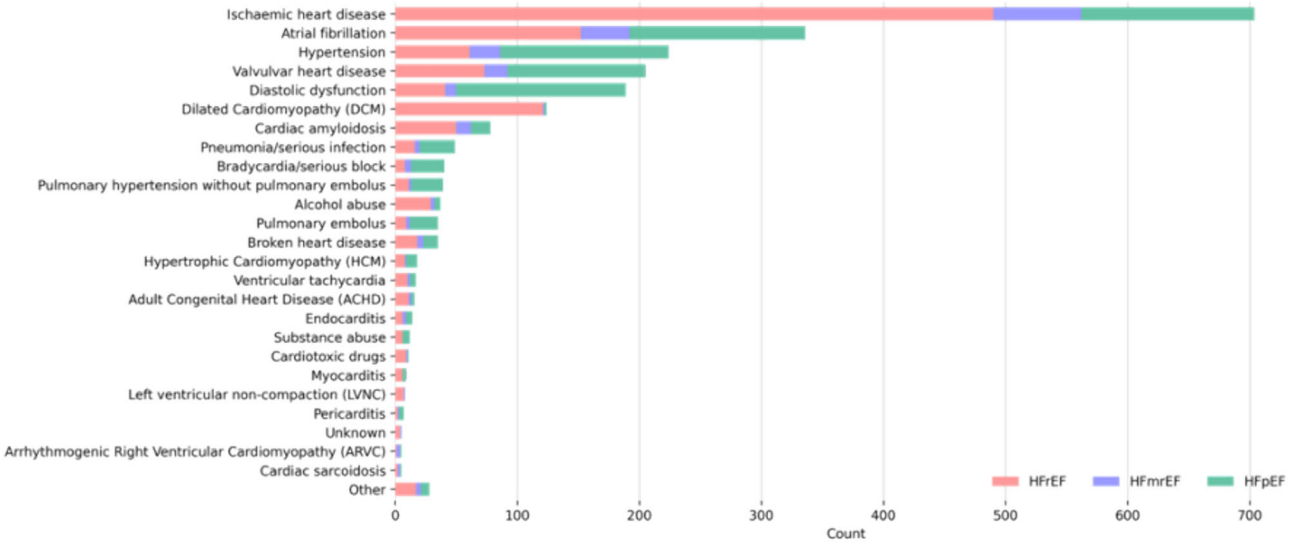
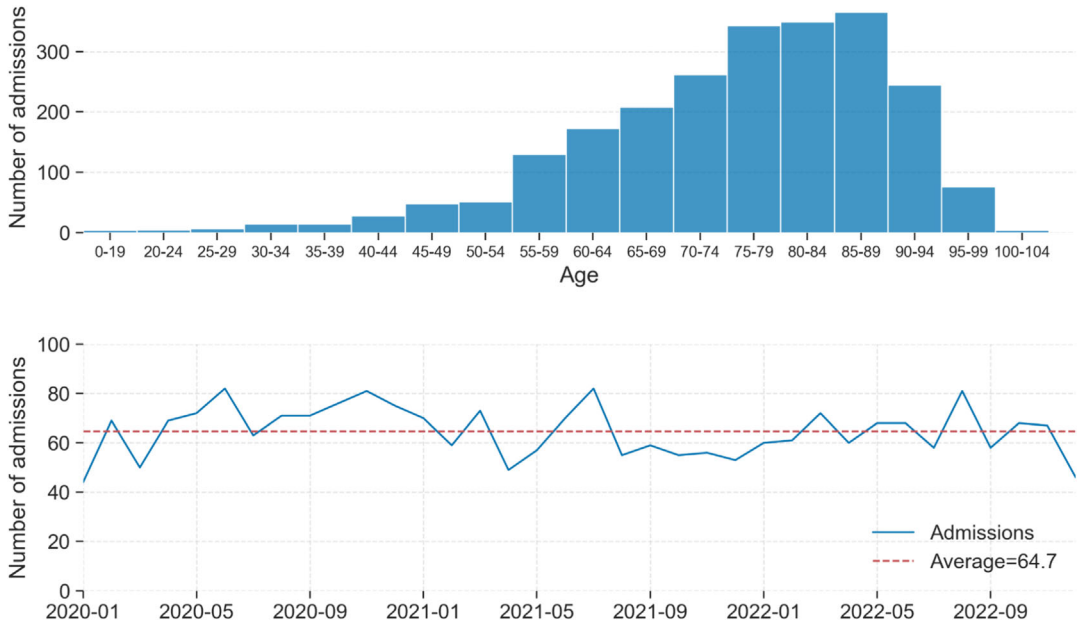


