PumpingMarvellous
for heart failure patients

Heart Failure Nurse Audit

Putting heart failure into context

THE IMPORTANCE OF PUTTING HEART FAILURE NURSING TEAMS INTO CONTEXT

It is important to understand heart failure and its context in the health system. We have provided a simple reference guide in the form of an infographic which demonstrates what it is, typical symptoms, aetiologies, health economic burden and guideline-driven best practice around the care of heart failure patients in the UK.

PDF

Click here!

The Pumping Marvellous Foundation

The Pumping Marvellous Foundation is the UK's heart failure patient charity and seeks to promote the highest quality of care for patients, and advocates for the patient at all levels. Please view our website at the Pumping Marvellous Foundation.

INTRODUCTION

The Pumping Marvellous Foundation is the UK's heart failure patient charity. The charity has frequently highlighted the significant role of the Heart Failure Specialist Nurse (HFSN), as a result of the feedback that they have received from patients and carers, who express the tremendous care and support that they receive from their HFSN. The All-Party Parliamentary Inquiry (APPG) into Heart Failure in 2016[1], took evidence from patients and organisations, who expressed the benefits of the role, finding that practitioners were highly skilled individuals who have shown to reduce morbidity and mortality and are able to provide patients and their carers with holistic and effective care[2]. However, it became apparent that there is variable access to Heart Failure Specialist Nurses across the country, and anecdotal evidence that posts are being lost due to decommissioning, failure to recruit or nurse retirement. There is no definition of the role and the exact number of nurses, where they are located and their skill levels are not known. A key recommendation of the inquiry was that numbers and localities, qualifications of Heart Failure Specialist Nurses should be obtained so that planning can take place to ensure that the work force is able to meet demand.

The Pumping Marvellous Foundation held a heart failure summit in 2017[3], comprising of multi-stakeholders who looked at all ten recommendations of the inquiry. Three areas of priority were identified, including that related to the role of the heart failure specialist nurse. The Foundation made the commitment to lead and implement the APPG recommendation and set in motion the first national Heart Failure Specialist Nurse audit in England. Originally, the audit proposed to look at England alone but widened the scope to include the devolved nations in order to establish a picture of the provisioning of services across the whole of the UK.

Click here!

All-Party Parliamentary Group on Heart Disease - Focus on Heart Failure 2016

Recommendation Six: Health Education England should work with the Royal College of Nursing, Nursing and Midwifery Council and others to build a picture of the number, location and qualifications of Heart Failure Specialist Nurses (HFSNs) and other Cardiac Nurses treating people with heart failure; and urgently develop plans to ensure that the workforce is sufficient to meet demand.

METHODOLOGY

The Pumping Marvellous Foundation obtained funding from Boston Scientific, who provided an independent educational grant to finance the project. Two groups were drawn up to lend steer to the project. The charity, being a patient led organisation, believed that the project should be led by a patient steering group who were able to bring a patient focus to the project. Secondly, the project should be supported by a clinical technical team led by Professor M R Cowie and Lynda Blue - who led the first instrumental research into heart failure specialist nursing in the UK - with further members representing Heart Failure Specialist Nurses, Cardiologists and General Practice.

It was decided that the audit would be conducted via an online tool and would sit within the Pumping Marvellous Foundation's own website. Consisting of a drop-down menu approach, it was felt that teams would find it quick and easy to complete.

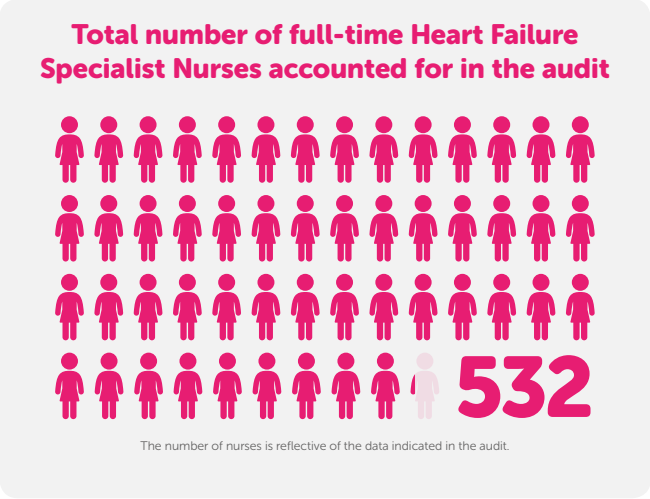
The audit focused on five distinct areas:

