Change NHS: Build a health service fit for the future – Cardiomyopathy UK response

Q1. What does your organisation want to see included in the 10-Year Health Plan and why?

About Cardiomyopathy UK

Cardiomyopathy UK is the specialist national charity for people affected by cardiomyopathy, a condition that affects the heart muscle. Our vision is that everyone affected by cardiomyopathy should live a long and fulfilling life. We do this by providing services, such as a national helpline and peer support, and campaigning for change in health and welfare services.

What is cardiomyopathy?

Cardiomyopathy is a disease of the heart muscle: **'cardio'** means heart, **'myo'** means muscle and **'pathy'** means disease.

It isn't a single condition, but a **group of conditions** that affect the **structure of the heart** and reduce its ability to **pump blood** around the body. Around **1 in 250 people** in the UK are affected, this is an estimated **246,000 people**. For context, there are 153,000 people living with Parkinson's in the UK, but there is a lot less awareness of cardiomyopathy. The symptoms of cardiomyopathy include:

- Swollen ankles and/or tummy.
- Chest pain.
- Dizziness.
- Fainting/blackouts- this is medically referred to as 'syncope' and is caused by reduced oxygen levels blood flow to the brain, due to arrhythmias or obstruction.
- Reduced exercise tolerance- some people may note a decline or more difficulty carrying out activities they once could.
- Breathlessness.
- Tiredness.
- Palpitations.

Cardiomyopathy can be caused by a genetic variant in a person's DNA which affects their heart muscle. Genetic conditions may be inherited so cardiomyopathy can run in families. A child of an affected parent will have a 50% chance of inheriting the same familial genetic variant in HCM for example.

For these reasons, it is important that first-degree relatives (children, siblings and parents) of the person affected by cardiomyopathy are offered familial screening. This usually involves having imaging (scans) of the heart i.e. echocardiogram or a cardiac MRI, and an ECG and be under the care of a specialist cardiologist. Genetic testing of the relatives may also be considered. This involves looking at their genes for the same genetic variant that has caused cardiomyopathy in their relative.

There is currently no cure for cardiomyopathy, and the condition is progressive. In some people symptoms can be managed through medication, implanted devices and/or surgery, however for some people their only option is to undergo a heart transplant using a donated organ from a deceased person.

Cardiomyopathy is one of the leading causes of heart failure. Prevalence of heart failure varies according to the type of cardiomyopathy. Heart failure is not always detected at the point of diagnosis of cardiomyopathy, but many people with cardiomyopathy will go on to develop heart failure. The prevalence rates of heart failure in people with cardiomyopathy are as follows (TJ Cahill, 2013):

- In people with dilated cardiomyopathy, 47%.
- In people with hypertrophic cardiomyopathy, 67%.
- In restricted cardiomyopathy, including amyloidosis cardiomyopathy, 83%.

Our submission

Cardiomyopathy UK conducts a national survey of its community every two years. This submission is based on data from the survey conducted in 2022 (published in the State of Cardiomyopathy Care 2023) and the MyInsight survey conducted in summer 2024.

Cardiomyopathy UK wants to see included in the NHS 10-Year Health Plan **a focus on early detection and diagnosis**. The reasons for this are laid out below, but it is important to highlight that early detection and diagnosis can be central to supporting an individual to live well with a long-term condition for as long as possible. This is paramount in the case of cardiomyopathy, which is a disease of the heart muscle. Cardiomyopathy UK wants to see detection and diagnosis of cardiomyopathy included in plans around population health and cardiovascular disease.

As a member of the Genetic Alliance, Cardiomyopathy UK works in coalition with other organisations which represent people living with genetic conditions. The Genetic Alliance report, 'Good Diagnosis: Improving the experiences of diagnosis for people with rare conditions (Genetic Alliance, 2022), states that:

"A fast and accurate diagnosis can enable access to appropriate care and opportunities for interventions that may improve a person's health. Fast diagnosis can mean greater treatment choice and support informed decision-making, leading to people with rare conditions being able to better manage their condition."

Specific to cardiomyopathies, the key to early detection and diagnosis lies in primary care; however, this is where we find initial barriers. In research conducted by Cardiomyopathy UK (State of Cardiomyopathy Care 2023), people affected by the conditions reported the following:

- Just over half (53%) of people who first went to their GP with cardiomyopathy symptoms were diagnosed initially with a non-heart related condition.
- Only 29% of people were asked by their GP about the history of heart disease in the family.