Figure 3 Age distribution and number of admissions per month for admissions in 2020, 2021 and 2022.



variables. To date, one bachelor's thesis[31] and one master's thesis[32] from the University of Iceland have been published using data from the IHFR, one looking at HF phenotypes and survival and the other evaluating whether HF patients are receiving HF medication in accordance with the HF Guidelines of the ESC.[29] Both authors are currently writing manuscripts for publication in peer-reviewed medical journals. Their research is essential in mapping the landscape of HF in Iceland and evaluating the quality of HF treatment.

The importance of understanding HF phenotypes and aetiologies

As HF is a very heterogeneous disease, it is important not only to understand the different HF phenotypes and their prognoses but also to focus on the aetiologies. It is well known that HF is underdiagnosed, especially when it comes to HFpEF.[33] For this reason, it may not be possible to draw clear conclusions regarding the true incidence and prevalence

of different HF phenotypes from the IHFR. In the Nordic countries, HFpEF has primarily been treated by GPs. However, the HFpEF population is growing and is more heterogeneous, with a rise in metabolic syndrome. In Iceland, the prevalence of obesity was 23.9% and type 2 diabetes was 7.1%, according to the latest available data from 2016,[34] and has probably increased since then and may have contributed to a rise in HFpEF in Iceland.

The role of the IHFR in quality of care

Most patients with highly symptomatic HF (NYHA classes III–IV at presentation) are referred to Landspítali University Hospital, and the number of new HF diagnoses can give a rough estimate of the incidence of AHF in Iceland. Most of these patients, particularly those with new-onset HF, are offered a follow-up appointment at the HF outpatient clinic at Landspítali University Hospital. Currently, the medical team there is routinely contacted if patients registered in the IHFR are on suboptimal treatment. In this way, the IHFR is already being used as a quality-of-care indicator and can impact the treatment of all included patients, hopefully reducing the rate of readmissions and even optimizing HF management costs.

The advantages and limitations of a small nationwide registry

In the international context, Iceland is tiny. What can a small nationwide registry offer to the international community? The advantages are clearly the grade of precision and the high data coverage that is representative of the whole patient population in daily clinical practice. This makes the efficacy–effectiveness gap negligible, and registry trials based on the IHFR can be well suited to real-world effectiveness studies. Such studies can further improve knowledge on the generalizability of trial results for daily clinical practice.

The potential of artificial intelligence (AI) in registry data collection

The strong, accessible IT department at Landspítali – The National University Hospital of Iceland is the cornerstone of a strong registry that is constantly under development, with the adaptability and capacity of data collection processes growing continually. In contrast, a disadvantage of SwedeHF is its low coverage (54%) of prevalent HF in the inpatient setting.[35] While the IHFR nearly covers all HF admissions to the DC, a notable limitation is its exclusion of HF inpatients from the geriatric and internal medicine departments. However, there is potential for these departments to contribute to the IHFR in the future. HF patients in the HF outpatient clinic may also be included in the future. This will require further funding, as the only funding until now has been for the employment of medical students to conduct QoL assessments—a volunteer HF specialist has been carrying out the registration and assessing the underlying HF factors. However, the Icelandic Ministry of Health provides funds for the IT department to conduct various IT healthcare tasks. This includes their work on IHFR development, for which the automatization of data collection is vital because it is extremely important to increase the IHFR's feasibility and patient enrolment as well as to ensure external validity. The IT department, working alongside an AI expert from the University of Iceland, is exploring the use of AI for processing medical records in the IHFR through natural language processing (NLP). This involves inputting admission notes from EHRs, with all personal identifiers removed, into advanced language models like ChatGPT. The goal is to identify key variables and conduct analysis. Early experiments have yielded encouraging outcomes, as detailed in Appendix S1.