- Employer organisations, area of practice, case load management
- Access to diagnostics and monitoring
- Grading and skills within teams
- Access to a multi-disciplinary team and supportive services
- Qualitative feedback as to current progress and concerns within teams

With no existing current directory of Heart Failure Specialist Nurse teams, how to get the audit to the nursing community was a significant challenge, compounded by the fact that services appeared to be undergoing a constant change in employing organisations. By the use of social media, clinical nursing groups, the wider cardiology community and internet search facilities, a draft directory of organisations was produced which enabled teams to be contacted and asked to complete the audit.

Implementation of Audit Info

The audit commenced October 2017 and completed January 2018. In total, 165 organisational teams (an organisational team may consist of a number of sub-teams) completed the audit across the UK. This was believed to be approximately 75-80% of teams, accounting for 532 full-time nurse equivalents.



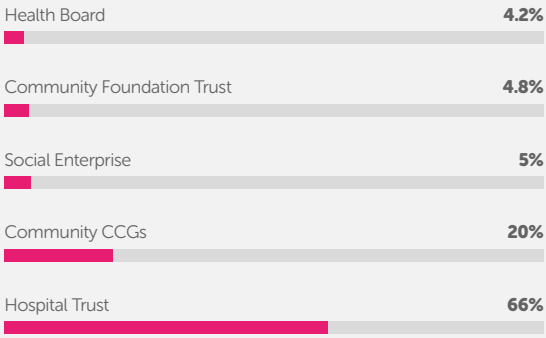
SECTION 1

66% of teams were employed by Hospital Trusts, a further 20% employed by Clinical Commissioning Groups, with the remaining teams employed by Health Boards of the devolved nations, social enterprises or Community Foundation Trusts. Teams may have been employed by a Hospital Trust, however practised purely in the community.

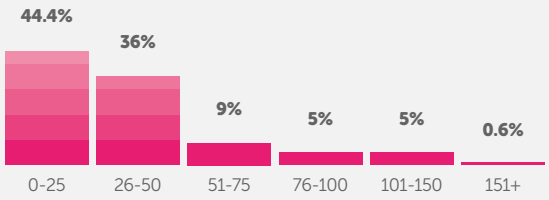
The majority of teams practised within a defined area i.e. hospital (33%) or community-based (38.5%). A number of teams provided more of an integrated approach to care, being hospital-based but providing an outreach service to the community (17%) or based in the community and providing an in-reach service (11.5%). Community care consisted of community clinics and a home visiting service, hospital teams conducted the reviewing and influencing of the management of patients or reviewing and managing patients, frequently a combination of approaches were adopted. All hospital teams undertook outpatients clinics.

60% of teams managed all types of heart failure, that is heart failure with reduced ejection fraction (HFrEF) or heart failure with preserved ejection fraction (HFpEF). 40% of teams managed patients with HFrEF only. The management of patients with HFpEF was a cause of concern for many teams due to three primary reasons. Firstly, that patients with HFpEF were often complexed with limited treatment options. Secondly, that teams were concerned that they were failing to provide a service for these patients and thirdly, how would they be able to incorporate these patients into their already extensive caseload.

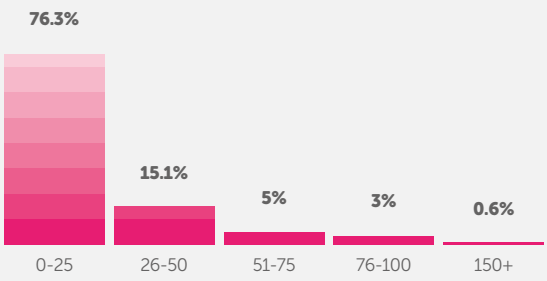
Description of employing organisation



Approximately how many referrals do you get per month?



Approximately how many patients do you discharge per month?

