myInsight

Cardiomyopathy UK
the heart muscle charity

Living with cardiomyopathy

A state of the nation report from Cardiomyopathy UK

November 2025

Foreword

As President of Cardiomyopathy UK, I am proud to introduce this *State of the Nation* report – a publication that brings together the voices, experiences and insights of over 1,300 people affected by cardiomyopathy across the UK.

Our motivation in producing this report is simple: to develop a clear and evidence-based understanding of the current state of cardiomyopathy care. Through the **MyInsight survey**, we have heard directly from those affected by cardiomyopathy about the challenges they face every day, from systemic delays in diagnosis and limited access to genetic testing, to fragmented care and a lack of emotional and rehabilitation support.

This report is published at a pivotal moment. Looking at the NHS 10 Year Health Plan in England, it rightly prioritises cardiovascular disease and the use of genomics in population health. These commitments are welcome. But cardiomyopathy – a condition that affects 1 in 250 people and is a leading cause of heart failure – must not be overlooked any longer. Its genetic nature, complexity and impact on quality-of-life demand urgent attention from policymakers.

Cardiomyopathy UK is committed to ensuring that the findings and recommendations in this report lead to real change. We are calling on policymakers to act – to embed cardiomyopathy within national frameworks, invest in workforce and digital infrastructure, and ensure that every person affected receives timely, equitable and compassionate care. We will continue to work alongside clinicians, researchers, charities and the NHS to make this vision a reality.

We are deeply grateful to everyone who shared their story and helped shape this report. Your voices are powerful, and they are driving the change we need.

Professor Perry Elliott
President, Cardiomyopathy UK

From the patient community

Living with cardiomyopathy is not just a medical journey – it's an emotional and practical one too. From diagnosis to daily life, the condition affects how we feel, how we function, and how we connect with others. Too often, people like me are left to navigate this journey alone, without the holistic and individual support we need.

This report is a powerful step forward. It reflects the real experiences of people affected by cardiomyopathy and highlights the gaps in care that urgently need to be addressed. With the stories and insights of those affected by cardiomyopathy at the heart of this report, it sets out a clear path for change that is grounded in the realities of those who understand the impact of cardiomyopathy best.

I'm especially encouraged by the focus on holistic care. As this report shows, cardiomyopathy impacts more than just the heart – it affects mental health, relationships, and the ability to work and live well. The recommendations in this report recognise that reality and call for a system that sees and supports the whole person.

This report gives us a voice. Now we need to be heard.

Stephen Kirkham
Patient Advocate and Chair of Trustees, Cardiomyopathy UK

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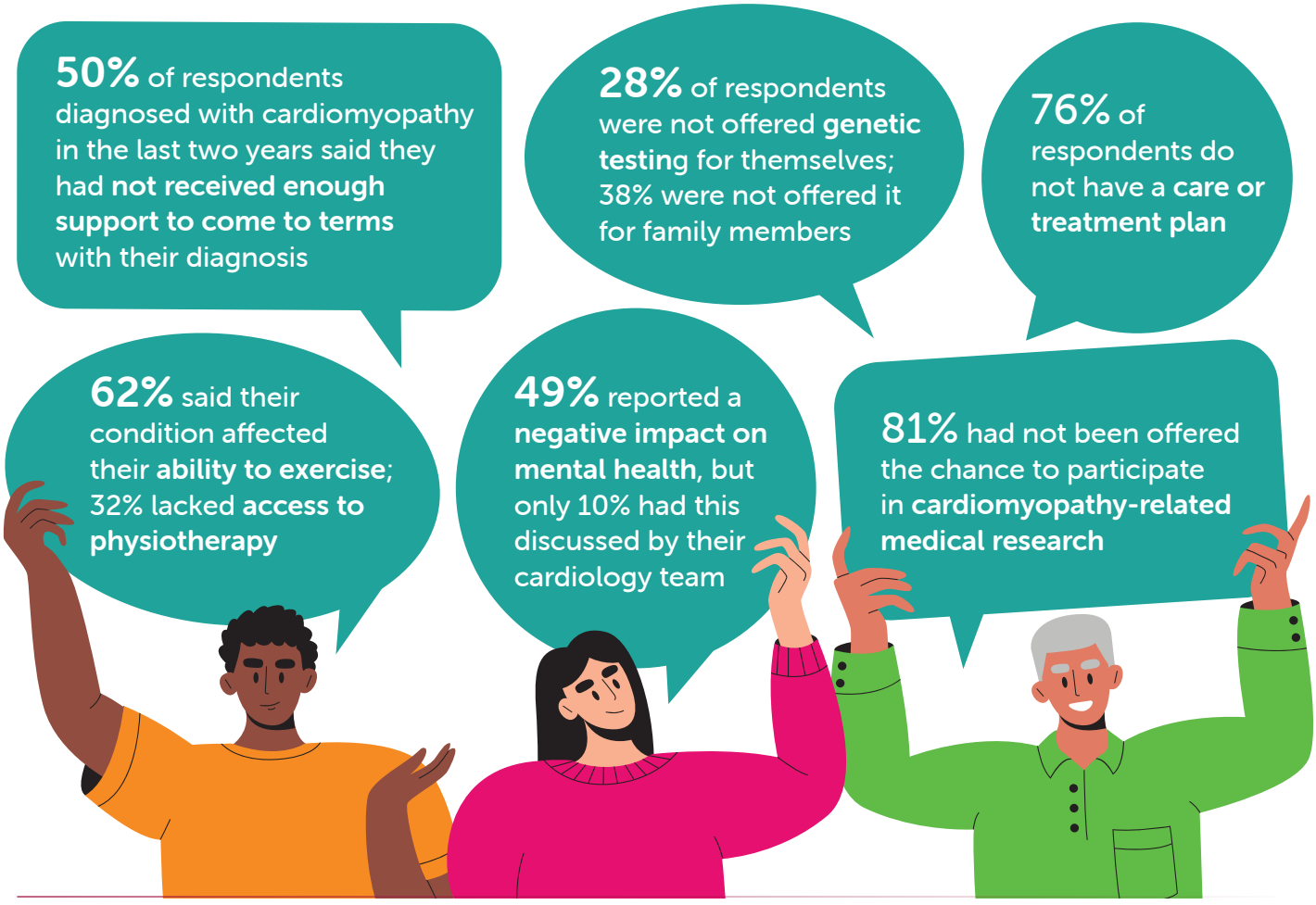
Executive summary

Cardiomyopathy is a disease of the heart muscle that affects 1 in 250 people in the UK. It can be inherited, progressive, and life-altering – yet people affected by cardiomyopathy continue to face delays in diagnosis, fragmented care, and limited access to personalised support and treatment.

