

The Heart Failure Association Atlas: Heart Failure Epidemiology and Management Statistics 2019

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Aims

The Heart Failure Association (HFA) of the European Society of Cardiology (ESC) developed the HFA Atlas to provide a contemporary description of heart failure (HF) epidemiology, resources, reimbursement of guideline-directed medical therapy (GDMT) and activities of the National Heart Failure Societies (NHFS) in ESC member countries.

Methods and results

The HFA Atlas survey was conducted in 2018–2019 in 42 ESC countries. The quality and completeness of source data varied across countries. The median incidence of HF was 3.20 [interquartile range (IQR) 2.66–4.17] cases per 1000 person-years, ranging from ≤ 2 in Italy and Denmark to > 6 in Germany. The median HF prevalence was 17.20 (IQR 14.30–21) cases per 1000 people, ranging from ≤ 12 in Greece and Spain to > 30 in Lithuania and Germany. The median number of HF hospitalizations was 2671 (IQR 1771–4317) per million people annually, ranging from < 1000 in Latvia and North Macedonia to > 6000 in Romania, Germany and Norway. The median length of hospital stay for an admission with HF was 8.50 (IQR 7.38–10) days. Diagnostic and management resources for HF varied, with high-income ESC member countries having substantially more resources compared with middle-income countries. The median number of hospitals with dedicated HF centres was 1.16 (IQR 0.51–2.97) per million people, ranging from < 0.10 in Russian Federation and Ukraine to > 7 in Norway and Italy. Nearly all countries reported full or partial reimbursement of standard GDMT, except ivabradine and sacubitril/valsartan. Almost all countries reported having NHFS or working groups and nearly half had HF patient organizations.

Conclusions

The first report from the HFA Atlas has shown considerable heterogeneity in HF disease burden, the resources available for its management and data quality across ESC member countries. The findings emphasize the need for a systematic approach to the capture of HF statistics so that inequalities and improvements in care may be quantified and addressed.

Keywords

Heart failure • Epidemiology • Incidence • Prevalence • Hospitalization • HFA Atlas

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Introduction

Contemporary data that describe the epidemiology of heart failure (HF) and resources for its management across a wide range of European countries are lacking. Equally, there is a paucity of assimilated information about reimbursement of HF treatments, as well as the organization and activities of the National Heart Failure Societies (NHFS) of the European Society of Cardiology (ESC) member countries. Such information is important for the design and development of strategic approaches to the prevention and treatment of HF.

In 2016, the ESC launched the ESC Atlas of Cardiology, a compendium of cardiovascular data from its 57 member countries, that drew attention to geographic variation in the prevalence of cardiovascular risk factors, the burden of cardiovascular disease and the delivery of healthcare.¹ In 2018, the Heart Failure Association (HFA) of the ESC launched the HFA Atlas,² a sub-speciality resource aimed at sourcing contemporary data concerning the epidemiology and healthcare resources for HF, as well as information about awareness and advocacy for HF within ESC member countries. The rationale, objectives and methods for the development of the HFA Atlas have been previously described.² The aim of the current article is to present, for the first time, data on HF epidemiology, resources available for its management, reimbursement strategies for guideline-directed medical therapy (GDMT), and the organization and activities of the NHFS across ESC member countries.

Methods

The HFA Atlas was designed and populated by the HFA Atlas Task Force composed of representatives of the HFA and the European Heart Health Institute. This was an investigator-initiated research (funded by the HFA of the ESC), conducted in collaboration with the NHFS of the ESC member countries.³ A description of variable definitions and methods of data collection have been published.² Data were collected in 2018–2019 via the HFA Atlas survey. Respective rate estimates were calculated using World Bank population data.

Heart Failure Association Atlas survey

The format and content of the HFA Atlas survey were developed through a series of reviews within the HFA, the NHFS and the European Heart Health Institute. The survey contained questions concerning HF epidemiology, management resources, GDMT reimbursement, and NHFS organization and activities. The data definitions used in the survey are provided in online supplementary Table S1.