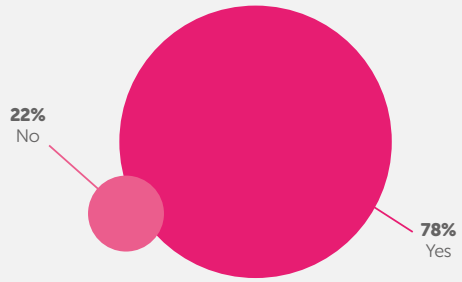


Teams stated that HFSN full-time equivalent managed a considerable active caseload with 32% managing between 101-250 patients and 33% between 250-500 patients. The majority of teams received between 0-25 (44.4%) referrals per month with 36% receiving 26-50 referrals per month. 76.3% of nurses were able to discharge 0-25 patients per month with 15.1% discharging 26-50 patients per month. Caseload management was of significant concern to teams and meeting ever increasing demand without additional resources was highlighted repeatedly. Furthermore, nurses were aware that demand would continue to grow. 42% of teams had no designated discharge pathway, which raised the concern of disjointed and fractured patient care.

SECTION 2

Teams had a considerable level of autonomy with 73.4% of teams able to admit patients directly into hospital, with a further 9.6% admitted after discussion with a Cardiologist or medical team. 100% of teams were able to order echocardiography, Holter monitoring and ECGs.

Does your team have access to natriuretic peptides for diagnostic purposes?



78% of teams had access to natriuretic peptide testing for diagnostic purposes, this was reduced for ongoing monitoring with 58.7% having access. 22% of teams had no access to diagnostic natriuretic peptide testing. The wider concept of access to natriuretic peptide was raised by the APPG[1] which recognised that this was a significant issue with access to testing variable across the country, believing that up to one third of GPs and Hospital Trusts have no access to natriuretic peptide testing.

SECTION 3

The majority of teams consisted of Band 6 or 7 Nurses, with 39 teams stating they had a Band 8A Nurse who led their team. 90% of teams stated they had at least one member of the team who is a non-medical prescriber. 70% of Nurses being non-medical prescribers. Over 80% of teams had Nurses who held clinical examination skills either at degree or master level. 85% of teams had accessed a heart failure module at an academic institution (Appendix 1). All Nurses had undertaken advanced communication skills training.

74% of teams stated that they had support from their employers for continuing education or continuing practice development to support their role. 96% of teams stated that they were members of the British Heart Foundation Alliance, which entitled them to apply for financial support from the British Heart Foundation to assist in ongoing development.

75% of teams used competency frameworks that have been developed locally or by the British Society for Heart Failure.

In terms of clinical support, 70% of teams had access to a Cardiologist, with 33% of teams stating that this was a Cardiologist with sub-specialist interest in heart failure. 33% of teams had access to Renal Physicians and a further 33% having access to a Physician for the elderly.

Recruitment and retention was addressed in the audit, with 14% of teams stating that they had difficulty in recruiting Nurses despite advertising and 16% stating that they had taken part in workforce planning. 66.5% of teams stated that they had not had any issues relating to these areas. With this being the first ever national look at Heart Failure Specialist Nurse delivery, we were unable to state if numbers have fluctuated over time. However, a baseline has now been provided and, with the development of the platform 'Just Heart Failure', Heart Failure Specialist Nurse teams will be able to update their own data. Once a year, teams will be asked to update their data, providing a current picture of Heart Failure Specialist Nurse teams in the UK.

SECTION 4

The make-up of a Multi-Disciplinary Team (MDT) varied, however, 84% of teams did have access to an MDT, with 67% of teams having palliative care representatives or having a physician with a sub-speciality in heart failure (44%). Only 5% of teams had representation from psychological services within their MDT.

Access to supportive services highlighted that 86.5% had access to palliative care and only 33% of teams stated that they were able to arrange IV/SC diuretic therapy in the home setting. 64% of teams said they had access to ambulatory care. 72.5% of teams were able to refer patients to cardiac rehabilitation, 24% of those teams stated that this included a home-based programme. Of note, the question asked related to 'access to', rather than specifically commissioned services for heart failure.

