Heart failure policy and practice in Europe

Germany

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The Heart Failure Policy Network

November 2020

About the Heart Failure Policy Network

The Heart Failure Policy Network (HFPN) is an independent, multidisciplinary network of healthcare professionals, advocacy groups, policymakers and other stakeholders from across Europe. It was established in 2015 with the goal of raising awareness of unmet needs and seeking meaningful improvements in heart failure policy and care. Our aim is to help reduce the burden of heart failure – on people living with it, those supporting them, health systems and society at large.

All members of the HFPN provide their time for free. All Network content is non-promotional and non-commercial. The Secretariat is provided by The Health Policy Partnership Ltd, an independent health policy consultancy based in London, UK.

Acknowledgements

This report is based on desk research undertaken in 2020 and interviews with experts who provided insights as to the national context. Research, coordination, drafting, expert interviews and member consultations were led by Marissa Mes, Sara C Marques and Ed Harding, with research assistance from Emily Kell. The report was edited by Madeleine Murphy and Kasia Trojanowska, and designed by Catarina Correia Marques

The HFPN would like to thank the following experts for supporting the development of this country profile:

- **Klaus Edel**, Cardiologist; Director, Clinic for Rehabilitation and Prevention, Centre for Cardiovascular Diseases, Rotenburg an der Fulda
- **Winfried Klausnitzer**, Founder and Board Member, Herzschwäche Franken e.V.
- **Gabriele Meyer,** Heart Failure Nurse, South Nuremberg Hospital; Board Member, Herzschwäche Franken e.V.
- **Stefan Störk**, Cardiologist; Professor and Head of Department of Clinical Research and Epidemiology, Comprehensive Heart Failure Centre, University Würzburg and University Hospital Würzburg

We would also like to thank the Project Advisory Group for *Heart failure policy and practice in Europe*. For a list of members, please see **www.hfpolicynetwork.org/project/heart-failure-policy-and-practice-in-europe/**

Please cite this report as: Heart Failure Policy Network. 2020. *Heart failure policy and practice in Europe: Germany*. London: HFPN

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About Heart failure policy and practice in Europe

Heart failure (HF) is a common and complex condition responsible for extensive avoidable morbidity, mortality and healthcare costs. There is a clear need to advance HF policy and practice across Europe, and this requires recognition of the real challenge in each country.

To this end, the Heart Failure Policy Network (HFPN) has developed *Heart failure policy and practice in Europe* – a comprehensive analysis of key gaps and best practice both in HF policy and in clinical performance across 11 European countries. In this work, we investigate each country's progress in addressing the HF challenge, for example in terms of the existence and implementation of HF policies and the provision of multidisciplinary and integrated HF care. Findings are presented in an overarching report, which outlines the methodology for this work and includes a pan-European narrative, and in standalone country profiles with dedicated national-level analysis.

Urgent action is needed to address the growing burden of HF and ensure the sustainability of our healthcare systems. This country profile aims to assist HF advocates across Germany in engaging healthcare system leaders to demand constructive changes to HF policy and care provision, to reduce the impact of HF on people living with the syndrome, their families and carers, the healthcare system and society.

Heart failure in Germany

SUMMARY

The burden of heart failure (HF) in Germany is high, both in terms of pressures on the healthcare system and in terms of impact on people with HF and their families.[1-4] Some of this burden is preventable – in 2012, there were an estimated 246,000 preventable hospitalisations for HF.[5] During the COVID-19 pandemic, emergency admissions and interventional treatments for HF have fallen dramatically,[6] and this may have long-term implications for people living with the syndrome.

The burden of HF has yet to be widely recognised by policymakers, sickness funds (insurance organisations) and the public.[7] While the statutory health insurance approved a formal Disease Management Programme for HF in 2018, progress has stalled.[7 8] The lack of appropriate reimbursement policies has restricted the benefits offered by HF specialist nurses on care quality and outcomes.[9]

Centres of excellence are leading the way in terms of multidisciplinary and integrated care,[10] but management of HF is typically fragmented in mainstream settings. Improvements are urgently needed in diagnosis,[7 9] hospital care and discharge,[11 12] and community care, including therapeutic education and cardiac rehabilitation programmes.[13 14] This will help to ensure equitable access to high-quality care and better outcomes for people living with HF.

