The heart of the matter: how Europe can shape the future of heart failure

Report from a virtual policy round table

9 December 2020



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Executive summary

On 9 December 2020, **Mr Billy Kelleher**, Member of the European Parliament, and the **Heart Failure Policy Network** (HFPN), hosted *The heart of the matter: how Europe can shape the future of heart failure*. This virtual policy round table featured leading figures in heart failure (HF) from across Europe. It sought to identify a consensus on future opportunities for supportive HF policies from the European Union (EU) and the potential for actions in HF to contribute to the growing debate on cardiovascular disease (CVD) policy in general.

POLITICAL CONTEXT

- Many challenges identified in HF policy and care are shared and interdependent between EU Member States. While primary responsibility for the organisation and delivery of health services lies at the national level, pan-European collaboration is likely to be crucial to address common challenges and improve the lives of the millions of people who are living with HF.
- The COVID-19 pandemic has drastically impacted care and outcomes for people living with CVD, including HF. The need to pool resources and coordinate pan-European learning, research, best practice approaches and policies in support of resilient, integrated and multidisciplinary services has never been more apparent.
- Protecting and maintaining the health and wellbeing of its citizens is an
 essential strategic remit for the EU, as the ageing population of Europe
 must remain economically productive to ensure long-term sustainability.
 Policy actions by EU institutions can complement national efforts and focus
 on preventing CVD, reducing inequality, meeting international health and
 sustainability targets, and increasing digitisation and multidisciplinary working.
- Few national and European policymakers recognise the extent of the burden of HF, in terms of its economic as well as societal impact. There is an urgent need to raise awareness of the syndrome and its fundamental linkages to key societal goals, such as reducing emergency hospitalisations.

PRIORITIES

The panel identified potential policy priorities that can guide the HFPN and key advocates in HF in their work with EU institutions. These priorities will lay the groundwork for an EU-level HF policy and advocacy strategy spanning 2021–23. They include:

- Increasing awareness and understanding of HF among policymakers to ensure that HF initiatives are considered for funding from the EU4Health programme, recently launched as part of the EU's recovery plan for Europe.
- **Investing in predictive analytics and developing robust European strategies** to prevent the development of HF.
- Encouraging collaboration between Member States to implement best practice care models and decrease regional and national disparities in the accessibility and quality of HF care.
- Supporting effective and scalable examples of innovation in HF to address shared challenges. This could include standardising NP testing across the EU, and exploring point-of-care testing and telemedicine approaches for HF.
- Allocating resources to support Member States' efforts to standardise and accredit the HF specialist nurse role.
- Incorporating HF initiatives into the existing targets and programmes of the EU, including efforts to meet the targets outlined in the United Nations' Sustainable Development Goals and the World Health Organization's Noncommunicable Diseases Global Monitoring Framework.

Why should heart failure be a policy priority?

Mr Billy Kelleher

Member of the European Parliament, Renew Europe Group

Across the EU, Member States are struggling to respond effectively to the challenge that HF and other chronic diseases pose to their societies and healthcare systems. Formal plans on HF vary dramatically between Member States, and we do not have a clear



European strategy. Concerted political action is more important than ever – the ageing of our populations and the increasing prevalence of chronic conditions are putting substantial pressure on healthcare systems.

'To produce meaningful change in heart failure, we must have strong engagement from clinicians and advocacy groups, and direct interaction with decision-makers at the national and European level.' The full impact of the COVID-19 pandemic has yet to be determined, but it will continue to affect healthcare provision in the years to come, particularly for people living with cardiac conditions. Therefore,

there is ample obligation for the EU to introduce policies to set the European norm for best practice care and prevention in HF, including measures to address known risk factors.

Barriers to political investment in long-term preventive healthcare strategies include short terms in political office, limited budgets and a lack of support for initiatives without an immediate pay-off. With further economic strain from the COVID-19 pandemic, we must educate policymakers on the burden of HF and its impact on healthcare systems to overcome long-standing policy inertia. There have been European success stories in other disease areas, such as cancer, and these lessons can be applied to our work in HF.