Patient information was provided by either the British Heart Foundation or the Pumping Marvellous Foundation, with over 90% of teams signposting patients to the respective charity's websites. 20% of teams offered patients a support group, with only 8.5% of teams having a patient representative in their service. Most teams did not take self-referrals (62.5%). If patients were discharged, 82.4% of teams facilitated patients to be able to refer themselves back into the service.

Do you have access to a Multi-Disciplinary Team (MDT)?

84% Yes

16% No

N.B. Our MDT in the audit was defined as; 1. Physician with sub-speciality of heart failure, 2. Heart Failure Nurse, 3. General Practitioner

QUALITATIVE FEEDBACK

Teams were asked three questions. Firstly, what were they most proud of about their service? Secondly, what the greatest pressure was within your service? Thirdly, what did they think was the most urgent aspect of heart failure to address?

HFSN teams stated how they have managed to grow and improve services made them most proud of their services. They described themselves as dedicated, committed, passionate, autonomous practitioners. This made the role of the HFSN enjoyable, they felt valued, got job satisfaction by providing patient focused, holistic, and high-quality care. Receiving excellent feedback from their patients and other professionals was a reoccurring theme. These sentiments were rated higher than being able to prevent hospital admission and provide evidence-based practice.

"I love my job and like being able to make a difference to patients and families by being able to explain their condition and by supporting them and by providing appropriate treatment."

- STP Midlands & East

"We have managed to continue to develop the service to meet the changing needs of our patients despite financial restrictions."

- STP Cornwall and Isle of Sicily

The biggest concern within the teams was related to being able to meet increasing demand and the difficulty in managing an increasing and complex caseload, especially those patients who were elderly and frail. This was compounded by teams stating that there was little evidence of further funding to develop services. Time restraints, limited access to administrative support and reduced access to PCs/Macs and mobile devices, office and clinical space was also highlighted.

"Service demand. The service and referrals have continued to grow; however, we are told there is no more money for extra staff. Therefore, we have had a waiting list for 18 months and no longer meet our KPIs."

- STP Hampshire and the Isle of Wight

They believed that the most urgent aspect in relation to heart failure delivery was to meet an increasing demand and develop staff to meet the complex caseload that they were facing. They believed the optimisation of therapy was an urgent aspect to address. They wished to see more services being able to deliver IV/SC diuretic therapy in the home setting and further development of HFSN community services and Primary Care.

"Desperately need more nurses in the community and hospital-based to deal with all aspects of heart failure in a timely manner."

- STP Surrey Heartlands Health and Care Partnership

"Patients who are currently managed in the community but are not up-titrated to prevent admission and deteriorated. If we don't tackle this now, then our caseloads will just increase and increase."

- Scotland

"Lack of support in primary care for patients with heart failure."

- Wales

LAUNCH OF PLATFORM

One of the primary reasons for the Heart Failure Specialist Nurse audit was to bring visibility to patients of Heart Failure Specialist Nurse teams in the UK. Through our social media community platforms, we know that patients value the Heart Failure Specialist Nurse second only to their primary carer (caregiver) or family member. The mapping project was significant, but the Pumping Marvellous Foundation wanted to bring the data alive and have a value to patients and their families. We decided through considerable consultation that building a consumer-friendly platform was the way to go; a platform that did not remind the user all the time that it was about heart failure.

The design reflects the expansiveness of the audit from coast to coast to the length and breadth of the UK, with representation across all the domains of England, Wales, Northern Ireland, Scotland and the Channel Islands. It is soft to the eye and informative. Its name "Just Heart Failure" personifies its purpose, just about heart failure.

Anybody can search for their local heart failure team and understand the service from the patients' perspective. The elements of data from the audit on public view are important to the patient but this constitutes no more than 5% of the actual data.

Patients are also able to rate their heart failure teams through a patient survey option. This will enable the Pumping Marvellous Foundation to further understand, from the patients' perspective, opportunities to develop service provision offerings. Feeding patient insights into the system has never been so important.

The platform provides teams with a secure log-in console where they can amend their whole audit details. This ensures that the data remains relevant and current. Teams that may have been missed have the opportunity to directly create an account, complete the audit questions and upload their team image. The team console page also has a resource area where important information can be accessed. We see this console as an opportunity to further bind teams and team members together to increase the community effectiveness. We know this works as we run a Facebook platform for HFSNs which has developed into a vibrant community run by the Nurses. With further investment, we will have the ability to personalise teams and members' experiences. We can just imagine what value this could bring to the patient where information is shared and learnt.