Data collection

A preliminary invitation was sent to the 57 ESC member countries, and the 44 countries that responded were invited to participate in the HFA Atlas survey (Austria, Azerbaijan, Belgium, Belarus, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Georgia, Greece, Hungary, Italy, Israel, Iceland, Ireland, Kazakhstan, Kirgizstan, Latvia, Lithuania, Lebanon, Luxembourg, North Macedonia, Moldova, The Netherlands, Norway, Poland, Portugal, Romania, Russian Federation, Slovakia, Spain, Sweden, Slovenia, Serbia, Switzerland, Turkey, United Kingdom,

Ukraine). In July 2018, the survey was electronically distributed to the National Coordinators from the NHFS with monthly telephone and email follow-up over the following 6 months by the HFA Atlas Task Force. The National Coordinators were advised to adhere to variable definitions in the HFA survey and to use information sources such as official national statistics, governmental and/or ministry of health documents, documents from academic institutions, published national registries/surveys, and registries/surveys developed by the HFA.

Quality control

The HFA Atlas Task Force reviewed all survey data to ensure that the answers to questions matched variable definitions. Entries were examined for outliers, which were only accepted if confirmed or corrected by the National Coordinators. Data entries were categorized by their sources as follows: category 1, unknown source; category 2, personal communication from National Coordinators; category 3, local publications without a defined survey methodology; category 4, publications based on defined populations (e.g. regional registries/surveys); category 5, prospective HFA-organized surveys (e.g. EURObservational Research Programme, EORP); category 6, national statistics, governmental and/or ministry of health documents and prospective national registries/surveys. Only data relating to categories 4, 5 and 6 were included for reporting the incidence and prevalence of HF, hospital admission and length of stay (online supplementary Table S2). Variables for which data were scarce, collected with variable methodologies, or were highly heterogeneous (e.g. 1-year and in-hospital mortality) were not presented. Source data about HF management resources are presented in online supplementary Table S3. Prior to finalization of the database, country-specific datasets and country profiles were approved by the respective NHFS. The final, unified database was reviewed and validated by HFA Atlas Task Force. Source data relating to the incidence and prevalence of HF are provided in online supplementary Tables S4 and S5 and for hospital admission and length of stay data in online supplementary Tables S6 and S7.

Statistical analysis and data presentation

Descriptive data are presented as medians and interquartile range (IQR) because of skewed distributions. National statistics for the most recently available year are illustrated using bar charts or tables. Because of variation in the completeness and sources of data, no statistical comparisons were undertaken. The 2018 World Bank definitions were used to classify countries as high-income or middle-income (a composite of lower- and upper-middle-income) as presented in online supplementary Table S8. Since not all countries participating in the HFA Atlas could provide age and sex-stratified information, age and sex standardization could not be performed.

Results

Geographical area and response rates

The HFA Atlas covers the geographical area of Europe, Mediterranean, Middle East and some of the former Soviet Union countries. Responses were received from 42 of the 44 invited countries (response rate 95.5%), comprising a total population of over 800 million people. Only France and Luxembourg did not respond. Response rates per country ranged from 29% to 76% for epidemiological variables, and from 59% to 81% for resource variables

