



# The clinical management of heart failure: What is the state of play in Europe?

This summary represents first findings of a literature review into the clinical management of heart failure (HF) at the European and national level in 12 countries: Belgium, Bulgaria, Finland, France, Germany, Ireland, Italy, the Netherlands, Romania, Spain, Sweden and the UK.

It is offered for discussion, as part of our work towards a comprehensive State of Play in Heart Failure report to be launched in Summer 2017.

**Many policy priorities are immediately apparent:**

## We have not got the care and management of heart failure right

- Outcomes for HF are worse than breast, prostate and bowel cancer.<sup>1</sup>
- HF is the leading cause of hospitalisations among people over 65 in Europe, and admissions are on the rise.<sup>2</sup>
- Readmissions are a major driver of all hospitalisations: one in four HF patients discharged from hospital is readmitted within one month,<sup>3,4</sup> and one in three will die within a year.<sup>2</sup>



## Best practice for HF is clear: namely multidisciplinary disease-management programmes

- Over 50% of unplanned admissions could be prevented<sup>5</sup> through better follow-up and transitions of care,<sup>2,6</sup> both of which are core elements of HF programmes.
- European Society of Cardiology (ESC) and other recognised guidelines endorse HF management programmes – led by multidisciplinary teams – as an excellent model for organising comprehensive, high-quality care.<sup>7</sup>
- HF management programmes can reduce mortality, hospital readmissions and associated healthcare costs, and improve quality of life for HF patients.<sup>7-11</sup>



## We know what to do, but we are not doing it

- Experts recognise that many people with HF are still not getting the right treatment.<sup>2</sup>
- Only seven of 26 European countries have organised HF programmes.<sup>9</sup>



## We must recognise and tackle policy barriers

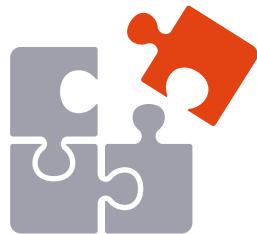
- The best practice models for HF programmes and multidisciplinary care that do exist are often stuck in ‘pilot’ mode because of logistic or institutional barriers, and are not implemented at scale.<sup>9,12</sup>
- Data on many aspects of HF programmes are poor, suggesting public oversight, accountability and system improvement efforts are currently compromised.
- Poor communication among professionals undermines multidisciplinary working for HF in everyday settings, typically between primary and hospital-based care, but also across other professional roles.<sup>13-15</sup>
- Reimbursement constraints, workforce shortages, and other structural issues continue to hold back multidisciplinary working, undermining any policy commitments where they exist.<sup>16-19</sup>



# Focus: Multidisciplinary disease-management programmes in HF

## What is it, and why is it important?

**HF is a complex condition requiring careful management.** Many HF patients will be first diagnosed in the acute setting (i.e. in a medical emergency). However, prior to discharge, ESC guidelines state that patients should be enrolled in an HF programme, and that '*the goal of management of HF is to provide a “seamless” system of care that embraces both the community and hospital throughout the health care journey.*'<sup>7</sup>



For example, HF programmes may typically span discharge planning, specialist follow-up, long-term monitoring, patient therapeutic education, cardiac rehabilitation, optimisation of medical treatment and psychosocial support, among other aspects of care.<sup>7</sup>

HF programmes therefore require delivery by multidisciplinary teams (composed of cardiologists, primary care physicians (GPs), nurses, pharmacists, physiotherapists, dieticians, social workers, surgeons, psychologists and so on).<sup>7</sup> They may be best delivered from **HF clinics (or units)**, led by specialist cardiologists and nurses, but other models are also possible.

**Evidence has shown that HF programmes can drive better care processes, such as follow-up after discharge.<sup>20</sup> They also improve outcomes, such as reduced mortality, hospital readmissions and associated healthcare costs, and improve quality of life for HF patients.<sup>7-11</sup>**



**KEY FINDING:** The management of HF across Europe is suboptimal, with great variation as to whether HF programmes exist, and which elements are performed to a high standard. While positive examples exist, few programmes are formalised and scaled-up at a national level. A 2006 European-wide study found that only seven of 26 European countries have organised programmes for HF care and follow-up.<sup>9</sup>

Although a more current comprehensive study is overdue, this finding is corroborated by more recent national data. For example:



In **Belgium**, despite efforts to set up HF programmes,<sup>21</sup> a study found that less than 30% of responding hospitals had one.<sup>17</sup>



In **Germany**, HF programmes are only open to those patients with HF *and* coronary heart disease.<sup>22-24</sup> As a result, approximately 40–50% of all HF patients in Germany are excluded.<sup>25</sup>



In **the Netherlands**, HF programmes have demonstrated many successes, but only exist at a third of hospitals.<sup>26</sup> Of these, there is variation as to which services are offered within different programmes.<sup>27 28</sup>