This State of the Nation report draws on insights from over 1,300 survey respondents, from a MyInsight survey conducted between July and September 2024. The survey was completed in collaboration with Picker, a leading international health and social care research charity, and part-funded by Bristol Myers Squibb and Cytokinetics.*

Informed by feedback from patients and carers on their experiences of NHS cardiomyopathy care, this report sets out Cardiomyopathy UK's vision for a system where every person affected receives timely, equitable, and compassionate care.

Key findings reveal significant gaps across the care pathway:



*These companies had no input on the content or methodology and will not have access to data gathered.

Drawing on these findings, we have identified three core priorities for transformation in the context of the NHS in England:

1. Early diagnosis and timely access to genetic testing

- Train and incentivise GPs to recognise the symptoms of cardiomyopathy and record family cardiac history
- Introduce Best Practice Tariffs* for timely genetic assessment and inherited cardiac condition (ICC) referrals, supported by broader investment in ICC centre capacity
- Support earlier diagnosis of cardiomyopathy by improving access to diagnostic services
- Embed cardiomyopathy within a stratified targeted screening programme focused on individuals with known family history or other risk factors

2. Holistic and person-centred care

- Ensure equal access to specialist cardiac care via integrated care plans
- Facilitate more routine access to mental health support, including via the national ICC service specification
- Incorporate cardiomyopathy into commissioning guidance for cardiac rehabilitation

3. Enhanced access to treatment and continuity of care

- Expedite the Single Patient Record for seamless care coordination
- Prepare the NHS for new therapies through workforce and tech investment
- Invest in research in line with the James Lind Alliance future research priorities for cardiomyopathy[1]

Cardiomyopathy UK stands ready to work with policymakers, clinicians and the wider system to turn these recommendations into reality – building on our existing work in healthcare professional education, peer support, benefits advice and tailored emotional wellbeing services.

*Best Practice Tariffs (BPTs) are national tariffs that have been structured and priced to incentivise and adequately reimburse care that is both high quality and cost effective.

Introduction

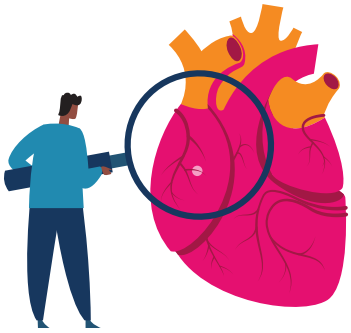
Following our 2022 State of the Nation report,[2] this report provides a stocktake of cardiomyopathy care in the UK and sets out Cardiomyopathy UK's vision, as the specialist national charity for people affected by the condition, for improving outcomes for people living with cardiomyopathy in the UK and their loved ones.

Our community's vision is for a system of care whereby people affected by cardiomyopathy receive:

1. **Early diagnosis and timely access to genetic testing, where appropriate**
2. **Holistic, person-centred care that reflects the full range of individual needs**
3. **Enhanced access to treatment and continuity of care**

These priorities are informed by feedback from those living with cardiomyopathy, their families and healthcare professionals, and supported by data from the **MyInsight survey**. Full details of the MyInsight survey methodology are included at the end of this report.

About cardiomyopathy



What is cardiomyopathy?

Cardiomyopathy is **a group of conditions that affect the heart muscle**. It is not 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.[3] There are many different types of cardiomyopathy and some subtypes of cardiomyopathy are also considered rare conditions (visit **our website** for more information on the different types).[4]

Cardiomyopathy can cause changes in the shape, size and thickness of the heart muscle walls, which can affect the normal functioning of the heart. This can lead to dangerous arrhythmias and cause cardiac arrest. Moreover, if not managed properly, this reduced efficiency can eventually **lead to heart failure**. This is a condition where the heart is unable to meet the body's demands for blood and oxygen.[5] When heart failure becomes severe, a transplant may be the only option to keep someone alive. Cardiomyopathy is one of the leading reasons patients go on to have a heart transplant.

Who does cardiomyopathy affect?

It is estimated that cardiomyopathy affects **1 in 250 people in the UK,**[5] impacting individuals across all age groups. In the majority of cases, cardiomyopathy is a genetic condition that can be passed down through families.[5] However, it can also be caused by viral infections, some medications (e.g. chemotherapy), or lifestyle factors e.g. excessive drug/alcohol use, among other causes.

How does cardiomyopathy impact people?

The different types of cardiomyopathy have different impacts on the heart. Therefore, **symptoms of cardiomyopathy vary depending on the type and severity**, but many overlap across different forms of the condition. For example, common symptoms can include shortness of breath, fatigue, swelling of the legs, heart palpitations, dizziness and arrhythmias (irregular heart rhythms).[6] Cardiomyopathy can also be asymptomatic.[6]

There is **no cure for cardiomyopathy**, and it **can impact people's quality of life**, from mental health and self-confidence to ability to exercise. However, with the correct diagnosis and treatment, most people with the condition can reduce and manage the symptoms it causes.[7] There are many treatment options available to help people manage their condition, including medication, surgery and implanted devices.[7]

This report delves further into the policy changes that are required so that everyone affected by cardiomyopathy receives earlier diagnosis, equitable access to high-quality treatment and care and can live well with the condition.

What is the economic impact of cardiomyopathy in the UK?

Whilst there remains a gap in economic research focused on cardiomyopathy-specific data, we know that the broader cost of **cardiovascular diseases in the UK is estimated to be around £29 billion annually**, with healthcare costs estimated to be about £12 billion of this.[8] It is therefore critical that barriers to earlier diagnosis and high-quality care for those affected by cardiomyopathy are addressed to reduce additional burden on the healthcare system.