GOING FORWARD

This has been the first UK based Heart Failure Specialist Nurse audit and provides, for the first time, a current picture of HFSN teams in the UK. It is hoped that teams who did not take part in the original audit will now take the opportunity to submit their data.

The "Just Heart Failure" platform has the ability to affect how we look at heart failure across the UK and beyond. With the right investment, it may even "uberise" what happens to heart failure for the benefit of the patient. The platform was built as a modular design. The opportunities to invest and develop conversations, understanding the system and building further insights are considerable. Opportunities exist to bring out into the open provisioning of further services where improvements and investment may be made.

The data has already begun to generate significant interest with several clinical networks asking for anonymised data for their area, to identify services and address equity of care.

The Pumping Marvellous Foundation will now look to build on the audit by approaching relevant NHS bodies to highlight the current and ever-increasing demands of heart failure on the NHS and how the role of the HFSN can have a significant positive benefit to the patients, carers and the NHS. As the APPG recognised, we need to address the issue of a workforce that is able to meet that demand.

The significance and benefits of the Heart Failure Specialist Nurse are constantly raised by patients and carers. The Foundation would like to take this opportunity to thank all the HFSN across the UK, who commit daily to provide the highest quality of care to their patients.

NOTES FOR COMMISSIONERS AND POLICY MAKERS

Heart failure and it's aetiology

Heart failure means that your heart is failing to pump or fill as efficiently as it should, in order to supply the body with the oxygen and nutrients that it needs. There are two common types of heart failure -

- Heart Failure with Reduced Ejection Fraction (HFREF) where the heart is not pumping correctly
- Heart Failure with Preserved Ejection Fraction (HFPEF) where the heart is not filling properly

Generally there is a reason why the heart is not pumping correctly. The most common reason is that the heart muscle has been damaged by a poor blood supply such as after a heart attack. Other causes include;

- High blood pressure
- A virus that has affected the muscle of the heart
- As a result of the hearts rhythm being abnormal for example, atrial fibrillation
- A genetic condition which may have affected the muscle of the heart as in Cardiomyopathy
- Excessive alcohol intake
- The valves of the heart are damaged
- Some types of chemotherapy
- In rare cases a form of heart failure in pregnancy or just after delivery called Peripartum Cardiomyopathy.

NICE Chronic Heart Failure in Adults 2018 Guideline key points

- **Team Working** – There should be a heart failure multi-disciplinary team, who work in-conjunction with the Primary Care Team and include a specialist with a sub-speciality in heart failure responsible for making the diagnosis of heart failure, a heart failure specialist nurse, a healthcare professional with specialist prescribing expertise in heart failure.
- **Care-planning** – The MDT should a produce summary for each person with heart failure which should form the basis of a care plan, highlighting diagnosis, aetiology, treatment and care.
- **Diagnosing Heart Failure** – Measure N-terminal pro-B-type natriuretic peptide (NT-proBNP) in people with suspected heart failure.
- NT-proBNP > 2,000ng/litre (236 pmol/litre) refer urgently, to have specialist assessment and transthoracic echocardiography within 2 weeks.
- NT-proBNP 400 - 2,000ng/litre (47 to 236 pmol/litre) refer to have specialist assessment and transthoracic echocardiography within 6 weeks.
- **Treatment** – First line treatment for heart failure with reduced ejection fraction (HF-REF) should consist of Beta-blockers, ACE inhibitors, and an MRA if symptoms persist.
- **People With HF-Ref And Chronic Kidney Disease** – updated guidance relates eGFR and chronic kidney failure to the prescribing of treatment.
- **Giving Information To People With Heart Failure** – there has been an emphasis on addressing the need for good communication and supportive patient education. Patient's should have their diagnosis and prognosis discussed in an open and sensitive manner, patients and their families and carers should be encouraged to ask questions and provide information when needed throughout their care.
- **Palliative Care** – long term oxygen therapy should not be used for patients with advanced heart failure, unless underlying conditions present such as chronic obstructive hypoxic pulmonary disease. Patients with heart failure should have their condition discussed with the heart failure MDT.
- **Cardiac Rehabilitation** – patients should be offered structured programme including monitoring, physical activity and psychological support
- **Lifestyle** – Patients should not routinely be advised to restrict their salt and fluid intake but review on a regular basis.