HF is a common syndrome, with some regions particularly affected

Between 4% and 6% of people in Germany live with HF.[15 16] Prevalence varies significantly between regions. In 2017, it was estimated to range from 3% in Rhineland-Palatinate to 12% in Bavaria, with more cases noted in rural communities and areas of high social deprivation.[16]

The true incidence and prevalence of HF in Germany may be higher than suggested by available estimates. National studies of HF typically rely on health insurance claims, which may underestimate the true burden of the syndrome by up to 55% due to issues with data collection and quality.[17]

While there are no recent estimates of HF incidence in the literature, the number of new cases per year was estimated at 524,000 in 2011.[15] This is likely to have increased, as prevalence of HF has risen across Europe in recent decades, mostly due to ageing populations and improved survival rates for cardiovascular and other long-term conditions.[18]

542,000

new HF cases per year

HF is associated with high expenditure

HF is responsible for significant costs in Germany. In 2012, direct costs were estimated at more than USD $5.3 billion (approximately €4.1 billion).[2] In the same year, HF-related indirect costs were estimated at USD $2 billion (approximately €1.6 billion).

€4.1bn

direct costs of HF

Patient outcomes are often poor, with frequent hospitalisation and high mortality

People living with HF have been reported to be at higher risk of depression than the general population.[19] HF is also linked with frequent and lengthy hospitalisation. It is the leading cause of hospitalisation in Germany:[17] in 2017 HF accounted for 464,000 hospital admissions.[3] The World Health Organization Regional Office for Europe identified HF as a major contributor to preventable hospitalisation in Germany, with an estimated 246,000 preventable hospitalisations in 2012.[5] Recent data from a large hospital network suggest that emergency admissions for HF declined by 22–28% during the COVID-19 pandemic, following a trend seen in other cardiac interventions.[6] This is concerning, as it may have a long-term impact on people living with HF.

HF is the third most common cardiovascular cause of death in Germany, after coronary artery disease and heart attack. In 2018, it accounted for almost 38,000 deaths – approximately 11% of deaths nationwide.[4] In-hospital mortality of people with HF is high, estimated at 9.5% between 2005 and 2016.[20]

Heart failure policy in Germany

Formal plans on HF

Germany has no national HF strategy

National authorities are yet to devote strategic focus to HF and cardiovascular disease more widely.[21] This is of concern, as a coordinated response at the national level is particularly important in Germany due to the high number of stakeholders involved in organisation of healthcare.[22]

Since 2000, the Federal Ministry of Health and the Association for Social Security and Policy Research have addressed aspects of health promotion and care in national health targets – plans that outline strategic objectives for key stakeholders in the healthcare system.[23] Individual health targets cover a number of topics including type 2 diabetes, breast cancer and smoking cessation. They are yet to be developed for HF or cardiovascular diseases more broadly,[21] potentially due to limited awareness among decision-makers of the challenges they represent.[7]

Investment in integrated HF models and facilitative tools

HF diagnostic tests are reimbursed, but current policies may not encourage their use

National experts report that essential tests to diagnose HF, including echocardiography and natriuretic peptide (NP) testing, are typically reimbursed across care settings.[7] However, some policy barriers may prevent the use of NP testing in primary care settings. Experts suggest that reimbursement may be too low to encourage NP testing, general practitioners (GPs) who request the test may see their income effectively reduced due to perverse incentives, or the cost of acquiring and maintaining the testing equipment may pose a barrier even when reimbursement is adequate.[7]

Progress has stalled on a national Disease Management Programme for HF

Policymakers approved a national Disease Management Programme (DMP) for HF in 2018 following calls from experts,[24-26] but it has yet to be implemented.[7 8] It was designed as a multidisciplinary care programme covered by the public health system (statutory health insurance),[27] which would support the national implementation of integrated HF care. The DMP aims to enhance patients' quality of life, reduce the overall burden of HF on people and healthcare systems, and improve management of co-existing health conditions (comorbidities).[26]

