18th December 2020

**British Society for Heart Failure report prepared for the Health Foundation CoViD-19 Impact Inquiry**

**The situation:**

Heart Failure (HF) is the endpoint for most cardiovascular disease, with HF patients at significantly higher risk of having adverse outcome from SARS-COV2 disease. Cardiovascular disease is recognised as the world’s number one killer[[1]](#endnote-1) with worldwide 26 million people suffering from heart failure and it being the predominant cause of death[[2]](#endnote-2).

The risk of complications from HF outweighs the risk of dying from CoViD-19 (Banerjee A et al. OurRisk.CoV; unpublished October 20) but the CoViD-19 pandemic has made a devastating impact[[3]](#endnote-3) directly and indirectly on people with complex long term conditions such as HF. Excess deaths are being driven by cardiovascular diseases[[4]](#endnote-4),[[5]](#endnote-5) (also Ahmad Shoaib et al. unpublished data: increased deaths in the community and 30 day mortality). There has been a rise in people with HF due to suffering heart attacks and not accessing emergency care[[6]](#endnote-6). The most striking drop in cardiovascular admissions however was seen for HF where a 66% drop[[7]](#endnote-7) in hospital attendance for HF[[8]](#endnote-8) up to April with no noticeable upturn yet seen in those with HF presenting to hospital. Across nine UK hospitals, a study published in the BMJ in October showed total admissions and emergency department attendances decreased after lockdown (23 March 2020) by 57.9% and 52.9% respectively, compared with the previous year[[9]](#endnote-9). From the patient perspective, there was concern and anxiety: 32% of people with HF (of the 1050 who responded to a survey conducted by UK HF patient charity, Pumping Marvellous Foundation), expressed reluctance to attend hospital - 25% stated they would only attend hospital if there was no alternative and 7% stated that they would not attend hospital at alli.

According to recent (as yet unpublished) data there are circa 4,000 people with aortic stenosis currently waiting for intervention and there is a recorded deficit of 45,501 procedures during the CoViD-19 period (March–May)[[10]](#endnote-10). People hospitalised with CoViD-19 are at increased risk of developing HF with heart damage occurring in at least 10 per cent of those admitted with infection[[11]](#endnote-11) and those with existing HF at higher risk of developing complications and death. The true impact is likely to be an underestimation as HF services have had staff redeployed to deal with the pandemic impacting on the care of both HF patients as in- and outpatients. However, lack of detection is also likely to be a factor. CoViD-19 and HF both present with breathlessness and collapse and compared to other cardiovascular conditions, heart failure patients are predominantly cared for in generalist wards where access to appropriate investigations in particular echocardiography has been even more difficult though the pandemic.

HF patients on recognised treatment pathways have also been impacted by the pandemic. Conversion to remote Follow Up clinics means that even more work has been pushed to the community nurses as unstable patients need to be seen pace to face. These community HF services are already under- resourced pre COVID (reference the BSH position statement). A clear example of the lack of HF nurse specialist resource is the fact that NICE approved therapies have not been delivered. The NICE impact review of sacubitril valsartan (a therapy with a 20% mortality benefit) up to March 2020 showed less than 2 thirds of the expected number of patients (predicted by NICE in its post approval resource assessment document) had actually been commenced on therapy. (<https://digital.nhs.uk/data-and-information/publications/statistical/nice-technology-appraisals-in-the-nhs-in-england-innovation-scorecard/to-march-2020/2.-estimates-report>). These delays to treatment have been further compounded as sacubitril valsartan clinics were put on hold during the pandemic. New HF therapies with additional mortality benefit are being approved by NICE but will sit in a ‘queue’ behind sacubitril valsartan which was approved 4 years earlier.

Local data from a large tertiary centre correlates with national data (Duckett S. et al. unpublished Nov 2020) showing there has been a huge drop of in inpatient and ambulatory referrals for HF. This is leading to a backlog of HF patients requiring review and treatment which will result in the NHS facing a tsunami of untreated HF patients as a result of the pandemic - way in excess of the 54,000 additional detections/ diagnoses by 2023/24 promised in the NHS Long Term Plan. Furthermore, there is clear evidence that CoViD-19 does not affect all population groups equally with death rates from CoViD-19 being higher for Black and Asian ethnic groups when compared to White ethnic groups[[12]](#endnote-12). We have a present and particular need to grow the clinical knowledge base, neutralise the inequalities and break down the barriers that exist at the toxic intersect of those with multi-morbid long-term conditions such as HF, living in areas of multiple deprivation, being of a BAME community in the pandemic to be able to build resilience for potential clinical crises arising

**Making the case for HF as an exemplar of long term conditions:**

Whilst large reports are valuable, in addition, we believe there is a need for demonstrable solutions which can be translated across disease states. HF is a common condition where affected individuals commonly have a spectrum of comorbidities[[13]](#endnote-13) and moreover, it is a common end-syndrome of many cardiovascular and cardio-metabolic diseases. Therefore, HF is well-placed to be used as an exemplar to develop actionable, implementable solutions and, as the UK’s professional association of HF specialists, the British Society for Heart Failure is in a position to start to tackle these issues, improving lives and reducing inequalities for people with multi-morbidity.