Incidence and demographics of AHF in Iceland

A clear strength of the IHFR is that it captures nearly all AHF cases in Iceland. Given the size of the Icelandic population and the fact that approximately 800 admissions of AHF are hospitalized every year, the incidence of AHF is around 2 cases per 1000 inhabitants per year. This is consistent with the median annual HF incidence of 3.2 cases per 1000 person-years in the 12 participating countries in the ESC HF Atlas.[19] In Europe or the United States, the reported HF incidence has been shown to be between 1 and 9 cases per 1000 person-years, depending on the diagnostic criteria used and the population studied.[36] We did not observe seasonal variation in AHF admissions, but notably, it has been reported for other countries.[37] Possibly, this seasonal effect is not as strong in Iceland as there is less seasonal variation in the weather compared with other countries, and further data would be required to detect it. As of the end of 2022, 68.8% [95% uncertainty interval (UI): 66.5%–71.1%] of patients in the IHFR were aged 70 years or older.

Updates to the IHFR and harmonization with international guidelines

Updates to the IHFR were carried out on 1 January 2021, 2022, 2023 and 2024. Variables have been added but none removed, so the IHFR is still comparable to the SwedeHF registry. On 1 January 2024, the registry underwent an update to include additional variables such as laboratory results, echocardiogram parameters and more comprehensive details on HF patients with amyloidosis as an underlying cause. More precise data registration on cMRI findings is on the drawing board.

The impact of Covid-19 on the IHFR

The registry started at the beginning of the Covid-19 pandemic, and here, we briefly address its impact on the IHFR. The Icelandic authorities conducted a mitigation strategy against Covid-19 from the very beginning, and the Icelandic government developed a national vaccination strategy operation to vaccinate the entire population.[38] Therefore, the Covid-19 situation was manageable, and the health system held its ground. No increase in the number of HF admissions to the DC (and thus registrations in the IHFR) was noted during Covid-19 in 2020 and 2021, as these patients were treated in special Covid-19 wards and intensive care units at Landspítali University Hospital. The number of myocarditis admissions at the hospital was unchanged from 2019 to 2020 and was only slightly higher in 2021, seeming to reflect normal variation.[39] It is not unlikely that Covid-19 myocarditis has been underreported in the intensive care units of our hospital, but this was not observed in the DC. There was a significant reduction in HF follow-up visits to the HF outpatient clinic in 2020 due to the pandemic, and the original plan to invite these patients to the IHFR registration was abandoned, leaving only HF admissions to the DC for decompensated HF or AHF.

The future of international collaboration in HF research

In 2019, the ESC decided to co-ordinate the development of the EuroHeart.[40] Their primary goal was to establish a network of national registries with standardized data variables, thereby improving the quality of the collected observational data related to CVD. The EuroHeart project's concept was based on the success of established registries, such as the Swedish Web-system for Enhancement and Development of Evidence-based care in Heart disease Evaluated According to Recommended Therapies (SWEDEHEART).[41] During the pilot phase, six countries, including Iceland, adopted the proposed EuroHeart standard and began collecting data according to its specifications.[42] On 1 January 2022, the IHFR was updated to include all 84 Level 1 (mandatory) variables and most of the 79 Level 2 (optional) variables. These variables are distributed across nine defined domains of HF care: demographics, patient characteristics and comorbidities, presentation details, medication prior to encounter, health-related QoL, investigations, in-hospital management, discharge details and discharge or post-encounter medication.[43]

In the years to come, it is hoped that value can be added by combining national HF registries into a EuroHeart-like network to initiate and collaborate on quality improvement efforts, observational research and registry-based randomized controlled trials. For the burden of disease to be correctly estimated and the right conclusions drawn regarding the outcomes of all patients in registries, data collection needs to be of good quality and have sufficiently high coverage of the population. This would give a more realistic picture of healthcare management. AI may become a revolutionary factor in data collection and data quality in the near future. Therefore, Iceland can soon be at the forefront of international collaboration in HF research. Linking epidemiological data from the IHFR to a biobank would be a crucial step in further underpinning the genetic basis of a disease, improving preventive measures and even contributing to personalized (precision) medicine in the future.