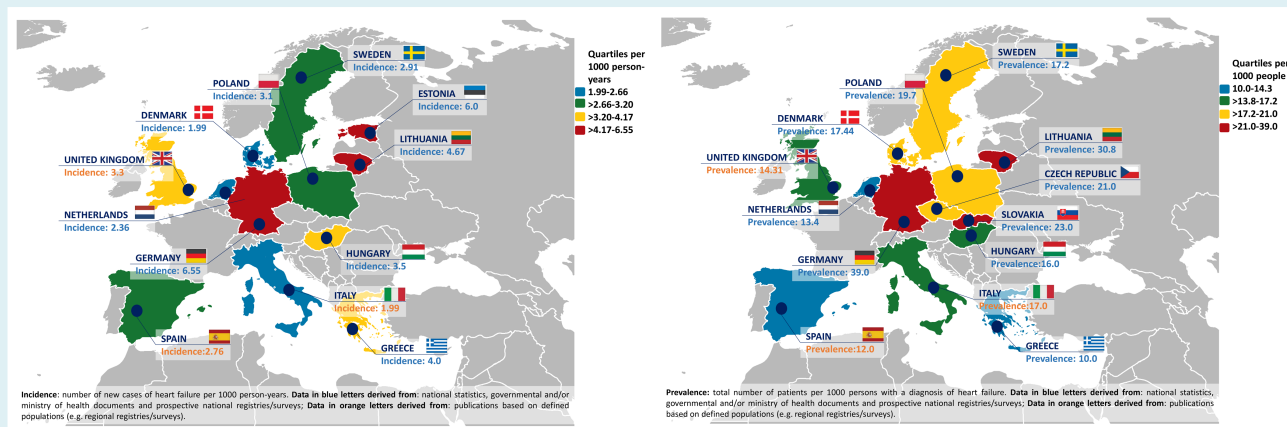
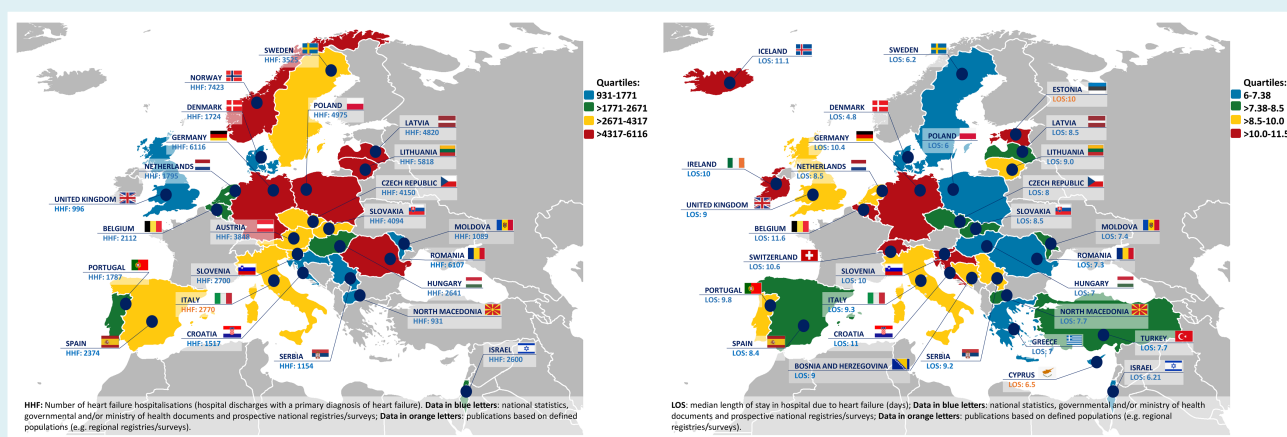
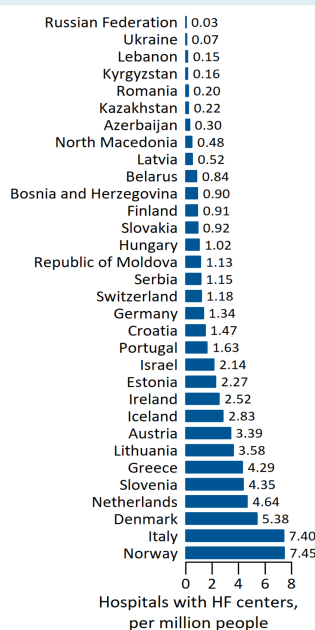


Figure 1 Incidence of heart failure per 1000 person-years (left), and prevalence of heart failure per 1000 persons (right).





Source: HFA Survey, 2018 or latest year

Data not available: Belgium, Bulgaria, Cyprus, Czech Republic, Poland, Republic of Georgia, Spain, Sweden, Turkey, United Kingdom.

*Since Iceland has a population of approximately 350,000, data also expressed per 100,000: 0.28 HF centers.

Figure 3 Hospitals with dedicated heart failure (HF) centres per million people.

department, cardiac magnetic resonance (CMR) imaging, or cardiopulmonary exercise testing (CPET). Data were obtained from 29 countries (69%). A median of 3.58 (IQR 1.38–8.53) emergency departments per million people offered natriuretic peptide measurement, ranging from none in Kyrgyzstan and North Macedonia to nearly 20 in Germany (Figure 4). The median number of hospitals with CMR imaging per million people was 1.20 (IQR 0.49–2.73) (Figure 4). Data on CPET were obtained from 29 countries (69%). The median number of hospitals with CPET per million people was 1.08 (IQR 0.30–2.83), ranging from none in Kyrgyzstan and Republic of Moldova to >5 in Norway and Belgium (Figure 4).