We need a political platform in the Commission and other EU institutions to increase awareness of HF and its burden among policymakers, and to develop and implement evidence-based strategies to address the syndrome in the short and long term.

Keynote speaker

Professor Giuseppe Rosano

President-Elect, Heart Failure Association of the European Society of Cardiology; Consultant cardiologist and Professor of Cardiology, St George's University Medical School, London; Scientific Director, Nutramed programme, IRCCS San Raffaele, Rome

establishing networks for HF management, education and research.

The mission of the Heart Failure Association (HFA) of the European Society of Cardiology (ESC) is to improve quality of life and longevity through better prevention, diagnosis and treatment of HF. One of the ways of achieving that is by



HF is a common syndrome. Data from the HFA Atlas, an initiative spanning 42 ESC member countries, show an estimated median prevalence rate of 17.2 per 1,000 people. Mortality from HF remains high; in chronic HF, median one-year mortality is estimated at 18%, whereas in-hospital mortality is estimated at roughly 8%. Despite

its poor prognosis and high economic and societal costs, HF is yet to receive the same political attention as cancer.

'Heart failure is as lethal as most forms of cancer.'

The COVID-19 pandemic,

lockdown measures and social distancing restrictions have had a drastic impact on care for people living with CVD, including HF. In England and Wales, CVD mortality increased between March and May 2020 compared with the historical average. Nearly half of these deaths occurred at home or in care homes and hospices. A study in Paris found a 100% increase in the incidence of out-of-hospital cardiac arrests compared with previous years. Studies conducted in London found a fall in the rate of hospital admissions for acute HF, an increase in the severity of HF symptoms at admission and greater in-hospital mortality. These findings suggest that during the pandemic people may not have sought medical attention or may not have received specialist support early enough.

The HFA recommends the development of Quality of Care Centres (QCCs), which are healthcare institutions that provide multidisciplinary HF care across primary, secondary and tertiary care. With input from national HF societies, the HFA has developed a multidisciplinary QCC model. The model includes primary care professionals, specialists in HF and other conditions, pharmacists, patients and their families, as well as psychological and social support. The HFA plans to accredit QCCs, to standardise the quality of HF care and promote professional collaboration, education and scientific exchange. The model is flexible and can be adapted to different country contexts.

The HFA is fully supportive of the HFPN in their efforts to expand HF advocacy and unify HF voices in Europe.

Expert presentations

Ms Marissa Ayano Mes, PhD

Programme Lead, Heart Failure Policy Network

The HFPN is an independent, multidisciplinary group of healthcare professionals, patient organisations, policymakers and other stakeholders from across Europe. The Network has been active since 2015, working to drive greater government recognition of HF. In 2018, we launched <u>The handbook of</u>



multidisciplinary and integrated heart failure care, in which we outline why this type of care is essential for HF. The handbook highlights known issues and key areas for improvement, and makes a European call to action based on measurable policy and system elements.

Our latest report, <u>Heart failure</u> <u>policy and practice in Europe</u>, sought to build on the 2018 call to action and create a foundation for political change. It was developed in consultation with more than 50 national experts in

'The state of heart failure policy and practice evidences a serious strategic deficit in European healthcare systems.'

HF and has been endorsed by more than 30 organisations, including professional societies and patient organisations. It offers a comprehensive analysis of national policy issues in HF, key gaps in care and examples of best practice in 11 European countries: Belgium, Denmark, England, France, Germany, Greece, Ireland, Italy, Poland, Portugal and Spain.

We found that few countries display the central strategic leadership needed to overturn systemic barriers and drive transformation in the field of HF. For example:

- Few countries have a strategy on HF, and where such plans do exist, they may lack funding, may need to be updated or may have stalled.
- Inconsistent reimbursement of diagnostic tests, such as NP testing, hinders the timely diagnosis of HF. In most of the countries analysed, NP testing was not reimbursed in primary care settings, highlighting a missed opportunity to diagnose HF before people present in hospital with acute HF.
- National shortfalls in key healthcare professionals and a lack of formal accreditation for HF specialist roles hinder the future evolution of the HF workforce. For example, the HF specialist nurse role is recognised through formal accreditation only in England, Germany and Ireland.