Conclusion

The IHFR, established in 2019, has become a vital resource for understanding HF in Iceland. Focusing primarily on AHF admissions, it gathers extensive data on patient backgrounds, clinical conditions and treatments. This wealth of information offers insights into HF causes, treatment effectiveness and patient outcomes. The IHFR not only benefits Icelandic healthcare but also serves as a model for other countries' HF registries. Its ongoing development and potential expansion promise to enhance HF research and patient care both nationally and internationally.

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Conflict of interest statement

The authors have no conflicts of interest to declare.

Data availability statement

Datasets presented from the IHFR are not open to the public, but some lists of the variables are available in Appendix S1.

Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix S1. Supporting Information.

References

1. Conrad N, Judge A, Tran J, Mohseni H, Hedgecott D, Crespillo AP, *et al*. Temporal trends and patterns in heart failure incidence: A population-based study of 4 million individuals. *Lancet* 2018;**391**:572-580. doi:10.1016/S0140-6736(17)32520-5
2. Virani SS, Alonso A, Benjamin EJ, Bittencourt MS, Callaway CW, Carson AP, *et al*. Heart disease and stroke statistics—2020 update: A report from the American Heart Association. *Circulation* 2020;**141**:e139-e596. doi:10.1161/CIR.0000000000000757
3. Mosterd A, Hoes AW. Clinical epidemiology of heart failure. *Heart* 2007;**93**:1137-1146. doi:10.1136/hrt.2003.025270
4. van Riet EE, Hoes AW, Limburg A, Landman MA, van der Hoeven H, Rutten FH. Prevalence of unrecognized heart failure in older persons with shortness of breath on exertion. *Eur J Heart Fail* 2014;**16**:772-777. doi:10.1002/ejhf.110
5. van Riet EE, Hoes AW, Wagenaar KP, Limburg A, Landman MAJ, Rutten FH. Epidemiology of heart failure: The prevalence of heart failure and ventricular dysfunction in older adults over time. A systematic review. *Eur J Heart Fail* 2016;**18**:242-252. doi:10.1002/ejhf.483
6. Benjamin EJ, Virani SS, Callaway CW, Chamberlain AM, Chang AR, Cheng S, *et al*. Heart disease and stroke statistics—2018 update: A report from the American Heart Association. *Circulation* 2018;**137**:e67-e492. doi:10.1161/CIR.0000000000000558
7. Bibbins-Domingo K, Pletcher MJ, Lin F, Vittinghoff E, Gardin JM, Arynchyn A, *et al*. Racial differences in incident heart failure among young adults. *N Engl J Med* 2009;**360**:1179-1190. doi:10.1056/NEJMoa0807265
8. Dunlay SM, Roger VL. Understanding the epidemic of heart failure: Past, present, and future. *Curr Heart Fail Rep* 2014;**11**:404-415. doi:10.1007/s11897-014-0220-x
9. Roth GA, Forouzanfar MH, Moran AE, Barber R, Nguyen G, Feigin VL, *et al*. Demographic and epidemiologic drivers of global cardiovascular mortality. *N Engl J Med* 2015;**372**:1333-1341. doi:10.1056/NEJMoa1406656
10. Savarese G, Lund LH. Global public health burden of heart failure. *Card Fail Rev* 2017;**3**:7-11. doi:10.15420/cfr.2016:25:2
11. Chioncel O, Mebazaa A, Maggioni AP, Harjola VP, Rosano G, Laroche C, *et al*. Acute heart failure congestion and perfusion status—Impact of the clinical classification on in-hospital and long-term outcomes: Insights from the ESC-EORP-HFA heart failure long-term registry. *Eur J Heart Fail* 2019;**21**:1338-1352. doi:10.1002/ejhf.1492
12. Shah SJ, Katz DH, Deo RC. Phenotypic spectrum of heart failure with preserved ejection fraction. *Heart Fail Clin* 2014;**10**:407-418. doi:10.1016/j.hfc.2014.04.008
13. Kessler EL, Oerlemans MIFJ, van den Hoogen P, Yap C, Sluijter JPG, de Jager SCA. Immunomodulation in heart failure with preserved ejection fraction: Current state and future perspectives. *J Cardiovasc Transl Res* 2021;**14**:63-74. doi:10.1007/s12265-020-10026-3
