

# Improving heart failure services for people in London

*Review, recommendations and offer of support from the London Cardiac Clinical Network*

## Acknowledgements

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## Introduction | Heart failure in London

Heart failure is a long term condition in which the heart is unable to pump blood properly around the body. It is characterised by relapses and remissions, and in end stage disease, many people have multiple admissions to hospital and high contact across many healthcare services. Heart failure cannot be cured, but with appropriate symptom management people with heart failure can be supported for many years. The total cost of heart failure to the health service has been estimated at 2 per cent of the annual NHS budget<sup>1</sup>. Historical data<sup>2</sup> suggests that approximately 66 per cent of the healthcare costs in heart failure relate to hospitalisations. However, where specialist services are available, hospitalisation rates are reduced<sup>3</sup>.

Evidence shows that well-developed heart failure services consume less budget overall. One study noted that such services can reduce the proportion of expenditure on hospitalisation to 40 per cent of the total heart failure budget<sup>4</sup>. These specialist services follow the level of care recommended in national<sup>5</sup> and international<sup>6</sup> guidelines, by focussing on:

- » the organisation of multi-disciplinary care;
- » interventions that support transitional care;
- » ongoing follow up; and
- » coordination across primary and secondary care.

Optimal pathways and treatments to manage chronic heart failure are well understood. To reduce unwarranted variation in the management of heart failure, commissioners, clinicians and service providers need to consider ways to enhance compliance with NICE guidance in local areas.

Oversight of the whole pathway, from detection and diagnosis, through treatment and rehabilitation and into ongoing management in the community, including end of life care, is a shared responsibility, and must be shared by commissioners and providers alike. Often changes are made to a system but the impact of that system change is not assessed. Additionally, the impact of the whole system on a patient journey is not regularly monitored by those organising or commissioning services. This could be improved by the setup of a local group of committed clinicians who have oversight of governance across the pathway. It is expected that this will improve care and reduce cost.

## Introduction | Heart failure in London

This report documents the outcome of the London Cardiac Clinical Network review of the current provision of heart failure services in the capital. It highlights the huge variability in heart failure care pathways across London, as well as, unsurprisingly, similar variability in admission rates, length of stay and readmission rates for patients with heart failure. Such variances in care must correspond to clear cost differentials between the best and worst performing areas.

Against this background, we can seek out opportunities to ensure optimal pathways and treatments are followed for better outcomes for all chronic heart failure patients in London. A number of these opportunities are developed as recommendations within the report, which will require collaboration between commissioners, service providers and others. This collaboration is already a requirement of delivering London's five Sustainability and Transformation Plans (STPs) and these partnerships provide a suitable geography within which to prioritise and deliver quality improvements to heart failure services.

The support the London Cardiac Clinical Network will provide in 2017/18 and 2018/19 to help improve heart failure services for people in London is also set out.

This report documents the London Cardiac Clinical Network's review of the current provision of heart failure services in the capital, along with recommendations and support offers by the network.

*Working together, we can create high quality heart failure care for all Londoners.*

### Introduction | Prevalence and recording

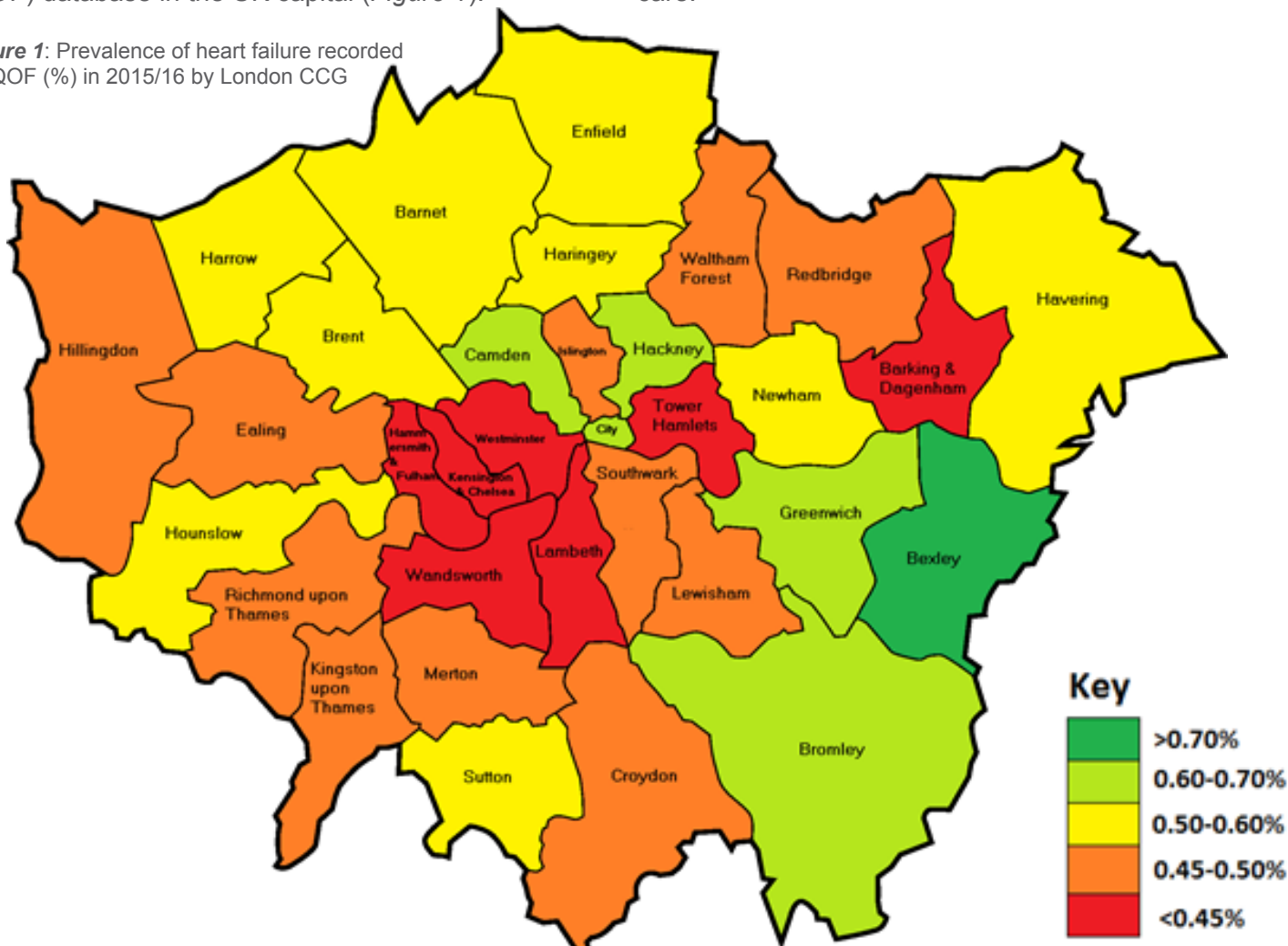
Epidemiological studies suggest that heart failure is present in approximately 1 to 2 per cent of the population<sup>7</sup>. In 2015, 9.6 million people were recorded on GP registers in London. The recorded prevalence of 47,250 patients, or 0.5 per cent, represents significantly fewer people diagnosed with heart failure in London when compared with the expected prevalence. Although London has a younger population than the rest of the UK, its population also has significantly higher ethnic diversity, and so the overall impact is that the prevalence should still be around the expected 1 to 2 per cent of the population.