• Most countries lack national HF registries and audits that provide valuable oversight of HF care. Only England and Denmark have comprehensive and mandatory HF registries, but they do not consider primary care data.

Common challenges between countries include delayed diagnosis of HF and the absence of essential components of HF care in community and hospital settings. For example:

- Diagnosis of HF is hindered by limited awareness of the syndrome and suboptimal use of diagnostic tests.
- Specialist-led hospital care and discharge planning are not a consistent reality across Europe. There may be geographical variation in access to HF specialists, and specialist-led hospital discharge tends to be available only in centres of excellence or smaller units that have developed their own protocols.
- Essential components of HF care are missing in community settings. Cardiac rehabilitation, therapeutic education and psychological support are rarely provided for people living with HF.

Heart failure policy and practice in Europe identifies five urgent actions that are needed in most, if not all, countries we have analysed (see *Figure 1*).

Many of the challenges identified in this work are shared and interdependent between EU Member States. Therefore, pan-European collaboration is likely to be crucial to address existing challenges in HF and improve the lives of the millions of people living with the syndrome.

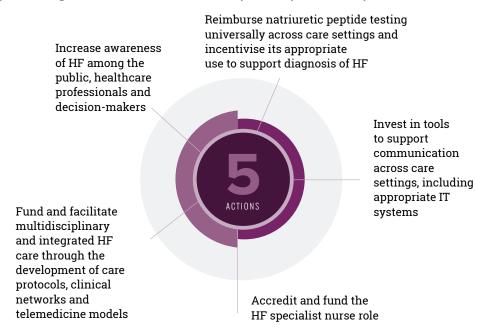


Figure 1. Five urgent actions identified in Heart failure policy and practice in Europe

Professor Damien Gruson

Head of the Clinical Biochemistry Department, Cliniques universitaires Saint-Luc, Belgium: Member of the European Commission's Expert Panel on Effective Ways of Investing in Health

NP testing is an important component of integrated HF care pathways. It offers significant opportunities to streamline HF



diagnosis and care, and its cost-effectiveness has been demonstrated in studies.

Measurement of NP levels by general practitioners (GPs) can support early detection of HF and appropriate prioritisation for further diagnostic tests, such as echocardiography. NP testing can also guide the ongoing management of HF and can be used in conjunction with other biomarkers to characterise HF type, which supports the delivery of personalised care and treatment. More recently, NP testing is being used to assess the efficiency of new treatments for HF. It has also been used more broadly to assist healthcare professionals in identifying people at risk of poor outcomes due to COVID-19 infection.

A recent survey by the European Federation of Laboratory Medicine found that NPs are the preferred biomarker for the diagnosis and management of HF. However, further efforts are needed to continue the implementation of personalised medical

decision limits for HF and the impact of confounding factors, such as kidney failure and obesity. In addition, NP testing needs to be standardised at the European level to avoid variability between measurements, potentially by using specific types of NPs.

'There is still a need to standardise biomarker testing, such as natriuretic peptide testing, at the European level.'

Point-of-care NP testing offers a fast method to monitor HF remotely. The performance of these devices will improve with the standardisation of testing and training of healthcare professionals, such as GPs and nurses, in their use. Future innovation and application of artificial intelligence (AI) in HF care may support early risk estimation, improve diagnosis and enhance precision care and outcomes monitoring. This would contribute to the long-term sustainability of healthcare services, for example, by reducing the overuse of laboratory testing.

Dr Ambrose McLoughlin

Chairman, HeartBeat Trust; former Secretary General, Department of Health, Ireland

The European Parliament, European Commission and Council of the European Union must recognise several key issues in HF.