14. Roger VL. Epidemiology of heart failure. *Circ Res* 2013;**113**:646-659. doi:10.1161/CIRCRESAHA.113.300268
15. Borlaug BA, Sharma K, Shah SJ, Ho JE. Heart failure with preserved ejection fraction: JACC scientific statement. *J Am Coll Cardiol* 2023;**81**:1810-1834. doi:10.1016/j.jacc.2023.01.049
16. Lund LH, Carrero JJ, Farahmand B, Henriksson KM, Jonsson Å, Jernberg T, *et al*. Association between enrolment in a heart failure quality registry and subsequent mortality—A nationwide cohort study. *Eur J Heart Fail* 2017;**19**:1107-1116. doi:10.1002/ejhf.762
17. *Statistics Iceland [Internet]*. Reykjavík: The Largest Population Increase Ever; 2023. Available from: https://www.statice.is/publications/news-archive/inhabitants/the-population-on-1-january-2023/. Accessed 13 May 2023
18. Einarsson H, Thorgeirsson G, Danielsen R, Olafsson O, Aspelund T, Gudnason V. Heart failure among older Icelanders: Prevalence, incidence, risk factors and prognosis. *Icelandic Med J* 2017;**103**:429-436. doi:10.17992/lbl.2017.10.155
19. Seferovic PM, Vardas P, Jankowska EA, Maggiori AP, Timmis A, Milinković I, *et al*. The Heart Failure Association atlas: Heart failure epidemiology and management statistics 2019. *Eur J Heart Fail* 2021;**23**:906-914. doi:10.1002/ejhf.2143
20. Jonsson Å, Edner M, Alehagen U, Dahlström U. Heart failure registry: A valuable tool for improving the management of patients with heart failure. *Eur J Heart Fail* 2010;**12**:25-31. doi:10.1093/eurjhf/hfp175
21. *International Statistical Classification of Diseases and Related Health Problems 10th Revision [Internet]*. Geneva: ICD-10 Version; 2019. Available from: https://icd.who.int/browse10/2019/en. Accessed 12 July 2023
22. Rabin R, de Charro F. EQ 5D: A measure of health status from the EuroQol Group. *Ann Med* 2001;**33**:337-343. doi:10.3109/07853890109002087
23. Spertus JA, Jones PG. Development and validation of a short version of the Kansas City Cardiomyopathy Questionnaire. *Circ Cardiovasc Qual Outcomes* 2015;**8**:469-476. doi:10.1161/CIRCOUTCOMES.115.001958
24. Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: The GAD-7. *Arch Intern Med* 2006;**166**:1092-1097. doi:10.1001/archinte.166.10.1092
25. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med* 2001;**16**:606-613. doi:10.1046/j.1525-1497.2001.016009606.x
26. White P, Myers M. The classification of cardiac diagnosis. *JAMA* 1921;**77**:1414-1415. doi:10.1001/jama.1921.02630440034013
27. Killip T, Kimball JT. Treatment of myocardial infarction in a coronary care unit. A two year experience with 250 patients. *Am J Cardiol* 1967;**20**:457-464. doi:10.1016/0002-9149(67)90023-9
28. Brodovicz KG, McNaughton K, Uemura N, Meininger G, Girman CJ, Yale SH. Reliability and feasibility of methods to quantitatively assess peripheral edema. *Clin Med Res* 2009;**7**:21-31. doi:10.3121/cmr.2009.819
29. McDonagh TA, Metra M, Adamo M, Gardner RS, Baumbach A, Bohm M, *et al*. 2021 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure: Developed by the Task Force for the diagnosis and treatment of acute and chronic heart failure and the European Society of Cardiology (ESC) with the special contribution of the Heart Failure Association (HFA) of the ESC. *Eur Heart J* 2021;**48**:3599-3726. doi:10.1093/eurheartj/ehab670
30. Bozkurt B, Coats AJS, Tsutsui H, Abdelhmaid CM, Adamopoulos S, Albert

N, *et al*. Universal definition and classification of heart failure: A report of the Heart Failure Society of America, Heart Failure Association of the European Society of Cardiology, Japanese Heart Failure Society and Writing Committee of the Universal Definition of Heart Failure. *Eur J Heart Fail* 2021;**23**:352-380. doi:10.1002/ejhf.2115