1. Early diagnosis and timely access to genetic testing

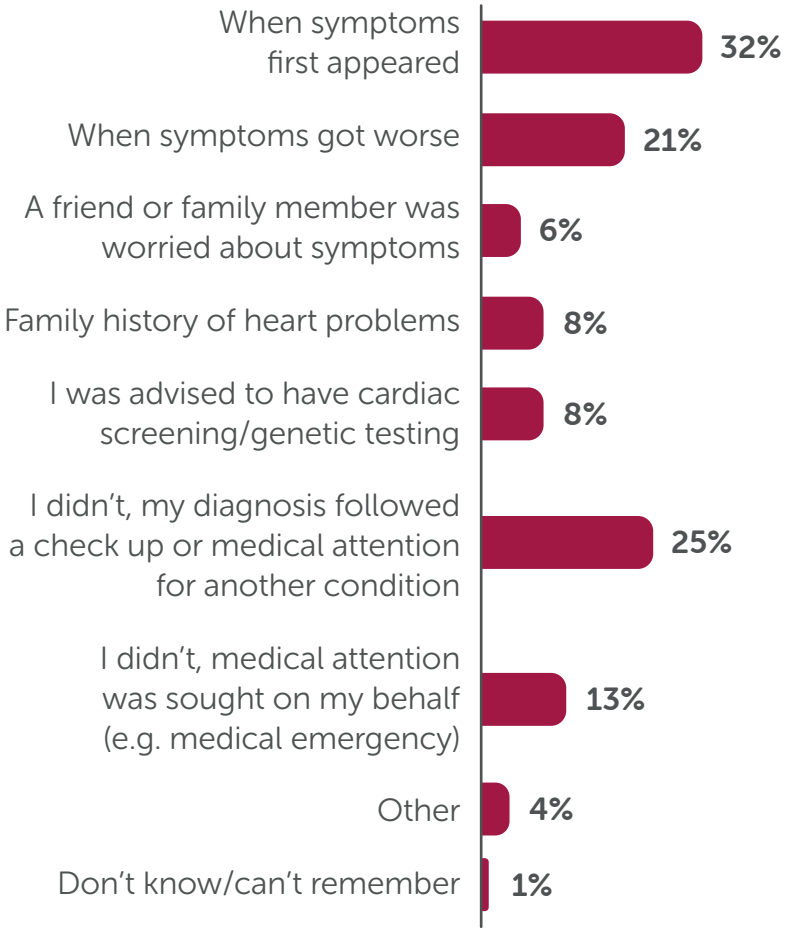
Timely and accurate diagnosis is essential for people with cardiomyopathy. Yet many individuals face delays, misdiagnosis, and missed opportunities for genetic testing. These challenges are often rooted in low clinical awareness and a lack of access to genetic assessment. This section explores the barriers to early diagnosis and outlines the steps needed to ensure that everyone affected by cardiomyopathy receives the right care at the right time.

Barriers to timely diagnosis

Many people are not diagnosed with cardiomyopathy until they experience severe symptoms or a cardiac event, such as heart failure.[9] Symptoms are frequently missed or mistaken for other conditions, particularly among women.[10] This is often due to limited awareness among non-specialist clinicians and the public about the signs and symptoms of the condition.[7]

Because many types of cardiomyopathy are inherited, family history can be a vital part of diagnosis.[5] It was of note that the MyInsight survey found that 8% of respondents were first prompted to seek medical attention before their cardiomyopathy diagnosis due to being aware of a family history of heart problems.

Figure 1: What first prompted you to seek medical attention before your cardiomyopathy was diagnosed? (Please select all that apply) (n=192)



We also know, from wider research into recording of interactions in UK general practice, that family history is not being systematically recorded in patient records.[11] Without this information, opportunities to identify inherited forms of the condition are lost. Cardiomyopathy UK's education programme for healthcare professionals, **CardioCare**, is working to raise awareness of common cardiomyopathy symptoms among non-specialist healthcare professionals, but more needs to be done at a national policy level to overcome this systemic barrier.

The ability to access echocardiography – a key diagnostic tool for cardiomyopathy[12] – is another growing challenge. A 2022 survey undertaken by the British Society of Echocardiographers found that 37% of patients waited over six weeks for an echocardiogram, up from just 4% in 2020.[13] This is largely due to workforce shortages, with over 10% of the UK echocardiography workforce made up of temporary workforce.[14] Without timely imaging, diagnosis and treatment initiation are delayed. As discussed later in this report, these limitations also hinder access to some therapies that rely on echocardiographic monitoring.

Moreover, data from the MyInsight survey shows that once a diagnosis is made, there is a perception amongst some people affected by cardiomyopathy that there is not enough support in primary care to come to terms with their diagnosis. This means they rely on overstretched secondary care services. In fact, 50% of survey respondents that were diagnosed with cardiomyopathy in the last two years said they had not received enough support to come to terms with their diagnosis.

"The person I care for gets no real care from the GP other than repeat prescriptions. No check-ups or support. The hospital care is great so we try to bypass the GP if we can."

All of these diagnostic delays underscore the need for targeted training and incentivisation to drive consistency of these practices in primary care.

Unequal access to genetic testing

Genetic testing is a key part of diagnosing and managing cardiomyopathy, but access remains inconsistent. Our MyInsight survey found that **28% of respondents had not been offered genetic testing* for themselves and 38% had not been offered testing for their family members**. Regional and ethnic variation was observed in how likely respondents were to report that they were offered genetic testing, while those who had another physical or mental health condition were less likely to report being offered genetic testing than those without another condition.

*The sample was unweighted and not nationally representative.

Clinicians face challenges in determining who should be screened and how this should be approached, factors which can lead to variations in practice between centres. Moreover, digital infrastructure to support screening is lacking, leading to reliance on paper-based systems. European Society of Cardiology guidelines for the management of cardiomyopathies state that once a genetic cause is established in one family member, cascade testing of other family members should be considered.[15] However, these guidelines are not mandatory.

One area where clinicians do not have a choice, is determining who should be screened relates to the age limits set by the National Genomic Test Directory. This gives upper age limits of 60 and 65 respectively for genetic testing eligibility for hypertrophic cardiomyopathy and dilated cardiomyopathy patients.[16] This is problematic, as older patients are preemptively denied the opportunity to find out whether their cardiomyopathy is genetic, regardless of the clinical merits of testing in their individual case. Over a half (57%) of of MyInsight survey respondents were aged 61+.

Alongside the lack of mandatory recommendations, in England there is a lack of national levers to drive implementation of best practice, for example via financial incentives – and could be limiting uptake of the guidance.

This also means that the system relies too heavily on families themselves to communicate genetic risks, which can lead to gaps in care.

"The most frustrating part of the genetic process is that not all family members are spoken to, or seen by, the same professional each year. The past history does not always reflect the original [family] history as it depends on what is remembered or written down [by family members]."

In addition to improving clinical awareness and family history recording, there is a potential role for the UK National Screening Committee in addressing variation in early diagnosis. Given the genetic nature of many cardiomyopathies and the impact of delayed detection, a stratified targeted screening programme – focused on individuals with known family history or other risk factors – could help identify cases earlier and reduce unwarranted variation in practice. We hope to see cardiomyopathy embedded within a new targeted national screening programme to cascade testing to those with relatives who may also have cardiomyopathy. This would support a more proactive approach to diagnosis and complement existing efforts to improve access to genetic testing and specialist care.

Addressing these gaps will require national policy levers and investment to ensure consistent access to genetic testing and cascade testing across the UK for people affected by cardiomyopathy.

