

Midlands Regional Heart Failure Report 2022



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Foreword

Heart failure represents a challenge to clinicians, the health services across multiple disciplines and provider within our systems, and the diagnosis has a major impact on patients' physical abilities, life-expectancy, mental health, personal and family life. We have seen massive advances in treatment of heart failure with new disease-modifying medications, devices, and expansion of structural procedures to improve cardiac function. Patients' prognosis and outcome has been improved with our much-upgraded toolkit we have at our disposal, but the challenge continues. Timely diagnosis, assessment by specialist teams, swift optimisation of treatment, re-admission prevention, multi-disciplinary team support for the whole heart failure population we are serving, without unwarranted variation and patients' experience at the centre of our efforts.

This is one of the priorities within the Cardiac Pathway Improvement Programme (CPIP) and remains also a focus for AHSN for the West Midlands, British Heart Failure Society and NHS England while sharing the same desire to improve patients' care and experience on an individual and population-based level.

Data is important to guide us in our ambition to improve care and service provision and existing national audit data focused on heart failure management in secondary care settings and not across the whole patient pathway which includes primary and community care. Capturing meaningful data spanning across the patients' whole pathway is desirable without overburdening the system with bureaucracy and stifling the process of improvement.

This report describes current heart failure provision in the Midlands includes examples of fantastic care, excellent services, and ongoing challenges. The dedication of heart failure teams and the ambition to improve the care for patients is undeniable and with sharing experiences, defining agreed goals and standards we continue working towards a common aim for the benefit of the population we are serving.

Dr Kai Hogrefe – Consultant Cardiologist, University Hospitals of Northamptonshire and East Midlands Cardiac Network Chair
AND

Professor James Cotton – Consultant Cardiologist, Royal Wolverhampton Hospitals NHS Trust and West Midlands Cardiac Network Chair

The WMAHSN are thrilled to collaborate with the NHS Midlands CPIP Heart Failure. In view of an increasingly aging population, increased incidence of heart valve disease, poorly managed hypertension and improved survival following heart attacks, prevalence continues to increase.

The priorities of both the CPIP HF team and WMAHSN CVD team are to support systems/service providers to address unwarranted variations in access to services and improve uptake of evidence-based therapies that are known to improve outcome in people with heart failure.

This report enables us to identify the key challenges within the system, identify the opportunities to support patients with heart failure, and how best to support the delivery of innovations to improve heart failure care within the health and social care systems.

Dr Nazish Khan - Consultant Pharmacist CVD (QEHB) CVD Clinical and Programme Lead (WMAHSN)

Executive Summary

This report presents the findings of a survey designed by the Midlands Cardiac Pathways Improvement Programme (CPIP) team. The survey was sent to all heart failure services within the Midlands to scope what services were currently being delivered, how they were set up, and identify what opportunities there were to enable the delivery of the CPIP programme and the Long-Term Plan ambitions.

Questions were designed to identify best practice and gaps within the pathway as well as highlight enablers and barriers in the set up of heart failure teams.

We recognise that data collection was varied among teams and so not all information was available consistently; however, it has enabled some key gold standard recommendations to be identified.

Key points identified have been;

- Access to diagnostics is good within the region, however timely diagnostics remains an issue.
- There is variation in delivering the 4 pillars of treatment for heart failure patients
- 60% of services have access to cardiac rehabilitation for heart failure patients
- 60% of services have access to palliative care services
- There is variation in access to MDT meetings, and members of that MDT do not always include professionals from the whole pathway.
- There is large variation in waiting lists and caseloads.
- Services recognised the need for workforce planning
- Data collection is not standardised and does not consider targeting health inequalities.
- The use of telehealth is limited within the region

This report will be used as a baseline for both the CPIP work and AHSN project work to enable the teams to identify what key interventions are successful for improving heart failure care within the region.

Introduction

Heart failure is a clinical syndrome with typical symptoms (breathlessness, ankle swelling, and fatigue) and signs (elevated jugular venous pressure, basal crepitations, and peripheral oedema). Heart failure is caused by a structural and/or functional abnormality that produces raised intracardiac pressures and/or inadequate cardiac output at rest and/or at exercise. ¹

Heart failure affects around 900,000 people in the UK, and this number is likely to rise, due to an ageing population, more effective treatments, and improved survival rates after a heart attack. Heart failure is a large burden on the NHS, accounting for 1 million bed days per year, 2% of the NHS total, and 5% of all emergency admissions to hospital. ²

Within the Midlands we have huge variability within heart failure care and therefore have numerous opportunities to optimise pathways and treatments to improve outcomes for our population of heart failure patients.

The introduction of NHS England's Cardiac Pathway Improvement Programme (CPIP) enables us to address these opportunities, resulting in reduced variation of heart failure care across our region.

The CPIP programme works in alignment with existing national programmes, focusing on key goals and priorities, and supports Cardiac Networks and Systems to deliver a comprehensive approach to whole pathway improvement and transformation. Heart failure is one of the designated CPIP pathways that have been created to ensure a minimum standard of quality and should complement existing resources such as NICE and Specialist Society guidelines.

The Midlands CPIP has aims set by NHS England and delivered through Cardiac Networks to;

- Reduce CVD mortality;
- Deliver focus on preventative and proactive care;
- Improve quality and safety of care across the pathway through the delivery of national standards of care;
- Restore services and reduce waits following the COVID pandemic;
- Improve experiences of care;
- Deliver equitable access to high quality care reducing inequalities in outcomes, access and experience;
- Ensure sustainability in costs. ⁴

As part of this they have several strategic and operational objectives with one being;

'Undertake comparative benchmarking of current provision to map gaps in cardiac pathways and determine network improvement priorities. This should span the whole pathway of care from prevention through to tertiary care, rehabilitation, and end of life care.' ⁴

The Midlands CPIP team have worked collaboratively with the West Midlands Academic Health Science Network (WMAHSN) to deliver this 'State of the Region' report that can be used by heart failure services within the region to identify the gaps and opportunities within heart failure care services. The WMAHSN is one of the 15 Academic Health Science Networks (AHSNs) across England, established by NHS England in 2013 to spread innovation at pace and scale – improving health and generating economic growth. Therefore, by working collaboratively on this report, challenges can be turned into an opportunity to deliver innovative solutions.

The British Heart Foundation (BHF) *Blueprint for Change* report in 2020 made a series of recommendations, including using data to drive change. The report noted that currently, the only nationally available mandated dataset for heart failure is the Heart Failure Audit managed by NICOR. The audit contains data collected about heart failure patients admitted to hospital in England and Wales. NICOR data include trends in symptoms and demographics, as well as data relating to patients' access to diagnostics, specialist input to their treatment and the types of treatment they are prescribed. The audit also provides data on mortality both in hospital and post-discharge. However, this information is not linked to primary and community data. Local systems currently struggle to get their own data back out of the audit, making it more useful for describing the national picture than informing local improvements. ³

The Midlands CPIP HF Clinical Leads therefore wanted to acquire a deeper analysis of what community and acute services offer, broadening the data sets obtained from the NICOR data, and produced a survey that was sent to all services within the Midlands region. There were 17 responses in total; 3 were too late for data analysis but will be used in future baseline comparison assessments.

This report will provide the NICOR data and the regional survey results, and will then offer recommendations for services, with case study examples, and a toolkit for services to implement.

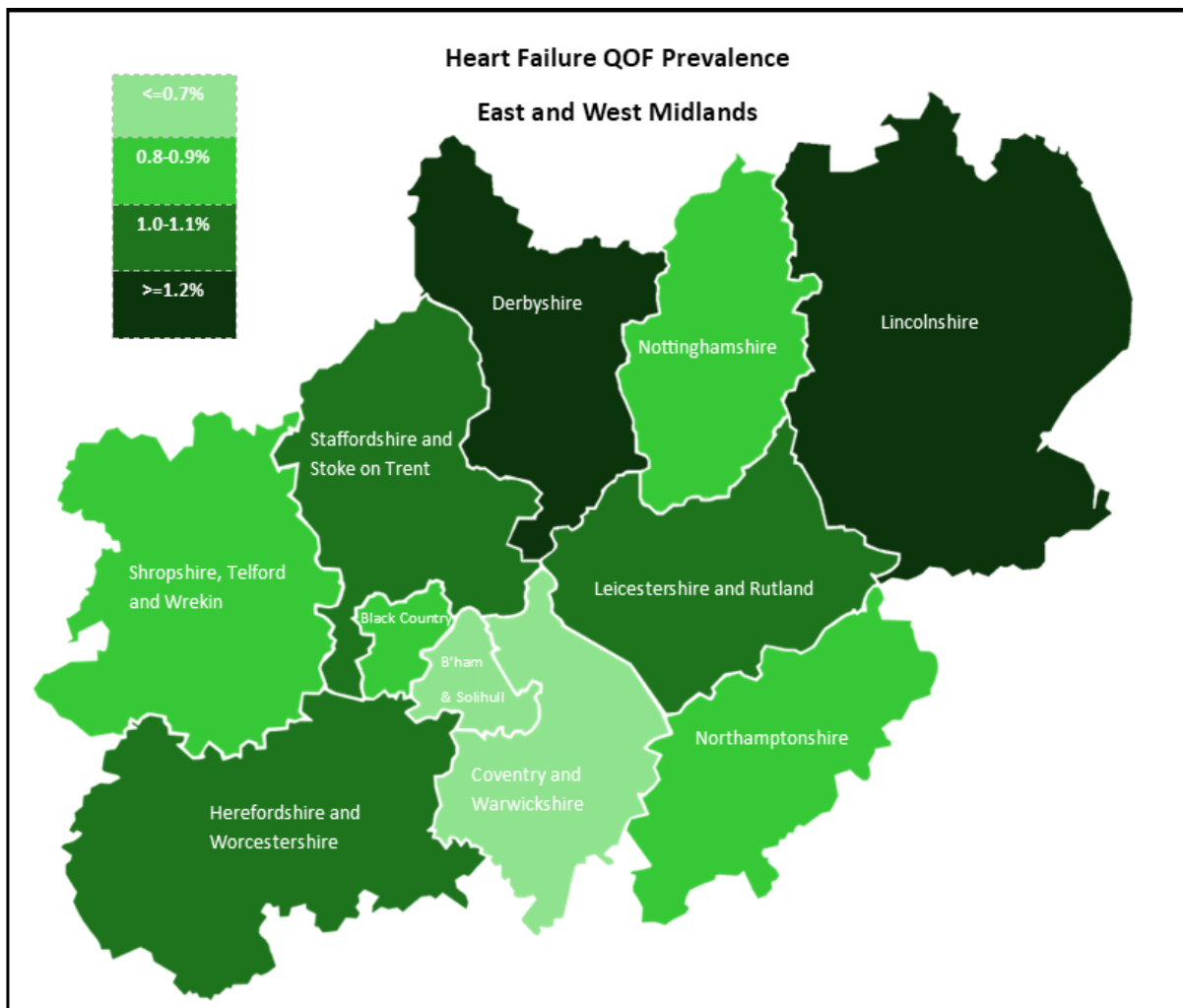
This information will then provide a passage for the development of optimum pathways and the implementation of innovative practice in heart failure care.

Prevalence and admissions

The incidence of heart failure in Europe is about 5 per 1000 person/years in adults and prevalence is 1–2% in adults: increasing from around 1% for those < 55 years to > 10% for those aged over 70 years.¹

In England in the 20/21 QOF data, the England prevalence was 0.9%, and in the Midlands 1.0%.

However, this prevalence varies across the individual ICB's within the region.



