08.04.16

# Alliance for Heart Failure

Submission to the APPG Inquiry **Living with Heart Failure**

1. The Alliance for Heart Failure (AHF) is a coalition of charities, patient groups, professional bodies and corporate members for the purpose of raising the profile of heart failure in Government, the NHS and media. Our mission is to achieve better outcomes for people with heart failure by ensuring every person with heart failure is diagnosed on time and has access to the right care and support.

## Summary

2. Heart failure is often a progressive condition and there is significant potential for deterioration of the disease if left unmanaged. Yet good treatment of heart failure approximately doubles life expectancy.

3. Given the significant impact of heart failure on the NHS (projections indicate hospital admissions for heart failure will rise by 50% within 25 years), a national heart failure outcomes strategy is needed to drive improved diagnosis, treatment and care for people with heart failure.

4. All patients are entitled to receive the best possible care. Currently, heart failure is poorly identified in primary care, and public awareness is poor. Improved education among all stakeholders is required.

5. NICE guidance for acute and chronic heart failure states that patients should be cared for by a heart failure specialist multidisciplinary team. Current provision is inconsistent; more teams should be established and patient access improved.

6. Every person with heart failure should undergo a regular clinical review.

7. Access to palliative care services remains poor, and varies by region. The National Heart Failure report notes that palliative care referrals remain low, which is both surprising and disappointing given the high age of the heart failure patient population and level of mortality within one year of discharge. Heart patients should have the same access to palliative care as cancer patients.

## Heart failure: a national picture

8. Heart failure is debilitating and life threatening. Outcomes are poor: 5 year survival rate for heart failure is worse than breast or prostate cancer[1]; 30-40% of those diagnosed with heart failure die within the first year.[2]

9. Heart failure represents a major and growing cost to the NHS and wider society. It is the leading cause of hospital admission in over 65s[3] and is one of the five long-term conditions responsible for 75% of unplanned hospital admissions.[4]

10. The 2013 Cardiovascular Disease Outcomes Strategy only made reference to heart failure in chapter 4 in five brief points. Given the significant impact of heart failure on the NHS and with projections indicating hospital admissions for heart failure are set to rise by 50% in the next 25 years due to an ageing population[5], a National Heart Failure Outcomes Strategy is needed to tackle poor outcomes for people with heart failure and set out the ambition to improve mortality and hospital admissions for people with heart failure.

## Diagnosis of heart failure

11. Heart failure is poorly identified in primary care and its symptoms often mistaken for respiratory conditions, such as chronic obstructive pulmonary disease (COPD).[6]

12. Heart failure affects 550,000 people in the UK[7], but with many more undiagnosed[8]. Delayed diagnosis is a serious issue, compounded because symptoms are similar to other pathologies such as COPD.

13. Heart failure is a progressive condition and there is significant potential for deterioration of the disease if left unmanaged.[9]

14. Diagnosis of heart failure must be timely and accurate. Nice guidelines CG108[10] show clear guidelines that should be followed.

15. NICE guidelines and quality standards set out best practice for diagnosing chronic and acute heart failure. However, evidence suggests these standards are not always met. In 2014, there was a 4 month window from presenting or exhibiting symptoms to confirmed chronic heart failure diagnosis.[11]

## Variable access to diagnostic tests and heart failure specialists

16. A variety of diagnostics tests can support a diagnosis of heart failure. Cardiologists are the primary clinicians responsible for diagnosis. An echocardiogram is used in 95% of patients. Other diagnostic tests include electrocardiogram, physical examination, chest x-ray and a patient's medical history.

17. NICE recommends GPs refer patients suspected of chronic heart failure with a previous myocardial infarction or very high levels of serum natriuretic peptides to a specialist within 2 weeks.[12] However, access to diagnostic tests for natriuretic peptides in primary care varies, with up to one third of GPs not having access (32%).[13] This hinders patient referral to a heart failure specialist.

18. The NHS does not nationally collate data to confirm whether chronic patients are being seen within 2 weeks as the NICE Quality Standard recommends.

19. Similarly, NICE recommends patients admitted to hospital with acute heart failure have input within 24 hours of admission from a dedicated specialist heart failure team, but data is not publicly available to determine if guidance is being met.[14]

20. A postcode lottery may determine the level and quality of treatment and care as there is a geographical variance across the UK in available clinical expertise in heart failure.