Recommendations for change

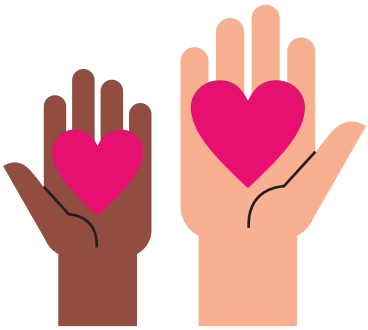
To tackle the systemic challenges outlined above – from missed symptoms and poor recording of family history to variation in access to genetic testing – we recommend the following actions to bridge the gap between current practice and best care:

1. Integrated Care Boards should work with Primary Care Networks (and Neighbourhood Health Services), charities and professional bodies (e.g. the Royal College of General Practitioners and the British Cardiovascular Society) to ensure GPs are trained to recognise the symptoms of cardiomyopathy and are incentivised to take and record detailed family cardiac histories where cases are suspected

2. The Department of Health and Social Care should introduce Best Practice Tariffs to incentivise hospitals to assess people with cardiomyopathy and their families for genetic testing and ensure timely, standardised referral to ICC centres. This must be supported by broader investment in ICC centres to manage any corresponding increase in demand

3. The Department of Health and Social Care should support earlier diagnosis of cardiomyopathy by improving access to diagnostic services. This includes retention and expansion of the trained NHS echocardiography workforce.

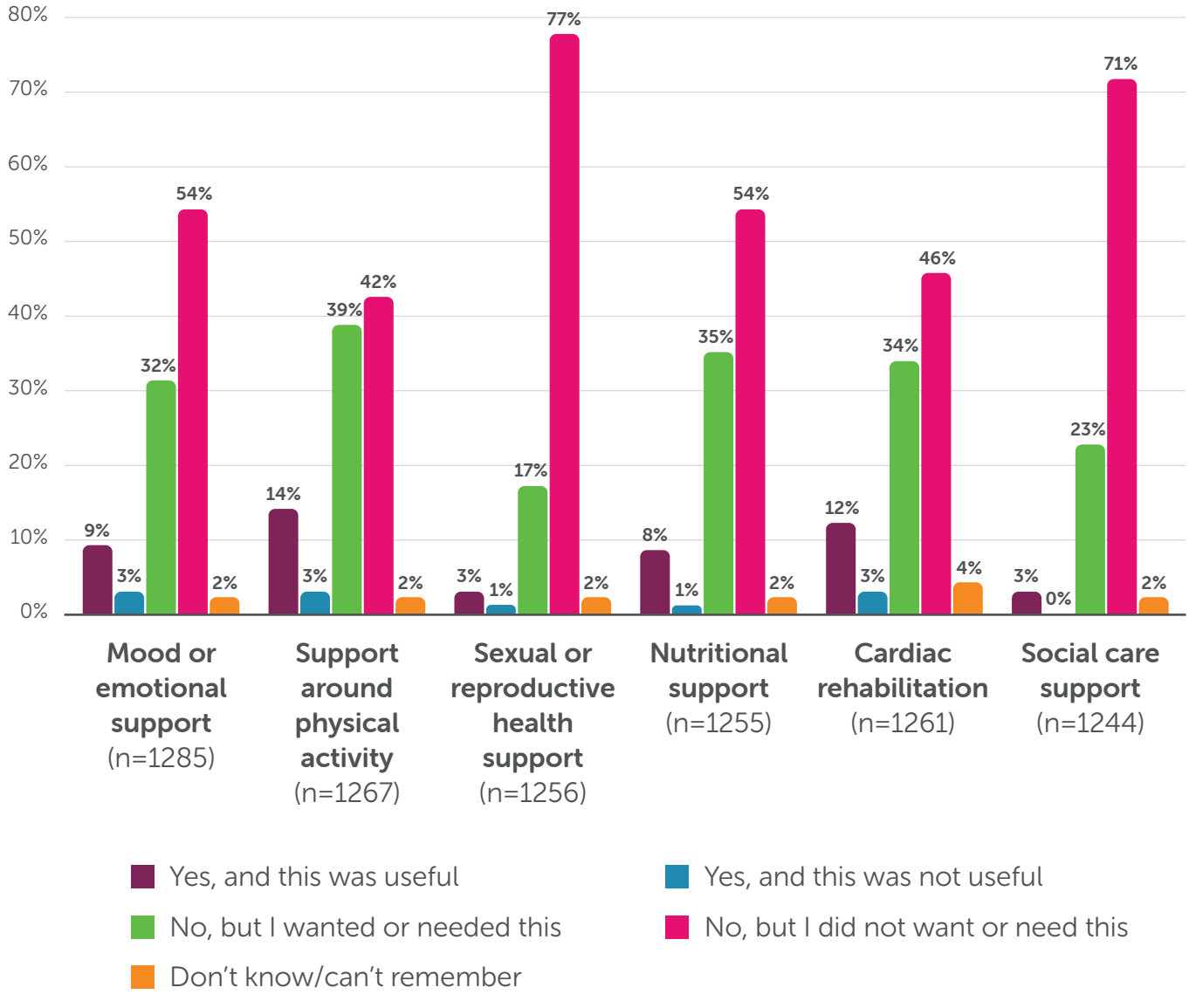
4. The UK National Screening Committee should embed cardiomyopathy within a stratified targeted screening programme, focused on individuals with known family history or other risk factors, to support earlier diagnosis and reduce variation in care



2. Holistic and person-centred care

Living with cardiomyopathy affects more than just the heart. It can impact mental health, physical wellbeing and everyday life.[17] However, too many people report feeling unsupported and disconnected from the care they need (see figure 2). This section explores gaps in personalised care, rehabilitation and emotional support – and sets out how the system must evolve to meet the full spectrum of needs for people with cardiomyopathy and their families.

Figure 2: In the last two years, have you received any of the following forms of health or social care support? (Participants selected all that applied)



Gaps in personalised care

76% of respondents said they did not have a care or treatment plan. This appears to mark a notable shift from our 2022 survey, in which 44% of respondents said they did not have a care or treatment plan, though the difference may be at least partially due to different question wording.[2]

Those who do have a care plan are more than twice as likely to report very good overall care compared to those without a plan (14% vs 6%), highlighting the importance of tailored, person-centred care. Having a care plan in place is also critical in empowering people with cardiomyopathy to be an active partner in their care. While only 35% of respondents reported that they 'definitely' feel involved in decisions about their care and treatment overall, those who had been given a care or treatment plan were more likely to report feeling involved.

Many respondents also reported a lack of contact between diagnosis and formal check-ins, leaving them feeling abandoned and unsure of what support is available. These findings underline the need for structured, ongoing and personalised support.

People with cardiomyopathy often live with complex, long-term health needs.[9] The Government's commitment in the 10 Year Health Plan to provide personalised care plans for people with long-term conditions is therefore welcome.[18] As this commitment is implemented, the NHS must take into account the complex needs associated with cardiomyopathy and ensure that it is prioritised in the roll-out of personalised care plans.