Data on left ventricular assist device (LVAD) implantation were available for 31 countries. A median of 0.26 (IQR 0.11–0.57) hospitals per million people reported LVAD procedures with a median of 1.90 (IQR 0.41–3.49) implants per million people per year (Figure 5). Data on the availability of catheter-based mitral valve interventions (i.e. implantation of MitraClip® device) were available for 33 countries (76%) with a median of 0.29 (IQR 0–0.53) hospitals per million people undertaking the procedure, ranging from none in Estonia, Iceland, Kazakhstan, Kyrgyzstan, Lithuania, North Macedonia, Republic of Moldova, Serbia, Ukraine to >1.50 in Germany and Italy (Figure 6). Data on ultrafiltration therapy reported by 25 countries (59%) showed a median of 1.19 (IQR 0.43–2.72) hospitals per million people performing the procedure (Figure 6). Finally, data on HF rehabilitation programmes were reported by 27 countries (64%) where the median number of hospitals offering such programmes was 0.85 (IQR 0.36–3.17) per million people (Figure 6).

Reimbursement of guideline-directed medical therapy

All 42 countries provided data on GDMT reimbursement (the percentage of drug cost covered by the national government) (online supplementary Figure S2). Full or partial reimbursement of beta-blockers (BB) and angiotensin-converting enzyme inhibitors/angiotensin receptor blockers (ACEI/ARB) was reported in 41 countries (98%) participating in the survey, but not the Russian Federation. Mineralocorticoid receptor antagonists (MRA) were reimbursed in 38 countries (90%) but not in the Russian Federation, Azerbaijan, Kyrgyzstan and Kazakhstan. Ivabradine was reimbursed fully or partially in 32 countries (79%), but not in the Russian Federation, Azerbaijan, Kyrgyzstan, Kazakhstan, Ukraine, Bosnia and Herzegovina, Republic of Moldova, North Macedonia and Cyprus. Reimbursement for sacubitril/valsartan was provided by only 29 countries (43%) and was full in only 11 (Norway, United Kingdom, Ireland, the Netherlands, Germany, Czech Republic, Switzerland, Italy, Slovenia, Republic of Georgia and Israel).

Organization and activities of the National Heart Failure Societies

Information about the organization and HF educational activities of the NHFS was received from all participating countries. The existence of a dedicated National HF Society or Working Group was reported in 37 countries (88%), which in 33 countries (79%) included a broad range of healthcare professionals in addition to cardiologists. Regular HF congresses and meetings were organized