In **Spain**, a study of 62 active HF units and/or clinics showed that there is great variation in how each is organised and services delivered. In addition, only 29% of the units had a full-time trained nurse, and only 16% involved collaboration with internists, geriatricians, psychologists and social care workers.<sup>29</sup>

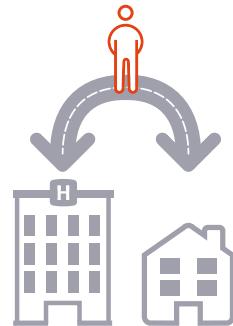


In **Ireland**, of the 11 national HF units, six operate in Dublin, with only five across the rest of Ireland.<sup>30 31</sup> This uneven distribution has caused regional variation in survival and rehospitalisation trends for HF.<sup>16</sup>

# Focus: Discharge planning and specialist follow-up

## What is it, and why is it important?

Discharge from hospital is a critical moment in comprehensive, multidisciplinary HF care. Even if a patient is judged fit to leave hospital and continue care as an outpatient, medical reviews must be set and conducted, and ongoing treatment adhered to. Patients may face a steep physical, psychological and therapeutic adjustment,<sup>32-34</sup> and many will remain vulnerable in the coming days and weeks.<sup>16</sup>



The 2016 ESC guidelines recommend that all patients are reviewed by their GP within one week of discharge, and seen by the hospital cardiology team within two weeks of discharge if feasible.<sup>7</sup> National guidelines in Germany, England and Wales make similar recommendations.<sup>35-36</sup> To achieve this, careful planning and effective multidisciplinary networks are an important element in ensuring patients are not 'lost'.

**KEY FINDING:** Despite examples of best practice, the general picture is of inconsistent and fragmented follow-up. For example:



In **Italy**, follow-up is typically fragmented between any of the GP, the ambulatory specialist, hospital ambulatory specialists or private cardiologist. Each provides a one-off consultancy rather than a complete continuum of follow-up care.<sup>37</sup>



In **Scotland**, cardiology patients stated that poorly managed discharge from hospital, poor information and lack of follow-up in the community were the main challenges to their care.<sup>38</sup>



In **France**, only 29% of patients attend a visit with a cardiologist in the first month after hospitalisation.<sup>39</sup>

**KEY FINDING:** Good practice is possible, but consistency remains the key challenge.

For example:



In **the Netherlands**, a 2003 survey found that hospitals with HF programmes performed well at follow-up – 73% of patients were offered follow-up by a cardiologist and 99% were offered follow-up by a HF nurse.<sup>20</sup> However, such programmes only covered a third of hospitals.<sup>26</sup>



In **England and Wales**, 70% of HF patients discharged from hospital had cardiology follow-up, and 60% had HF specialist nurse appointments post-discharge.<sup>6</sup> However, these rates are higher for those admitted to cardiology wards, at 75% and 68% respectively – suggesting inequalities for other patients.<sup>6</sup>

# Focus: HF specialist nursing

## What is it, and why is it important?

ESC guidelines are clear that multidisciplinary team working is essential to HF care and management, and specialist nurses have a vital role in this. They can offer much-needed continuity of care across the entire care pathway, and act as a key contact and coordinator for patients before and after discharge, including patient monitoring, support and referral.<sup>7</sup> They are also widely considered a cost-effective and economically sustainable option.<sup>40</sup>



HF specialist nurses may operate in inpatient or outpatient settings (including HF clinics), at primary care clinics, or via home visits. There is good evidence that HF specialist nurses can help to reduce hospital admissions and improve quality of life and adherence to treatment for HF patients.<sup>19 41-46</sup>

**KEY FINDING:** Generally, HF specialist nursing roles are poorly developed across Europe. For example:



In **France**, the HF specialist nurse role has not been developed and is not recognised or remunerated, and there are no formal education programmes.<sup>47</sup>



In **Bulgaria**, there are no HF specialist nurses and an overall low number of general nurses available compared with other EU averages (due, in part, to migration of health workers).<sup>48</sup>



In **Spain**, a 2011 study noted a lack of full-time nursing staff even in specialist centres: 20 of 44 centres lacked a full-time nurse.<sup>49</sup>

**KEY FINDING:** While no country yet offers comprehensive HF specialist nursing, there are success stories and many examples of large-scale delivery, albeit with ongoing challenges. For example:



**Sweden** has paved the way for specialist nursing in HF management. Nurse-led HF clinics began in 1990 and have since spread to almost 70% of Swedish hospitals.<sup>50</sup> Nurses are often responsible for providing follow-up to patients after hospitalisation, including via telephone counselling.<sup>50</sup>