Mental health and emotional wellbeing

The emotional toll of cardiomyopathy is significant. Nearly half (49%) of respondents with cardiomyopathy said their mental health had been negatively affected in the last two years due to their diagnosis. Yet only 10% reported that their cardiology team had discussed mental health and wellbeing with them during that time. A further 40% said they wanted or needed this support but had not received it.

A key contributing factor to this issue is that cardiologists often lack the time during short appointments to address mental wellbeing.[19] While it is notable that the service framework for ICCs includes psychological support as a requirement, in reality we understand that few centres offer or integrate this into routine care, and to date there has been limited consensus on the optimal approach for psychological interventions.

The **consensus statement** on mental health and cardiovascular disease recently published by the European Society of Cardiology marks an important step forward in this area, promoting a psycho-cardio approach that integrates mental health assessment and management into routine cardiovascular care.[20]

While the consensus statement acknowledges that many research gaps remain,[20] its principles should be applied wherever possible as cardiomyopathy services evolve in response to the service specification for ICCs.

To close this gap, mental health support must be embedded into ICC services and informed by emerging best practice, ensuring cardiomyopathy patients receive psychological care as part of routine treatment.

Uncertainty around nutrition, exercise and everyday health

Cardiomyopathy can limit physical activity but in some types (e.g. dilated or hypertrophic)* exercise-based cardiac rehabilitation has been shown to improve both capability and quality of life.[21] Yet many people report uncertainty around what they can safely do and what support is available to help them manage their condition day to day. 62% of our MyInsight survey respondents said their condition had negatively impacted their ability to exercise. A third (32%) were unable to access a physiotherapist or exercise physiologist, even though they wanted or needed this support.

Nutrition is another area where tailored advice is helpful. A heart-healthy diet can help reduce symptoms,[22] and support cardiac function. However, many people with cardiomyopathy struggle with appetite, fluid restrictions, or confusion about what foods are safe.[22] 35% of those that said they wanted or needed nutritional support did not receive it – we would like to see all patients that would like this support be able to access it.

Sexual and reproductive health is also an important but often overlooked aspect of care.[23] People with cardiomyopathy may experience reduced sexual function due to changes in blood flow, medication side effects, or emotional strain.[24] Fear of triggering a cardiac event during intimacy is common, even though the physical exertion involved is generally mild.[25] Without clear guidance and support, many individuals experience distress and reduced intimacy.[23] Only 3% of respondents reported receiving useful sexual or reproductive health support.

In some cases, people's ability to stay as well as possible with cardiomyopathy, for instance through diet and exercise, may be restricted by a lack of information on the condition. Only 26% of respondents reported that, when first diagnosed, they were definitely given information about their condition in a way they could understand – with 9% not receiving any information at all. Moreover, restrictive commissioning guidance is contributing to variation in care and limiting access to rehabilitation services.[27]

*Guidelines on exercise vary and it is difficult to give general recommendations as it depends on the type of cardiomyopathy you have, and how it affects you. Any individual with cardiomyopathy wanting to participate in high intensity or competitive sport should do not do so without seeing a sports cardiologist for specialist screening and advice. Additionally, for most people with ACM they should only participate in low or low- moderate intensity exercise and should also avoid large volumes of endurance exercise.

> **"I just got the diagnosis, was given pills and that's about it. I have never been advised of exercise, nutrition or any other everyday things that can affect my condition."**

Whilst others described the transformative impact of rehabilitation:

> **"Cardiac rehab was a total game changer for me, in a very positive way."**

People with cardiomyopathy need clear and tailored NHS guidance that explicitly includes their condition, beyond what is currently recommended for people living with heart failure.[27] This includes access to rehabilitation and advice from staff who understand cardiomyopathy. Shortages in specialist cardiac staff[28] make it even more important that national guidance is clear and consistent. Guidance should also keep pace with new technology – such as wearable devices – which could in future be integrated more routinely into care plans to help patients monitor symptoms and manage conditions more effectively.[29]

Impact on work and daily life

Cardiomyopathy can prevent people from being able to work. Half of our MyInsight survey respondents said their ability to work had been affected in the last two years, either directly or – for those looking after loved ones with the condition – through caring responsibilities.

> **"I was unable to work for many years and was not able, even after the recovery of function, to work to the level I had prior to being diagnosed."**

Beyond the economic impact on the individual, cardiomyopathy is a leading cause of heart failure and contributes to the wider cost of cardiovascular disease in the UK, estimated at £29 billion annually – with £12 billion attributed to healthcare costs alone.[5]

As the Government develops a Modern Service Framework for cardiovascular disease (CVD), it is essential that the complex and long-term needs of cardiomyopathy patients are reflected in its design and implementation – including access to rehabilitation, psychological support and personalised care planning. Without this, variation in care will persist and many patients will continue to fall through the gaps.

Recommendations for change

The barriers explored in this chapter – from lack of care plans and mental health support to gaps in rehabilitation and everyday guidance – demonstrate the need for a more holistic, person-centred approach to cardiomyopathy care. To embed this approach across ICC services and ensure that care reflects the full spectrum of needs for people with cardiomyopathy, we recommend that:

5. The Department of Health and Social Care and Integrated Care Boards should ensure that the Modern Service Framework for cardiovascular disease ensures people with ICCs such as cardiomyopathy have equal access to specialist cardiac care, supported by integrated care plans and clear signposting to holistic support, including charity-led groups

6. The Department of Health and Social Care should support NHS regions and Integrated Care Boards to implement access to specialist mental health professionals in ICCs, as outlined in the European Society of Cardiology consensus on mental health and cardiovascular disease

7. The Department of Health and Social Care should develop clear commissioning guidance for ICC centres on the role of cardiac rehabilitation for people living with cardiomyopathy, reflecting the benefits of tailored physical rehabilitation services for people with cardiomyopathy

3. Enhanced access to treatment and continuity of care

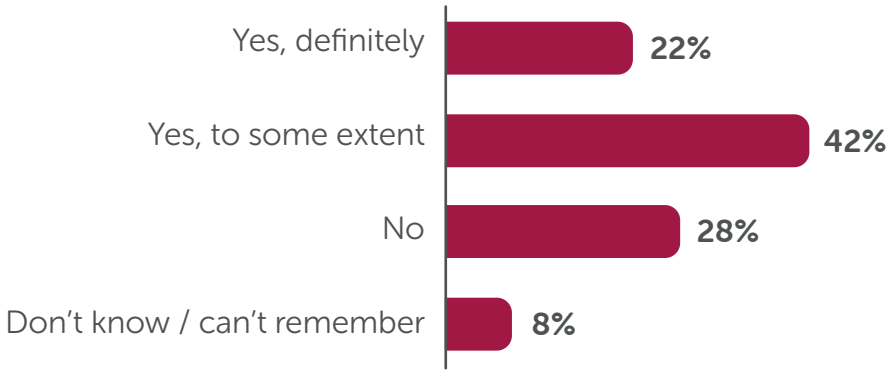
Access to effective treatment for cardiomyopathy should not depend on where someone lives or their ability to navigate a complex healthcare system. Yet many people face delays in accessing guideline recommended medicines, fragmented care across providers, and limited opportunities to participate in cardiomyopathy-specific medical research. This section highlights the structural barriers to optimised care faced by many people with cardiomyopathy, and outlines the policy levers needed to ensure continuity, equity and innovation in treatment pathways.