There is immense variability in the prevalence of heart failure by clinical commissioning groups (CCGs), recorded in the Quality and Outcomes Framework (QOF) database in the UK capital (*Figure 1*).

For example, the prevalence of heart failure in NHS Wandsworth CCG (0.32 per cent) is less than half the prevalence in NHS Bexley CCG (0.77 per cent). In both areas, the recorded prevalence is still lower than the expected prevalence of heart failure, and overall, 78 per cent of CCG areas recorded less than half of the expected number of patients with heart failure.

This variability in recorded prevalence alongside the low overall prevalence suggests that many people living in London are not being diagnosed with heart failure. Patients expect that data about their diagnosis and treatment is shared between providers but this is not always the case. They are missing out on therapy that may prolong their life or improve the quality of life and minimise inappropriate admissions to secondary care.

**Figure 1:** Prevalence of heart failure recorded on QOF (%) in 2015/16 by London CCG



## Recommendations and London Cardiac Clinical Network support

### Recommendations

#### Recommendation 1

It is essential that services are coordinated within each of the five STP footprints in London by a group committed to treating and managing heart failure, responsible for governance across the whole pathway in the area they serve. The group will need to consider detailed analysis of the incidence, prevalence, admission, readmission rates and mortality in order to allow deficiencies in the service to be identified and corrected in a timely manner.

#### Recommendation 2

These groups must develop a work plan that will ensure services are delivered in line with NICE guidance<sup>8</sup> and have an overview of progress against delivery.

#### Recommendation 3

Heart failure services must ensure that the diagnosis and treatment information is shared along the pathway. Providers and commissioners should work with IT suppliers to ensure that data sharing happens in a timely manner.

### Support

Support from the London Cardiac Clinical Network in 2017/18 and 2018/19 can improve governance and information sharing by:

- » Providing commissioners with guidance on the appropriate treatment and management pathways for their heart failure services, including examples of where these pathways are already being delivered.
- » Championing consistent recording and timely information sharing on patients with a new heart failure diagnosis, as well as improving data quality around those who already have a diagnosis.

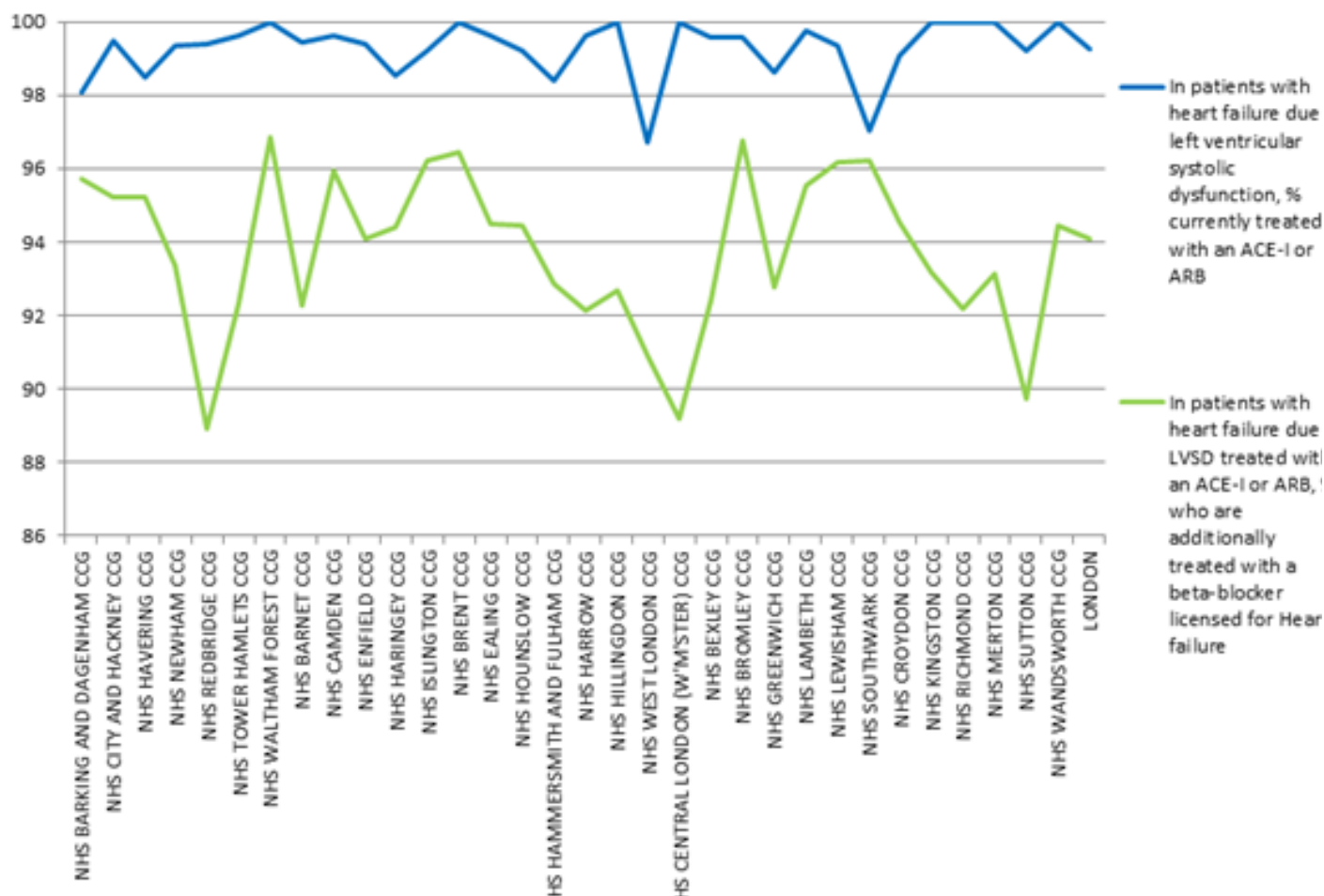
## The care pathway | Diagnosis and testing