Experts have suggested that the most critical barrier to implementation of the DMP is disagreement over its content. For example, experts had called for the DMP to cover all people with HF regardless of HF type, but the approved DMP focuses solely on HF with reduced ejection fraction (HFrEF).[27] In addition, it does not outline the responsibilities of members of the HF care team at each moment in the care journey, nor options to tailor care based on patient needs and preferences.[7 28] The DMP recommends GPs as care leaders, as is standard practice for other DMPs, but the complexity of HF calls for close collaboration between GPs and cardiologists in joint management of HF, as highlighted by national experts and in guidelines.[7 29]

Inadequate information technology infrastructure hinders integration of care

Limited interoperability of information technology (IT) systems in Germany is a challenge. Systems typically differ between healthcare settings and medical information is often only accessible to different healthcare professionals when a direct referral is made between care settings.[11] National experts report that the integration of HF care remains difficult because an IT platform that incorporates the country's many systems and applications has yet to be developed.[7]

Development of the HF healthcare workforce

HF specialist roles are formally recognised, but there is a need for further investment in the HF workforce

In Germany, cardiology is a sub-specialty of internal medicine; internists pursue an additional two years of education to become cardiologists.[30] Continuing medical education in HF is provided by the German Cardiac Society (Deutsche Gesellschaft für Kardiologie) in the form of basic and advanced courses open to physicians and nurses with an interest in HF.[31]

The role of HF specialist nurses is recognised and accreditation is obtained following successful completion of a training course.[9] The courses are open to nurses with at least three years of clinical experience in cardiovascular disease, and are offered annually by the German Society of Health and Nursing Science in Essen and the Comprehensive Heart Failure Centre in Würzburg.[32 33] The programme in Essen combines 100 hours of face-to-face learning with an estimated 300 hours of self-study and coursework, while the programme in Würzburg consists of 120 hours of teaching and 80 hours of practical education.[33 34] A total of 41 nurses attended these courses in 2016/17, and 52 nurses registered in the following year.[34]

Despite recognition of the role, the full potential of HF specialist nurses is hindered by a lack of funding. National experts report that the HF nurse role is not covered by the public health system and, owing to the national shortage of nurses, hospitals typically fund these roles only if they include part-time work in other clinical departments.[9] In addition, nurses trained in HF may not continue working in the field because the local organisation of care does not always support this role.[7]

Guidance and local care pathways for delivery of quality care

A national HF guideline outlines multidisciplinary recommendations, implementation strategies and patient information

The National Healthcare Guidelines (Nationale VersorgungsLeitlinien) combine clinical recommendations in one guidance document for all healthcare professionals.[35] The guideline on HF presents a multidisciplinary consensus among healthcare professionals and people living with HF based on the national context and international guidelines, such as those from the European Society of Cardiology (ESC) and the American Heart Association.[29] The HF guideline not only makes clinical recommendations but also covers their implementation. The first edition was launched in 2009,[36] and the latest version, published in 2019, outlines recommendations for all care settings.[29] It describes the role of different members of the HF care team, including cardiologists, GPs and nurses, as well as pharmacists and palliative care professionals.

National Healthcare Guidelines are reviewed every five years and include a Patient Guideline that offers accessible information for patients and their families or carers.[37 38]

Comprehensive HF networks support integrated care

The German Cardiac Society has introduced a system of best-practice accreditation to support the integration of HF care (see *Case study 1*).

CASE STUDY 1.

Comprehensive HF networks to support integrated care

In 2016, the German Cardiac Society launched the HF-NET programme to link hospital and outpatient HF services through a system of accreditation.[25] To join the programme, healthcare providers must apply to the Society for accreditation as:

- an HF practice (typically an outpatient HF service led by cardiologists)
- an HF hospital (typically a local or district hospital with a multidisciplinary HF team)
- an HF supra-regional centre (typically an academic hospital equipped to care for complex or advanced HF).[39]

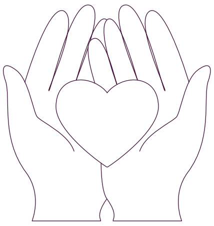
Accredited centres in the same region are connected within an HF network (HF-NET) through the implementation of care pathways and standard operating procedures.[39] Accreditation is renewed every three to five years.