NOTES FOR COMMISSIONERS AND POLICY MAKERS

Key facts

- There are up to 920,000 people with heart failure in the UK.[4]
- Heart failure is debilitating and outcomes are poor: 5 year survival rate is worse than breast or prostate cancer.[5]
- 30-40% of those diagnosed with heart failure die within the first year.[6]
- Heart failure is a major cost to the NHS. It is a leading cause of hospital admission in over 65s.[7]
- Only 66% of GPs are confident to diagnose heart failure due to left ventricular systolic function, compared to 95% of Cardiologists (the primary clinicians responsible for diagnosis).[8]

Findings of the first National Heart Failure Specialist Nurse Audit

- The audit looked at 165 organisational teams comprising 532 full-time nurses
- Heart Failure Specialist Nurses were highly specialised and experienced with 73.4% of teams being able to admit patients directly into hospital, 100% of teams being able to order significant investigations, and 70% of nurses being independent non-medical prescribers
- The biggest concern of heart failure nurses was the significant case-load that they were having to manage and that demand on their services was increasing without further resources
- 60% of teams did manage those patients who had heart failure due to preserved ejection faction, however this resulted in 40% of patients, who were often highly complex patients, being unable to access support
- Teams frequently operated in distinct settings (hospital or community) with only 28.5% of teams crossing the community/ secondary care setting
- 84% of teams had access to a MDT, but only 44% included a physician with a sub-speciality in heart failure
- Heart Failure Specialist Nurses loved their job, they described their passion, dedication, for the role, feeling valued by clinicians and patient, providing holistic and high-quality care

Obligation

Heart failure not only has a poor prognosis if not managed correctly but has a huge societal effect. We know what works but NICE evidenced based guidelines are still not being universally followed. With the new NICE 2018 guidelines out on the management of chronic heart failure in adults aligned with this Heart Failure Nurse Audit 2018 we all should recognise the importance of evidence based practice.

With the Heart Failure Specialist Nurse being clearly placed at the centre of the defined MDT (Multi Disciplinary Team) we should not be letting patients down by not making them available where the evidence guides us.

REFERENCES/APPENDIX

1. All-Party Parliamentary Group (2016) Focus on Heart Failure, 10 Recommendations to Improve Care and Transform Lives. British Heart Foundation.

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3. Pumping Marvellous Foundation Grand Heart Failure Summit (2017) http://pumpingmarvellous.org/what-we-do/heart-failure-summit/

4. NICE Chronic heart failure guidelines for adults 2018

5. Stewart et al. Population impact of heart failure and the most common forms of cancer. Circulation: Cardiovascular Quality and Outcomes. 2010. Available at: http://circoutcomes.ahajournals.org/content/early/2010/10/05/CIRCOUTCOMES.110.957571.full.pdf

6. Cowie MR, Wood DA, Coats AJ et al. Survival of patients with a new diagnosis of heart failure: a population based study. Heart. 2000. 83: 505–10. Available at: http://heart.bmj.com/content/83/5/505.long

7. NICE. Acute heart failure: diagnosing and managing acute heart failure in adults. October 2014. Available at: https://www.nice.org.uk/guidance/cg187

8. NICE. Chronic heart failure: Management of chronic heart failure in adults in primary and secondary care. August 2010. Available at: https://www.nice.org.uk/guidance/cg108

APPENDIX 1: UNIVERSITIES OFFERING HEART FAILURE MODULE

- Glasgow Caledonian University – Chronic Heart Failure: Optimising Health and Well-Being
- Edge Hill University – no module listed at present
- University of Brighton
- University of West England - This is a one-day course
- University of Hertfordshire
- University of Sheffield - Long-Term Condition Module which covers heart failure
- University of Birmingham - Three-day course focusing on Primary Care
- Education for Health - Heart failure courses at various levels via Warwick University
- Bradford University

PumpingMarvellous
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