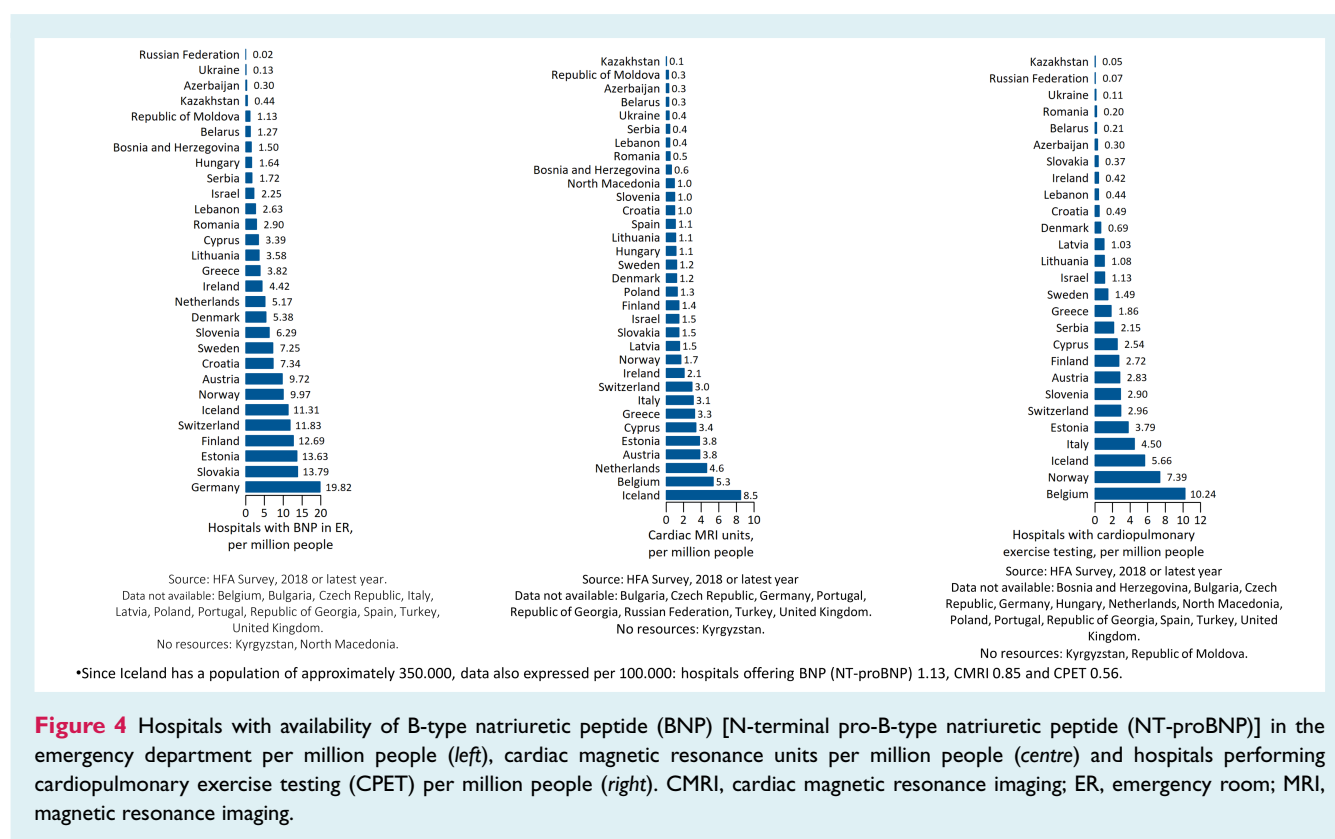


Figure 4 Hospitals with availability of B-type natriuretic peptide (BNP) [N-terminal pro-B-type natriuretic peptide (NT-proBNP)] in the emergency department per million people (left), cardiac magnetic resonance units per million people (centre) and hospitals performing cardiopulmonary exercise testing (CPET) per million people (right). CMRI, cardiac magnetic resonance imaging; ER, emergency room; MRI, magnetic resonance imaging.

in 34 countries (81%) and nearly half (48%) reported HF patient organizations. HF patient education was conducted in 37 countries (88%). The use of the ESC/HFA guidelines in implementing and prioritizing patient care was reported in all countries, while 20 (48%) reported a translated version on the ESC/HFA guidelines, and 19 (45%) also had national HF guidelines. Dedicated programmes for continuous medical education on HF were present in half of the countries. Organization of the Heart Failure Awareness day was reported by 36 countries (86%). The national website dedicated to HF was reported in 24 countries (57%). The translated version of the ESC/HFA website heartfailurematters.org was available in 10 languages. In 55% of countries, HF care was the shared responsibility of cardiologists and specialized nurses, but further details about nurse-led activities were not collected and specialist certification of cardiologists was carried out in only five countries (12%).

Discussion

The HFA Atlas has brought together a contemporary and comprehensive map of HF statistics across a large sample of ESC member countries. The only comparable initiative dates back to 2013, when a smaller HFA survey demonstrated a paucity of real-world HF statistics in ESC member countries.³

Response rates

Our report shows that data completeness remains variable with a lack of information most evident for the epidemiology of HF. Only

three countries (Denmark, Italy and Lithuania) provided complete epidemiological data, whereas 11 countries could not provide any. Response rates were generally higher for HF management resources, although data were incomplete for several HF specific resources such as ultrafiltration therapy and exercise programmes for HF patients. In contrast, the full set of data was available on GDMT reimbursement policies, and organization and activities of the NHFS.

Epidemiology of heart failure

The estimates of disease incidence and prevalence in the present study are consistent with the 2013 HFA survey and other international studies which reported an overall HF incidence of 1 to 4 cases per 1000 person-years and a prevalence of 10 to 30 cases per 1000 persons.^{3–6} However, there was considerable heterogeneity across the participating countries, which likely reflects multiple factors, including methodological issues for data collection, as well as inability to provide standardization for age, sex and other relevant population characteristics. Importantly, this fact also precludes any comparison between national HF statistics. Despite a strong link between aging and HF disease burden,^{7,8} differences in population age structure can only partly explain international discrepancies in HF epidemiology, since, apart from Germany and Greece, the reported HF incidence was not above the median in other countries with a high percentage of older people (Italy, Spain, Denmark, Sweden). Other factors driving international heterogeneity include differences in socioeconomic status and variable prevalence

