

Health & Social Care Committee Inquiry:
Delivering Core NHS and Care Services during the Pandemic and Beyond
Response from the Alliance for Heart Failure

About the Alliance for Heart Failure

The Alliance for Heart Failure was established in September 2015. A coalition of charities, patient groups, professional bodies and healthcare companies, its purpose is to raise the profile of heart failure in Government, the NHS and the media and improve outcomes for people with heart failure.

Members of the Alliance collaborate on overarching policy issues with the aim of securing prioritisation of heart failure and extending access to existing first-class care, treatment and services from the NHS to make it available to everyone with heart failure.

Alliance for Heart Failure member organisations

- Abbott
- Bayer
- British Association for Cardiovascular Prevention and Rehabilitation
- British Association for Nursing in Cardiovascular Care
- British Society for Echocardiography
- British Society for Heart Failure
- Cardiomyopathy UK
- Cardiovascular Care Partnerships
- Education for Health
- Medtronic UK
- National Heart & Lung Institute
- Novartis Pharmaceuticals UK Ltd
- Pumping Marvellous Foundation
- Roche Diagnostics Ltd
- South East Clinical Networks
- UK Heart Failure Pharmacy Forum

The Alliance for Heart Failure is supported and funded by Abbott, Bayer, Medtronic Limited, Novartis Pharmaceuticals UK Ltd, and Roche Diagnostics Ltd.

Further information can be found at: www.allianceforheartfailure.org

Reason for submitting evidence

1. Heart failure is an important, often under-diagnosed, under-recognised, and highly complex condition:
 - Over 650,000 people in the UK are affected by heart failure, with many more remaining undiagnosed, estimated to be 920,000 in total.ⁱ
 - The overall cost to the NHS is currently £2.3 billion annually, approximately 2% of the total NHS budget.^{ii iii}
 - 70% of the annual cost of heart failure is related to hospitalisation, presenting an opportunity for significant cost savings.^{iv}
 - Heart failure currently accounts for approximately 5% of all emergency medical admissions to hospital; over the next 25 years the proportion will rise by 50% – largely due to an older population.^v
 - Earlier intervention is associated with improved wellbeing and better long-term outcomes for heart failure patients.^{vi}

2. Heart damage has emerged as a possible complication of Covid-19 as well as a significant risk factor associated with poorer outcomes.
 - People with pre-existing heart disease, and the risk factors for heart disease, are at a greater risk for severe cardiovascular and respiratory complications from Covid-19.^{vii}
 - People with previously undiagnosed heart disease may be presenting with previously silent cardiac symptoms unmasked by the viral infection.^{vii}
 - Some people may experience heart damage that mimics a heart attack. This scenario can occur when the heart muscle is starved for oxygen, which in the case of Covid-19 may be triggered by a mismatch between oxygen supply and oxygen demand.^{vii}
 - There is a subset of people with Covid-19 - some of them previously healthy and with no underlying cardiac problems - who develop fulminant inflammation of the heart muscle as a result of the virus directly infecting the heart.^{vii}
 - Patients with serious heart conditions have been avoiding hospital for fear of contracting Covid-19^{viii}. This may lead to an increase in heart failure cases.

Summary of response

“An opportunity to improve heart failure services in the long-term for the benefit of both patients and the NHS, while addressing the projected increase in demand.”

Our response addresses the following areas of the Inquiry’s scope:

- Meeting the wave of pent-up demand for health and care services that have been delayed due to the coronavirus outbreak
- Meeting the needs of rapidly discharged hospital patients with a higher level of complexity
- How to ensure that positive changes that have taken place in health and social care as a result of the pandemic are not lost as services normalise.

Our recommendations are designed to ensure heart failure services respond to the increased demand that is anticipated after the pandemic, both from delayed services and additional cases. They also aim to ‘lock in’ the beneficial changes from the pandemic response – as Simon Stevens suggests in his statement - in order to seize the opportunity to implement future improvements to services, utilising digital technologies, remote consultation, and remote monitoring to deliver services without the risk of exposure to Covid-19.

By maximising the use of technology, they align closely with the recommendations in the NHS Long Term Plan, as well as NHSX and NHS Digital strategies, and are in accordance with NICE guidance. Importantly, they enable high risk patients to easily and safely benefit from more modern approaches to care, while reducing the impact of Covid-19 and the disruption the pandemic has caused.

Executive summary: key recommendations:

1. The immediate resumption of normal heart failure services, including face to face consultations with patients
2. The rapid repatriation of community service personnel to meet the increased demands from heart failure patients to enable treatment, titration of medication and monitoring to resume
3. Greater use of video technology for patient consultations
4. Access to diagnostic testing at cold sites to include NT-proBNP and echocardiogram
5. The increased use, and access to, virtual and ambulatory monitoring
6. The increased use of online or home-based programmes to support heart failure rehabilitation
7. Provision of palliative care services for heart failure patients

Our experience tells us that the NHS workforce is ready and willing to respond to these opportunities and challenges. The flexibility and speed of change seen to date confirms the motivation of the heart failure community to deliver these recommendations.