QOF data for 2015/16 (Figure 2) demonstrates that patients in London with heart failure due to left ventricular systolic dysfunction (LVSD) receive evidence based treatment, with 99.3 per cent prescribed an angiotensin converting enzyme inhibitors (ACE-I) or angiotensin receptor blockers (ARB).

Education is an important factor in the early recognition of symptoms. Poor awareness of heart failure among both patients and professionals can lead to delays in the patient seeking medical help, obtaining an accurate diagnosis and getting appropriate treatment as quickly as possible.

Prompt and accurate diagnosis of heart failure is the necessary first step in the care pathway. Diagnosis of heart failure involves a combination of expert clinical insight into the patient's signs and symptoms, along with laboratory tests and imaging procedures to confirm the diagnosis.

Figure 2: Treatment of heart failure from QOF 2015/16 by London CCG





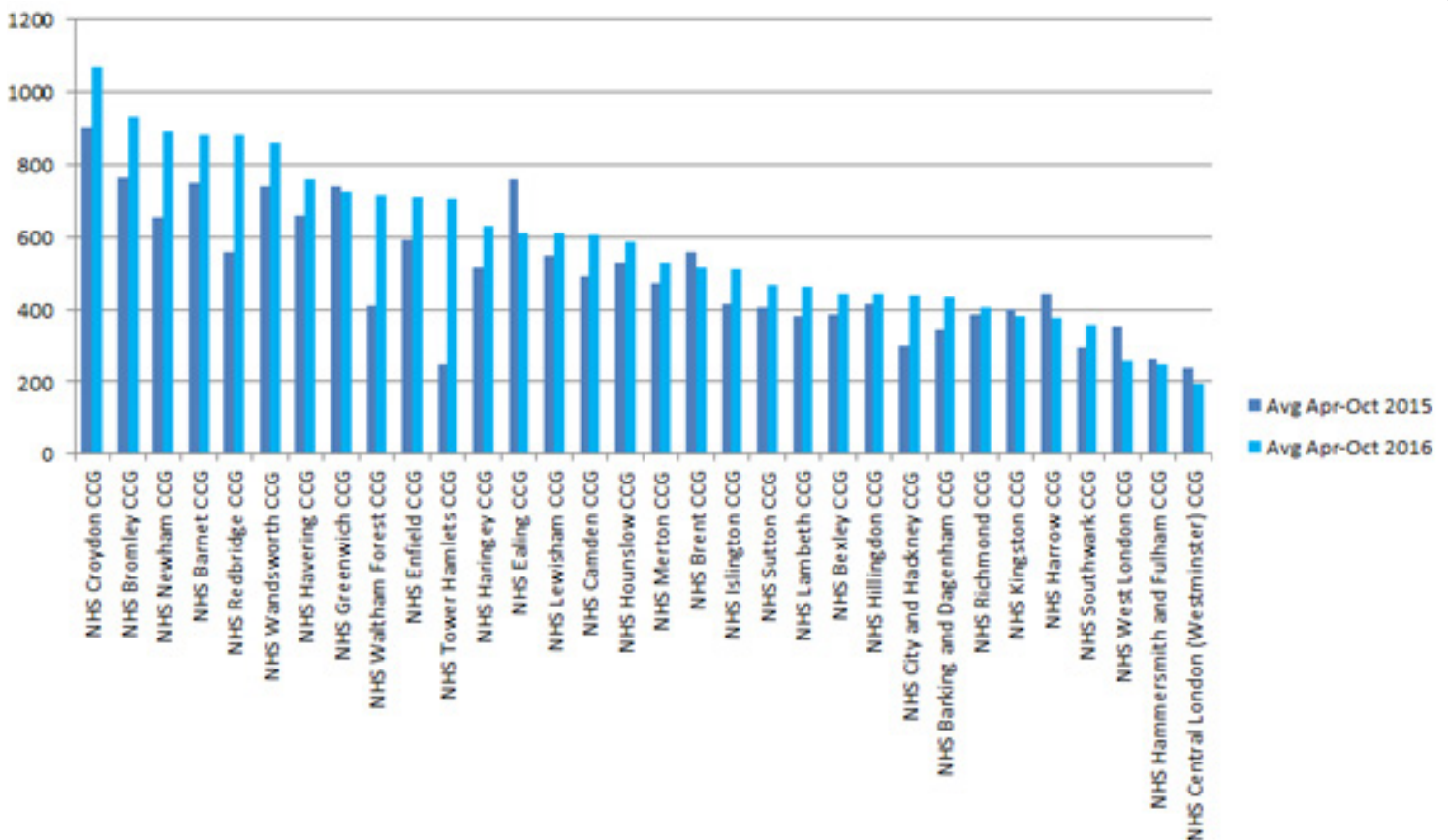
## The care pathway | Diagnosis and testing

Serum natriuretic peptides (B-type natriuretic peptide [BNP] or N-terminal pro-B-type natriuretic peptide [NT pro BNP]) circulate as hormones to act in various tissues in the body and are an extremely useful tool for the diagnosis of heart failure. Low levels of circulating natriuretic peptides can effectively rule out a diagnosis of heart failure. This simple blood test has been recommended by NICE for more than 10 years and is useful in rationalising the use of more invasive and costly diagnostic tests such as echocardiography. Nevertheless, there are several CCGs within London where access to natriuretic peptide testing is not available.