As of October 2020, the HF-NET programme has accredited 51 HF practices, 42 HF hospitals and 34 HF supra-regional centres.[40] Notable challenges for the programme have included the recruitment of sufficient HF practices to expand the coverage of HF-NETs, and the implementation of standardised protocols and IT systems to support multidisciplinary and integrated ongoing care.[7]

Public audits of performance and high-level assessment initiatives

Hospitals publish basic data on HF, but deeper benchmarking of outcomes and a coordinated national HF audit are lacking

There is no national registry of HF care services able to provide a comprehensive analysis of performance and patient outcomes. Direct comparison between hospitals is only possible based on the number of HF cases seen each year. Hospitals are required to publish performance reports based on a standardised set of indicators,[41] but to date, this set does not include HF outcomes. Performance reporting is not mandatory in other settings, but credible voluntary schemes exist. The Institute of Applied Quality Improvement and Research has published a set of quality indicators for primary care and other ambulatory settings.[42 43] There are 12 indicators for HF covering a wide range of criteria for suspected and diagnosed HF, including diagnostic testing, regular follow-up and monitoring, evidence-based treatment and management of comorbidities.



Heart failure practice in Germany

Diagnosis

Diagnosis of HF is delayed due to limited awareness of HF, suboptimal use of diagnostic tests and long waiting times for specialist appointments

National experts report that limited public awareness of HF often leads people to dismiss their symptoms and not seek medical attention, while limited professional awareness contributes to delays in referral for specialist-led diagnosis.[7 9] Early detection of HF is also complicated by the typically older age of people showing HF signs and symptoms, which resemble those of other conditions or natural signs of ageing.[8] Local and regional initiatives led by healthcare professionals aim to support early detection of HF (see *Case study 2*), but national efforts to address the challenge are limited.

Insufficient use of diagnostic tests and long waiting times for specialist appointments frequently delay diagnosis of HF, according to national experts.[7 9] Despite the fact that NP testing is usually reimbursed in primary care settings, it is not consistently used by GPs, partially due to inadequate incentivisation. In addition, only about half of all people with suspected HF identified in primary care are seen by a cardiologist within two years.[7] The number of cardiologists varies considerably across Germany, meaning that waiting times for a specialist appointment can range anywhere from three to eight months.[8 9] These waiting times may frustrate or discourage GPs, potentially acting as a barrier to GPs making specialist referrals.[7]

CASE STUDY 2.

Empowering people with symptoms of HF to seek medical attention

A team of cardiologists in Rotenburg an der Fulda developed the German Heart Failure Test (Deutscher Herzinsuffizienz-Test, DeHiT) to empower people with symptoms of HF to pursue a diagnosis.[44] The questionnaire includes 12 questions on the presence of common HF risk factors and symptoms, including breathlessness, high blood pressure, extreme fatigue, fluid retention, swelling and heart palpitations. The questions help people determine whether HF is unlikely, possible or probable, and guide them in their decision to seek medical attention.[44]

The DeHiT is not a clinical decision-making tool or replacement for medical advice, but aims to empower people with HF signs and symptoms to seek help and receive a timely diagnosis. The questionnaire is available online[45] and as a smartphone application.[46]

Hospital care and discharge

There is significant national variation in the management of acute HF

While some hospitals have HF units with specialist cardiologists and nurses, this is not standard practice across Germany.[7 8] People hospitalised with acute HF may be seen by professionals with limited experience in HF, which can have a negative impact on care and outcomes.[47] In contrast, centres of excellence offer multidisciplinary care led by HF specialist cardiologists and nurses, often supported by additional funding secured through research grants or government programmes.[10]

Hospitals are required to offer structured discharge planning to all patients, including those with HF.[12 48] However, national experts report that in practice, post-discharge care often remains fragmented with insufficient communication across settings.[8] This may be due partly to the national process for data sharing, which requires that people being discharged give written consent to participate in discharge planning programmes.[12] If consent is not secured, essential information (such as medical history, treatment plan and laboratory test results) is not transferred to primary care professionals, which may hinder HF care in the community.