Having an accurate assessment of prevalence of heart failure within each ICS is beneficial to both patient outcomes and the health economy. The heart failure indicators within the Quality Outcomes Framework enables health systems to receive appropriate payments for quality care provided to patients. Equally having accurate heart failure registers enables recall of patients for regular reviews as recommended in the NICE guidelines. This facilitates patients to be optimised on NICE recommended treatments, and to be given appropriate

self-management advice, which in essence will aid patients seeking advice earlier and therefore beneficial for admission avoidance.

Lincolnshire in 2019 ran a primary care driven quality improvement programme. This involved code cleansing their heart failure registers, development of heart failure review templates, and education for practice nurses. Virtual reviews with support of a clinical pharmacist were undertaken to optimise patients, and a virtual MDT was initiated for those requiring secondary care input. This whole system approach has resulted in an increased in the recorded prevalence, and the whole pathway redesign will enable better patient outcomes. ⁶

Primary care case finding tools are very beneficial for code cleansing of heart failure registers. The Midlands CPIP survey did not audit what ones were in use within the Midlands, and this may be a useful audit collection in the future to determine what innovations are possible to improve heart failure case finding.

According to the NICOR Heart Failure Audit there were 58,981 HF admissions in England in 20/21, and 11,628 of these were in the Midlands region. This equates to 19.7% of the recorded heart failure admissions in England.

As shown in Fig 1. there is variation among centres in the number of admissions. However, it is recognised that some of these will be large cardiology tertiary referral centres and therefore cover a larger population. It has been recognised that lower prevalence of heart failure can result in higher admission rates; however, there does not appear to be a direct correlation to this within our region. Royal Hospital Derby has the highest number of admissions, but Derbyshire has a prevalence of 1.2% which is the second highest recorded prevalence in the Midlands. Equally Birmingham and Solihull have the lowest recorded prevalence, and although admissions are high (specifically at QE and Heartlands), they do not fall within the top 5 of highest number of admissions.

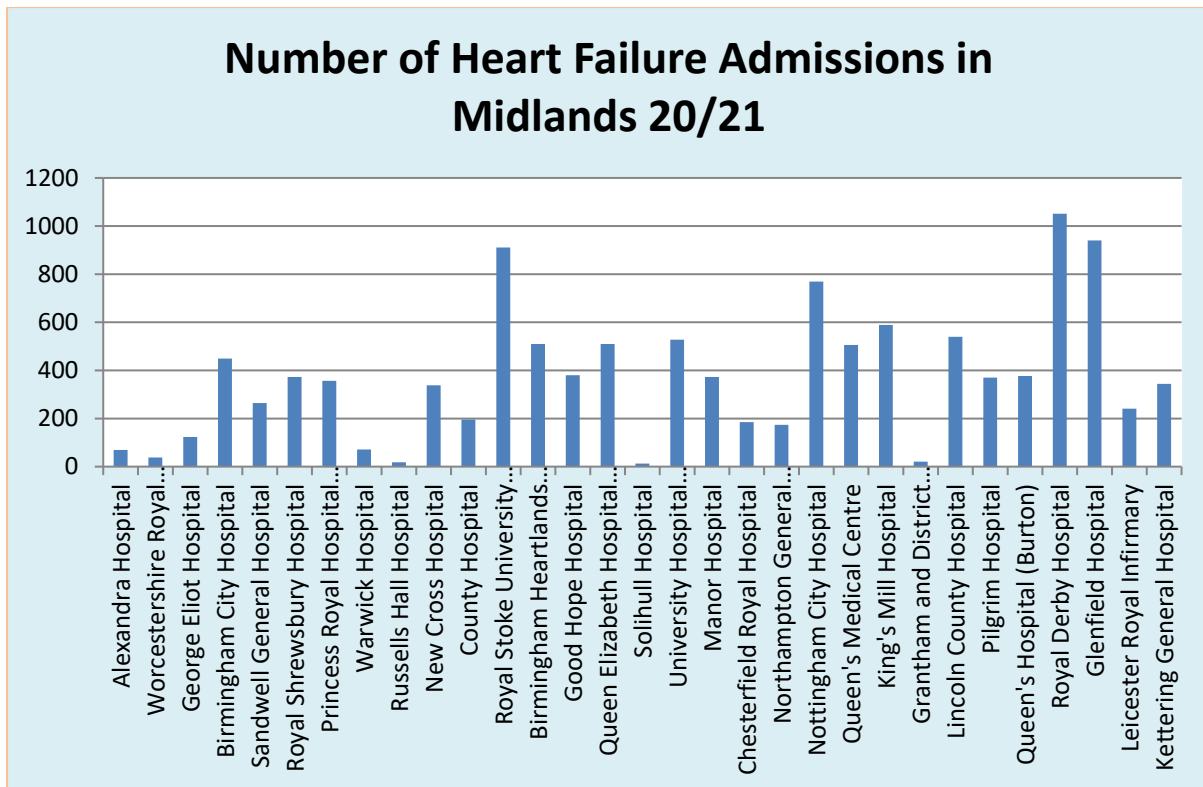


Fig 1. No of heart failure admissions per acute trust in Midlands. Source: NICOR Heart Failure Audit 20/21

We can see that within the region we have some very high rates of hospital admission and despite readmission reduction policies, we know that nationally 30-day readmissions have increased, impacting the least affluent and ethnic minority groups. We also recognise that integration between the different parts of the NHS system can vary and lead to disjointed care and poor patient experience. NICOR recognises that place of care is a key quality indicator for HF as care in cardiology wards is associated with lower in-hospital and subsequent mortality, better treatment for patients with HF rEF on discharge, and more access to specialist care.

The NICOR data states that the average percentage of people admitted under cardiology is 48%. Fig 2 shows how the Midlands hospitals compare to this average. Again, we can see there is a large variation in this, although recognise that some of these hospitals will transfer cardiology patients to another campus within their trust for cardiology care, i.e., Nottingham University Hospital Trust care for cardiology patients at the City Campus rather than the Queens Medical campus.

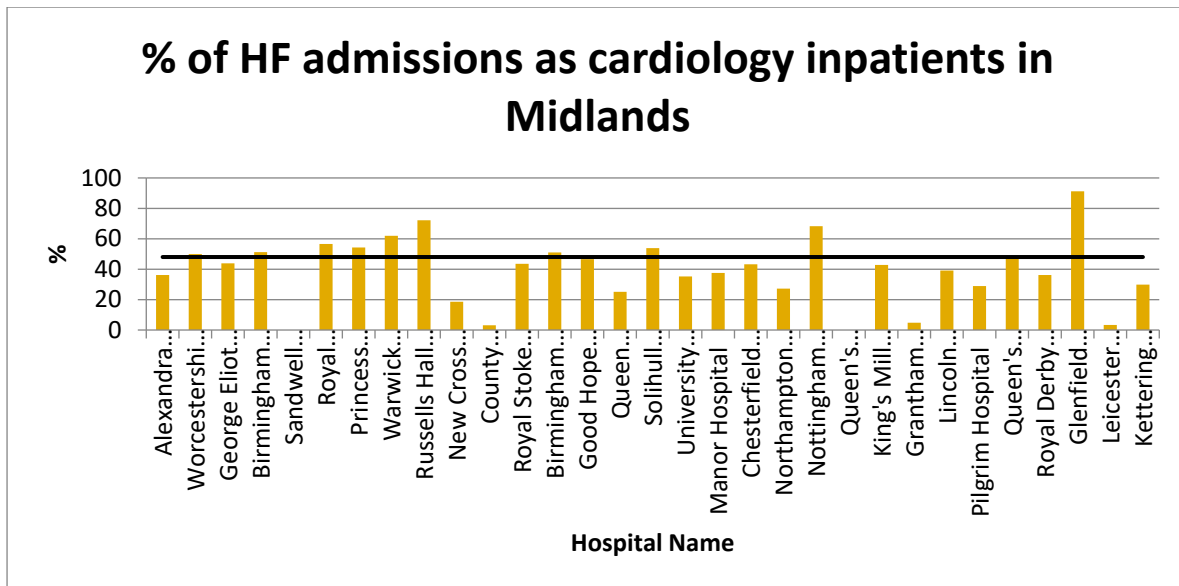


Fig 2. Source: NICOR Heart Failure Audit 20/21

NICOR also recognised that access to cardiology wards was lower for those >75 years at 42% versus 60% for those ≤75 years. Similarly, females were less likely to get to cardiology (42%) than men (52%) and recommend that improving access to a Cardiology ward needs to be addressed locally as a matter of urgency. There is an aspirational target of 60% of HF admissions being managed in a cardiology ward, only 13% of trusts are achieving this nationally, and only 4 hospital sites within the Midlands are achieving this aspiration; Warwick, New Cross, Nottingham City and Glenfield.

To address variation in heart failure care, we need to consider all aspects of the pathway from diagnosis to end of life care.

The CPIP heart failure pathway (Appendix A) is designed to consider all elements of the pathway, and to enable systems to meet the national policy targets within the NHS Long Term Plan, and the requirements set for the primary care Direct Enhanced Service Contract Specification through the Impact and Investment Fund. However, it is recognised that pathways will need to be adapted locally to meet the needs of local populations. The BHF *Blueprint for Change* (2020) report highlighted that many services are being made available based on how they fit into the local system rather than the needs of the patients they serve and recommend that designing of services should be focused on people rather than structures.³

The Care Pathway – Diagnosis and Testing

It is well documented that heart failure is often diagnosed late, with 80% of diagnoses being made during emergency admissions.

Traditionally Heart failure services have been commissioned to accommodate patients with a reduced ejection fraction (HFrEF) confirmed by imaging; however, those with a preserved ejection fraction (HFpEF) are increasing in numbers and have a higher comorbidity burden which can make them more complex patients to manage.

Within the Midlands CPIP survey all services are commissioned to see HF_rEF patients, and 7/15 (47%) are commissioned for HF_pEF patients, although others stated that they see them despite not being commissioned. The ESC recently also added in the definition of HF_mEF as LV ejection fraction 41-49%. The survey responses stated that 14/15 (93%) of services are commissioned for HF_mEF patients, again others saw them but not commissioned or unsure of commissioning. Treatment varies for all these groups, and so it is important to have accurate diagnosis for effective evidence-based treatments to be introduced.

The diagnosis of heart failure relies on clinical expertise to promptly and accurately recognise the signs and symptoms, as well as have timely access to the laboratory tests and imaging procedures needed to confirm the diagnosis.

Therefore, education for primary care clinicians and patients is a key factor to enable early recognition of symptoms. Patients seeking help earlier, and health care professionals recognising signs to then access diagnostics and commence treatments earlier can prevent hospital admissions.

Within the Midlands CPIP survey we asked services whether primary care had regular heart failure education or training. 11 out of the 15 (73%) services believed that this happened. This was usually delivered by the heart failure nurses or cardiologists. The WMAHSN has also delivered their Impulse CVD training programme within the West Midlands to 4 of the ICB's, which resulted in 222 primary care health care professionals attending heart failure education sessions. It was also commented on by one of the services that the COVID-19 pandemic had halted their education sessions, and capacity restraints have delayed these restarting.

Diagnosis within primary care is reliant on access to NTproBNP blood tests and echocardiography (ECHO). Within the survey 100% of services recorded that GPs have access to NTproBNP testing, which is positive.

A quality improvement project undertaken in Kent, Surrey and Sussex however highlighted through audit that approximately 10% of patients with a normal NT pro BNP still had a specialist referral and echo requested with none of these patients resulting in a diagnosis of heart failure. In 5 months, a saving of £1323 could have been made by stopping unnecessary echo's where NT pro BNP test results were normal and stopping repeat NT pro BNP testing in hospital when a heart failure diagnosis was already known.⁵ This highlights that education is still key in ensuring that correct NICE guidance is followed and that unnecessary NTproBNP testing will potentially have an impact on echo availability for patients that correctly require echo. This may be a further audit opportunity for the future.