GPs in Tower Hamlets do not have access to BNP testing, and this appears to be influencing the recorded prevalence of 0.40 per cent of population. In contrast, the most recent data suggest that clinicians in Tower Hamlets are ordering many echocardiograms (*Figure 3*) which would be unnecessary if BNP were used to better triage services.

In areas where BNP testing is not available, a business case to introduce natriuretic peptide testing must be developed. It is expected that successful implementation of the business case would reduce unnecessary – and costly – echocardiography procedures and increase recorded prevalence of heart failure.

Figure 3: Number of echocardiograms (per month) by London CCG (Source: Unify2)



## The care pathway | Hospital admission and readmission

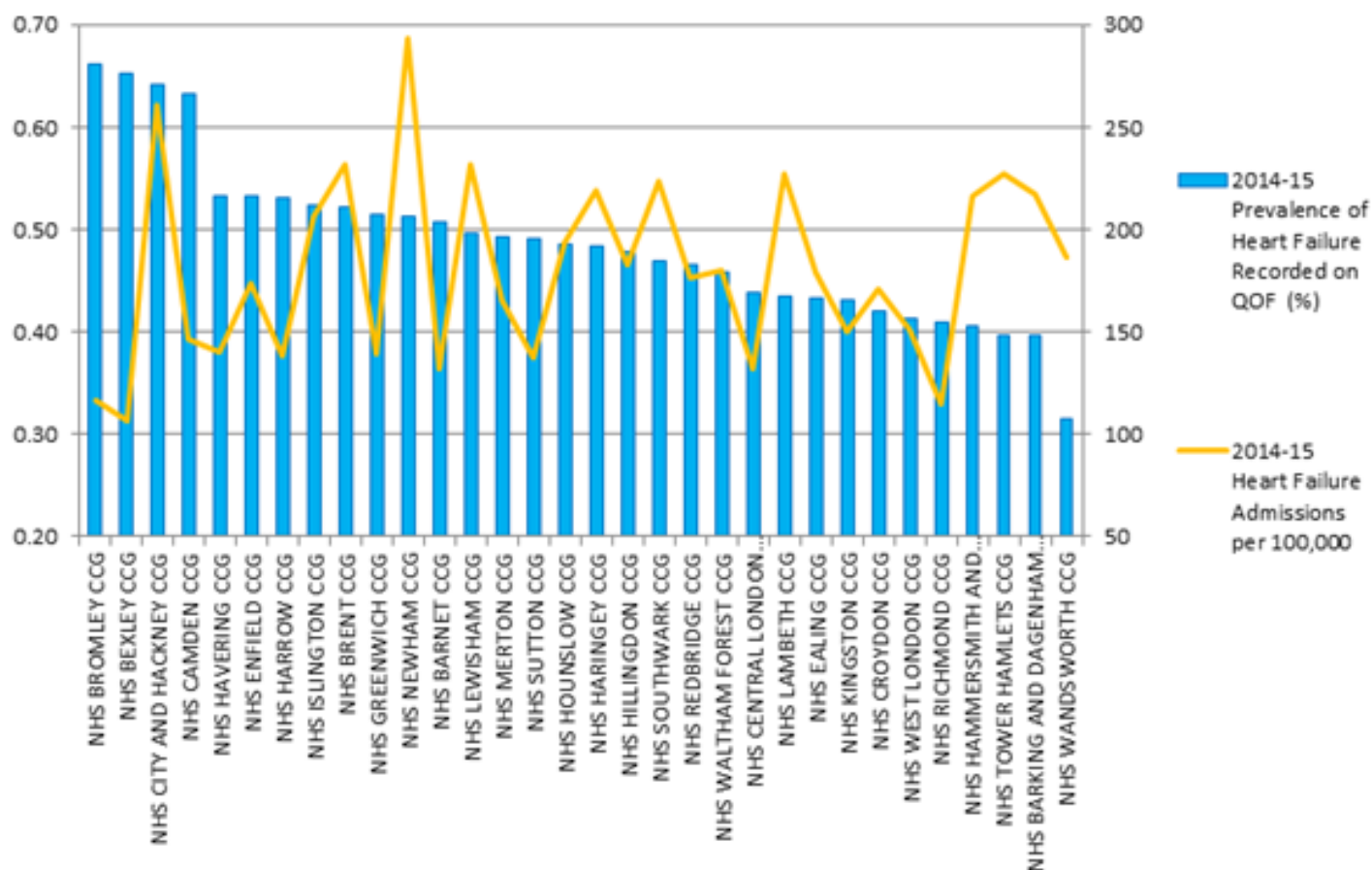
A large proportion of the expenditure in heart failure occurs during admission to hospital. Heart failure was recorded as the primary or secondary diagnosis in 2.5 per cent of all hospital admissions<sup>9</sup>. The mean length of stay in hospital is typically between 9.5 days and 13.5 days, depending on whether specialist care is received<sup>10</sup>.

A large proportion of the expenditure in heart failure occurs during admission to hospital.

There is major variation in heart failure hospitalisation rates across London (Figure 4). NHS Bexley CCG, with a recorded prevalence of 0.77 per cent, has an admission rate approximately one-third of that in NHS Newham CCG (107 compared to 293 per 100,000). High rates of hospitalisation with heart failure are sometimes reported in areas with low reported prevalence. Tower Hamlets reports a low recorded prevalence rate of 0.40 per cent with a high admission rate of 227 per 100,000. This variation gives clear opportunities to improve care and reduce cost.