The economic and social viability of the EU and its Member States is dependent on a healthy population, particularly in light of the COVID-19 pandemic. There are unacceptable variations in HF care across

of the COVID-19 pandemic. There are unacceptable variations in HF care across the EU, with innovative care models limited to a few centres of excellence and

'Policymakers across Europe have to seriously consider how they deal with the cost of preventable morbidity and mortality resulting from heart failure.' dependent on the initiative of healthcare professionals. The development of registries in HF, similar to those in cancer, will improve accountability for healthcare services and guide improvement.

There are three important Ps in HF – prevention, protection and prediction. From the

perspective of a policymaker, the ability to predict who is likely to develop HF is crucial for the development of strategic responses to the syndrome. Predictive analytics are part of the 21st-century response to growing health needs and improving patient outcomes. The EU must act to protect and maintain the health and wellbeing of its citizens, as the ageing populations must remain economically productive to ensure sustainability. The EU must take a lead role in preventive cardiology and facilitate the networking of research and academic experts across Member States to deliver appropriate solutions for the future of HF care. Large economic gains can be made through the encouragement of innovation and creation of jobs in the pharmaceutical, medical technology and medical devices industries.

Similar to the success of the plain packaging of tobacco products, there is an opportunity to drive meaningful policy change for HF in the EU that will ultimately benefit every one of its citizens.



Ms Penilla Gunther

Former Member of Parliament, Sweden; Founder and Programme Director, FOKUS Patient

HF can affect anyone at any age, not just people over the age of 65. It is closely linked to other health conditions, such as diabetes and stroke. Therefore, appropriate strategies to



prevent its development should be implemented at the European level. While there may be some initial resistance to strategic collaboration with the EU in Member States' national healthcare strategies, we can see that successful European policy

initiatives, such as those in rare diseases, can support Member States in improving diagnosis, care and access to information.

The European Commission and the European Parliament should take a similar approach in their response to HF, especially in light of the COVID-19 pandemic and its impact on people living with 'It is imperative that each Member State receives support from the EU to address heart failure and further improve care at the national level.'

the syndrome. Some Member States may already have tools in place to improve HF care, such as the quality register and national guidelines in Sweden. However, overarching support from the EU is needed to drive improvements in HF in a consistent manner across Member States.

Mr John F. Ryan

Director for Public Health, Country Knowledge and Crisis Management, DG SANTE, European Commission

Article 168 (protection of public health) of the Treaty on the Functioning of the European Union declares that Member States hold primary responsibility for the organisation and delivery of health services and medical care. Therefore, EU health policy



serves to complement national initiatives. It is directed towards improving public health, for example, by coordinating approaches to major health scourges such as CVD. Key challenges in tackling CVD include gender inequality in patient outcomes and inequality in disease burden within the EU, with a greater burden in newer Member States, such as Lithuania, Romania and Bulgaria. Healthcare capacity is also a major issue facing Member States as a result of population ageing and the demand it places on healthcare systems. The European Commission is interested in the prevention of health scourges. It has the power to legislate on products and services that impact cardiovascular health. For example, EU legislation on the regulation and advertisement of tobacco products supports efforts to reduce tobacco consumption and prevent diseases, including CVD. The Audiovisual Media Services Directive obligates Member States to encourage the development of codes of conduct for the advertisement of foods high

'I would invite the Heart Failure Policy Network to engage with the work that is going on in the European Union.' in fat, salt and sugar, in particular to children and adolescents. The Directive also restricts alcohol advertising and bans tobacco advertising.

The Commission is committed to supporting EU countries in their efforts to meet international

targets on non-communicable diseases (NCDs), such as CVD. These include the targets outlined in the World Health Organization's NCD Global Monitoring Framework and the United Nations' Sustainable Development Goals. Every year, the Commission liaises with Member States to discuss their priorities in NCDs and proposes and funds appropriate best practice interventions. The HFPN is welcome to suggest best practice examples identified in *Heart failure policy and practice in Europe* for presentation to the interested Member States, with financial backing by the Commission.

The HFPN and HF advocates should engage with the ongoing work of the Commission, including the European Health Data Space, EU projects on integrated care models and consultation activities for the Communication on the Pharmaceutical Strategy for Europe. The Commission also plans to expand its European Reference Networks (ERNs). These virtual networks involve healthcare providers from across Europe, and there may be potential for an ERN for HF.