21. There is an acute shortage of echocardiographers in the UK. The British Society for Echocardiography states that only 44 individuals were trained in the area last year, and severe delays impact patients waiting for an echocardiogram.

22. Clinical Commissioning Groups (CCGs) should report data on the timely and accurate diagnosis of heart failure. The following indicators on diagnosis for heart failure, based on NICE quality standards, should be included in the CCG outcomes indicator set:

    i. Adults with suspected chronic heart failure who have been referred for diagnosis have an echocardiogram and specialist assessment. (Quality statement 1, chronic heart failure quality standard).
    ii. Adults with suspected chronic heart failure and either a previous myocardial infarction or very high levels of serum natriuretic peptides, who have been referred for diagnosis, have an echocardiogram and specialist assessment within 2 weeks. (Quality statement 2, chronic heart failure quality standard).
    iii. Adults admitted to hospital with acute heart failure have input within 24 hours of admission from a dedicated specialist heart failure team. (Quality statement 1, acute heart failure quality standard).

## Awareness of heart failure amongst the public and in primary care

23. Healthcare professionals may find diagnosing heart failure challenging as many patients may have comorbidities and non-specific symptoms and signs. In addition, a misperception in primary care of the 'typical' heart failure patient hinders diagnosis. Research shows only 66% GPs are confident to diagnose HF, compared to 95% cardiologists. GPs and other primary care professionals may benefit from further training and awareness campaigns on heart failure.[13]

24. Awareness and understanding of heart failure amongst the public is poor: 44% of respondents suffer or know someone who is suffering or have suffered from heart failure, yet fewer than 1 in 14 (7%) could spot three common signs and symptoms of the disease.[15] In addition, 85% of respondents mistook at least one of the potential symptoms of heart failure for the normal signs of ageing. Furthermore, 1 in 4 people (24%) would wait a week or more to seek medical advice, or would not seek medical advice at all, when experiencing the symptoms of heart failure.

25. AHF recommendation:

    i. NHS England and Public Health England should continue to produce and fund regional and national breathlessness campaigns. Further public awareness campaigns should be developed to promote awareness of heart failure, particularly in light of the ageing population and rising prevalence.
    ii. NHS England and Health Education England should review the provision of education, training and awareness campaigns on heart failure for healthcare professionals in primary care.

## Treatment and care of heart failure

26. Good management of heart failure can improve survival rates by almost double, and reduce costly hospital admissions.

27. Evidence suggests that effective multidisciplinary specialist services have a positive effect on life expectancy and can help to reduce recurrent hospital stays by up to 50%.

28. NICE guidance for both acute and chronic heart failure states that patients should be cared for by a heart failure specialist multidisciplinary team (including consultants, nurses, psychologists, GPs, pharmacists and others). Specialist input can come from any team member.

29. "*Heart failure care should be delivered by a multidisciplinary team with an integrated approach across the healthcare community*." (NICE, Chronic heart failure guideline, 2010)

30. "*All hospitals admitting people with suspected acute heart failure should provide a specialist heart failure team that is based on a cardiology ward and provides outreach services*." (NICE, Acute heart failure guideline, 2014)

31. The key areas that should be considered to improve care and treatment for people living with heart failure:
    i. specialist input in the hospital.
    ii. specialist input in the community.
    iii. regular clinical assessments.
    iv. access to innovative treatments and devices.

***Specialist input in the hospital***

32. Evidence from the National Heart Failure Audit 2013-14 indicates that whilst most people with heart failure in hospital receive specialist input, many continue to be treated without it. This may have a detrimental impact on outcomes: only 7% of hospital patients treated in cardiology wards died in hospital compared with 11% of patients treated on general medical wards and 14% of patients treated on other wards.[16]

33. The National Heart Failure Audit reveals:
    i. Around 80% of patients admitted to hospital with symptoms of heart failure were seen by a heart failure specialist in some capacity both on first admission and on readmission (indicating the balance ~20% are not receiving specialist input).
    ii. Around 60% of patients on general medical or other wards were seen by a heart failure specialist (indicating that ~40% are not seen by a specialist).
    iii. Men were more likely to have input from a heart failure specialist or cardiologist than women.

34. Thus, there is a need for continued improvements in access to heart failure specialists in hospital to ensure all heart failure patients receive appropriate care and treatment.