An average heart failure admission costs £3,796<sup>11</sup>. If NHS Lambeth CCG, with an admission rate of 227.4 per 100,000 and 318 admissions in 2014/15, had performed at the average rate for London CCGs of 180.3 per 100,000, it would have avoided 66 admissions and saved £250,000. NHS Newham CCG, which had the highest admission rate of 293 per 100,000, would have avoided 145 admissions and saved £549,000. In London there are examples of best practice, where services are designed to manage patients at home, when possible.

Figure 4: Prevalence of heart failure recorded on QOF (%) vs admission rate (per 100k) by London CCG (2014/15)



## The care pathway | Hospital admission and readmission

### **Case study: Camden Rapid Response Admissions Service**

Patients at risk of admission can be referred to the Camden Rapid Response Admissions Service 24 hours a day. This team, one of whom is a specialist heart failure nurse, can administer intravenous (IV) diuretics to appropriate patients, allowing patients to stay at home and reducing admissions and readmissions. The inclusion of a heart failure nurse as part of this team allows training and upskilling of other members to deliver care. The team also works closely with a very well established community heart failure service consisting of four nurses.

Access to appropriate services operating 24 hours a day, seven days a week is key to patient-centred management of heart failure in the community.

The on-call services need not have specific heart failure expertise if this expertise is available from community heart failure services during work hours. As in Camden, these specialists can provide a treatment plan for the on call services to follow.

Access to appropriate services operating 24 hours a day, seven days a week is key to patient-centred management of heart failure in the community.

# London Cardiac Clinical Network

Improving heart failure services for people in London

London Clinical Networks

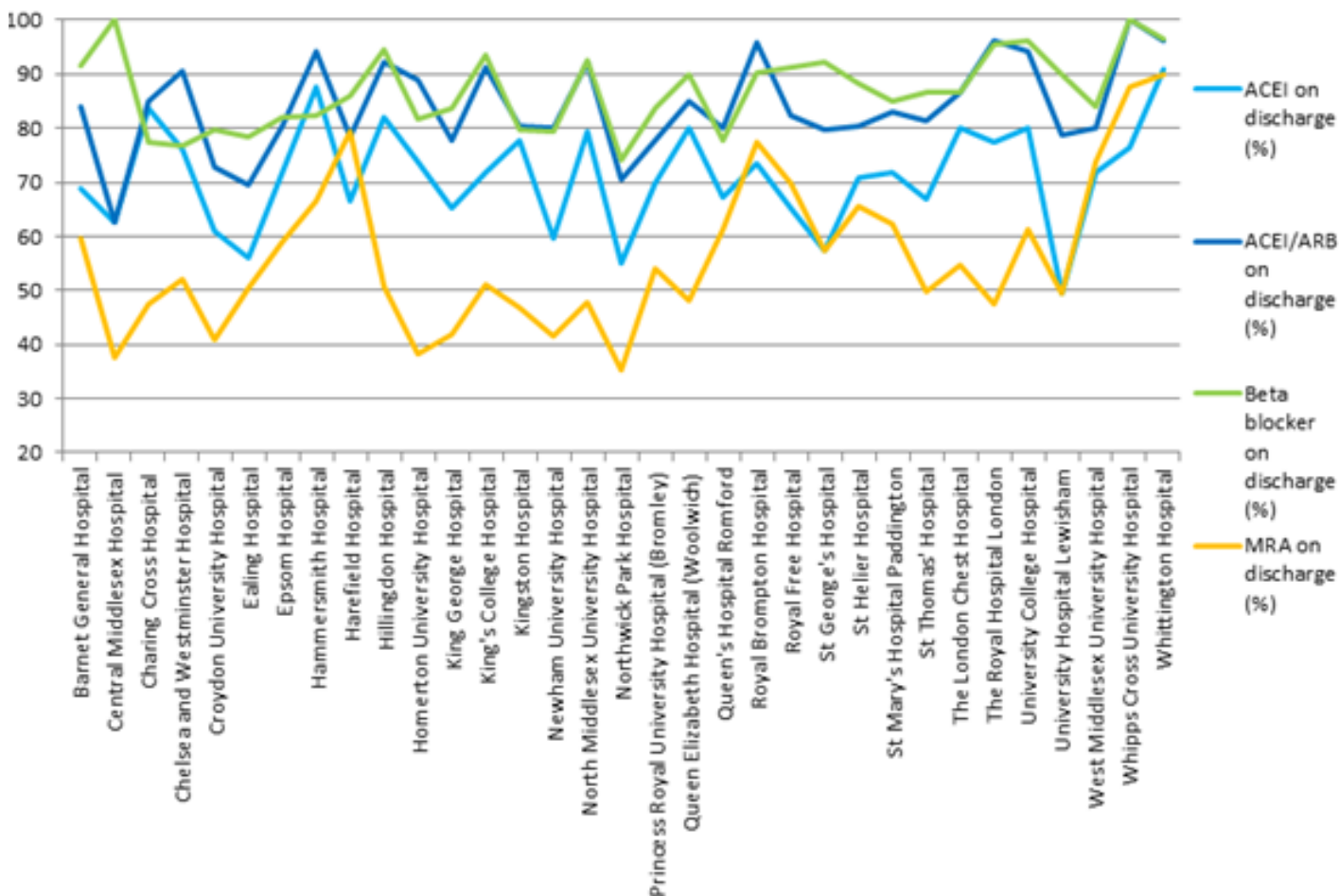
## The care pathway | Treatment of heart failure

Angiotensin converting enzyme inhibitors (ACEI), angiotensin receptor blockers (ARB), beta blockers, mineralocorticoid receptor antagonists (MRA) and, most recently, a neprilysin inhibitor<sup>12</sup> have been shown to reduce mortality and improve morbidity for patients suffering from heart failure. This has been proven through studies of populations and, importantly, in real life groups. The National Heart Failure (NHF) Audit<sup>13</sup> of 53,608 patients admitted with heart failure in England – which included 6,945 patients in London – found that treatment with ACEI, beta blocker and MRA substantially reduced mortality in the year following discharge.