The European Commission recently published its recovery plan for Europe to repair the economic and social damage caused by COVID-19 and lay the foundation for a more modern and sustainable EU. Over the next seven years, the budgets for the health programme and research will be approximately €5.6 billion and €8 billion.

Stakeholder responses and discussion

Following the presentations, Mr Ed Harding (Network Director, HFPN) moderated comments from the audience and a panel discussion, taking into consideration questions raised by attendees.

The importance of HF specialist nurses



Mr Ber Oomen

Member of the Advisory Committee, European Specialist Nurses Organisation

The European Specialist Nurses Organisation (ESNO) supports the work of the HFPN. Our aim as specialist nurses is to provide the best possible care for our patients, and for this to become a reality, education is essential. We must explore the educational gaps in our profession. Specialism in HF should be incorporated into standard and advanced nursing education, resulting in designated career pathways in HF.

Professor Ekaterini Lambrinou

Cardiology and Gerontology Specialist Nurse; Associate Professor, Cyprus University of Technology; former President, Association of Cardiovascular Nursing and Allied Professions, European Society of Cardiology

The specialisation of cardiovascular and HF nurses and its related legislation varies among European countries. To minimise disparities and standardise the specialisation, EU-level legislation should be introduced, similar to that in oncology nursing.

Professor Giuseppe Rosano

President-Elect, Heart Failure Association of the European Society of Cardiology

Nurses have a pivotal role in an HF care team. In the UK, it is thanks to the nurses that we can continue to provide excellent care. Unfortunately, that is not the case in other European countries. There is an urgent policy need to develop and standardise the HF specialist nurse role across the EU.

Innovation and novel therapeutics

Professor Dr Yigal M. Pinto

Head of Department of Experimental Cardiology, Deputy Head of Department of Clinical Cardiology and Scientific Director of the Heart Centre, Academic Medical Centre, the Netherlands

In the Netherlands, all people living with HF have access to specialist outpatient clinics. HF nurses working in these clinics can titrate medications and monitor care using remote devices. Data have shown that this type of HF management prevents unplanned hospital readmissions. In other countries, there may be geographical variation in access to HF specialist settings, which poses a barrier to high-quality care. In these settings, platforms that support the delivery of remote care models may be necessary for high-quality, ongoing HF care. Remote monitoring could become more widespread as the choice of HF medications grows, and it will be important to understand the best way to support people living with HF using remote monitoring approaches.

Professor Giuseppe Rosano

President-Elect, Heart Failure Association of the European Society of Cardiology

Novel therapeutics in CVD are not required to undergo revision by the European Medicines Agency (EMA), unlike novel therapeutics in neurology, diabetes and cancer. Recently, there have been significant barriers to the introduction of novel cardiovascular therapeutics at the national level. Sodium-glucose co-transporter 2 (SGLT2) inhibitors have been shown to reduce hospitalisation and mortality rates by as much as 20%, and healthcare professionals should have the ability to prescribe them. However, there are substantial variations and inequalities in the reimbursement of therapeutics in CVD compared with cancer, for example. Reimbursement of beneficial CVD therapeutics should be of political concern.

European Commission initiatives

Dr Bernarda Zamora

Senior Economist, Office of Health Economics, UK

It is important to understand how the European Commission is trying to implement the United Nations' Sustainable Development Goal for universal health coverage and harmonise its uptake across Member States. Also, how are they monitoring reimbursement and the impact on catastrophic health expenditure?

Mr John F. Ryan

Director for Public Health, Country Knowledge and Crisis Management, DG SANTE, European Commission

The EU is preparing a cancer plan that will be published in January 2021. The plan is divided into four chapters covering prevention, early detection, treatment and

access, and patient care pathways. The HFPN could look at this plan in terms of CVD to see where the linkages might be. The HFPN should also ensure that CVD is considered in the European Strategy for Data and that the importance of standard training curricula and specialist HF staff is recognised by departments that legislate on the European healthcare workforce.