- Of the people who went to accident and emergency (A&E) first, 92% were immediately diagnosed with a heart related condition and 76% saw a cardiologist within 3 months.
- People with lived experience of cardiomyopathy tell us of the issues of delays in getting a diagnosis because the GP thought the symptoms were associated with another health condition (e.g. breathlessness is often misdiagnosed as asthma).

The issues of delaying detection and diagnosis have costly financial implications on the NHS, as well as a negative impact on people affected by cardiomyopathy.

We call for:

- **GPs to 'think cardiomyopathy'**: Increased awareness of the signs and symptoms of cardiomyopathy amongst GPs to make timely referrals to cardiologists.
- **Know the history:** GPs to ask, and record, a detailed family cardiac and medical history (given cardiomyopathy can be genetic).

Cardiomyopathy is one of the causes of heart failure and Cardiomyopathy UK is a member of the Alliance for Heart Failure. Heart failure is often diagnosed too late in many cases. As the first NHS long term plan stated, 80% of heart failure cases are diagnosed in hospitals, despite 40% of patients having symptoms that could have triggered an earlier assessment in primary care (NHS England, 2019).

As the British Heart Foundation 'Hearts Need More' report (2024) highlights, more work needs to be done to identify people at risk of having a heart attack or developing heart diseases. One way to do this is to systemically identify people living with hypertension, which is a symptom of heart failure (which can be a symptom of cardiomyopathy). The British Heart Foundation (2024) estimates that 8 million people in the UK are living with undiagnosed or uncontrolled high blood pressure.

As a member of the Alliance for Heart Failure, we support the calls for a heart failure case finding service in pharmacy, built on existing hypertension checks**.** The Alliance is already working with the Company Chemists Association to explore a pilot of an additional heart failure check built into the existing hypertension case finding service in pharmacies. We support the Alliance's call for:

- Access to a point of care NT-proBNP blood test, a biological marker for heart failure that gives an indication of a patient's risk of heart failure and can be used to triage patients for urgent referral to a specialist.

Cardiomyopathy UK also wants included in the NHS 10-Year Health Plan a clear and actionable strategy to **connect mental and physical health**.

In the 2024 MyInsight national survey of the cardiomyopathy community (yet to be published data, 2024):

- Nearly half of respondents (49%) said their mental health had been negatively impacted by cardiomyopathy.
- Two-fifths (40%) said they had not discussed mental health support with their cardiology team in the last 2 years, but they needed to.
- In those people diagnosed less than a year, just over half (53%) said they had not discussed mental health support with their cardiology team, but they needed to. This is not surprising given that the diagnosis can be a shock and may require a change in lifestyle – for example, some people have led physically active lives, enjoyed hiking or participated in team sports, and they are suddenly told that they can not longer do so – this leaves a person feeling like they have lost part of their identity.

As a member of the Long-Term Conditions - Mental Health Coalition, we want to see:

- **Integrated mental and physical health care:** The Government and NHS to centre mental and physical health care integration within their plans for improving the health service so that people living with long term physical health conditions (including advanced serious illnesses) receive person centred mental health care.

Cardiomyopathy UK believes that the NHS 10-year plan needs to prioritise **equal access to specialised treatment, care and services**.

Having an agreed treatment or care plan enables a person with cardiomyopathy to have a better understanding of their condition and a clear idea of the support and treatment that they should expect. Plans help people know where they are in the NHS system and feel more in control of their lives. The best care and treatment plans include not only details on the treatment of an individual's condition but also highlight their mental health needs and the support they require for day-to-day living. There is strong evidence that care and treatment plans lead to better outcomes. The King's Fund (2018) has called for a 'shared responsibility for health' between patients and clinicians, over the next five years and for the NHS to ramp up support for people to manage their own health.

In the 2024 MyInsight national survey of the cardiomyopathy community (yet to be published data, 2024):

- Over three-quarters (76%) of respondents do not have a care and treatment plan.
- Nearly two-fifths (39%) of respondents have been provided with some, but not enough information about their ongoing care and treatment. Nearly one-fifth (18%) of respondents received little or no information.
- Just over two-fifths (42%) of respondents feel involved in decisions to some extent about their care. While just over one-fifth (22%) do not feel involved in decisions about their care.
- Nearly a third (32%) of respondents had not had access to but had needed access to a nutritionist or dietician in the last two years.