Within the Midlands CPIP survey, the waiting times for routine echo within the region varied from 6 weeks to over 6 months, with 2 services unable to provide this data. Large variations are apparent again across the region, and although nationally echo times have been recognised nationally as a concern, especially since the COVID 19 pandemic, pathway reviews along with workforce strengthening, will aid improvements in reducing ECHO waiting times.

Urgent echocardiography within 2 weeks is recommended by NICE for patients with the most elevated NTproBNP levels. 14/15 (93%) services state GPs can refer for this, however 2/15 (13%) services declared that the waiting time is currently more than 2 weeks. 14/15

(93%) of the heart failure services themselves can request echo. However, 4/15 (26%) of the services stated that they did not have a dedicated pathway or referral process to facilitate booking of an urgent echo, and the ability to arrange this within the recommended 2 weeks ranged from <10% to 100%.

In addition, electrocardiography (ECG) is a crucial diagnostic tool for heart failure in combination with the NTproBNP and echo. In the survey there was limited data available when asked whether GP practices have same day access to perform ECG's, 8/15 (53%) did not have this data, and other responses varied from 'all' or 'most' to 'less than 5%'. Although 12/15 (75%) of the services responded that they have a pathway in place from primary to secondary care for timely interpretation of ECGs, and this was predominantly through the advice and guidance service. 15/15 (100%) of the heart failure services can request ECG themselves, and 14/15 (93%) can request halter monitoring which will enable a longer period of rhythm monitoring.

Breathlessness is one of the symptoms experienced with heart failure patients, but with so many other possible causes it can be difficult to distinguish. The CPIP programme includes breathlessness as part of the pathway, and some areas within England have established breathlessness clinics to enable patients to gain support to help manage their symptoms with this as well as helping diagnose patients. These along with the introduction of community diagnostic hubs could be beneficial to improve timely diagnosis.

The Care Pathway – Management and Treatment

Heart failure treatment has developed significantly over the last decade, and often we talk about the 4 pillars of pharmacological heart failure care for those patients with HFrEF.

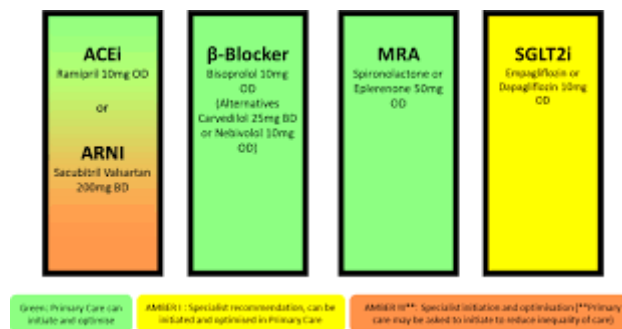


Fig 3. Source <http://www.lhp.leedsth.nhs.uk>

However, we know that titration to reach optimisation can be complex, either through patient intolerances or through pathway design issues and workforce capacity and knowledge.

The NICOR National Heart Failure Audit can inform us of what percentage of people are discharged following an admission with heart failure on 3 of these pillar treatments (ACEi/ ARNI, beta blocker and MRA), and the Quality Outcomes Framework can record how many of those recorded with a diagnosis of heart failure are treated with ACE Inhibitors and Beta Blockers.

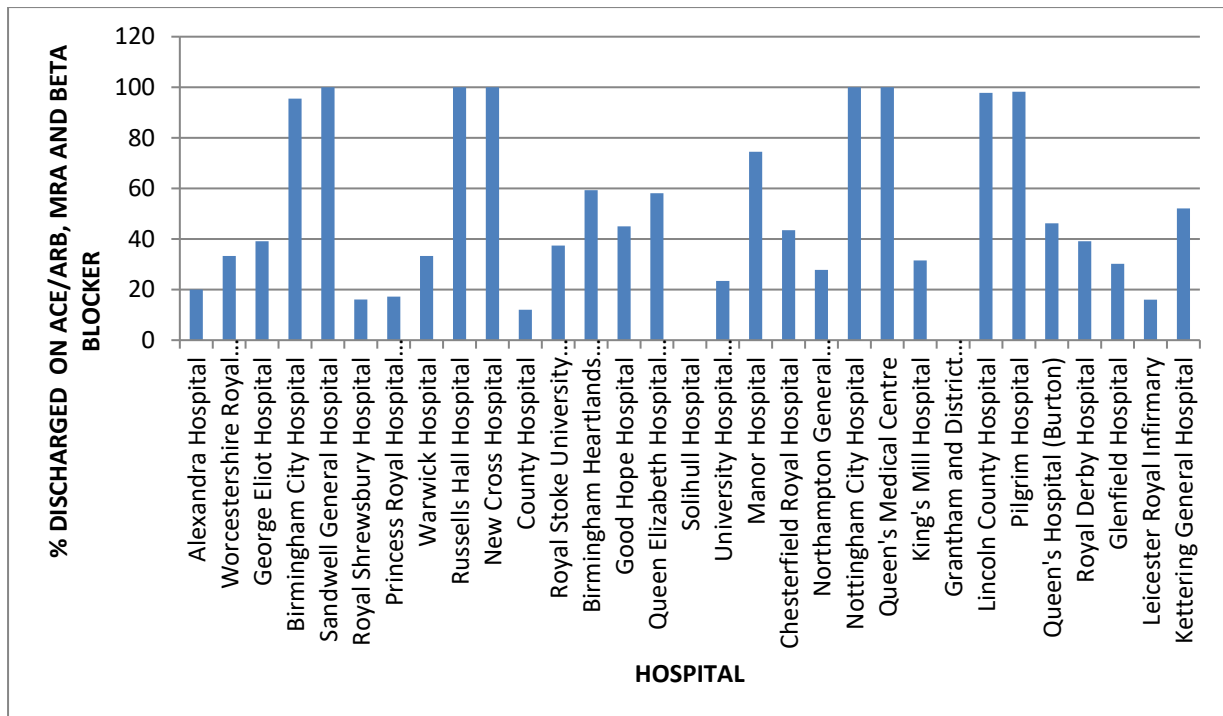


Fig 4. Source NICOR Heart Failure Audit 20/21

Prescription of an angiotensin-converting enzyme inhibitor (ACEi), beta blocker (BB) and mineralocorticoid receptor antagonist (MRA) are key performance indicators for patients with HF_rEF as these drugs are associated with better survival, lower hospitalisation rates and improved quality of life. It is noted that nationally only 51% of patients are discharged with the first 3 pillars of the recommended treatment, and only 39% of our services submitting to the NICOR National Heart Failure Audit are achieving above the national average, and less than this achieving the 60% benchmark. Although it is not possible to ascertain from these data whether treatments are being withheld appropriately, and therefore excluded, it does show there is still variation in prescribing of evidence-based treatments. It should also be noted that the NICOR data up to now only includes 3 pillars (ACEi/ ARNI, beta blocker and MRA), SGLT2 inhibitors being a relatively new intervention

Within the Midlands CIP survey 11/15 (73%) services stated that they have a designated discharge pathway into primary care to enable management to continue, although many of these mentioned that this was only done once the patient had been optimised. Therefore, although the patients have been discharged from hospital, their management often continues under the acute trust services before discharge back to primary care. There is no data to evidence whether the patients are optimised on the three or four pillars of care prior to transfer into primary care services to have their heart failure managed.

Timely prescribing of heart failure medications is crucial, and we understand that there are many interdependencies within the system that can affect this. For example, communication mechanisms between secondary care and primary care are often delayed, there is often a lack of patient understanding on how crucial it is for them to follow up with their heart failure team or primary care contacts, and of course the current climate of our NHS workforce pressures having an impact on appointment waiting times.

It is recommended that patients are seen by heart failure teams within 2 weeks following discharge to aid in timely optimisation. Within the Midlands CPIP survey 7/15 (46%) of the services did not record this information, and the 8 services that did respond stated that the percentage of patients seen within 2 weeks of discharge ranged from 50-100%.

The services were asked on how this 2 week follow up was arranged. Some systems commented on how the referral was done, i.e., responded that a referral is made through an online system, or through emailing or telephoning the appropriate heart failure team to follow up. However, others commented on how they interacted with the patient. 5 of the services commented that this initial 2 week follow up is done by telephone, and then face to face appointments made to those most complex, or one example was that all new patients get a home visit via the community team.

The way in which heart services are set up, i.e., all community based, separate acute and community providers, or integrated acute and community teams appears to cause variations with our HF pathways within the Midlands. There are more teams nationally looking at integrated team approaches, and many of those that have achieved this have seen positive results. A service in Torbay, Devon, noted improved identification of patients admitted with HF, higher levels of specialist HF in-patient care, improved use of disease modifying HFrEF medications, and a greater number of patients benefiting from early HFN follow-up. Despite increasing admission numbers of sicker patients, they have seen improved 30-day mortality and HF-related readmission rates in the HFpEF cohort. They suggested that an integrated heart failure service can be developed and introduced without major additional resource and with simple service re-design and could be applicable across the NHS to improve HF care and clinical outcomes.⁷

Timely prescribing can also be affected by the method the patients receive prescriptions. Heart failure nurses being able to prescribe, and the use of pharmacist prescribers has been influential in improving this. Nurses having to task cardiologists or general practitioners to prescribe medications places increased delays within the system and increases capacity for an already overstretched workforce.

Within the Midlands CPIP survey, between 33 – 100% of their heart failure nurses are prescribers (Fig 5).

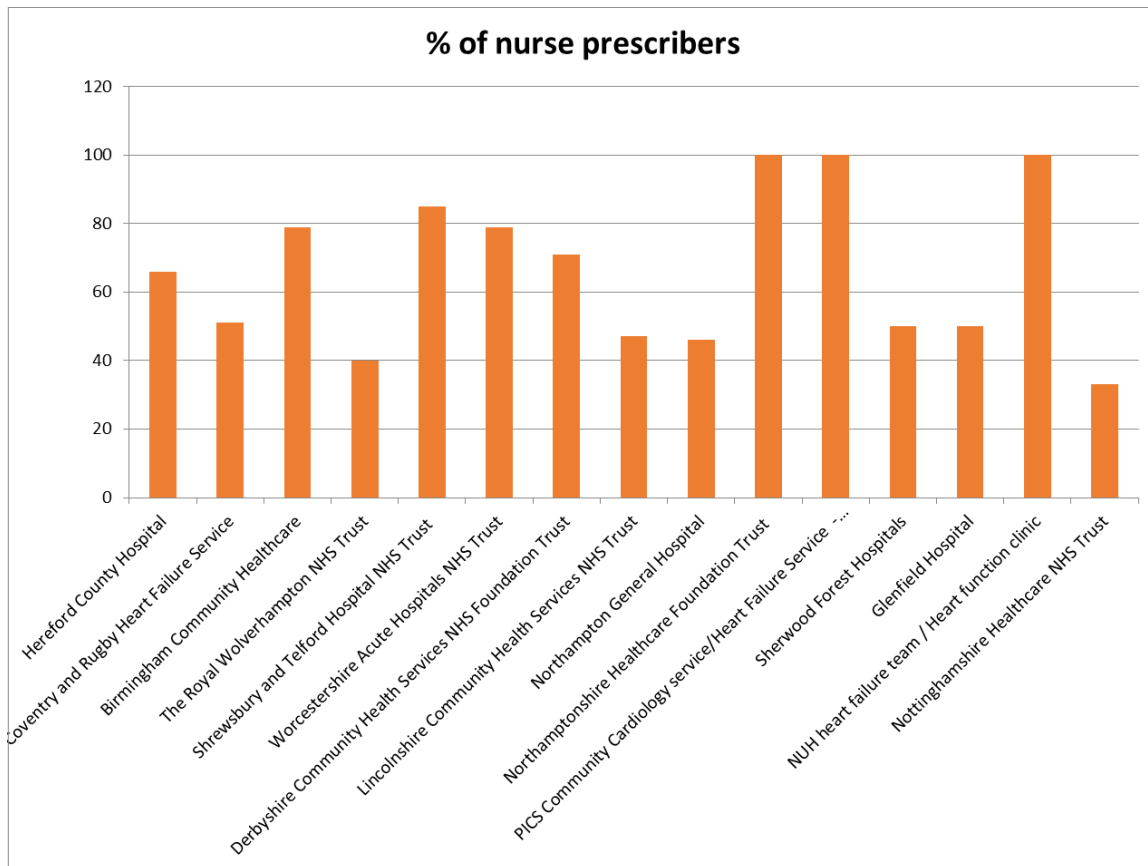


Fig 5. Source Midlands CPIP HF SURVEY

When asked whether the heart failure nurses can access/prescribe new treatments such as Sacubitril Valsartan, SGLT2i or IV iron, 15/15 (100%) of services stated that they could, but with a few exceptions. 5/15 (33%) of the services specified that they are unable to prescribe IV iron. 1/15 (6%) of the services stated that they were still waiting for Dapagliflozin to be added to their formulary. Many mentioned that these novel therapies were only prescribed following MDT discussion. When asked about the barriers regarding the prescribing of these drugs, acute trust capacity was the main concern with regards to intravenous iron.