The impact on patients:

“The pandemic has had a considerable impact on people living with cardiomyopathy. They have seen appointments cancelled or delayed and struggled to find clarity about how Covid-19 affects people with their condition. There has been a 400% increase in people using our services and, worrying, many more people are now afraid to go to hospital or reluctant to contact their healthcare team.

“One of the simplest ways to provide efficient and appropriate services during the pandemic and beyond is to build greater flexibility into systems so that they can be more personalised to individual needs. We want to see systems that can determine who needs to be seen in person or who can be seen remotely.”

Joel Rose
Chief Executive, Cardiomyopathy UK

“Heart failure is a condition that demands regular management both from the heart failure specialist, primary care and the patient.

“During the COVID-19 pandemic, patients have seen an erosion of specialist HF services across the country as local decision making has pushed the specialist to the front line of fighting the pandemic. This has been most widely seen in areas where there is no strong advocacy or leadership in heart failure to push back and make compelling, evidence based, counteracting arguments. This has been particularly acute outside of London. Patients want their heart failure teams back. The levels of anxiety have been extremely high in our community of people living with heart failure due to a clear lack of direction from the centre and inconsistent messaging from a locally decentralised, decision making base.

“It is important we reinstate our heart failure specialist nurses, especially those based in the community or integrated outreach services, who are more prone to redeployment but are our most impactful weapon. They are the hub for the brittle patients’ treatment and care planning, as per the NICE Chronic Heart Failure Guideline NG106.

“Heart failure lives at home and if we can manage patients better in the home and community hubs, this may reduce the incidence of decompensating heart failure causing costly admissions, higher mortality and a worse quality of life for patients especially through the COVID-19 pandemic. You do not want to acquire COVID-19 in any circumstance if you have heart failure.”

Nick Hartshorne-Evans
Chief Executive (Founder)
Pumping Marvellous Foundation

1. Recommendations: the primary care pathway

- a. Rapid access to heart failure services for patients should continue in next phase of the pandemic, with the following patients considered for urgent review:
 - New referrals of symptomatic patients with NT-proBNP >2000 pg/ml from primary care or recent A&E attendance
 - Known heart failure patients with symptoms of decompensation
 - Recently discharged patients following admission with acute heart failure
 - Patients with advanced care plans and receiving palliative care in the community
- b. All other patients referred from primary care (NT-proBNP 400-2000 pg/ml) should continue to be triaged for routine assessment within 6 weeks while making use of alternative monitoring where appropriate and available.
- c. The use of video consultations should be maintained in the long term. These are the preferred method of alternative consultation to enable clinicians to make judgements about a patient's condition. Heart failure symptoms can include breathlessness and swelling in the legs, which cannot necessarily be detected as effectively in a telephone consultation.
- d. Where necessary, face to face consultations should be conducted on cold (non-Covid-19) sites or a separate, designated area of a health centre or hospital.
- e. The NICE-approved diagnostic pathway, as set out by the British Society for Heart Failure in its [position statement](#), should continue to be followed. Ensuring all primary care teams have access to NT-ProBNP and an appropriate onward referral pathway is essential.
- f. Greater education to enable primary care clinicians to recognise the symptoms of heart failure and adhere to the new recommendations is required, accessing specialist support via virtual multi-disciplinary team meetings.

2. Recommendations: secondary care

- a. Where possible, patients should continue to be treated in heart failure units (in-patient or ambulatory as appropriate). Where this is no longer possible, repatriation of heart failure specialist teams should be a priority to ensure that out-reach support can continue.
- b. It will be necessary to continue with rapid discharge, however it is imperative that patients are first seen by a heart failure clinical specialist.
- c. Some hospitals should be designated to continue to provide normal services, such as rapid access to heart failure services.
- d. The recommendations set out in the 2018 National Confidential Enquiry into Patient Outcome and Death (NCEPOD) should be implemented:
 - Serum natriuretic peptide measurement should be included in the first set of blood tests in all patients with acute breathlessness and who may have new acute heart failure.
 - A guideline for the clinical management of acute heart failure should be available in all hospitals. These guidelines should include standards for:
 - Initial investigations required to diagnose acute heart failure, including a standard protocol for the use of:
 - BNP/NT-proBNP testing
 - Echocardiography

3. Recommendations: transitioning care

- a. Virtual - and ambulatory - monitoring continue to be key in the next phase of the pandemic. Anecdotal feedback from patient groups tells us that more people are getting used to telemedicine; some say that they enjoy not having to spend a day at hospital for routine check-ups. The technology and infrastructure already exist, and would therefore not require significant additional investment, many heart failure patients have implanted devices that allow more accurate monitoring to take place. Establishing effective models of care that make the best use of local services and workforce should be explored as a priority.
- b. Reconfiguration of services due to Covid-19 has provided an opportunity for better use of standalone home monitoring systems, implantable monitors, and use of data from pacemakers or defibrillators. Providing safer practice with reduced exposure for healthcare professionals and patients alike. Their continued use should be considered in order to facilitate better care and treatment for our high-risk complex heart failure patients.
- c. Accelerate the assessment and implementation of technologies that support or enable remote monitoring, by NICE, NHSX and NHS-England.
- d. Access to monitoring using smartphone apps that empower patients and healthcare professionals to nurture meaningful partnerships in approaching care should be broadened.