Although most people recorded on the heart failure register in primary care are receiving an ACEI or ARB and beta blocker, patients in hospital may not be

receiving comparable care. Following an admission to a London hospital for heart failure, treatment rates with ACEI or ARB vary from 65 per cent to 99 per cent at discharge (*Figure 5*). There is even more variation in the prescription rates of MRAs, a third class of drugs known to improve prognosis. The data on prescription rates for this class is not recorded in primary care but in secondary care at discharge the rate varies from less than 40 per cent in three hospitals (Central Middlesex, Homerton University and Northwick Park) to 90 per cent (Whittington Hospital). Data from the National Heart Failure Audit clearly demonstrates that people discharged on, and tolerating, triple therapy (ACE inhibitors or ARB plus beta blockers and MRA) have a better prognosis, and are less likely to be readmitted with heart failure.

Figure 5: London hospital treatment comparison from NHF Audit (2014/15)



### The care pathway | Treatment of heart failure

One of the hurdles faced by providers is the range of different IT systems which do not directly transfer information to each other. For example, in Camden, University College London Hospitals NHS Foundation Trust uses e-CareLogic, the Royal Free London NHS Foundation Trust use Cerner Millennium, the community nurse provider Central and North West London NHS Foundation Trust (CNWL) uses SystemOne, and local GP practices use EMIS Web.

The lack of interconnectivity and notes sharing can have a significant impact on patient care and the sharing of clinically important information between providers. The impact of this is that service providers are unable to see notes made by clinicians in other providers. This leads to unnecessary duplication of appointments, repeated investigations and in the worst-case scenario prescribing errors and harm. As well as worsening the quality of service received, this also increases the cost.

## Recommendations and London Cardiac Clinical Network support

### Recommendations

#### Recommendation 4

All commissioned heart failure services must provide universal and easy access to appropriate diagnostic services. This will include access to measurement of natriuretic peptides, rapid access to echocardiography and assessment by a specialist.

#### Recommendation 5

All patients must receive access to the appropriate drug regimens when admitted to hospital as well as having access to community services that support the ongoing person-centred management of their condition.

### Support

- » Support from the London Cardiac Clinical Network in 2017/18 and 2018/19 can enable the development of heart failure services by:
- » Providing commissioners with guidance on including the appropriate diagnostic services within their heart failure pathways.
- » Giving service providers access to up to date information on current service performance. The network will explore the possibility of working with existing providers of cardiac services data to give quarterly reports to providers on the quality of services.
- » Working with commissioners and the London Digital Programme to enable service providers to share data, encouraging compliance with data sharing standards when procuring IT solutions, and assisting with the development of structured heart failure datasets.

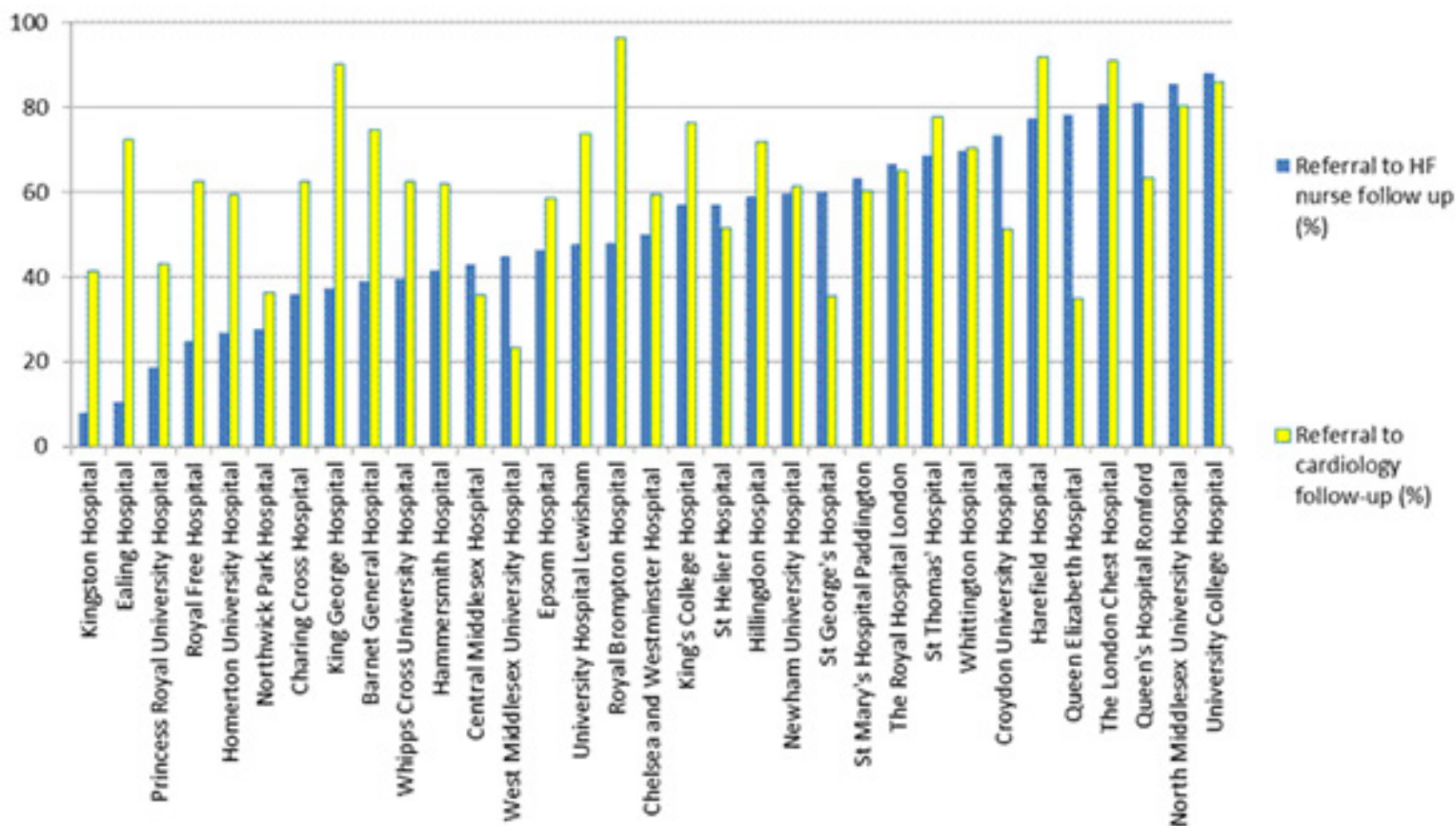


## The care pathway | Follow up

Effectively coordinated follow up is essential for good outcomes, with numerous studies documenting improvements in quality of life and reductions in hospital admissions and death<sup>14</sup>. This follow up should include time for optimisation of medical therapy, patient and caregiver education, self care support, psychosocial support, increased access to healthcare and exercise based rehabilitation. Nurse led care during the transitional period has been shown to be effective<sup>15</sup>. A survey of heart failure nurse services in London showed that all nurses in such services provide patients with education and psychosocial support, and view this as a key part of their role.