- Nearly a third (32%) of respondents had not had access to but had needed access to a physiotherapist or exercise physiologist.

As one person with cardiomyopathy said:

"Over a 10-year period with Dilated Cardiomyopathy I had repeated admissions through A&E, followed by discharge with changes to my medication. For weeks each time, I'd have a Specialist Nurse monitoring my progress, until the dreaded words "you're now stable; I'm discharging you to the care of your GP"... in reality meaning, "you're on your own, if (when) you need help before your next consultation, it'll have to be back through the dreaded A&E". (Change Agenda, 2020)

As a member of both the Specialised Healthcare Alliance and Genetic Alliance UK, we call for:

- **A tailored package of care and support:** All people diagnosed with cardiomyopathy to have access to an integrated package of care appropriate to the needs of patients, covering the following areas: emotional and mental health support, sexual health and family planning clinics, prescription of tailored exercise, information on welfare rights and nutritional support.

Cardiomyopathy UK also want to see included in the NHS 10-Year Health Plan **a stronger connection to early detection and diagnosis, access to specialised care and treatment and NHS workforce planning**.

In our 2024 MyInsight survey (yet to be published), nearly one-fifth (19%) of respondents reported that it took more than two years to get their diagnosis. One of the reasons in this delay in diagnosis is due to waiting lists. As the British Heart Foundation 'Hearts Need More' report (2024) highlights, the cardiac waiting list in England has risen significantly since 2020 and remains consistently high. There are persistently long waiting lists for echocardiograms, which is a key test to diagnosing cardiomyopathy. Along with the British Heart Foundation, we want to ensure the cardiology workforce is fit for now and in the future. We support the call for sustainable, long-term funding, alongside commitment to a structured workforce plan to train, retain and develop the careers of staff across the entire cardiovascular workforce including cardiac physiologists, pharmacists, physiotherapists and psychologists.

The example of a new drug for cardiomyopathy demonstrates how shortages in workforce affects access to specialist treatments. In 2023, the first cardiomyopathy specific drug, Mavacamten, was approved by NICE and the SMC. Despite this approval, the NHS infrastructures are not in place to ensure equal access to the medication. Anecdotally, we are hearing that the rollout of mavacamten is slow leading to inequalities in access across the country.

One of the barriers to prescribing mavacamten is the need for regular echocardiograms in the first year of taking the medication. This is connected to workforce planning in the NHS. The is an issue as there are long waiting lists of echocardiograms due to a shortage in the echocardiographer workforce. The reasons for a shortage of

echocardiographers are complex and identified by the British Society of Echocardiography in its workforce report from 2022. Echocardiographers are Clinical Scientists. We support the Society's recommendations and want to see:

- Support in implementing a formal national career pathway in echocardiography to make services sustainable and promote retention.
- Recognise the advanced level role of an echo educator.
- Enable diagnostics by increasing training capacity and utilising new models such as introducing a slow lane and attracting returners.
- Develop new roles which help distribute work such as administrators, data managers and support workers.

Cardiomyopathy UK has also witnessed inequalities in access to medications as a result of medicine shortages. Disopyramide is provided off-licence to people with Hypertrophic Cardiomyopathy with Obstruction (HOCM), as the drug was originally approved for arrhythmias. However, there are other suitable alternative anti-arrhythmic medications for people with arrhythmias. Disopyramide is currently the only available medication which helps to reduce the symptoms experienced due to symptomatic HOCM. This means if there are shortages of Disopyramide and people are unable to obtain supply their symptoms return, which for some people affect their daily life.

The impact of this can be very stressful on individuals as they are left to call round multiple pharmacies to find a supply. Some people have even resorted to looking for medication abroad. The Royal Pharmaceutical Society has recently published a report on medicine shortages, 'Medicine Shortages: Solutions for Empty Shelves' (2024). We support the recommendations in this report, mainly:

- Publish a UK wide strategy for shortages: A cohesive cross-government and NHS strategy across the whole UK is needed to improve medicines supply chain resilience and medicines security.
- Improve data connectivity: Better demand forecasting with information shared between wholesalers, manufacturers and healthcare providers will improve coordination and mitigate shortages.

Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

Cardiomyopathy UK sees the main challenge in the move of more care from hospitals to communities is access to specialist care for people living with less common conditions, such as inherited cardiac conditions (like cardiomyopathy). Currently, expertise is centralised around a small number of specialist centres. In order to make care, especially post-diagnosis and ongoing support, more localised there would need to be a concerted effort to support the establishment of disease specific networks with agreed referral pathways. To enable this to happen, we call for:

- The establishment of networks of care with specialised centres. This would reduce burden on specialist clinics, reduced overall costs and make it easier for patients to receive quality care nearer to where they live.

Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Cardiomyopathy is a long-term health condition of the heart muscle, which is not always preventable in the same way as many other cardiovascular diseases. However, a timely diagnosis, timely access to treatments and care, and access to genetic testing can enable a person to live well for as long as possible. This could also support a person in making lifestyle choices to prevent the onset of other conditions, for example cardiovascular diseases. At Cardiomyopathy UK, we see the biggest challenges to spotting the conditions earlier and tackling the causes of ill health as:

- Recognition of signs and symptoms of cardiomyopathy in primary care. This has been set out and answered in question 1.
- Access to specialist treatments and care. In our answer here, we explain the importance of a tailored package of care and support, to include cardiac rehabilitation and information on physical activity, to ensure a person with cardiomyopathy can do the right levels of exercise for their needs, without putting strain on the heart.
- Access to genetic testing. More details of this and how this is an enabler to spotting illnesses earlier are set out below.

A diagnosis of cardiomyopathy often comes with many questions. One of those being around exercise. As a population, we are familiar with the messaging around exercise and how exercise can prevent the development of many long-term conditions such as cardiovascular diseases; however, for some people with cardiomyopathy, they are told they cannot exercise as much as they have enjoyed in the past. In our 2024 national survey, nearly two-fifths (39%) of respondents have not received support around physical activity, but they wanted or needed this.

Furthermore, in our 2024 national survey, we found that just over a third (34%) of respondents have not received cardiac rehabilitation but wanted or needed this. You can read Sophie's story on how she has changed her exercise routine so as not to put too much pressure on the heart. The story highlights the importance of information about the types of exercise and safe heart rate levels for the individual, while preventing the onset of other long-term health conditions such as cardiovascular diseases.

A way to tackle this would be:

- **A tailored package of care and support:** All people diagnosed with cardiomyopathy to have access to an integrated package of care appropriate to the needs of patients, covering the following areas: emotional and mental health support, sexual health and family planning clinics, prescription of tailored exercise, information on welfare rights and nutritional support.

It is worth noting that, in our 2024 national survey, nearly two-thirds (62%) of respondents reported that they have been living with one or more other physical or mental health condition expected to last for 12 months or more.

Another challenge to spotting illnesses earlier is a lack of access to genetic testing, given cardiomyopathy can run in families. Family screening and the use of genetic testing are the best ways to identify people who are most at risk of cardiomyopathy and ensure that they have access to the support and treatment they need. We asked people living with cardiomyopathy about their experiences of family screening and genetic testing in the MyInsight survey 2024.

On the positive side, we see that genetic testing is increasing, although there is still room for improvement. In 2022, just over half (56%) of respondents had been offered genetic testing. In our 2024 survey, this had increased to 59%. However, almost a fifth (19%) of respondents said that they had not been offered genetic testing, but that they would like this.

In some parts of the country, the lack of genetic assessment is because of lack of provision.

“Our whole family life was decimated when my sister, who had dilated cardiomyopathy, died from an out-of-hospital cardiac arrest, aged just 31. Grief for me, was interspersed with intense worry about what might happen to me. I wonder: is it worse not to know of the genetic nature of the condition, or, as in my case, to have the awareness but be told that there is no provision for genetic assessment where you live?”

Cardiomyopathy UK recommends:

- All patients diagnosed with cardiomyopathy to be considered for genetic assessment and to understand the implications, with every hospital having this ability, or a clear and timely process of referral to an existing Inherited Cardiac Conditions clinic.

In line with the recommendations in the British Heart Foundation report, ‘Hearts Need More’ (2024), Cardiomyopathy UK calls on the Government to include systemic data collection on all health professionals in cardiac care, which includes clinical geneticists and genetic counsellors, and include this in the workforce planning.