Key components of quality care in community settings

Continuity of care is common in community settings, but time constraints may affect the quality of care for HF

Historical health insurance data suggest that people living with HF tend to experience a high level of continuity of care in community settings,[11 15] and national experts confirm that this is still the case today.[13] Insurance claims from 2009 and 2013 show that most people living with HF had a follow-up appointment in ambulatory care at least once every quarter in the two years following diagnosis.[15] While more recent data are unavailable, this level of continuity is encouraging. However, national experts report that GPs typically have a heavy workload and limited time for consultations, and that this may affect the adjustment of HF medication and the quality of care provided.[7 8]

Cardiac rehabilitation is not consistently provided for people with HF

Cardiac rehabilitation programmes for HF are hospital-based and implementation is low.[8 14] In 2011, people living with HF made up only 2% of those referred for cardiac rehabilitation, while heart attacks and coronary artery disease accounted for 61% and 20%, respectively. Some centres of excellence specialise in cardiac rehabilitation for HF,[49] but other care settings tend to lack tailored programmes.[8]

Patient empowerment and therapeutic education are not standard practice in HF care

Self-care support for people living with HF is lacking in community settings.[9] To fill this gap, patient organisations have collaborated with hospitals to set up HF support groups in the community (see *Case study 3*). However, the demand for these support groups far outweighs their capacity.[13] The cost of implementing support groups and educational sessions has been identified as a potential barrier to patient empowerment and therapeutic education; the lack of reimbursement by the public health system means the cost falls solely on hospitals.

CASE STUDY 3.

Empowering and educating people living with HF through monthly meetings of patient support groups

Herzschwäche Franken e.V, the national HF patient organisation, holds monthly meetings of support groups for people living with HF, in collaboration with hospitals in Nuremberg, Roth and Rotenburg an der Fulda. Sessions are led by an HF specialist, often a nurse or cardiologist, and cover essential self-care topics such as dietary restrictions, sexual health and travelling.[9 13] Each session is followed by an hour of peer support and socialising. Attendance ranges from 10 to 50 people per meeting.[13]

A lack of clarity on the benefits and delivery of palliative care hinders its provision for people with HF

The public health system covers advance care planning and palliative care for most health conditions,[50] but there are several barriers to implementation of these elements of care in HF. Healthcare professionals report differing views on who should lead palliative care and when it should be initiated. Some may feel hesitant about initiating palliative care because they view it as failure of their treatment approach.[50] Others report that people living with HF and their families/carers do not fully understand the severity and prognosis of HF, and may view palliative care as 'a form of euthanasia'.[51] The absence of a clear structure for multidisciplinary collaboration in palliative care contributes to this lack of consensus and the limited provision of palliative services.[50]

Tools and methods to support multidisciplinary and integrated ongoing HF care

Centres of excellence offer various tools and methods to encourage multidisciplinary HF care, which are largely unavailable in other settings

Overall, the implementation of tools and working methods that can promote multidisciplinary and integrated HF care has been inconsistent – even in centres in the HF-NET programme. In theory, these centres are required to have standardised and integrated protocols for HF management,[39] but experts report that this is not consistent practice.[7]

Successful models of integrated care can be found in selected regions and centres of excellence (see *Case study 4*). Wider roll-out of these models could offer significant benefits. For example, a trial of a remote monitoring system for HF, which enabled information sharing and communication between GPs and cardiologists, demonstrated benefits in terms of hospitalisation and all-cause mortality among people with HF with reduced ejection fraction.[52] These findings became the basis for Telemed5000 – a programme funded by the Federal Ministry for Economic Affairs and Energy that aims to increase the capacity of telemedicine services for HF using artificial intelligence.[53] Telemedicine approaches are increasingly being explored as supplements to HF care provided by GPs and cardiologists and to address regional variation in care.[54]

CASE STUDY 4.

Comprehensive Heart Failure Centre

The Comprehensive Heart Failure Centre at Würzburg University was founded by physicians and scientists to implement novel approaches to HF research and care.[10] It is a leading centre of excellence that houses research groups, clinical and animal imaging, experimental laboratories and outpatient care facilities.