4. Recommendations: community services

- a. Community teams should be immediately repatriated in order to meet the increased demands for heart failure services.
- b. Post discharge patients have a high risk of readmission and mortality, they should be carefully considered for either face to face or virtual follow up within 2 weeks as per the current NICE (2018) guidance. This should include patients gaining access to appropriate evidenced-based treatment at sufficient doses.
- c. Virtual or telephone monitoring should be used to assess all patients and where symptoms of deterioration are noted, a rapid face to face review arranged.
- d. Titration of medications in high risk patients can be achieved via telephone clinics with the support of home monitoring devices.

5. Recommendations: cardiac rehabilitation

- a. The ability for heart failure patients to follow a self-care rehabilitation intervention including an exercise programme without leaving the home has never been more pertinent. Cardiac rehabilitation programmes are undertaking initial assessment of patients' rehabilitation needs and personalised goal setting by telephone/video consultations and offering home based programmes, manual based programmes and technology driven options such as web-based platforms and mobile apps. Evidence-based cardiac rehabilitation programmes that can be used at home in patients with heart failure include:
 - The REACH-HF Manual – a self-help manual for people with heart failure and caregivers to help them manage their condition using the principles of cardiac rehabilitation. The manual is designed to be used with the support of a specially trained cardiac nurse or 'facilitator'. Free online training courses are available in the summer of 2020 with separate purchase of the HF Manuals from the NHS Lothian's Heart Manual Department heart.manual@nhslothian.scot.nhs.uk

These resources could be purchased centrally and made available online free of charge.

- There are other telehealth interventions using digital technologies that may be effective however, there are no robust peer-reviewed evaluations for heart failure patients in the UK, further exploration of these is recommended.

6. Recommendations: palliative care

- a. It is essential that heart failure patients have rapid access to co-ordinated palliative and end of life care, predominantly delivered in the community and/or other appropriate care setting by a multi-disciplinary team (MDT) which ideally is co-ordinated by the Specialist Heart Failure nurse.
- b. Access to a specialist heart failure/palliative care clinician to support timely decision making is vitally important and should be accessed by virtual MDT where possible.
- c. Patients with advancing disease who are considered to be approaching end of life, and their families, should have an anticipatory care plan that reflects evolving discussion related to preferred care wishes, timely deactivation of devices, DNA CPR (Do not resuscitate) and management guidance of escalating physical and psychological needs. It is essential the Advance/Anticipatory Care Planning (ACP) is formally communicated to all appropriate professionals involved with the patient.
- d. Cohesive working is essential with health and social care professionals working across different care boundaries to ensure effective, responsive and co-ordinated delivery of high-quality palliative and end of life care.

ⁱ British Heart Foundation (BHF). UK Factsheet January 2020. Available from: <https://www.bhf.org.uk/what-we-do/our-research/heart-statistics> [Last accessed February 2020]

ⁱⁱ About the National Health Service (NHS) in England – NHS Choices'. NHS Choices. Department of Health. Available online at: <http://www.nhs.uk/NHSEngland/thenhs/about/Pages/overview.aspx> [Accessed February 2019]

ⁱⁱⁱ Brown R. and Clark A. L. Reducing the cost of heart failure while improving quality of life. *British Journal of Cardiology*. 2013;20:45–6.

^{iv} The heart failure epidemic: a UK perspective, Martin R Cowie, MD MSc FRCP FRCP(Ed) FESC, Feb 2017 doi: [10.1530/ERP-16-0043](https://doi.org/10.1530/ERP-16-0043)
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5435875/#bib3> [Accessed February 2020]

^v NICE. Chronic heart failure in adults: diagnosis and management. Clinical guideline [CG106], September 2018. Available at: <https://www.nice.org.uk/guidance/ng106> [Accessed February 2020]

^{vi} The Importance of Early Intervention in CHF – Signs and Symptom Relief, Heribert Schunkert, March 2000
<https://doi.org/10.3317/JRAAS.2000.028> [Accessed February 2020]

^{vii} Coronavirus and the heart, April 14 2020: <https://news.harvard.edu/gazette/story/2020/04/covid-19s-consequences-for-the-heart/> [Accessed May 2020]

^{viii} Public Health England: Emergency Department Syndromic Surveillance System: England
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/877600/EDSSSBulletin2020wk13.pdf [Accessed May 2020]