As reimbursement is a national health competence, Member States are reluctant to engage in discussions with the Commission on the reimbursement of medical care and treatment. The Commission has processes in place in the EMA, where a number of products are subject to EU authorisation. Cardiovascular medications can be submitted to the EMA for review, but it is a national decision to reimburse and use them.

In terms of health economics, the HFPN should engage with the Organisation for Economic Co-operation and Development, as they are currently looking at best practices in the area of prevention.

Which elements of the HFPN strategy should we wish to present to the Commission and other EU institutions as a helpful and constructive vision for pan-European competencies in advancing HF?

- Ed Harding, Network Director, HFPN

Dr Ambrose McLoughlin

Chairman, HeartBeat Trust; former Secretary General, Department of Health, Ireland

The HFPN should connect with the European Health Data Space to help improve healthcare for people living with HF. The Commission's guidance on prevention is very innovative – delivering preventive measures for HF may require upskilling our healthcare workforce, including HF nurses. The HFPN should consider how to address the disparities in the burden of HF across the EU with the Commission, and work with the pharmaceutical and medical technology industries to explore solutions. We must strive for an EU in which there is equality in healthcare delivery.

Ms Penilla Gunther

Former Member of Parliament, Sweden; Founder and Programme Director, FOKUS Patient

Patients across the EU must have the same opportunities to access medications and care. FOKUS Patient is currently working with the European Charter of Patients' Rights, and we have learnt that the most common medications prescribed for HF are more than 40 years old. Better health can be achieved with access to new, innovative medications and this requires serious conversations about the financing of such therapies. Taking into account that Member States are at different stages of strategic readiness, how will an integrated strategy for HF and cardiometabolic disorders be taken forward at individual healthcare levels? What role can we, the HFPN and HF specialists, play in that?

- Sandra Mulrennan, Heart Failure Specialist Nurse, St Bartholomew's Hospital Heart Failure Service, London

Mr Ed Harding

Network Director, HFPN

The HFPN is actively pursuing a discussion with the European Heart Network, which has recently published a *Blueprint for EU Action* with the ESC, to see where HF can fit in. In 2021, the HFPN will have the opportunity to hold further policy briefs which may be useful in addressing this issue.

Professor Damien Gruson

Head of the Clinical Biochemistry Department, Cliniques universitaires Saint-Luc, Belgium

We must consider a standardised data set for HF care to ensure that clinical and laboratory information can be sent to electronic health records in a structured way across the EU. This is an important issue for the HFPN and ESC to consider, as it is fundamental to the interoperability of data structures between care settings as well as to the efficiency and sustainability of an integrated care system.

RESOURCES

Heart failure policy and practice in Europe

Heart failure and COVID-19

Population impact of heart failure and the most common forms of cancer: a study of 1,162,309 hospital cases in Sweden (1988 to 2004)

Place and causes of acute cardiovascular mortality during the COVID19 pandemic: retrospective cohort study of 580,972 deaths in England and Wales, 2014 to 2020

Out-of-hospital cardiac arrest during the COVID-19 pandemic in Paris, France: a population-based, observational study

The impact of COVID-19 on heart failure hospitalization and management: report from a Heart Failure Unit in London during the peak of the pandemic

<u>Temporal trends in decompensated heart failure and outcomes during COVID-19: a</u> multisite report from heart failure referral centres in London

Heart Failure Association of the European Society of Cardiology Quality of Care Centres Programme: design and accreditation document

Multidisciplinary team approach to heart failure management

Update on current practice in laboratory medicine in respect of natriuretic peptide testing for heart failure diagnosis and management in Europe. The CARdiac MArker guideline Uptake in Europe (CARMAGUE) study

Heart Failure Association of the European Society of Cardiology practical guidance on the use of natriuretic peptide concentrations

Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases

Recovery plan for Europe



To find out more about the Heart Failure Policy Network and this work, go to **www.hfpolicynetwork.org**

If you have any comments or questions, please get in touch at **info@hfpolicynetwork.org**

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