The September 2018 updated NICE chronic heart failure guidelines highlighted a greater role for pharmacists across primary and secondary care. It also recommended that stable patients were reviewed by the primary care team every six months. The increasing numbers of pharmacists taking up roles in primary care networks enables them to meet this requirement. In the Midlands CPIP survey, 5/15 (33%) of the services responded that they work with clinical pharmacists in the community to help with titration of medications, but only 1 service stated that they had a protocol in place of how to interact with community pharmacists, and this was stated that this was through the MDT meetings.

It is well documented that more patient care should be delivered within community settings, therefore emphasising that heart failure patients can be professionally managed within primary care. It is therefore essential that systems should be considering pathways that enable only complex patients to be managed within a secondary care setting, for example those that are requiring device therapy. As heart failure becomes more severe, cardiac function and symptoms may no longer be controlled by pharmacological treatment alone and

can be improved by the implantation of a cardiac rhythm device. 10/15 (66%) of the services surveyed, enable heart failure nurses to refer for these devices, and these decisions are usually discussed through the MDT meetings, although some areas mentioned they have separate device therapy meetings.

11/15 (73%) of the services link into a tertiary centre to access complex device therapies, and in addition utilise these centres for remote monitoring of the devices. This figure includes those that are services within a tertiary centre. However, some of these services use both local and tertiary centres, although not specified whether this was for both device insertion and remote monitoring, or just remote monitoring.

IV diuretic therapy has previously been a secondary care delivered therapy, but there have been recent innovative pathway redesigns to drive this into community settings. Almost 10 years ago the British Heart Foundation funded a pilot project which promoted discussions about this concept. Despite reliable results the set-up of these services remains challenging, the pilot did note that the organisation of offering home-based IV diuretics in rural communities are more challenging than in an urban setting and that given low patient numbers, maintaining competence in cannula insertion can be a challenge, and staff need to be regularly involved in delivery of this treatment to maintain competence. Therefore, when considering this innovation, services need to ensure that the setting where they provide IV diuretic therapy meets the needs of their population.

Within the Midlands CPIP survey, it was difficult to establish exact numbers of who had access to deliver IV diuretic therapy at home, as many services did not respond to this question, however no services declared that they did provide this service, although one service did say they have organised this service occasionally to be delivered through community matron teams, and another service stated that the service protocols have been developed but not been initiated as yet. 1 service stated they were able to provide subcutaneous diuretics delivered at home and 2 services declared that they could provide IV diuretic day therapy in clinic.

Management and treatment of heart failure should be a coordinated multi-disciplinary approach. The NICE 2018 chronic heart failure guideline recognises the importance of the specialist heart failure multidisciplinary team (MDT) and states that it should comprise of a lead physician with training in heart failure, a specialist nurse, and a healthcare professional with expertise in specialist prescribing - working in collaboration with the primary care team. The specialist MDT should confirm the diagnosis for all new patients, initiate and optimise treatment for patients with a new diagnosis or worsening symptoms and provide a written care plan.

The BSH also wrote a position statement regarding MDT's and recommended other additional members such as; Care of the elderly/complex medical care consultant, Palliative care clinician, Renal medicine consultant, Imaging cardiologist, Occupational therapist, Physiotherapist, Dietician, Cardiac physiologist/echocardiographer, Pharmacist, General Practitioner with an Extended Role (GPwER) in heart failure, Cardiac surgeon, and trainees in all disciplines.

In the Midlands CPIP survey 13/15 (86%) of the services have access to regular multi-disciplinary meetings. Not all services specified who attended these meetings. However, 3

services specified renal and palliative care teams attended, 1 specified diabetes teams and others mentioned rehab team and pharmacy colleagues attended. 1 service mentioned GP's with specialist interest attended.

8/13 (62%) services that have MDTs (Multi-Disciplinary Teams) meet weekly, 3/13 (23%) meet fortnightly, 1/13(8%) meets monthly and 1/13 (8%) meets twice a week. The number of hours per month spent in the MDT varies from 2-16 hours (see Fig 6 Below) and the number of patients reviewed in these meetings vary from 3-20.

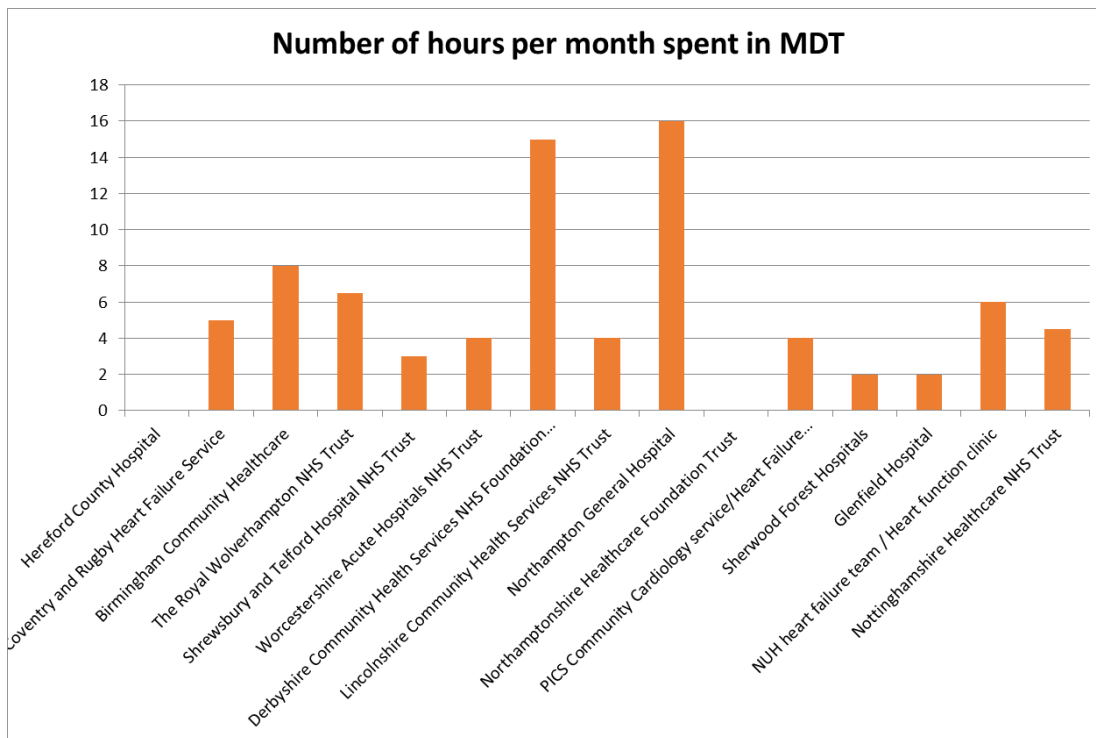


Fig 6 Source Midlands CPIP HF SURVEY

Consultant support for the heart failure teams is important, so that management and treatment can be coordinated in a timely manner. Many of the services surveyed commented that there was no commissioned consultant support, particularly with the community teams, although they commented that they have regular access to the acute trusts consultants. The number of HF consultants for other areas varied from 0.5-5 WTE (Whole Time Equivalent).

The Care Pathway – Support and Self- management

Following a heart failure admission, ongoing support should be available, not only for optimisation of treatment, but for psychosocial input, self-management education, care-giver education, and the opportunity to access cardiac rehabilitation. Therefore, it is recommended that all discharged patients should be seen within 2 weeks by the heart failure team. The NICOR National Heart Failure Audit shows that nationally 47% of patients are referred, 15 /31 (48%) of the acute trusts in the Midlands are above this national average as shown in Fig 7 below.

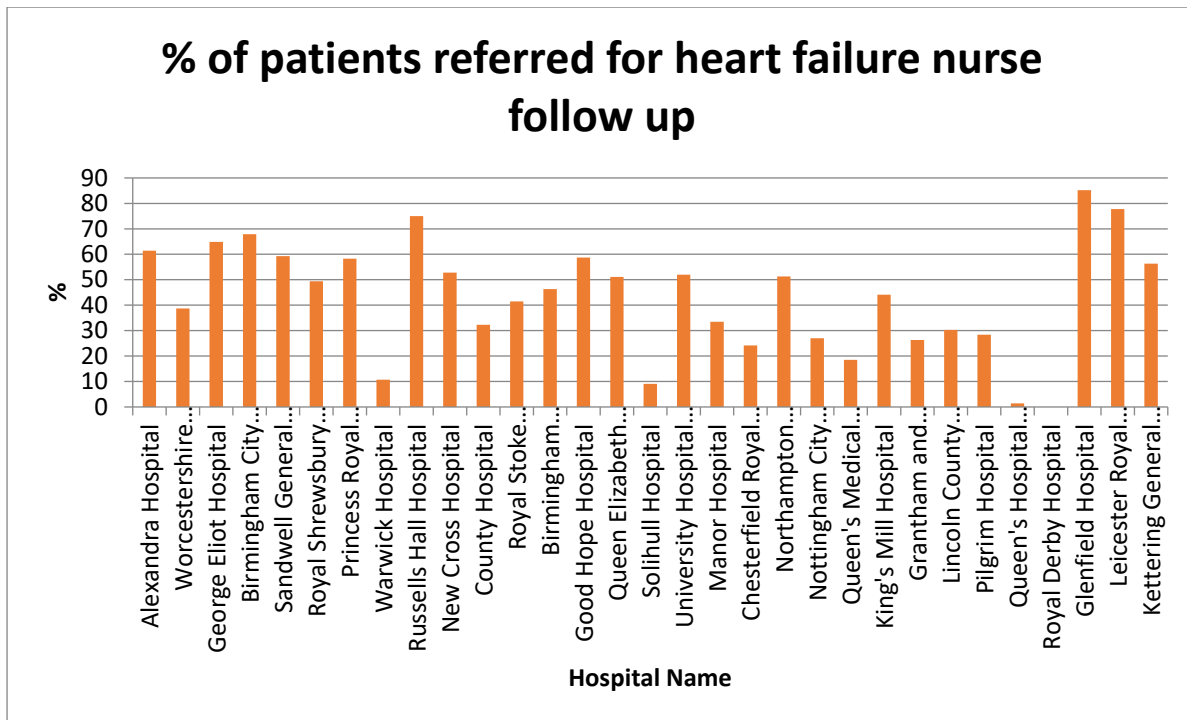


Fig 7. Source NICOR Heart Failure Audit 20/21

The survey asked the question on how long patients are waiting to be seen by the heart failure service if there is a waiting list. It was difficult to capture, as not all services formally collated this data. However, 2/15 (13%) services stated there was no waiting list, but those that could give a timing, figures varied from 1 week to over 6 months, so again there is a large variation, and most were not achieving the 2 week wait.