**Major considerations:**

**Patients** with long term conditions cannot afford delays - HF is a multi-system condition that rarely exists in isolation affecting almost 1 million people in the UK[[14]](#endnote-14). Despite robust guidelines; significant advances in treatment and prevention, patients with HF have reduced life expectancy compared to the general population with half of those diagnosed with HF dying within five years of diagnosis. Yet the average time from presentation to diagnosis for someone with HF is 15 months (NHS England). We need to deepen our understanding of the wider socio-economic determinants, improve data recording of faith and ethnicity and increase community participatory research. Further, quality of life is of paramount importance and should be prioritised alongside mental health and wellbeing. The CoViD-19 pandemic has caused significant anxiety amongst HF patients regarding CoViD-19 and HF. Cancellation or postponement of scheduled clinic appointments, investigations, procedures, prescription and monitoring services were implicated as sources of anxiety.[[15]](#endnote-15)

**Data** is crucial to understanding and improvement but currently UK data does not capture all we need and therefore doesn’t serve the community as well as it should. Our health system pits primary against secondary care and specialists against generalists exacerbated through a lack of linked data between the two settings. Disease-specific audits can only ever convey part of the story. We have an opportunity to build a robust, inclusive and real time reporting system, aligning current affairs with current data to improve health outcomes.

**Specialist** advice and guidance is essential in the planning of care pathways and for specialist intervention. All patients with chronic conditions should have access to a multidisciplinary team. Support from MDT has proven to have up to 50% reduction in mortality for people hospitalised with HF. Patients need the expertise of a specialist to inform their personalised management plan and empower patients in self-care and monitoring. Accountability should spring from the expert guidance but responsibility rests with all stakeholders across the pathway and throughout the patient journey - from diagnosis to death. With strong leadership, an integrated and flexible approach with suite of options can be offered with greater individualised and protected care. The specialist team needs to think less in silos and more laterally; communicating and providing cross disease solutions

Hence, we are calling for recommendations to be created in collaboration with The Health Foundation that highlight the need for:

1. Specialist leadership to support accountability across the patient pathway
2. Standardised surveillance data across primary, secondary and tertiary care
3. Reducing inequalities, increasing inclusion by targeting specific areas of need
4. Consideration of the whole patient and their circumstances

With the NHS about to face a tsunami of HF for which it is ill prepared, it will be essential to diagnose faster, treat optimally, manage closely those with the condition - the most vulnerable and least accessible need to be included as a priority: there should be “no man left behind” due to their circumstances.

HF needs to be recognised as a condition as serious as cancer with detection and diagnosis being as urgent as for cancer. Data on HF patients is inconsistent with no expectation for primary care practitioners to supply in-depth data on their patient to a nation audit, leading to poor understanding of the extent of the problem. Improving data across the primary, secondary, tertiary care interface to establish the HF phenotype (and help with prioritisation) should increase early and accurate intervention.

As HF is the endpoint of most CVD it should be the key condition on which to focus if outcomes are to be improved. Standardisation of the care of HF as an exemplar, improvement of which can directly improve comorbidities and can be replicated for other complex LTCs, will provide a blueprint for building robust provision/ resilience for NHS into the future. And it is the HF Specialists who are best positioned to guide and advise the practical solutions to HF care.

**The Ask:**

We respectfully ask The Health Foundation to consider funding HF Specialists under the aegis of the British Society for Heart Failure to conduct an exploratory study on CoViD-19 impact on HF pathways based in 3 exemplar sites. We would like to begin by focusing on the most intersectional populations in the 3 selected sites focusing on HF admissions/ index of multiple deprivation/ BAME representations/ CoViD-19 deaths:

**Methods:**

Track referrals/ investigations/ outcomes: e.g. how changes in treatment of conditions AF/ ACS etc. has impacted: HF or death

Look to build back better referral pathways

Primary-secondary-tertiary care data linkage

Specialist leadership

Wider multi-disciplinary team

**In conclusion:**

As the UK’s professional association of heart failure specialists, the British Society for Heart Failure truly believes that by focusing on heart failure as one of many LTCs - but one that can affect so many other outcomes[[16]](#endnote-16),[[17]](#endnote-17) such as renal impairment and diabetes as well as the relief of symptoms such as breathlessness. We can really shine an empowering light on a direction in which to improve the health of the nation. With or without a pandemic. Investment in HF now would bring significant clinical, social and psychological advantage.

**References:**

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