Genetic testing in cardiomyopathy: ensuring our future health systems leave no family behind

2026

This report was led by the International Cardiomyopathy Network (ICoN), with support from The Health Policy Partnership. The content was developed with input from the project's Steering Committee and ICoN trustees as well as other key experts. The report was sponsored by Bristol Myers Squibb, Cytokinetics, Pfizer, Amicus and Alnylam. The experts provided their time for free.

ICoN International Cardiomyopathy Network

The Health Policy Partnership

About the International Cardiomyopathy Network

The International Cardiomyopathy Network (ICoN) is a newly established association of medical, scientific and lay stakeholders with the mission of improving the health of people affected by cardiomyopathy and related diseases. For more information, visit:
https://www.cardiomyopathy-icon.org

About this policy paper

The policy paper has been developed based on desk research, 12 semi-structured interviews and an online survey. Experts interviewed included healthcare professionals with experience in cardiomyopathy and relevant fields, and people living with the condition and their relatives. The survey was distributed to representatives of the 27 European Union Member States, including selected experts and representatives of national cardiac societies; responses were received from 12 of 27 countries (Belgium, Czechia, Estonia, Finland, France, Germany, Italy, Malta, the Netherlands, Portugal, Romania and Spain).

Coordination, research and drafting were led by Perry Elliott at ICoN and Karolay Lorenty, Ed Harding, Mo Forman and Kasia Trojanowska at The Health Policy Partnership, with design by Catarina Correia Marques. The Steering Committee, as co-authors, closely guided the development of the paper and validated findings.

This policy paper is endorsed by

ARVC Selbsthilfe
Arrhythmogenic Cardiomyopathy Association Germany

CardioGen
Asociația pacienților cu boli cardiace genetice din România

Czech Society of Cardiology

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Rare Cardiovascular Disease Care & Prevention

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Foreword

We are at a pivotal point for cardiovascular health, rare diseases and personalised medicine. After decades of cardiovascular health being overlooked and underprioritised, the European Union (EU) Safe Hearts Plan promises coordinated action on early diagnosis and personalised care. We can expect a revitalisation of global, regional and national cardiovascular strategies to follow. Momentum is also growing for a more ambitious and aligned approach to genomics, data and rare diseases.

While these are timely and welcome developments, the task ahead is sobering. European health systems lag far behind these visions of sustainable, equitable approaches to cardiovascular health, and we must now turn to action. This paper highlights a critical bottleneck which must be addressed: the lack of equitable and prompt genetic testing.

Cardiomyopathies are in the vanguard of innovation. We increasingly understand the genetic mechanisms behind them, and a growing number are amenable to interventions that promise improved quality of life and longevity. However, to unlock the potential of this new knowledge, it is essential that people with or at risk of developing cardiomyopathy have timely access to genetic testing, and the interpretation of these tests by experts.

This paper, the first of its kind, shows that there are many gaps in provision of genetic testing, resulting in inconsistent and uneven care pathways that lack support by professionals with adequate knowledge and skills. Based on these findings, we call for a series of ambitious but feasible actions designed to improve equity of care for people with cardiomyopathy and protect the sustainability of health systems.

We thank our friends and partners for their support – and invite colleagues from the clinical, scientific, patient, policy and operational communities to join us in our mission. Together, we can ensure that no one is left behind in the transition to personalised cardiomyopathy care.

Perry Elliott
Chair of the International Cardiomyopathy Network

Jagat Narula
President of the World Heart Federation

ICoN International Cardiomyopathy Network

WORLD HEART FEDERATION

Executive summary

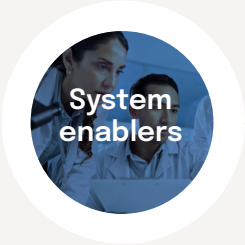
Cardiomyopathy care is at the forefront of cardiovascular genomic innovation. Genetic testing is a recognised standard of care, yet large numbers of people and families across Europe are not able to access it. Cardiomyopathy is a complex heart muscle condition that is partly caused by genetic factors;[1,2] up to 40% of people with cardiomyopathy have a known family history.[3] The discovery of associated genes was a turning point for cardiomyopathy and broader cardiovascular care.[4,5] Since then, cardiomyopathy has emerged as a pioneer in targeted treatment development in cardiovascular disease area.[1,2,6,7]

Genetic testing for cardiomyopathy remains inconsistently implemented, under-resourced and unevenly reimbursed between countries and care settings. This is both a missed clinical opportunity and a systemic weakness that perpetuates avoidable harm across generations. Genetic testing has the potential to transform the lives of people with cardiomyopathy and their families. It can facilitate identifying people at risk who were previously unaware and enable people to receive the right treatments. Specific benefits include:

- **differentiating between cardiovascular conditions** that have similar clinical presentation yet require different treatments[1,8]
- **identifying undiagnosed relatives** at higher risk of life-threatening events[9-11]
- **enabling preventive therapies** in people diagnosed with cardiomyopathy at higher risk of life-threatening events[1,8]
- **reducing uncertainty** about the cause and progression of cardiomyopathy in people who share the same clinical presentation[1]
- **administering the correct dose of targeted treatment** for specific types of cardiomyopathy[12]
- **facilitating reproductive counselling** to support decision-making around family planning.[1,8]

Beyond clinical benefits, genetic testing also enables health system resources to be allocated effectively and for innovative treatments to be developed. Costs have continued to decline for genetic testing, and studies have shown that it is cost-effective, as it removes the need for regular monitoring of relatives, while ensuring early treatment and reduced hospitalisations.[13-19] Further scientific advances will likely expand the role of genetic testing to assessing increased risk caused by multiple gene variants and predicting how people will respond to treatment, as well as accelerating the discovery of targeted treatments.[20,21]

Unlocking the potential of genetic testing in cardiomyopathy



Key actions	Current realities and challenges		
Health systems must **finance genetic testing** to ensure universal and equal access to innovation and personalised treatment for families with cardiomyopathy, regardless of their ability to pay.	• Only 37% of adults with cardiomyopathy receive genetic testing, and just 62% of their relatives do.[22]	• Four of twelve countries surveyed did not fully reimburse genetic testing for first-degree relatives of people diagnosed with cardiomyopathy.	• Four of twelve surveyed countries did not reimburse post-mortem genetic testing, with families having to pay out of pocket or through private health insurance.
Data-sharing systems and infrastructure are needed to support innovation and the development of new targeted treatments.	• Experts report difficulties in accessing and sharing data that could support care delivery and research.[23]	• While most of the surveyed countries had established guidelines for data management, guidance remains limited and inconsistent.	• Cross-border data-sharing is not structured or consistent in the European Union (EU), especially for post-mortem data.
Providing **genetic education and training for the workforce** will allow health systems to deliver quality genetic testing in the future.	• Four of twelve countries surveyed reported the availability of structured training and certification for cardiogenetic professionals.	• More than one in three experts surveyed did not have access to a dedicated cardiogenetic service or genetic lab.[24]	
Equal access to high-quality genetic testing can be supported by initiatives such as formal **reference centres, care pathways and expert centre networks**.	• Eight of twelve countries surveyed reported having no national reference network for genetic testing for cardiomyopathy or having a network that needed further development.	• While nine of the surveyed countries had national reference centres, three countries reported having none or only having a centre under development.	
Shared decision-making ensures that people with cardiomyopathy understand the rationale for genetic testing and its implications.	• Experts report that some centres have struggled to implement shared decision-making tools and processes, and families are often ot actively involved in care decisions.[25]		
Psychosocial professionals are valuable members of the multidisciplinary team who support people with cardiomyopathy to understand their diagnosis and its impact on their lives.	• Experts report that many health systems do not currently provide access to or reimbursement of psychosocial support.[26,27]	• Without adequate support, people with cardiomyopathy often face fears and anxieties after receiving the diagnosis or genetic test results.[15,26,27]	

The rise of genomics in cardiovascular care

Advances in genomics have already started transforming cardiovascular care, particularly for people with cardiomyopathy. The discovery of genes associated with hypertrophic cardiomyopathy in 1990 was a turning point in the field of cardiovascular disease, highlighting the importance of genetics.[4,5] This improved understanding of the genetic causes of cardiomyopathy has precipitated the development of targeted treatments that can delay the worsening of clinical symptoms.[2,6,7] The first such treatment for hypertrophic cardiomyopathy was approved by the European Medicines Agency in 2020,[28] and treatments for other types of cardiomyopathy are under development.[29]

Clinical guidelines indicate that access to genetic testing is a standard of quality care for cardiomyopathy. International professional societies have established consensus that genetic testing can transform the diagnosis and care of cardiomyopathy.[1,2] In 2023, the European Society of Cardiology published updated guidelines for cardiomyopathy, recommending that every person with confirmed cardiomyopathy be offered genetic testing.[1] In the case of hypertrophic cardiomyopathy, a pharmacogenetic test also provides vital information on the appropriate dose of treatment, and is required by the European Medicines Agency.[12,28]

Despite clinical recognition, access to genetic testing remains uneven, varying greatly by region. In recent years, the costs associated with genetic testing have declined and testing has become more widely available in some countries.[30] But access still differs significantly depending on resources available, with notable variations between countries.[13,14,27] Even in countries with wider access, uptake has been slow and expertise may be limited to centres of excellence and specific regions.[30,31]

'My father-in-law was initially diagnosed 25 years ago, but nobody told him he had a genetic disease and that his children should get tested.