Fragmented care and lack of continuity

Continuity of care is essential for people with cardiomyopathy, yet many of our MyInsight survey respondents reported having to organise their own care due to poor coordination between services. This includes gaps between hospital departments, and between primary and secondary care.

> **"There seems to be no cooperation between my Cardiac centre, my local hospitals, and my GP so I am fed up of repeating myself and leading my own health care."**

Figure 3: In your opinion, do the different healthcare professionals involved in your care work well together (n=1307)



Continuity is also lacking in genetic testing pathways. Families often describe the process as time-consuming and stressful, with an over-reliance on the first person diagnosed to manually share paper-based information with relatives. In many cases, relevant data is not shared between providers – leading to delays and anxiety for families.

There is growing interest in 'hub-and-spoke' networks for managing care, which see care coordinated at the regional level by ICC 'hubs', but delivered closer to patients' homes when more specialist care is not required. As a result, this may see more people with ICCs such as cardiomyopathy consulted in primary and secondary care settings.[30,31] Similarly, there is an ongoing process to move to a networked model of care for amyloidosis, which should improve care for people with transthyretin amyloid cardiomyopathy.[32] This shift makes continuity of care even more critical – not just at diagnosis, but throughout the patient journey. Without investment in workforce training, digital interoperability, and integrated care pathways, care may be disjointed, particularly when patients are discharged from specialist services back to their GP.[33]

In fact, our MyInsight survey found that patients often felt abandoned – underscoring the urgent need to strengthen the network of care and ensure that all providers are equipped to deliver high-quality, coordinated support.

Currently, there is insufficient data being collected and shared on the diagnosis and treatment of inherited cardiac conditions, due the lack of requirements to compel trusts to do so. There is no dedicated national audit capturing the activity, capacity or outcomes of ICC centres.[34] This limits the ability to benchmark services, identify regional variation, and drive quality improvement. The National Institute of Cardiovascular Outcome Research (NICOR) publishes an annual audit containing data about heart failure patients but would benefit from expanding its remit to include ICCs such as cardiomyopathy, a key cause of heart failure.[35] This would enable more consistent data collection, support service planning and ensure equitable access to specialist care across the UK.

These gaps in coordination across primary, secondary and specialist care show the need for shared records, workforce training and integrated care pathways to support cardiomyopathy patients throughout their journey.

Delayed access to innovative medicines

People with cardiomyopathy are also facing delays in accessing new treatments. Medicines approved by NICE are not always added to local NHS formularies* in a timely way, creating a postcode lottery for care. In some cases, hospitals are capping the number of patients who can be put forward for certain treatments due to capacity constraints.

*A local NHS formulary is a list of medicines and treatments approved for use in a specific geographic area.

"Struggle to get medication... Been waiting for mavacamten for almost a year and still not sure when will be able to start being available."

Cardiomyopathy UK welcomes the Single National Medicines Formulary pledged in the 10 Year Health Plan,[18] which offers an opportunity to close these gaps and ensure equitable access to approved treatments. The patient experience should be considered front and centre when this formulary is being developed.

Slow uptake of new treatments and regional variation in prescribing highlight the need for reform of hospital formularies and clinician education to ensure equitable access for cardiomyopathy patients.

System preparedness for new therapeutics

Limited capacity in diagnostic services, particularly echocardiography, affects not only the diagnostic pathway but also treatment and ongoing management. Some medicines for cardiomyopathy require specialist prescribing and monitoring,[36] meaning the limited capacity in echocardiography services can impact access to treatments.

"I live in Cornwall but travel to London with my twin daughters who also have the condition. We get better and faster care there."

To overcome these challenges, the system must:

- Consider optimal adoption of medical technologies that streamline clinical workflows. For example, AI-supported echocardiography analysis, which in future could reduce the need for manual annotations and measurements, potentially saving time while maintaining accuracy and compliance with international guidelines. While these technologies are promising, their introduction must be carefully evaluated and evidence-based to ensure patient safety

- Implement hub-and-spoke models more routinely. In this model, specialist centres act as hubs, supporting local "spoke" services. This approach could reduce capacity pressures in diagnostic services including echocardiography, improve continuity of care, maintain consistent quality, and increase access to new therapeutics across regions

By taking these steps, the NHS can help ensure that people with cardiomyopathy have timely access to both diagnostics and novel treatments, while strengthening the echocardiography workforce to meet future demand.

Limited opportunities for research participation

Clinical research is vital to improving diagnosis, treatment, and quality of life for people with cardiomyopathy. Yet 81% of respondents said they had not been offered the opportunity to take part in cardiomyopathy-related research or trials in the last two years. This is perhaps unsurprising against a broader context of diminishing clinicial research capacity across the NHS.[37] This highlights a missed opportunity to involve those affected in shaping future care and innovation – and to expand research and clinical trials. We want to see a level-playing field for involvement across all types of cardiomyopathy in line with transthyretin amyloid (ATTR) cardiomyopathy. 70% of our survey respondents advised they had been offered the opportunity to take part in ATTR cardiomyopathy research – highlighting the levels of patient participation which can be achieved with concerted effort.

Recommendations for change

The barriers outlined in this chapter – from fragmented care and delayed access to medicines, to limited opportunities for research participation – highlight the need to strengthen continuity of care, accelerate access to new treatments and ensure that people with cardiomyopathy are included in shaping future research and service delivery. As such, we recommend that:

8. The Department of Health and Social Care expedite implementation of the Single Patient Record to enable seamless information sharing across care settings for people with cardiomyopathy

9. The Department of Health and Social Care work with Integrated Care Boards, patient charities, and industry to ensure that newly approved cardiomyopathy treatments are not only accessible but actively prescribed. This includes developing implementation plans, facilitating clinician education, and monitoring uptake to ensure that innovations translate into improved patient outcomes

10. The Department of Health and Social Care and the Department of Science Innovation and Technology work with the NHS, academia, patient charities and industry to invest in clinical researchers and research to enable earlier diagnosis, targeted treatments and improved quality of life for those in the UK affected by cardiomyopathy, in line with the James Lind Alliance priorities.[1]

Time to make change happen

Cardiomyopathy UK's MyInsight survey reveals a clear and urgent need for systemic change in how cardiomyopathy is diagnosed, treated, and supported across the UK. While the commitments set out in the NHS England 10 Year Health Plan – particularly around tackling cardiovascular disease and delivering person-centred care – are welcome, they must now be actioned with urgency. Our MyInsight survey has shown that people affected by cardiomyopathy continue to face delays, inequities, and fragmented care, often having to navigate the system alone.