However, follow up services are often fragmented and access to this level of care varies. Following hospital discharge not all patients are referred for coordinated follow up (*Figure 6*). One London hospital, for example, arranges follow up with a cardiologist in only 41 per cent of cases and just 8 per cent of patients to a heart failure nurse. In comparison, another London hospital refers over 86 per cent to cardiology follow up and 88 per cent of its patients to nurse led follow up. Given the importance of effective follow up and the central role of heart failure nurses in heart failure management, this suggests that there are improvements in this area that would benefit many patients in London.

Figure 6: Referral for follow up by London hospital from NHF Audit (2014/15)



### The care pathway | Follow up

A survey carried out across London by the Cardiac Clinical Network in 2015/16 showed that the majority of community heart failure follow up is provided through clinics, home visits or telephone follow up and, where resources allow, tailored to patient need. Community services in Tower Hamlets and Bromley do not provide home visits, and so patients are required to attend a face-to-face clinic for their follow up. In both of these areas, heart failure nurses have higher than average patient caseloads.

The 2016 European Society of Cardiology (ESC) guidelines on heart failure<sup>16</sup> note the importance of integrating other healthcare services into the overall provision of care for people with heart failure.

In particular, the ESC notes close collaboration between clinicians treating heart failure and other experts, including the need to refer to psychological support when necessary. All heart failure services should contribute to the upskilling of these healthcare professionals whether they are part of the heart failure team or providing support externally (eg to Improving Access to Psychological Therapy [IAPT] services that support people with heart failure and depression).

For all common comorbidities<sup>17</sup>, heart failure services – both in hospital and the community – must know when and how to refer to specialist services and understand the local pathway for referral.



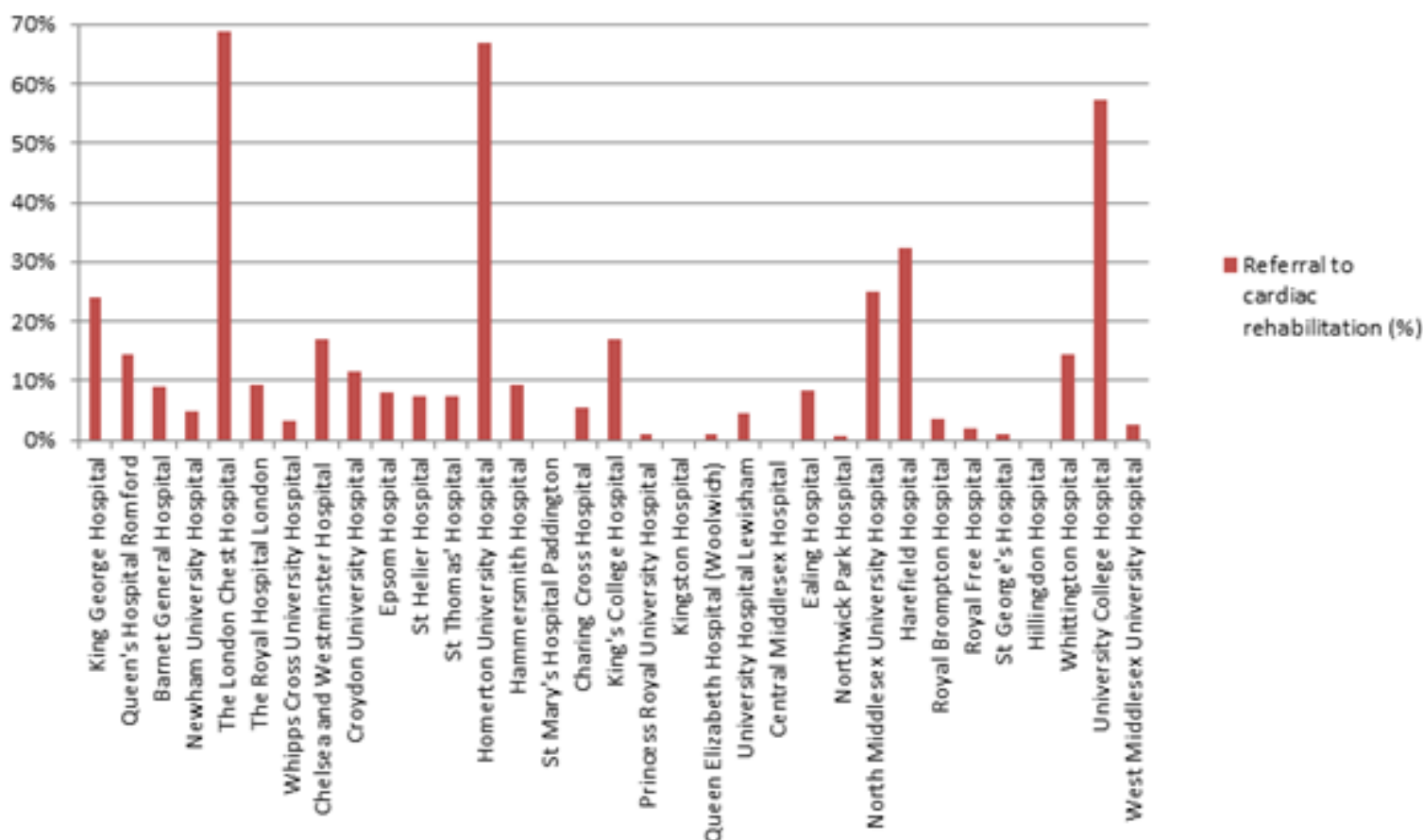
## The care pathway | Exercise programmes and cardiac rehabilitation

The 2017 Nuffield Trust research report<sup>18</sup> on moving care into the community, highlights that Cochrane reviews\* have demonstrated that cardiac rehabilitation is successful in reducing the risk of hospital admission for patients with heart failure<sup>19</sup>. For example, the risk of overall hospitalisation was reduced by 25 per cent for patients with heart failure taking part in exercise based cardiac rehabilitation.