31. Hansen JS. Acute Heart Failure in Iceland: Epidemiology, Phenotypes, Underlying Aetiology, and Prognostic Insights. *[Bachelor's dissertation, University of Iceland]*. Faculty of Medicine, University of Iceland; 2023. https://hdl.handle.net/1946/44357
32. Hauksdóttir H. Prescription of Pharmacologic Treatments According to Different Phenotypes of Heart Failure at Discharge From the Department of Cardiology of Landspítali – The National Hospital of Iceland. Are Icelandic Heart Failure Patients Receiving Treatment in Accordance With the Clinical Heart Failure Guidelines of the European Society of Cardiology? *[Master's dissertation, University of Iceland]*. Faculty of Medical Sciences, Department of Pharmacology, University of Iceland; 2023. https://hdl.handle.net/1946/43663
33. Loai S, Cheng HLM. Heart failure with preserved ejection fraction: The missing pieces in diagnostic imaging. *Heart Fail Rev* 2020;**25**:305-319. doi:10.1007/s10741-019-09836-8
34. *World Health Organization—Diabetes Country Profiles [Internet]*. Geneva: The Largest Population Increase Ever; 2016. Available from: https://cdn.who.int/media/docs/default-source/country-profiles/diabetes/isl_en.pdf?sfvrsn=e7729e98_38&download=true. Accessed 15 March 2024
35. Savarese G, Vasko P, Jonsson Å, Edner M, Dahlström U, Lund LH. The Swedish Heart Failure Registry: A living, ongoing quality assurance and research in heart failure. *Ups J Med Sci* 2019;**124**:65-69. doi:10.1080/03009734.2018.1490831
36. Shahim B, Kapelios CJ, Savarese G, Lund LH. Global public health burden of heart failure: An updated review. *Card Fail Rev* 2023;**9**:e11. doi:10.15420/cfr.2023.05
37. Gallerani M, Boari B, Manfredini F, Manfredini R. Seasonal variation in heart failure hospitalization. *Clin Cardiol* 2011;**34**:389-394. doi:10.1002/clc.20895
38. Cuschieri S, Pallari E, Hatziyianni A, Sigurvinsdottir R, Sigfusdottir ID, Sigurðardóttir ÁK. A year of Covid-19: Experiences and lessons learnt by small European island states—Cyprus, Iceland and Malta. *Eur J Public Health* 2022;**32**:316-321. doi:10.1093/eurpub/ckab217
39. Sigurbergsdottir AY, Thórsdóttir H, Gunnarsdóttir OB, Mohiddin S, Marelli-Berg F, Dyer C, Fanti S, Lúdvíksson BR, Brynjólfsson SF, Zemrak P, Sigfússon G, Óskarsson G, Hrafnkelsdottir T, Karlsson HD, Flygenring B, Arnar DO, Ingimarsdóttir IJ. Perimyocarditis after Covid-19 vaccination—A nation-wide study. [Manuscript in preparation]. 2024.
40. Wallentin L, Gale CP, Maggioni A, Bardinet I, Casadei B. EuroHeart: European Unified Registries On Heart Care Evaluation and Randomized Trials. *Eur Heart J* 2019;**40**:2745-2749. doi:10.1093/eurheartj/ehz599
41. Jernberg T, Attebring MF, Hambraeus K, Ivert T, James S, Jeppsson A, *et al*. The Swedish Web-system for Enhancement and Development of Evidence-based care in Heart disease Evaluated According to Recommended Therapies (SWEDEHEART). *Heart* 2010;**96**:1617-1621. doi:10.1136/hrt.2010.198804
42. *European Unified Registries for Heart Care Evaluation and Randomised Trials (EuroHeart) [Internet]*. Uppsala: EuroHeart Consolidation Phase Planning; 2023. Available from: https://www.escardio.org/static-file/Escardio/Research/Euroheart/EuroHeart_Consolidation_Phase_description-V2.0_14Apr2023.pdf. Accessed 2 July 2023
43. Aktaa S, Batra G, Cleland JGF, Coats A, Lund LH, McDonagh T, *et al*. Data standards for heart failure: The European Unified Registries for Heart Care Evaluation and Randomized Trials (EuroHeart). *Eur Heart J* 2022;**43**:2185-2195. doi:10.1093/eurheartj/ehac151