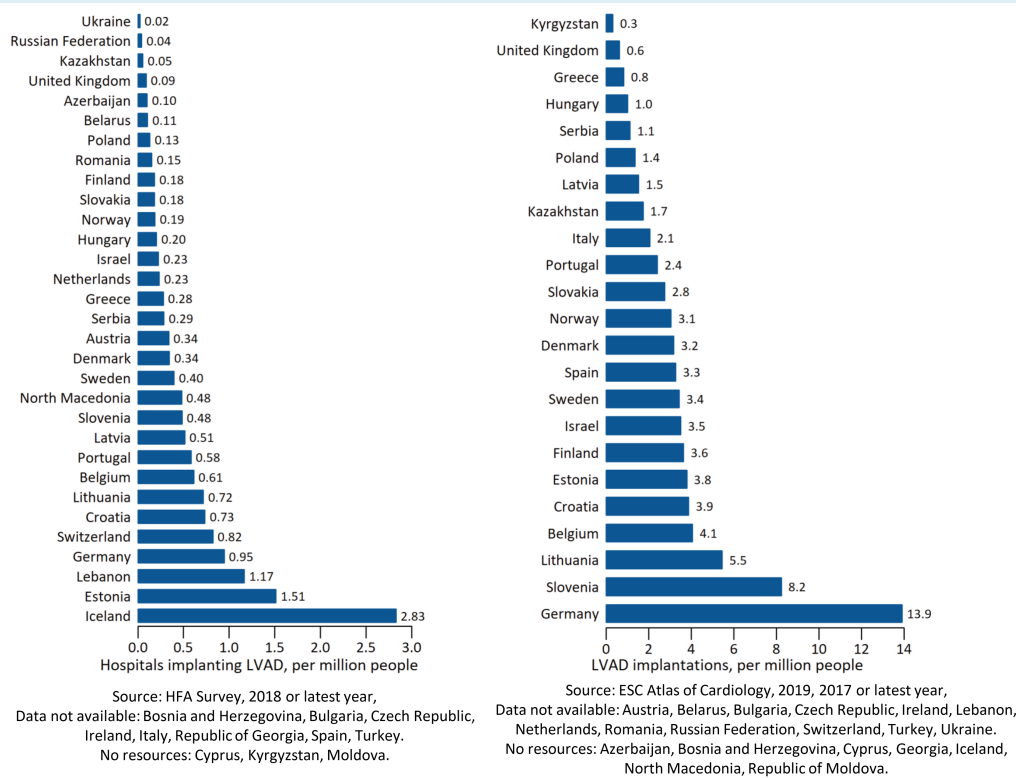


Figure 5 Hospitals implanting left ventricular assist devices (LVAD) per million people (left) and number of LVAD implantations per million people (right).

and management of major risk factors for HF (ischaemic heart disease, hypertension, diabetes, obesity, etc.).⁹ Indeed, socioeconomic deprivation has been associated with greater risk of developing HF at a younger age and with more comorbidities compared with more affluent individuals.¹⁰ Also, a recent report on the global burden of cardiovascular disorders suggests a growing prevalence of hypertensive heart disease (defined as symptomatic HF caused by direct, long-term effects of hypertension) due to population growth and aging.¹¹ Furthermore, inequalities in healthcare resources and diagnostic capacities, in particular limited implementation of contemporary diagnostic strategies,¹² may have resulted in under-reporting of HF with preserved ejection fraction in some of the countries. These factors might also account for the comparatively high incidence and prevalence of HF in some countries, where contemporary diagnostic and therapeutic resources may be more readily accessible through specialized services (e.g. dedicated HF centres). Furthermore, distinct national requirements for reporting new and prevalent HF cases may exist, being under the influence of reimbursement policies in some countries.

Heterogeneity was also observed in the number of hospitalizations with a primary diagnosis of HF, and length of hospital stay. This is likely reflecting differences in hospital admission policies and criteria, in-hospital level of care, access to out-of-hospital management resources and adherence to therapy.^{13,14} Access to dedicated

HF facilities could have also played a role, given that countries with a greater density of specialized centres for HF care (e.g. Norway and Germany) had a higher number of HF hospitalizations. Length of hospital stay also varied, perhaps influenced by hospital practice and reimbursement policies, adherence to GDMT and involvement in HF rehabilitation programmes and multidisciplinary management.^{13,14}

Heart failure management resources

Provision of basic and cost-effective healthcare for HF is an essential requirement of ESC member countries,¹⁵ but is unlikely to be achieved until inequality in hospital facilities and service provision is addressed. Although the availability of HF centres, equipped with services and trained personnel dedicated to HF management, has improved compared with 2013 (when HF centres were unavailable in ~15% of the countries),³ most countries continue to report fewer than three such centres per million people. ESC member countries have different organization, delivery and funding of healthcare and in some countries, national healthcare policies and funding may allow for the development of regional and national high-volume centres with specialized services and modern equipment, whereas in other countries HF care may be dispersed among smaller institutions with variable accessibility. Given the growing burden and complexity of HF management, the present