As well as reducing hospitalisation, regular aerobic exercise also improves quality of life for people with

heart failure. However, unlike the uptake of cardiac rehabilitation following myocardial infarction, few exercise programmes are provided for patients with heart failure. In London, few centres provide specific exercise training. Patients from hospitals able to access heart failure rehabilitation provided by University College London Hospitals NHS Foundation Trust refer high proportions of their patients (*Figure 7*). However, on the whole, fewer than 10 per cent of patients are referred for this level of quality heart failure outpatient care.

Figure 7: London hospital referrals to cardiac rehabilitation NHF Audit (2014/15)



\* Cochrane reviews are systematic reviews of primary research in human health care and health policy.

## The care pathway | Palliative and end of life care

The highest healthcare costs in the heart failure pathway are associated with the time of diagnosis and in the last three months of life<sup>20</sup>. Palliative care is an approach to end of life care which aims to make people as comfortable as possible in their physical symptoms, as well as addressing the psychological, social and spiritual needs of patients and their families/carers. The approach is built upon good communication and actively involves the patient and family in decision making. Such principles should be included early in the disease trajectory. Palliative care improves the quality of life of patients and their carers and easy access to a key worker streamlines use of healthcare resources<sup>21</sup>.

A London Cardiac Clinical Network survey of heart failure services in London in 2015/16 found that palliative care is provided by 93 per cent of heart failure nurses working in the community and 41 per cent of nurses working in secondary care heart failure services. Training of heart failure nurses to provide this level of support was provided by the British Heart Foundation<sup>22</sup>. People with heart failure can benefit from palliative care, however only 4 per cent of heart failure patients in England are currently referred into specialist palliative care services<sup>23</sup>. Given the known symptom burden associated with heart failure this seems a substantial inequity.

The highest healthcare costs in the heart failure pathway are associated with the time of diagnosis and in the last three months of life.

Commissioners must ensure an appropriate ongoing level of knowledge and skills to enable heart failure services to provide palliative care<sup>24</sup>, including where appropriate the knowledge of referral pathways into specialist services. The End of Life Care (EOLC) Clinical Network conducted a survey of existing EOLC services in London, including specialist palliative care. The data is currently being analysed and the results will be presented at London, STP and CCG level. The network has formed a Transforming EOLC Services working group to influence commissioning, share best practice and improve service provision.

## Recommendations and London Cardiac Clinical Network support

### Recommendations

#### Recommendation 6

Commissioners must ensure the availability of community services for heart failure patients that can provide optimisation of medical therapy, patient and family/carer education, self care support, psychosocial support and exercise based rehabilitation. These services must also have direct access to a secondary care heart failure specialist. Increased access to specialist healthcare services can be facilitated by providers understanding their local referral pathways.

#### Recommendation 7

Commissioners must prioritise provision of cardiac rehabilitation services that improve care for heart failure patients and directly reduce the number of unnecessary admissions and readmissions.

#### Recommendation 8

Commissioners should ensure that for people with heart failure:

- » palliative care services are robust and comprehensive;
- » specialist palliative care is universally available; and
- » all healthcare staff are adequately trained to refer them onto specialist palliative care when required.

### Support

Support from the London Cardiac Clinical Network in 2017/18 and 2018/19 can improve follow up and community care by:

- » Collaborating with the London Mental Health Clinical Network to upskill healthcare professionals in IAPT services to support people with heart failure and depression.
- » Promoting an understanding to those working in heart failure services of local pathways for referral to specialist IAPT services.
- » Working with commissioners to produce service specifications and business cases for cardiac rehabilitation services that can support heart failure patients, through the provision of exercise programmes.
- » Collaborating with the London End of Life Care Clinical Network to produce a competency framework for healthcare staff who provide palliative care for people with heart failure.

## Conclusions

Data on how heart failure patients are being managed is available through a range of sources, including the [National Heart Failure Audit](#), QOF and [National Cardiovascular Information Network \(NCVIN\)](#). These data will be of great value to the commissioners and providers of heart failure services in London. These data demonstrate low rates of detection, including examples of failure to record cases and poor communication between providers across settings, particularly between primary/secondary and community/primary care. Improving diagnosis of heart failure will ensure more patients receive the care they require and reduce the number of unnecessary, high cost emergency admissions. Accurate recording will allow clinicians and commissioners to review the quality of service heart failure patients are receiving.

QOF data shows that the patients admitted to hospital who are recorded on the heart failure register generally receive appropriate care. However, there are still improvements to be made in some areas, as well as known gaps in the provision of all the necessary services to enable high quality care. This unwarranted variation provides an opportunity to improve care in London. Providing more care in the community with access to specialist input as required is a key part of the *NHS Five Year Forward View*<sup>25</sup> and heart failure services must continue to adapt in this direction.

Ensuring patients receive the appropriate follow up after an admission for heart failure is fundamental to delivering the best possible outcomes. The availability of cardiac rehabilitation services providing appropriate support for heart failure patients around London is poor despite clear evidence that it is cost effective, reduces mortality and improves outcomes.

By addressing these issues together through the recommendations made within this guidance, we can create high quality heart failure care for all Londoners.

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## About the London Clinical Networks

The London Clinical Networks bring stakeholders together – providers, commissioners and patients – to create alignment around programmes of transformational work that will improve care for the 8+ million residents of the capital.

The networks provide the clinical expertise and leadership to drive commissioning decision making. In this way, the networks:

- » Improve quality outcomes
- » Advance the delivery of services
- » Reduce unacceptable variations of care