35. The introduction of the Best Practice Tariff (BPT) for heart failure in the National Tariff guidance 2016-17 proposal[17] is a welcome initiative, requiring at least 60% of patients recorded in the heart failure audit have received specialist input.

36. NHS England should ensure that Trusts are aware of the BPT and are supported in its implementation. The impact of the BPT should be reviewed regularly; with upwards adjustments to the target to ensure in the near future 100% of patients receive specialist input.

37. As people with heart failure are treated in different wards across hospitals, we would encourage clinicians, nurses, other healthcare professionals and hospital management to work collaboratively, in a multidisciplinary team, to ensure patients receive the best possible medical and psychological care and treatment.

***Specialist input in the community***

38. Management in primary care is not optimal and many patients do not have access to specialist heart failure teams even though evidence demonstrates this improves outcomes.

39. Heart failure nurses are essential in providing specialist input into the care of heart failure patients, particularly high risk patients, in the community, often as part of a team. A BHF evaluation of heart failure specialist nurses demonstrated their input is associated with a significant improvement in the quality of life of patients, as well as a 35% drop in hospital admissions, resulting in an estimated £1,826 saving per patient to the NHS.[18]

40. However, anecdotal evidence suggests the role of heart failure nurse roles is being decommissioned in favour of community nursing roles. Health Education England and NHS England should undertake to monitor and publish heart failure nurse numbers across the country.

41. Integration between community, primary and secondary care services is important in ensuring people living with heart failure receive appropriate specialist input. In relation to following-up patients post-discharge, the National Heart Failure Audit found:
    i. Of those patients who survived to discharge, half were referred to cardiology and heart failure nurse follow-up services (suggesting half were not referred).
    ii. Only 10% of patients were referred for cardiac rehabilitation.

42. Whilst the National Heart Failure Audit provides some data on follow-up post discharge, no data is available on specialist input in the ongoing treatment and care of heart failure patients in the community. Currently, the CCG outcomes indicator set includes only one indicator on heart failure: 12 month all-cause mortality. Indicators that measure access to heart failure specialist in the community would help ensure patients receive appropriate support.

43. AHF recommendation:

    i. NHS England should publish an annual review of the Best Practice Tariff and make appropriate upward adjustments to targets.
    ii. Hospital trusts and CCGs should ensure that specialist heart failure multidisciplinary teams are in place and collaborate on the management of patients.
    iii. The number and placement of heart failure nurses should be monitored and published by a National Cardiovascular Intelligence Network.
    iv. NHS England should include indicators on access to specialist input in the community and hospital in the CCG outcomes indicator set, based on current NICE Quality Standards.

***Regular clinical assessments***

44. Heart failure is often a progressive condition and there is significant potential for deterioration of the disease if left unmanaged. It is important that patients are regularly monitored and assessed to ensure they are receiving optimal management and care. The NICE chronic heart failure quality standard recommends people living with heart failure have a review of their condition at least every six months. However, data from the Healthcare Commission has shown only 49% reaching minimum requirements.[19]

45. There are few GPs in England with a specialist clinical interest in heart failure. Yet GPs care for the vast majority of heart failure patients and are incentivised, through the Quality and Outcomes Framework (QOF), to produce a register of heart failure patients and confirm diagnosis with an echocardiogram. However, QOF incentives are limited. Whilst GPs are incentivised to ensure patients are treated with evidence-based medicines, they are not incentivised to ensure patients are receiving the optimal dose. Many patients continue to be sub-optimally treated.

46. AHF recommendation:

    i. GPs should be incentivised to regularly review patients every 6 months through QOF, with the input of a heart failure specialist team where possible.

***Access to innovative treatments for heart failure***

47. Access to innovative technology and pharmaceutical treatments for people living with heart failure is critical. Such advances offer new approaches and hope for patients with this debilitating condition.

48. For instance, in 2016 a new medicine for heart failure was launched (sacubitril/valsartan). It was granted a positive scientific opinion under the Medicines and Healthcare Regulatory Agency (MHRA) Early Access to Medicines Scheme (EAMS) in September 2015[20], aimed at giving patients with life threatening or debilitating conditions access to medicines that do not yet have a marketing authorisation when there is a clear unmet medical need. It was the first time a medicine not intended to treat cancer was recognised under the scheme.

49. Medical technology provides cost-effective use of NHS resource. However, given the focus on cost acquisition rather than clinical or cost-effectiveness, commissioning is driven by budget management requirements rather than patient need.