As the Modern Service Framework for cardiovascular disease is developed,[17] it is vital that it reflects the full spectrum of cardiovascular conditions – including inherited and non-preventable diseases such as inherited cardiomyopathy. Policymakers must ensure the framework does not exclusively focus on high-prevalence or lifestyle-related conditions and overlook rarer or genetically driven diseases. A truly inclusive approach will help avoid widening inequalities and ensure that all patients benefit from system improvements.

The findings of this report highlight three core priorities for transformation:

1. **Early diagnosis and equitable access to genetic testing**
2. **Holistic, person-centred care that supports mental, physical, and social wellbeing**
3. **Enhanced access to treatment and continuity of care across the system**

Policy levers exist – from national incentives and workforce investment to digital integration and guideline reform – but they must now be activated with urgency and accountability. Integrated Care Systems, the Department of Health and Social Care, and the Medicines and Healthcare products Regulatory Agency all have a role to play in delivering the recommendations outlined in this report. Innovation, including the use of artificial intelligence and medical technologies, must be embraced to expand diagnostic capacity and improve care coordination.

Critically, people affected by cardiomyopathy must be at the centre of care planning, underpinned by shared decision making, clear communication, shared records, and consistent access to specialist support.

Cardiomyopathy UK stands ready to work with policymakers, clinicians, and the wider health system to turn these recommendations into reality – building on our existing work in healthcare professional education, peer support, benefits advice and tailored emotional wellbeing support. We are plannng a deep dive into how these policy changes must consider the devolved nature of healthcare and in turn the unique experience of people living with cardiomyopathy in the devolved nations.

In 2020, the British Heart Foundation published a blueprint for transforming heart failure care[38] – recognising the urgent need for earlier diagnosis, better coordination, and personalised support. Cardiomyopathy, as a leading cause of heart failure, was part of that vision. Yet four years on, little has changed in terms of real policy implementation or patient outcomes. Our report builds on that foundation and calls for a renewed urgency to deliver the change that cardiomyopathy patients have long been promised.

We call on policymakers to act on these recommendations and work with Cardiomyopathy UK and the wider cardiomyopathy community to build a future where every person with cardiomyopathy receives timely, equitable, and compassionate care – no matter where they live.

About Cardiomyopathy UK

Cardiomyopathy UK is the specialist charity supporting people affected by cardiomyopathy – a disease of the heart muscle. Our vision is that people affected by cardiomyopathy should live a long and fulfilling life.

We offer clear, compassionate support and information to help people feel more informed about their condition, less scared and better able to cope day to day. We also educate healthcare professionals so that they are better able to detect and treat the condition and work to raise awareness of the signs and symptoms of cardiomyopathy among the public, so that more people seek help.

In addition to this, we campaign for improved access to quality treatment through the NHS and work with the research community to ensure that their efforts meet the needs of people with cardiomyopathy.

We bring together the patient community, leading clinicians, researchers, policy makers and other key stakeholders to work collaboratively on tackling the issues that people affected by cardiomyopathy face – now and in the future.

Our MyInsight survey

In 2024, we collaborated with Picker,* a leading international health and social care research charity, to explore people's experiences of living with or caring for someone with cardiomyopathy. The findings of the **MyInsight survey** have shaped our *State of the Nation* report. We're incredibly grateful to everyone who took part and your insights are helping us strengthen our voice and ability to advocate for improved access to quality care.

How the MyInsight survey was developed

We used a step-by-step approach to build the MyInsight survey. This included:

- Reviewing past survey results and recent research
- Speaking directly with people affected by cardiomyopathy to find out what matters most to them, as well as to test the survey questions
- Getting advice from clinical experts

In total, we received 1,323 responses to the MyInsight survey. Not all respondents answered every question so percentages shown throughout this report are based on the number of people who responded to each specific question.

Listening to lived experience

We undertook five in-depth interviews with people affected by cardiomyopathy (including family members). These conversations helped us design questions that reflect real-life experiences. We made sure participants were UK based, aged 16+, and either diagnosed or caring for someone with cardiomyopathy.

What the MyInsight survey included

The final 44-item survey included:

- Screening questions (age, location, respondent type)
- 33 main questions (closed and open-ended)
- Demographics and contact preferences

We tested the MyInsight survey with eight people to make sure the questions were clear and easy to answer, and we refined the wording and structure in response to feedback.

*In addition to collaborating with Picker, the MyInsight survey was part-funded by Bristol Myers Squibb and Cytokinetics. These companies had no input on the content or methodology and will not have access to data gathered.

How the MyInsight survey was shared

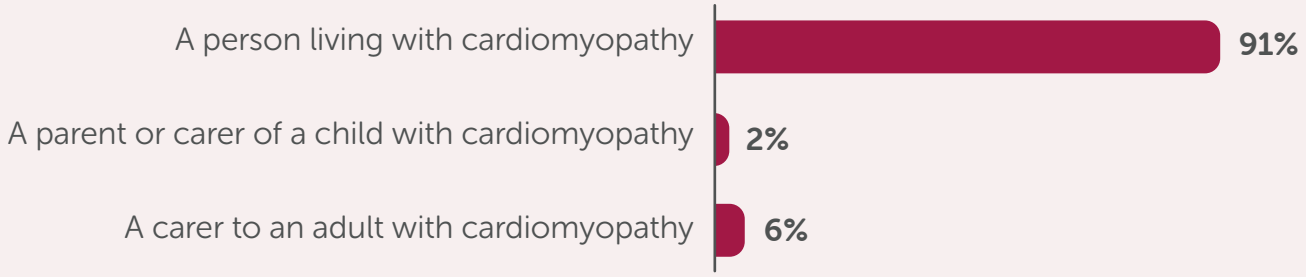
The survey ran from 23 July to 17 September 2024. We used different ways to share it with people:

- Online invitations to 3,737 individuals (hosted on Qualtrics with live response tracking)
- Postal surveys to 2,170 contacts (including a booklet, cover letter and freepost envelope)
- Wider promotion via social media, newsletters, clinics and stakeholder networks