Caseload numbers have always been a hot topic, and exceedingly difficult to recommend ideal figures, as is very dependent on individual populations. Areas of deprivation, rural populations and other population factors will be influential, and service design can also be a factor on what safe staffing levels should look like. However, the GIRFT Cardiology report (2021) report stated that 'current estimates are that between three and four heart failure specialist nurses or ACPs (Advanced Clinical Practitioner) are needed per 100,000 population to deliver the requirements of the Long Term Plan, as opposed to the one per 100,000 previously recommended'.⁹

Within the survey we asked the services what their caseloads were, and as you can see in Fig 8 below there is a large variation, as well as some services were unable to capture this data, or declared no active caseloads. Equally Derbyshire's large caseload is data across the whole ICS, but Nottinghamshire have provided information from each service individually.

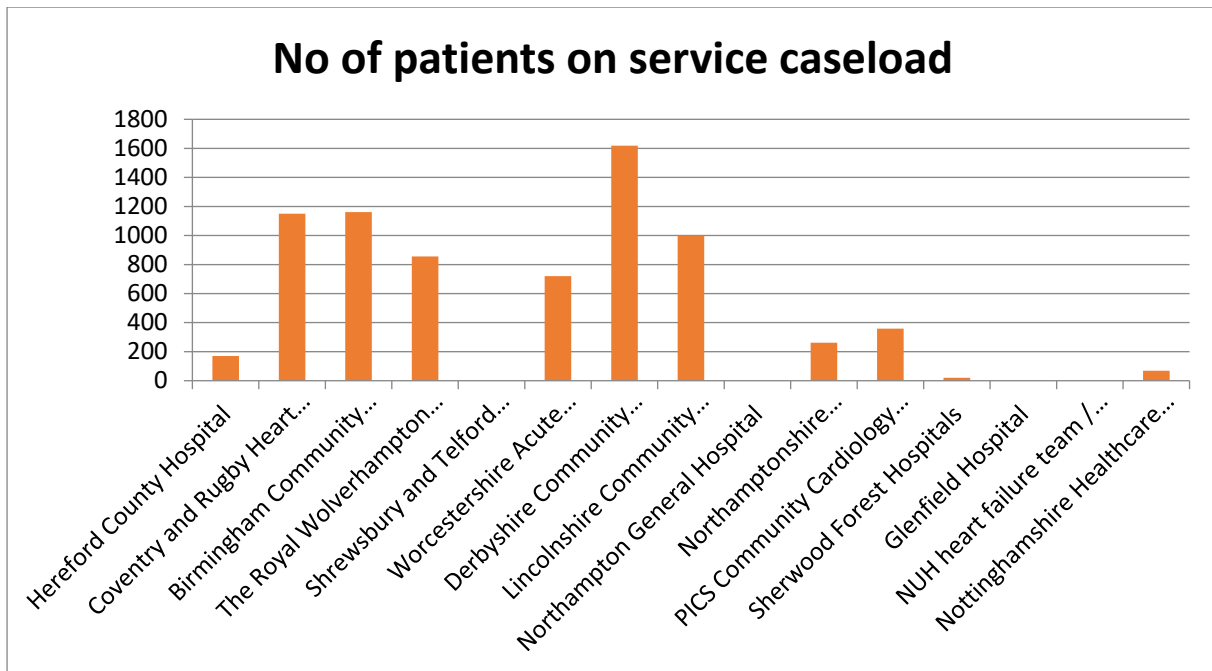


Fig 8 Source Midlands CPIP HF SURVEY

The survey asked what the caseload was for 1.0WTE nurse. Not all services could answer this due to the model in which they work, for example, patients are not always designated to an individual team member. However, those that did respond ranged from 34- 136. This again shows large variation, but populations the services cover needs to be considered here.

Workforce is a key priority within the NHS at present, with large numbers leaving their professions and insufficient training places made available. Effective workforce planning ensures appropriate levels of staff are available to deliver safe, high-quality care to patients. Within the survey 4/15 (26%) services recognised issues of failing to recruit staff within the team, with some specifically commenting that Band 6 nurses with relevant experience are difficult to recruit. No services have experienced posts not being replaced when staff have left, although a few specified that recruitment processes are lengthy, and so this often leaves a gap in workforce provision for considerable periods of time. No services have experienced heart failure nurse posts being redesigned to incorporate other long-term conditions. However, 6/15 (40%) of services raise the issue that workforce planning is required due to anticipated retirement, and 6/15 (40%) of the services had to have staff redeployed during the pandemic.

Health inequalities is equally high on the agenda within the NHS at present, capturing data to determine where the systems health inequalities are is important. When asked, none of the services had a demographic breakdown of their waiting lists by deprivation, ethnicity, and rurality apart from Chesterfield capturing ethnicity and rurality. Equally when asked what % of patients have English not as their first language, many services could not respond as this was not audited. Those that did respond, ranged from 0.05% in Worcester, to 20% in Birmingham, who noted that they had to place 229 interpreter service referrals in 12 months.

The survey asked how many new referral appointments they had per month and how many follow up appointments the services delivered per month. Again, some services could not capture either all or part of this data. Fig 9 below captures this.

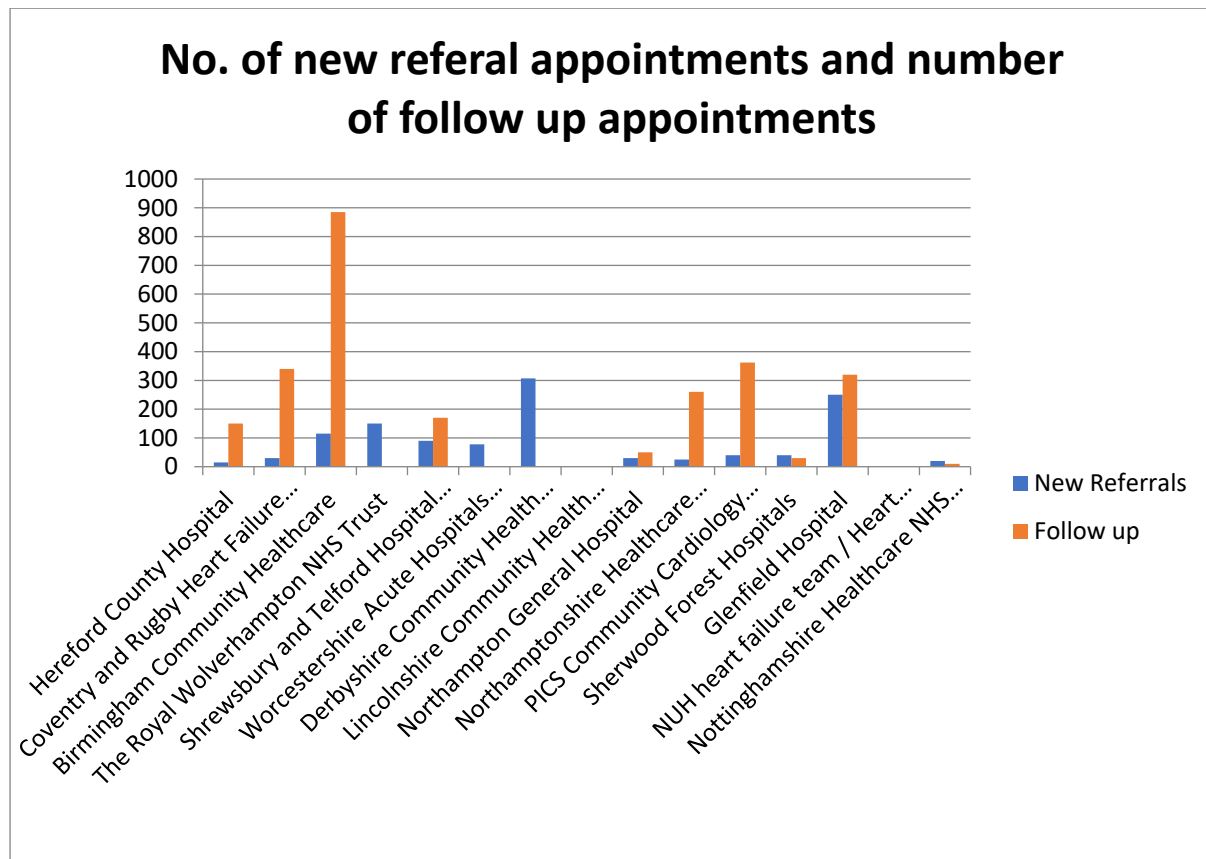


Fig 9 Source Midlands CPIP HF SURVEY

This shows the variability of capacity within the individual systems, and therefore demonstrates the importance of reviewing pathways to enable more capacity within those systems.

The introduction of the additional roles reimbursement scheme (ARRS) for primary care networks (PCNs) enables patients to see the right professional at the right time by ensuring there is a group of skilled professionals that add capacity within the primary care system. Their presence also creates opportunities for achieving PCN (Primary Care Network) priorities of developing personalised care and tackling inequalities. With heart failure being such a complex long-term condition and with an ageing population, it is a disease that creates pressure within an already overloaded system. Therefore, it is essential that maximum use is made of these additional roles to enable patients to access the most appropriate care, and for clinicians to be concentrating on their area of expertise.

When asked in the survey what other healthcare practitioners/nurses are involved in the management of heart failure patients, 1/15 stated general nurse consultant, 5/15 stated community matrons, 1/15 stated a long-term conditions nurse, 1/15 stated an inherited cardiac conditions nurse, 3/15 said nursing care assistants, 1/15 stated healthcare support

workers. Others mentioned were pacing assistants, exercise physios, pharmacists, and administrative teams. It is recognised that those completing the survey from an acute trust may be unaware of what other roles in primary care have contact with the patients regarding their long-term condition. However, it would be beneficial for those, especially in primary care and community services, to have an awareness of what additional roles are available that would be beneficial for the patient to access and understand how they refer into these services.

Discharging patients is sometimes hard; however, we know that the non-complex heart failure patients can be managed in primary care if appropriate pathways, effective communication, and knowledge and skills are evident.

Within the survey we asked how many new appointment patients were discharged, and how many follow up patients were discharged per month. We would like to think if appropriate referral systems are in place, the new appointment referral discharges should be low in number. Again, not all services collated all or part of this data, however Fig 10 below shows those that responded.