50. AHF recommendation:

    i. CCGs should ensure rapid implementation of NICE guidance and access to innovative medicines and devices for heart failure patients. Access to specialist heart failure multidisciplinary teams will achieve this.

**Palliative care**

51. Heart failure is a chronic condition with extensive morbidity and high mortality rates. For many patients, the end of life may be protracted and involve distressing secondary symptoms and emotional upset.

52. Access to palliative care services, including psychological services, for heart failure remains poor. The National Heart Failure report notes that palliative care referrals remain low, which is both surprising and disappointing given the high age of the heart failure patient population and level of mortality within one year of discharge.

53. Improved access to palliative care by patients with heart failure is urgently needed. Currently, access varies geographically.

54. AHF recommendation:

    i. Patients with heart failure should have the same access to palliative care services as patients with cancer.

[1] 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
[2] 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 online at: http://heart.bmj.com/content/83/5/505.long
[3] NICE. Acute heart failure: diagnosing and managing acute heart failure in adults. October 2014. Available online at: https://www.nice.org.uk/guidance/cg187
[4] NHS England. Emergency admissions for Ambulatory Care Sensitive Conditions – characteristics and trends at national level. March 2014. Available online at: http://www.england.nhs.uk/wp-content/uploads/2014/03/red-acsc-em-admissions-2.pdf
[5] NICE. Chronic heart failure: Management of chronic heart failure in adults in primary and secondary care. August 2010. Available online at: https://www.nice.org.uk/guidance/cg108
[6] Department of Health, Improving cardiovascular disease outcomes: strategy, 2013. Accessible online: https://www.gov.uk/government/publications/improving-cardiovascular-disease-outcomes-strategy
[7] British Heart Foundation. Cardiovascular disease statistics 2014. December 2014. Available online at: https://www.bhf.org.uk/~/media/files/publications/research/bhf_cvd-statistics-2014_web_2.pdf

[8] British Heart Foundation. An integrated approach to managing heart failure in the community. 2015. Available online at: https://www.bhf.org.uk/~/media/files/publications/healthcare-and-innovations/an-integrated-approach-to-managing-heart-failure-in-the-community---sirhf1.pdf

[9] Cardiac Care Network. Strategy for Community Management of Heart Failure in Ontario. February 2014. Available at: www.ccn.on.ca/ccn_public/uploadfiles/files/Strategy_for_Community_Mgmt_in_HF_in_ON.pdf

[10] NICE, Chronic heart failure in adults: management (Clinical Guideline 108, 2010). Available online at www.nice.org.uk/guidance/cg108

[11] Hall & Partner, Market research commissioned by Novartis, November 2014 (available on request)

[12] NICE, Chronic Heart Failure Quality Standard, 2015. Accessible online: https://www.nice.org.uk/guidance/qs9

[13] Hancock HC et al. Barriers to accurate diagnosis and effective management of heart failure have not changed in the past 10 years: a qualitative study and national survey. BMJ Open. 2014. Available online at: http://bmjopen.bmj.com/content/4/3/e003866.full#T2

[14] NICE, Acute heart failure quality standard, 2015. Accessible online: https://www.nice.org.uk/guidance/qs103

[15] TNS UK Limited, March 2014. 11,000 members of the public aged 50+ years old in Europe, including 1,000 in Great Britain. (Commissioned by Novartis, available on request).

[16] NICOR, National Heart Failure Audit 2013 -14, Novmber 2015. Available online: https://www.ucl.ac.uk/nicor/audits/heartfailure/documents/annualreports/hfannual13-14-updated.pdf

[17] NHS England & Monitor, 2016/17 national tariff proposals: currency design and relative prices, 2016. Available online: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/453397/Currency_design_and_relative_prices_final.pdf

[18] British Heart Foundation. Heart failure nurse services in England: executive summary. http://www.wales.nhs.uk/sitesplus/documents/986/BHF%20Heart%20Failure%20Nurse%20Evaluation%20in%20England%20-%20Exec%20Summary.pdf

[19] The Work Foundation. Bridging the quality gap: Heart Failure. March 2010. Available online at: http://www.health.org.uk/publication/bridging-quality-gap-heart-failure

[20] MHRA, Early Access to Medicines Scientific Opinion - Public Assessment Report (sacubitril valsartan), September 2015. Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/457515/EAMS_Sacubitril-valsartan_Public_Assessment_Report__PAR_-clean.pdf