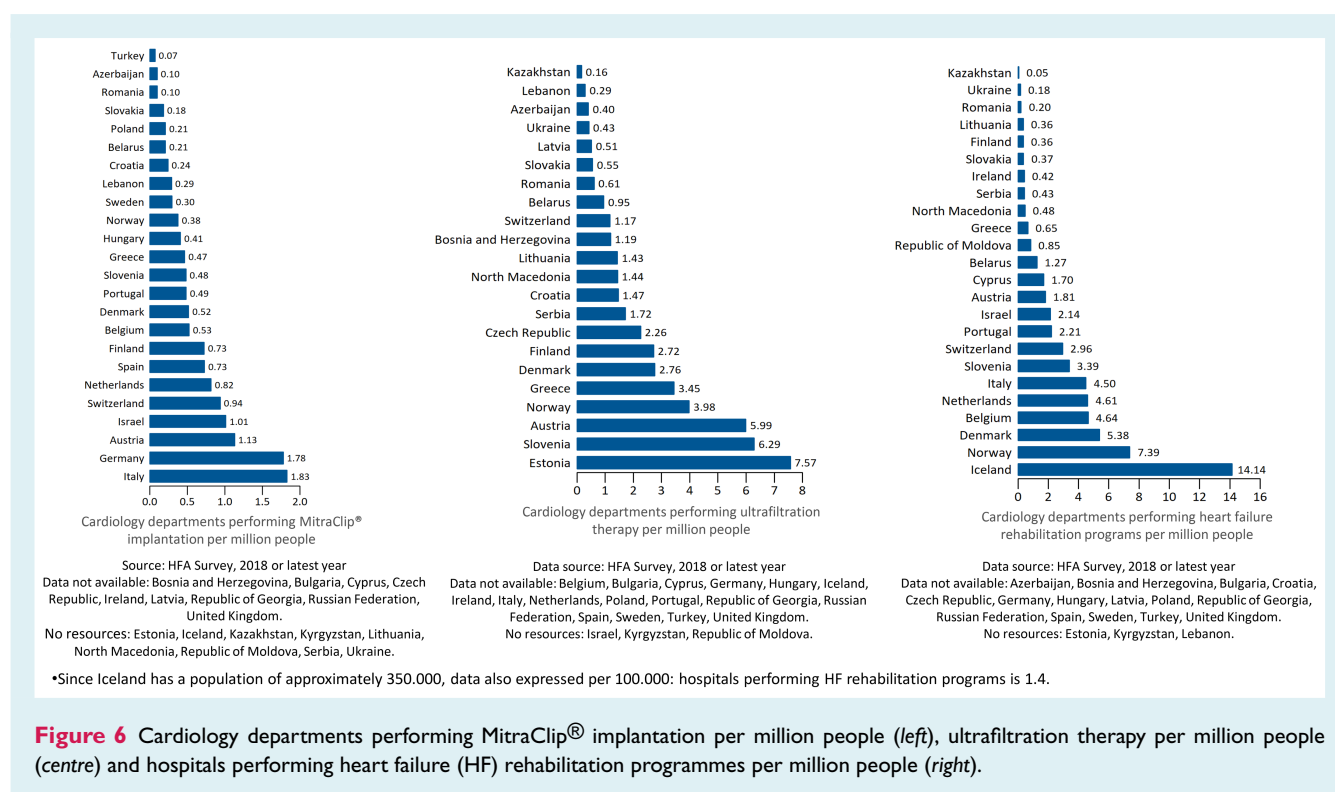


Figure 6 Cardiology departments performing MitraClip® implantation per million people (left), ultrafiltration therapy per million people (centre) and hospitals performing heart failure (HF) rehabilitation programmes per million people (right).