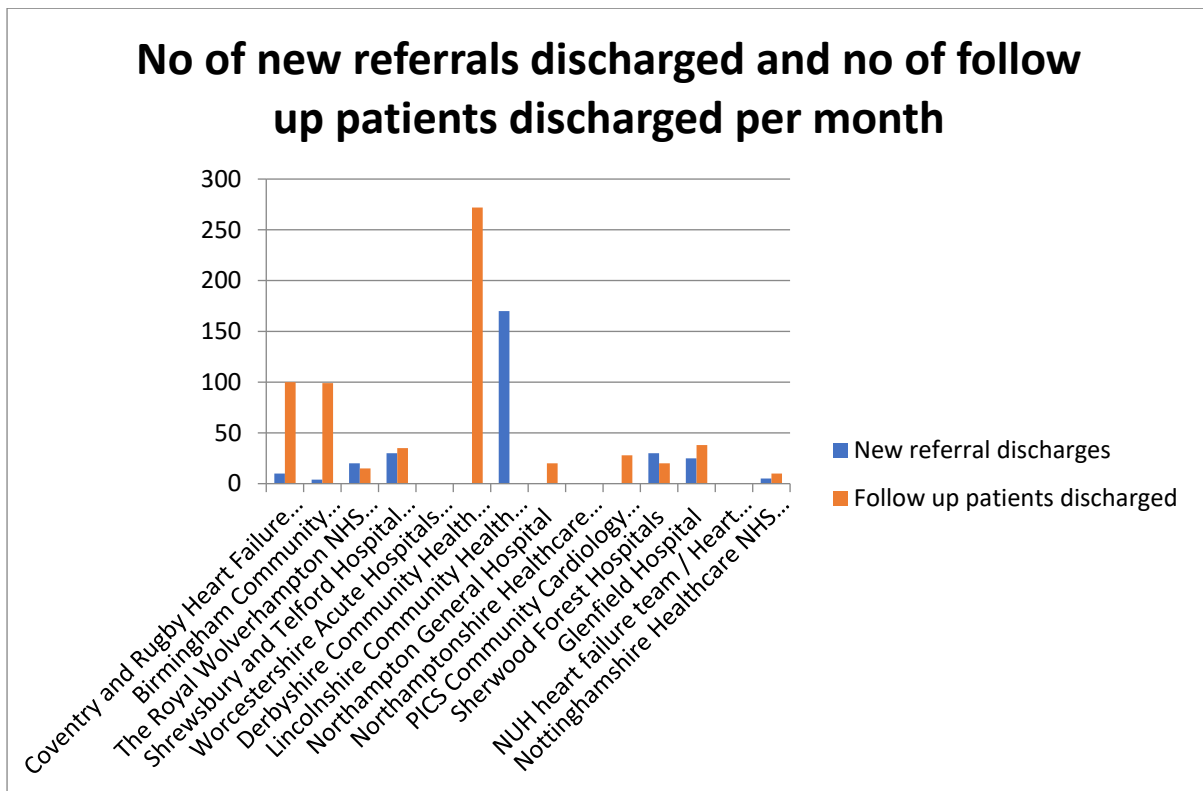


Fig 10 Source Midlands CPIP HF SURVEY

13/15 services responded that patients can self- refer into the service, and this was predominantly recorded that this is done through patient initiated follow up (PIFU).

PIFU is part of the outpatient's transformation requirements laid out in the 2022/23 Operational Planning Guidance and is a key part of the NHS' response to the COVID-19 pandemic, helping providers and systems manage waiting lists and to see the patients most

in need quicker. The approach helps empower patients to manage their own condition and plays a key role in enabling shared decision making and supported self-management in line with the personalised care agenda. Although not a new concept with heart failure patients, services are being encouraged to use this method.

When patients are referred into the heart failure services, assessment is key. This should not just include cardiovascular assessment, but also psychosocial elements. This can be time consuming, but essential for care planning. Throughout the pandemic, virtual consultations became the 'new normal.' Within the survey, services were asked how long they allocated for new patient appointments and for follow up appointments. Fig11 below shows this.

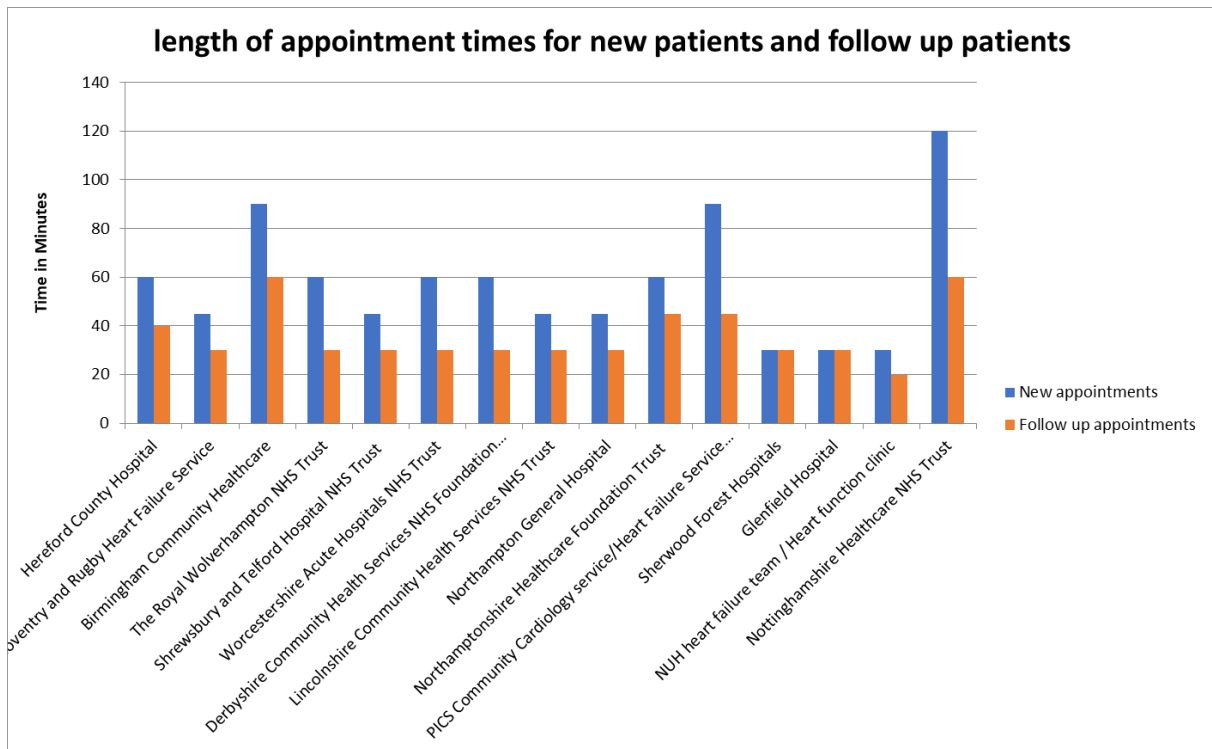


Fig 11 Source Midlands CPIP HF SURVEY

The setting in which patients are seen should be carefully thought out for both the health economy and patient benefit. Home visits can be better for some patients, but time to travel for appointments for heart failure teams can impact on the number of patients that can be seen. The NHS is attempting to ensure community care is a priority to reduce hospital capacity, but a clinic setting location needs to meet the needs of the population.

Below (Figs 12 and 13) shows the percentage of patients seen in clinics or as home visits in community services and the percentage of patients seen as inpatients and outpatients in acute service provision.

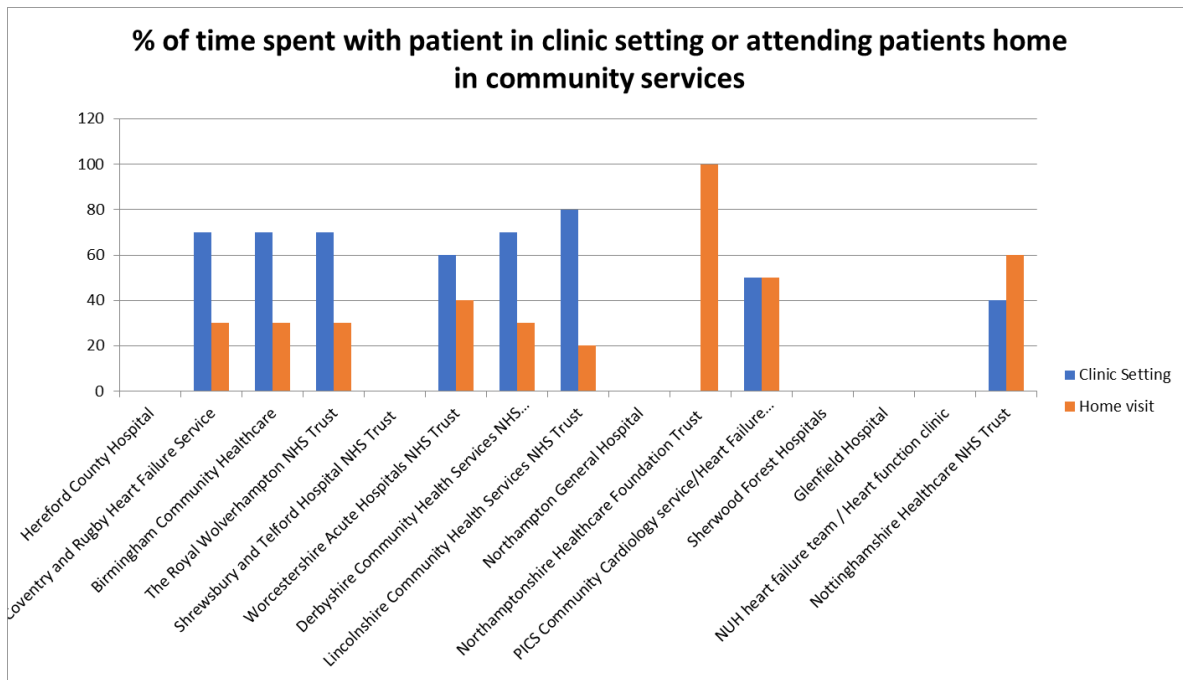


Fig 12 Source Midlands CPIP HF SURVEY

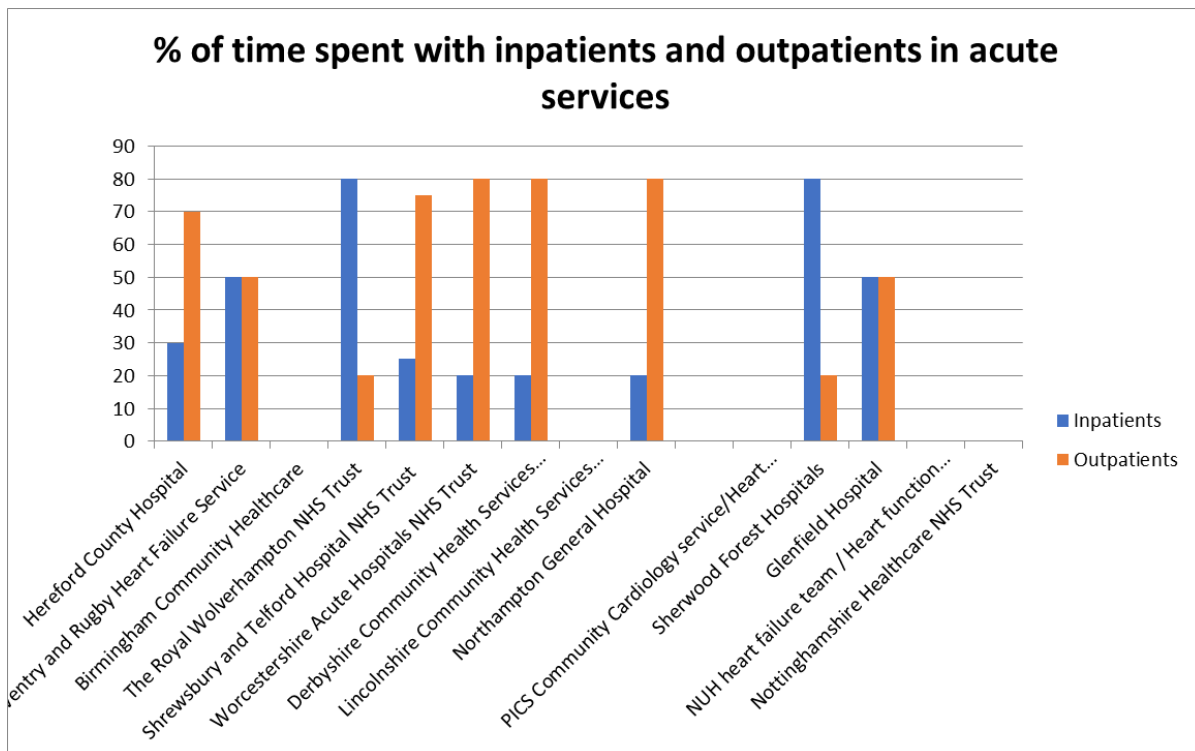


Fig 13 Source Midlands CPIP HF SURVEY

Since the COVID 19 pandemic, the use of technology for following up patients has come to the forefront. NHSE has delivered funding to some systems to pilot tele monitoring in their

Managing HF@home initiative. Managing Heart Failure @home aims to support people to manage their heart failure condition and keep well at home, using remote monitoring, supported self-management and education to minimise unnecessary face-to-face appointments and reduce avoidable hospital admissions.