Breakdown of MyInsight survey respondents

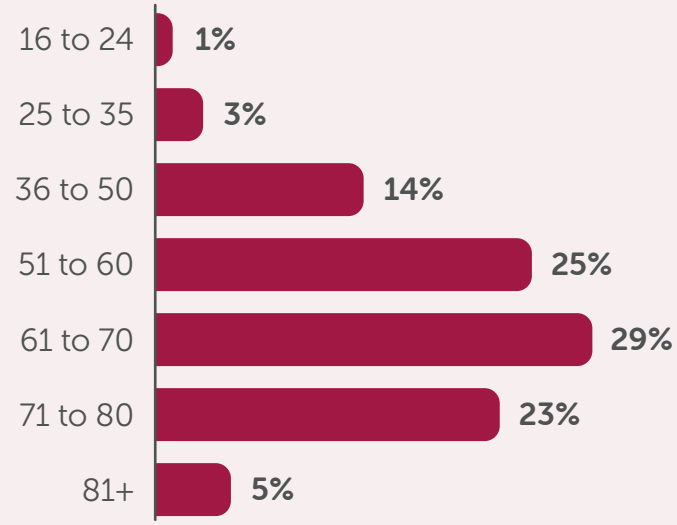
Type of respondent

Type of respondent (n=1323)



Age

Age of respondent (n=1323)



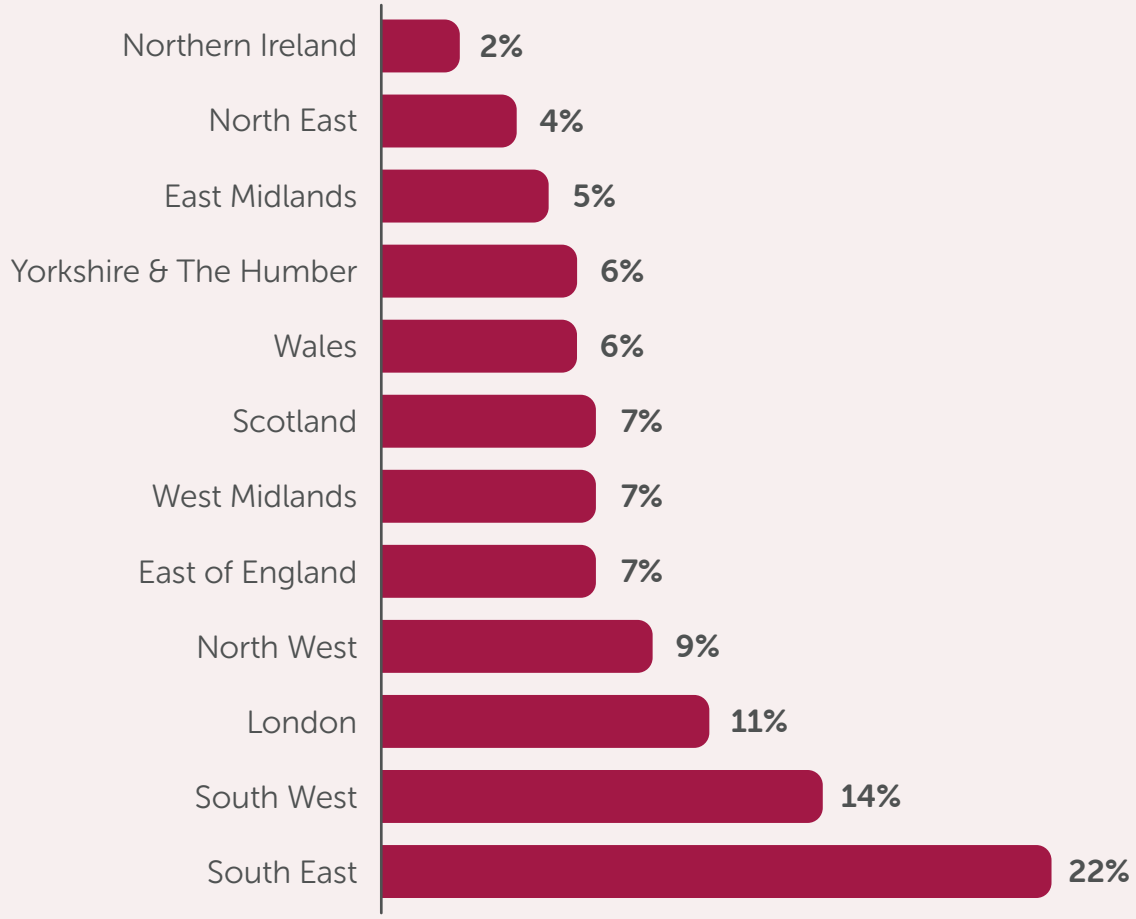
Gender

Gender (person with cardiomyopathy) (n=1298)

<1% (n=4) non-binary/prefer not to say

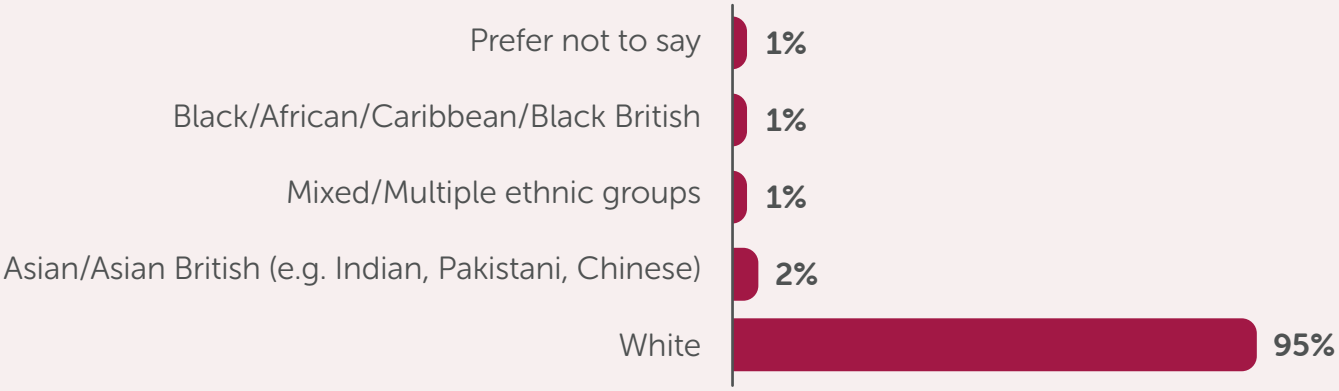
Geographical region

Region of respondent (n=1323)



Ethnicity

Ethnicity (person with cardiomyopathy) (n=1298)



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