In **England and Wales**, the National Heart Failure Audit showed that 60–68% of patients admitted to hospital for HF have a follow-up with a HF nurse.<sup>6</sup> However, in England, HF nurses have been largely supported by charities and independent funders.<sup>19</sup> Regional inequalities in access to HF nurses are noted in Wales, and those nurses that exist may be handling more than twice the intended caseload.<sup>18</sup>



In **the Netherlands**, where HF programmes exist, HF nurses are responsible for physical examination in 90% of programmes, and are involved in optimising medical treatment in 65%. Despite this, their remit is not clearly defined at a national level and there is a lack of formal education for the role.<sup>20</sup>

# What are the barriers?

**In practice, multidisciplinary working is often challenging for many reasons.** Commentators from across Europe note that levels of care are often determined by local arrangements, and reported problems include:

- Poor communication and inconsistent use of terminology<sup>37</sup>
- Lack of coordination, leading to poor discharge planning and follow-up care<sup>38 51</sup>
- Low numbers of HF units and limited availability of specialist nurses in those units<sup>52 53</sup>
- Lack of guidelines<sup>37 54</sup>
- GPs managing patients alone, without the resources of a multidisciplinary team.<sup>55</sup>

Mindsets and culture are also important, yet some healthcare professionals may not value the benefits of multidisciplinary working.<sup>9</sup>

But there are certain things we can do, and case studies of good practice across Europe.

# What can be done?



## Governments must define, and promote, a national vision for multidisciplinary care and HF programmes

Few countries have led a central vision or definition for multidisciplinary care – what it looks like to the patient, what the different professional roles are, how guidelines are to be translated into practice, and what goals are to be met and measured. Our review of the literature suggests that confusion persists in terminology, roles and responsibilities.



However, there are some positive examples in this area:

### BEST PRACTICE CASE STUDIES



In **Ireland**, the 2010–2019 national cardiovascular health strategy recommends multidisciplinary programmes for HF patients and outlines the core components of a multidisciplinary team. This includes consultant physicians (e.g. cardiologists) and clinical nurse specialists, as well as allied health professionals such as physiotherapist, occupational therapist services, dietician, psychologist/neuropsychologist, pharmacist and social worker services.<sup>56</sup> It also features auxiliary staff such as community liaison coordinators and database managers.



In **England** and **Wales**, the National Institute for Health and Care Excellence (NICE) guidelines on chronic HF in adults recommend that care is delivered by a multidisciplinary team with an integrated approach across the healthcare community.<sup>57</sup> NICE also recommends that a follow-up clinical assessment is undertaken by a member of the specialist HF team within two weeks of the person being discharged from hospital.<sup>36</sup>



## We need transparency and accountability in HF management programmes



**Data on the existence and performance of HF programmes are lacking across Europe.** The published literature is patchy and largely outdated. This suggests that oversight from policymakers, and accountability to patients, is severely hampered.

**Ideally, national data and monitoring systems would help to audit HF management for all patients.<sup>2 58</sup>** Yet few countries systematically record key elements of HF programmes – even those where there is significant good practice, such as the UK<sup>6</sup> and Sweden.<sup>59</sup> It also seems rare for individual HF programmes to build-in evaluation of outcomes.<sup>9</sup>

**At a minimum, key indicators for access to and uptake of management programmes, specialist nurses and follow-up after discharge would offer great insight.** This should be coupled with vital health outcome performance measures to help assess quality and impact,<sup>60</sup> and an assessment of the patient's health-related quality of life.<sup>7 61 62</sup>



### BEST PRACTICE CASE STUDIES

In **England** and **Wales**, the National Heart Failure Audit<sup>6</sup> is used to measure the implementation of NICE and ESC guidelines on HF. Findings have been used by several national bodies to scrutinise implementation, outcomes and effectiveness of guidelines. The audit includes indicators to measure and improve the quality of HF care in clinical practice, and systematic monitoring of follow-up care.

In **Ireland**, the Ministry of Health has announced a national needs assessment for HF cardiac rehabilitation services to look at regional inequalities in survival and rehospitalisation in HF.<sup>16 63</sup>



## We must invest in sustainable models of care for HF



In **Belgium**, there is no public funding for multidisciplinary care, so individual hospitals must pay for HF specialist nurses' training.<sup>64</sup> Provision of multidisciplinary care is always voluntary, so there is a need for better reimbursement and accreditation of HF specialists.<sup>64</sup>



In **the Netherlands**, insurance funds have discretion over the implementation of HF programmes.<sup>27</sup> Currently, only 10% of HF clinics are reimbursed, so healthcare organisations and life science industry often 'top up' funding.<sup>65</sup>



In **Scotland**, the number of specialist nurses is actually decreasing, falling short of national guidelines by 10% on average, with even lower ratios in rural areas.<sup>66</sup>



### BEST PRACTICE CASE STUDY

In **France**, the national insurance fund has been developing a HF follow-up management programme in collaboration with GPs, which has been implemented in five regions.<sup>67</sup>

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