Supporting people to self-manage at home has been vital during the pandemic and there is significant potential for changing the way we deliver care in the future to ensure that people get the care they need in ways that work for them, helping to reduce health inequalities and support the ambitions of the NHS Long Term Plan. Piloting projects will enable us to obtain evidence on the efficacy of using tele monitoring.

Within our region, the Royal Stoke University Hospital, used the digital tools Recap Health and Florence to monitor and educate heart failure patients following treatment for decompensated heart failure. The local team reported that this remote support and monitoring reduced hospital readmission rates and had a positive impact on heart failure care. They collaborated with Pumping Marvellous to identify that patients felt they improved their ability to manage their own health. Birmingham community heart failure nurses gained a BACPR qualification and enabled cardiac rehabilitation to be delivered remotely to their patients. Further funding has been offered to systems, and we are aware that many applications within the region were put in. If successful we hope to learn from these sites, so that we can enable other systems to introduce telehealth as a routine aspect of follow up care. However, we need to acknowledge that this is not an option for all patients and so this should be an introduced as an additional option to provide hybrid models of care.

Within the survey 3/15 services stated that they were using telehealth, Tunstall, Florence, and Spirit were all mentioned. Many of the other services stated that they were currently looking at this, and DOCABO was a potential resource that could be used.

Cardiac rehabilitation is well evidenced for heart failure patients. The NICE guidance states that we should offer people with heart failure a personalised, exercise-based cardiac rehabilitation programme, unless their condition is unstable. The programme:

- should be preceded by an assessment to ensure that it is suitable for the person
- should be provided in a format and setting (at home, in the community or in the hospital) that is easily accessible for the person
- should include a psychological and educational component
- may be incorporated within an existing cardiac rehabilitation programme
- should be accompanied by information about support available from healthcare professionals when the person is doing the programme.

The NICOR National HF audit captures the percentage of those referred for cardiac rehabilitation from acute trusts which is shown below (Fig14)

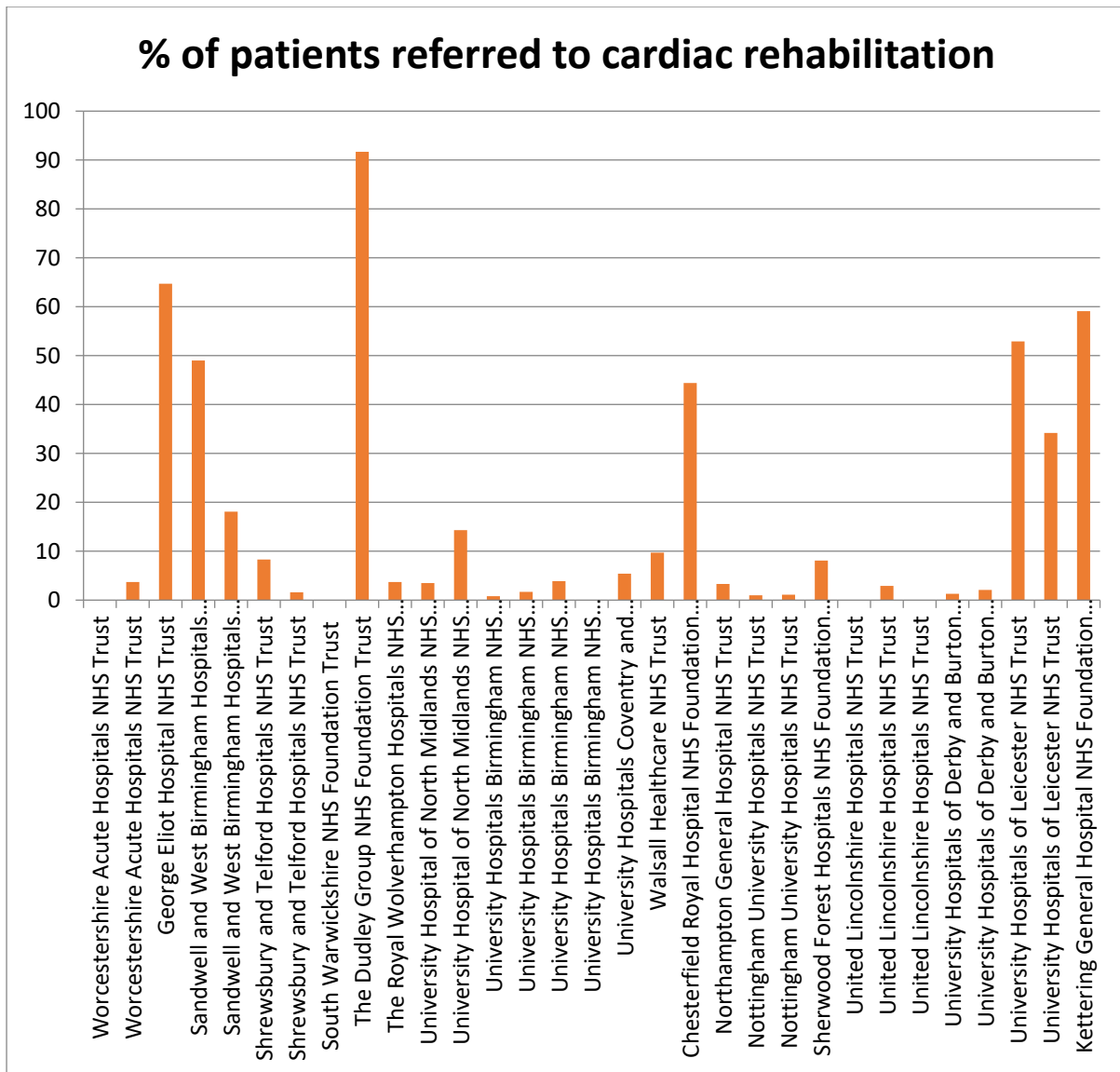


Fig 14 Source NICOR Heart Failure Audit 20/21

The Midlands CPIP survey showed that 9/15 (60%) services reported that they have access to cardiac rehabilitation for heart failure patients, although 2 of these are new, set up recently with NHSE funding for 1 year.

5/15 (33%) of the services offer a home-based exercise programme. The offer of REACH-HF (Rehabilitation EnAblement in CHronic Heart Failure) was offered to services recently through NHSE funding. It is a facilitated evidence based cardiac rehabilitation (CR) and self-management programme for use at home. It comprises the 'Heart Failure Manual,' a Relaxation CD, a choice of exercise (walking programme or a chair-based DVD) a 'Progress Tracker' for patients, and a 'Family and Friends Resource' for caregivers. There are many other online cardiac rehabilitation programmes that may be possible to tailor to heart failure patients. BHF set up an online cardiac rehab programme for services to use throughout the pandemic, and there are other online platforms, including Leicester's Activate your Heart programme, and the My Heart app.

Other areas, including Leicester, have focused on combining pulmonary rehab with heart failure specific rehabilitation. This was to enable the set-up of breathlessness rehabilitation, for patients with a primary symptom of breathlessness irrespective of the index diagnosis, or comorbid disease. Statistically significant improvements were seen in exercise capacity as well as reductions in shortness of breath and anxiety and depression scores.

However, we know through the National Audit of Cardiac Rehabilitation that even if offered, cardiac rehabilitation has only around 50% uptake for all patients, and this is less than 10% in heart failure patients.¹⁰ There needs to be a greater understanding of why patients do not take up this offer, despite there being advances in offering hybrid models of care. The WMAHSN is currently undertaking a project to understand this by reaching out to seldom heard communities and will ensure learning is shared from this.

Psychological support is equally as important for heart failure patients as well as clinical interventions, lifestyle advice and exercise programmes. Psychological interventions can help patients with heart failure self-manage, cope with symptom burden, and adjust to living with their condition. Only 4/15 (26%) of the services surveyed reported that they have access to this. BHF Heart Matters magazine undertook a survey of almost 3000 people who suffer with heart disease, and more than two thirds – 68% – said their condition had affected them mentally, emotionally, or psychologically. Below (Fig15) shows the results of this survey.

Emotional effects of heart condition

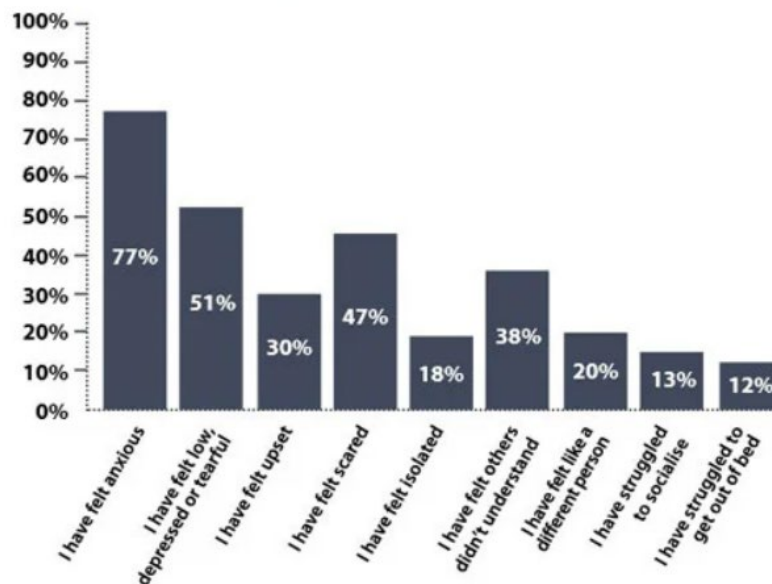


Fig 15 Source <https://www.bhf.org.uk/information-support/heart-matters-magazine/wellbeing/mental-health/mental-health-survey>¹¹

Only 4/15 (26%) of the services surveyed by the Midlands CPIP reported that they have access to psychological support services, hence many of our heart failure patients within the region may be struggling, with little additional support. Having access to this will also enable our specialist heart failure teams to be able to concentrate on the diagnosis, management

and follow up of patients, and refer patients onto specialist services to manage the psychosocial support.

The Care Pathway – End of Life

Patients at stage III and IV can be characterised as in advanced heart failure and are likely to have supportive and palliative care needs.

The NICE guidance states

If the symptoms of a person with heart failure are worsening despite optimal specialist treatment, discuss their palliative care needs with the specialist heart failure multidisciplinary team and consider a needs assessment for palliative care.

And

People with heart failure and their families or carers should have access to professionals with palliative care skills within the heart failure team.¹

It would be useful to understand how many heart failure nurses have palliative care training. It was recognised within the survey that 20-100% (mean 66%) of services nurses had undertaken a specialised heart failure module, which more than likely includes palliative care within it.

Therefore, access to palliative care services is important for heart failure patients, and it was encouraging to see that some services surveyed included palliative care clinicians within MDT discussions.

If palliative care and heart failure professionals working across primary care, community services, hospices and the acute trust collaborate, it is more likely that all disciplines will have a greater understanding of the management plan. Although there has been an increased focus on recognising that early conversations with patients, and collaboration with palliative care teams has improved access to palliative care services for heart failure patients, there are still small numbers of patients referred into palliative care services.