number of dedicated HF centres may be insufficient to provide comprehensive assessment in accordance with contemporary standards and evolving diagnostic and therapeutic possibilities. There remains an unmet need for further development of centres offering specialized, multidisciplinary HF management, at all levels of care (from primary to tertiary), including centres for advanced HF.¹⁶ None of the ESC countries reported access to natriuretic peptide testing in all of its emergency departments, despite strong recommendations.^{15,17} Likewise, CMR imaging and CPET show limited availability in many countries and several still do not provide these facilities. The use of echocardiography was not assessed in the present survey, considering that the 2013 HFA survey demonstrated that this technique was highly utilized for diagnostic assessment of HF patients.³ Availability of device therapies, cardiac surgery and heart transplantation has recently been described in the ESC Atlas of Cardiology.⁹ The present document extends the information on available non-pharmacological treatment options for HF in the ESC countries by providing data on LVAD implantation and catheter-based mitral valve interventions, ultrafiltration therapy and HF rehabilitation programmes.¹⁹ Our results indicate that these treatment modalities are disproportionately represented in countries with better access to specialized patient care, in comparison with many of the middle-income countries where these modalities are currently either unavailable or underserved. To close these gaps, support should be given to greater international cooperation in patient care, in addition to building strategies for more cost-effective provision of specialized HF services.

Reimbursement of standard heart failure medications

The HFA Atlas also provides important insights into the current European reimbursement policies for GDMT, with potentially strong implications on guideline implementation and patient outcomes. Accordingly, the present survey indicates high reimbursement for standard HF therapies, including ACEI/ARB, BB and MRA, which is in concert with a recent ESC registry demonstrating utilization of these medications in 89.20%, 88.90% and 59.30% of HF patients, respectively.¹⁸ However, contemporary data suggest insufficient uptake of other life-saving therapies such as sacubitril/valsartan,¹⁹ which might reflect low reimbursement even in high-income countries. Until these therapeutic shortfalls are corrected, heterogeneity in outcomes in HF across ESC member countries is likely to continue.

Organization and activities of the National Heart Failure Societies

The HFA Atlas shows that nearly all ESC member countries have a dedicated NHFS or working group. Contemporary management of HF depends on a multidisciplinary approach and it is reassuring that NHFSs include a range of healthcare professionals in promoting HF education and enhancing quality of care. The educative role of NHFS is promoted by organization of national scientific congresses and meetings in over 80% of countries while quality of care is enhanced through support in implementation of ESC/HFA guidelines. More work is now needed to provide translated versions of

these guidelines and to identify other obstacles to their implementation. The number of patient organizations has grown, and they are currently active in nearly half of ESC member countries. Increasing societal awareness of HF has been achieved through greater uptake of public activities such as the Heart Failure Awareness day.³ The educational HFA/ESC website 'heartfailurematters.org', a practical tool for providing advice for living with HF, is currently available in 10 languages.²⁰ Comparison with the 2013 HFA survey shows that the scope of NHFS and the activities of patient organizations have increased in the last 7 years,³ but there remains a need for further improvement, particularly an expanded availability of certified educational courses (currently utilized in only 12% of countries), as well as further development of social media in HF education, awareness and advocacy.

Limitations and future perspectives

Important limitations of the first edition of the HFA Atlas need to be acknowledged, particularly the significant extent of missing data, which was largely due to deficiencies in systematic reporting of standardized HF statistics at the national level. Data entry into the HFA Atlas survey was a voluntary contribution from the National Coordinators of the NHFS/HF working groups, for whom the task of obtaining national data was often made difficult by the absence of a universal definition of HF and the unavailability of reliable national statistics or registries. In many countries, the available data on HF epidemiology referred to select populations (e.g. older patients, specific geographical regions), and were therefore considered unrepresentative. Even when reliable sources were available, differences in the distribution of data between hospital and community settings and the different clinical types of HF further undermined international comparisons. There was limited information about national population characteristics which made presentation of age- and sex-standardized data for international comparisons impossible. Also lacking was a more nuanced analysis of the incidence and prevalence of different clinical types of HF. Finally, we were unable to collect reliable HF mortality data probably reflecting the variety of data sources used for capturing these data and variability in recording the cause of death.

The HFA Atlas will continue to evolve in order to establish a sustainable database on real-world HF statistics in the ESC member countries. It will be updated biennially and strategies to overcome difficulties in systematic capture and reporting of HF statistics will be developed through the HFA led training of NHFS representatives responsible for data collection. The second edition of the HFA Atlas will focus on providing a more detailed characterization of patient populations, epidemiology of different clinical types of HF, evolving demands in its management, as well as the burden and causes of mortality in HF patients. This will enhance the quality of the HFA Atlas and provide a basis for multiple cross-sectional analyses. Importantly the heterogeneity highlighted in this report will provide a stimulus for the establishment of HFA/ESC accredited Quality of Care Centres in order to enhance the treatment of HF and improve cardiovascular outcomes across ESC member countries.¹⁶

Supplementary Information

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

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Appendix

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