The Centre focuses on multidisciplinary collaboration, communication and education.[10] In addition to a strong research component, resident cardiologists collaborate with specialists in different fields to provide optimal care. The centre offers training in HF for nurses and junior physicians, and supports public outreach initiatives to improve awareness of the syndrome.[10 55]

The outpatient clinic at the Centre specialises in supporting people with complex HF from across the region.[56]

The way forward

HF poses a challenge to the sustainability of healthcare systems in countries across Europe, including Germany. It is a manageable – and often preventable – syndrome, yet it continues to affect a great number of people and its burden on the national health system and society is significant.

Programmes to address the growing burden of HF have been initiated, but progress has stalled and there is an urgent need to overcome inertia among policymakers, healthcare professionals and sickness funds.

SEVERAL ACTIONS ARE ESSENTIAL TO ADDRESS THIS CHALLENGE.

Increase awareness of HF among the public, healthcare professionals and decision-makers

Understanding of HF must be improved at all levels to overcome the inertia that currently surrounds it. Awareness campaigns aimed at the public may encourage people to see a healthcare professional as soon as they start experiencing signs and symptoms of HF. Professional societies can also support healthcare workers to expand their knowledge of the correct identification of the signs and symptoms of HF, and the accurate use and interpretation of diagnostic tests, via training opportunities. Targeted messaging for decision-makers is important to raise awareness of the challenge HF poses and drive the development of a coherent and robust national strategy.

Improve HF diagnosis through increased use of NP testing in primary care

Improving diagnosis of HF is a crucial step in a coherent response to the HF challenge. For this to happen, it is essential for primary care professionals to consistently use NP testing to prioritise referrals for specialist-led echocardiography. This will likely reduce waiting lists for specialist examinations and appointments. Professional bodies, particularly primary care societies, can also support the accurate use and interpretation of diagnostic tests for HF via training opportunities.

Amend and implement the DMP for HF, encourage participation in HF-NETs and ensure communication between the two initiatives

National guidelines recognise that HF is complex and therefore care must be multidisciplinary, integrated and flexible.[29] The DMP should better reflect this – it should include tailored pathways based on patient needs and preferences, comprehensive provision of cardiac rehabilitation, and joint management of HF by GPs and cardiologists. Regional governments and sickness funds should encourage or incentivise participation in HF-NETs to support accreditation of centres prepared to manage HF and ensure communication across care settings. The DMP and HF-NETs should be seen as complementary, as people with stable chronic HF can be enrolled in the DMP, while people with more complex or advanced HF can be managed within an HF-NET.[7]

Fund full-time HF specialist nurses to support patient-centred care

The benefits of nurse-led HF management and of involving multidisciplinary teams in HF care have been widely demonstrated in national research.[57 58] Regional governments and sickness funds must acknowledge this and cover the cost of HF specialist nurses working full time to meet growing demand and reduce the financial burden on hospitals. Full-time HF nurses will be able to improve care quality and patient outcomes by focusing on patient empowerment and therapeutic education, and coordinating care across hospital and community settings.

Develop a national HF registry or audit to allow for performance assessment and enable clear oversight of HF care

It is essential to regularly assess HF data to establish an accurate picture of performance and variation in care. This will help to identify gaps and best-practice approaches that may benefit from wider roll-out. Incorporating a short set of quality indicators for HF care into the hospital performance reports will enable benchmarking between centres and support a deeper understanding of regional variations in care.

Focusing on these priority areas will likely offer a cost-effective opportunity to improve life for people with HF, reduce hospitalisations and mitigate future pressures.

This is an investment in a more resilient and prepared health system, not just for HF but for chronic diseases more generally.

The creation and maintenance of national strategies and plans in HF is likely to be vital to long-term success. There are many strengths and existing resources within the healthcare system on which to build. Lasting success will require effective central oversight of inequalities and unacceptable variations, as well as long-term collaboration and commitment from decision-makers, patient representatives, healthcare professionals and the private sector. Failure to pursue the actions recommended in this report will allow HF to continue to challenge the sustainability of the healthcare system in Germany.

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