In the Midlands CIP survey 9/15(60%) of services stated that they have access to palliative care services for heart failure patients, however it was not recorded what percentage of their patients they refer.

SUMMARY

Heart failure teams are crucial to delivering evidence-based guidelines and treatment to heart failure patients. The services surveyed in the Midlands CIP survey consisted of both community and secondary care teams. Regular reviews of services are important as it is a way to find out if healthcare is being provided in line with standards and allows care providers and patients know where their service is doing well, and where there could be improvements. 4/15 (26%) of the services surveyed do not have specific key performance indicators for their service, and 3/15 (20%) stated that they needed reviewing.

3/15 (20%) of the services measure quality of life as part of patient outcome measures. 7/15(46%) record readmission rates and 5/15 (33%) record prescribing rates, for example target doses achieved.

Understanding the key issues within the Midlands is important, so we asked within the survey to identify what their key areas of best practice were, what the biggest pressure is, what are their top 3 priorities are and what the barriers are to achieve this.

The examples of best practice have been recorded in this word cloud below



Fig 16 Source Midlands CPIP HF SURVEY

The biggest pressures are shown below

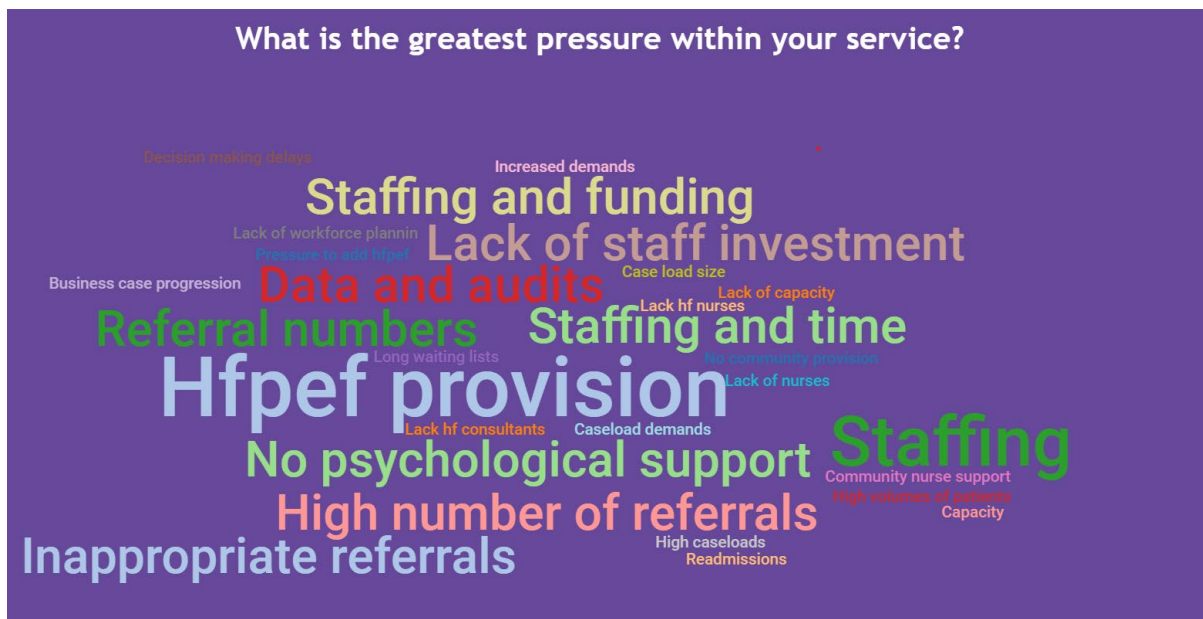


Fig 17 Source Midlands CPIP HF SURVEY

The top 3 priorities that services want to address across the region are recorded below.

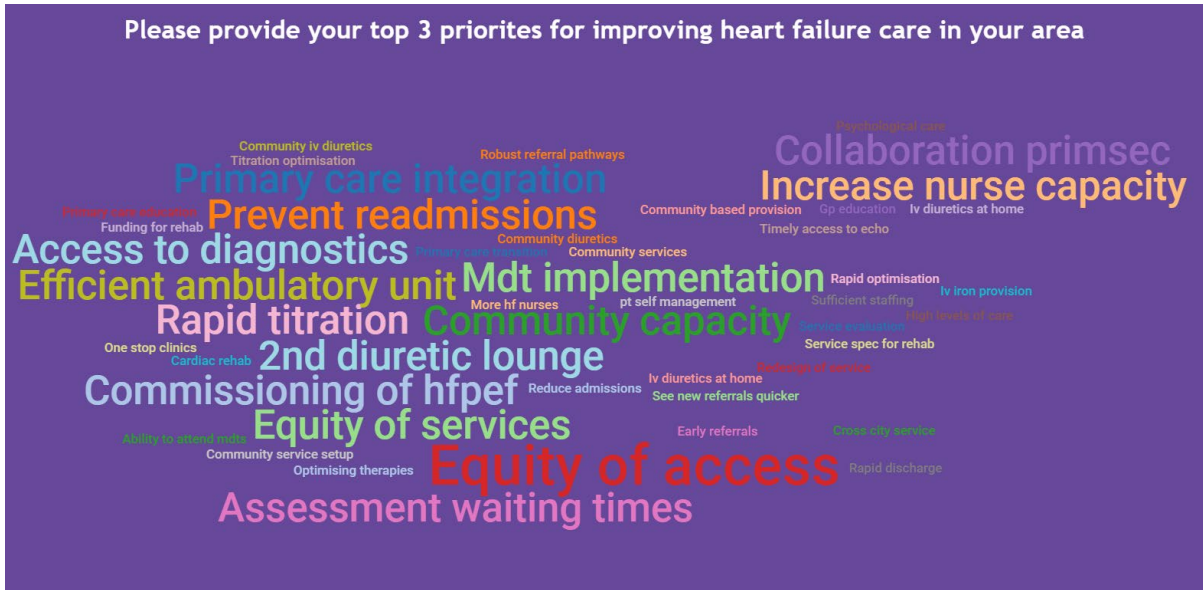


Fig 18 Source Midlands CPIP HF SURVEY

And the barriers to achieving these priorities are



Fig 19 Source Midlands CPIP HF SURVEY

It is positive to see that many examples of best practice were given. However, staffing, funding, and resource were identified as key pressures and barriers to achieve the changes that they wish to make to improve care for patients. IV diuretics, community provision, quicker referral pathways, medicines optimisation and access to cardiac rehabilitation appear to be common priorities.

Recommendations

The Midlands CPIP survey and the NICOR data will enable the Cardiac Networks to work with the regions teams to identify where gaps are in data as well as gaps in care provision. From this survey, and following a Midlands pathway mapping workshop held in November attended by heart failure specialists representing most Midlands systems the following recommendations were:

- Data – This report has highlighted that within the region we have plentiful missing data despite national and local sources being available. data collection is varied, and does not always truly identify the needs of the services. Therefore, we recommend a standardised approach to data collection to ensure that gaps can easily be identified to optimise opportunities for quality improvement. The data should be able to capture both community and acute services. Data should be accessible so that it is available at frequent time intervals, and it should include patient outcomes. This survey will be repeated to enable demonstration of the impact of the CPIP programme.
- Education – Education should be a key priority within the pathways and should include education for patients and their carers. Education is vital for primary care staff but should also consider education for non-specialist medics in acute trusts, and other teams across the pathway, i.e., palliative care teams.
- Diagnosis – Primary care need timely access to the NICE guideline recommended diagnostic tests required for heart failure diagnosis, and those that link into the breathlessness pathway. One stop clinics would be beneficial to ensure that this is timely and beneficial for the patient.
- Treatment and Management – All teams need to have access to the NICE recommended treatments for heart failure patients. This can be improved by ensuring there are adequate numbers of heart failure nurses that can prescribe, but equally ensuring that ambulatory units, virtual wards and telehealth resources are implemented to ensure hybrid models of care can be delivered. This will enable patient choice, resulting in improved collaboration between patients and clinicians.
- Holistic Management Plans – All patients should receive a management plan, and this should be personalised to them. It should highlight medical treatments but also identify opportunities to improve psychological support. A well informed, supported patient is more likely to engage with medical therapy.
- Integrated Working – Pathways should be written for integrated working, so that both primary care, community teams and acute teams can implement the holistic management plans. This will also provide opportunities to share good practice and identify how workforce can be utilised most effectively to meet the needs of the patients.
- MDT meetings – All heart failure teams should have an MDT, and this should have an integrated working model, that includes professionals from all parts of the pathway. Having primary care professionals, rehab teams and palliative care teams will enable discussions to be had regarding patients' needs and wishes from diagnosis to end of life.
- Patient support – Cardiac rehabilitation should be available for all heart failure patients. Well-being support should also be available for this group of patients. Consider utilisation of social prescribers and patient navigators to enable this to happen.

- Palliative Care – All patients should have access to palliative care services. This should be an integrated approach to ensure that advanced care planning is timely and personalised. This will enable ceilings of care and escalation plans to be identified.
- Workforce – Commissioners should consider workforce numbers to ensure that the Long Term Plan deliverables can be implemented and should consider utilising the workforce effectively to enable patients to have timely access for their diagnosis, treatment, and ongoing care.
- Patients with HFpEF – These patients are often forgotten and moved between different speciality teams. Clear pathways need to be identified for these patients to ensure that they are receiving the right treatment delivered by the most appropriate health care professionals.

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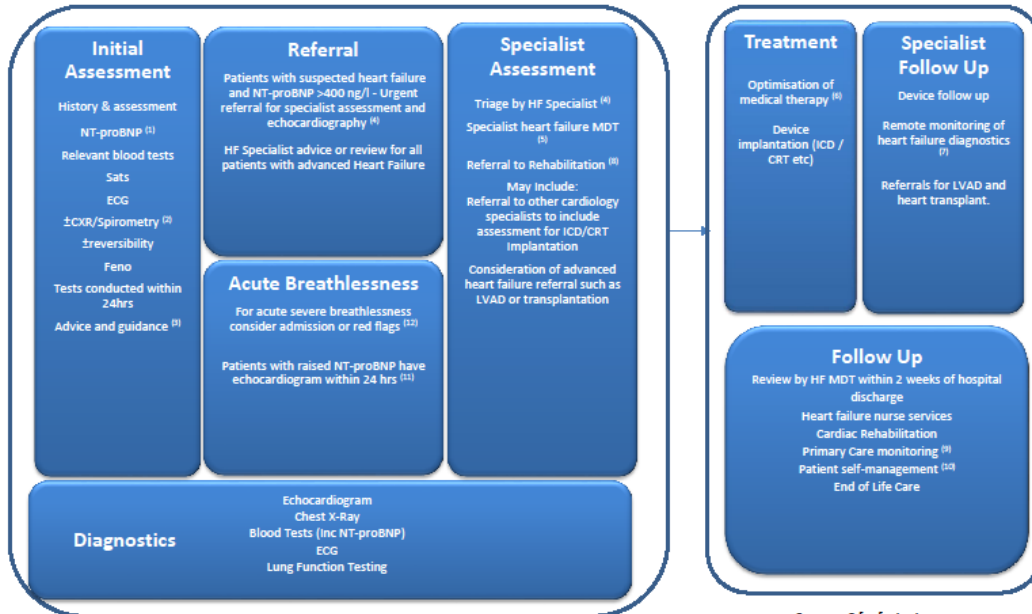
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Appendix A

Heart Failure



See page 2 for footnotes

Please note - ± symbol means that the test or intervention should be considered only if indicated.

Guidance