In 2019, my husband was diagnosed with hypertrophic cardiomyopathy. Only then did we find out that it comes from his father and his grandma.'

Camen Balan,
CardioGen Patients Association

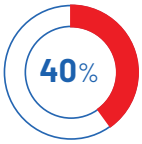
WHAT IS CARDIOMYOPATHY?

Cardiomyopathy is a complex condition that arises because of structural problems with the heart muscle.[1] These include thickening or scarring of the heart walls, and changes in the elasticity and strength of the heart muscle. There are five main types of cardiomyopathy, classified according to clinical presentation:[1]

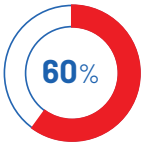
- **hypertrophic cardiomyopathy:** increased wall thickness of the heart muscle
- **dilated cardiomyopathy:** dilation of the heart muscle and reduced contractility
- **non-dilated left ventricular cardiomyopathy:** scarring and fatty tissue replacing the heart muscle
- **arrhythmogenic right ventricular cardiomyopathy:** abnormal structural changes of the heart muscle along with ventricular arrhythmia (abnormal heart rhythm in the lower chambers of the heart)
- **restrictive cardiomyopathy:** stiffening of the heart muscle walls

WHAT IS THE ROLE OF GENETICS IN CARDIOMYOPATHY?

Cardiomyopathy is partly determined by genetic factors, and in many cases, it has been passed on through generations.



Up to 40% of people with cardiomyopathy have a known family history of the disease.[3]



In hypertrophic cardiomyopathy, one of the most common types, genetic inheritance accounts for up to 60% of cases.

In many instances, the cause of cardiomyopathy remains unknown, possibly because the genetic link has not yet been identified.[1]

WHO IS AFFECTED BY CARDIOMYOPATHY?

A defining feature of cardiomyopathy is that it affects people of all ages. When cardiomyopathy occurs in infants and children, it is associated with more severe symptoms and higher risks of mortality.[1] However, it can occur at any age with varying degrees of severity: from mild or no symptoms, to heart failure and sudden cardiac death (abrupt, unexpected loss of heart function). In families affected by cardiomyopathy, a diagnosis may have been missed several generations ago.

'I have Naxos disease, a type of cardiomyopathy that is more common on the island in Greece where I'm originally from.

I was diagnosed before genetic testing appeared, but now the test has given a lot to my kids and my future grandchildren.'

Anargyros Vasilakis,
Nikos Protonotarios Association for Rare Cardiovascular Disease Care and Prevention

'I lost my daughter at the age of 14, when she had a cardiac arrest. After a genetic test, I found out she had a type of cardiomyopathy called ARVC.

In 2013, I founded the ARVC patient organisation in Germany, together with several family members.'

Ruth Biller,
ARVC-Selbsthilfe

The wider impact of genetic testing on people with cardiomyopathy and their families

Genetic testing has a wider role in increasing the readiness of health systems. Besides transforming the diagnosis and care for individuals and families affected by cardiomyopathy – leading to better outcomes and saved lives – genetic testing helps health system leaders allocate resources efficiently, as well as planning for and integrating emerging innovations.[1,2] This plays a role in paving the way for the future delivery of cost-effective, personalised care.[16–19,32]

Transforming care for people with cardiomyopathy

How does genetic testing help ensure the right diagnosis and treatment for people with cardiomyopathy?

- In people with the same clinical presentation, **genetic testing reduces uncertainty** about the cause and progression of cardiomyopathy. Genetic testing is not needed to diagnose cardiomyopathy itself, nor even to identify a type of cardiomyopathy, as clinicians can do this based on other diagnostic processes. However, the same type of cardiomyopathy (i.e. clinical presentation) can have different underlying causes and progress at different rates, ranging from lifelong stability to sudden cardiac death or severe symptoms at a young age.

- **Genetic testing differentiates between cardiovascular conditions** that have similar clinical presentation but require different treatments. People with some conditions (e.g. Fabry disease, Danon disease, amyloidosis) have structural and functional changes to the heart that resemble cardiomyopathy, but have different causes.[8,33] Where the underlying cause is unclear, genetic testing allows clinicians to identify the cause of the disease and enable more targeted therapy for each condition.

'My husband has a cousin who had no idea he had cardiomyopathy – it was silent, he didn't have any symptoms. But when he went to a cardiologist, he found out that he needed an implantable cardioverter defibrillator (or ICD). His condition was quite bad and his risk of sudden death was high.'

Carmen Balan,
CardioGen Patients Association

- For people diagnosed with cardiomyopathy who are at higher risk of life-threatening events, **genetic testing can help deliver appropriate preventive therapies**. Some genetic variants are associated with an increased likelihood of abnormal heart rhythms, heart failure, heart transplantation or sudden cardiac death.[9-11] Testing can identify people with these variants and so guide decisions about risk management and preventive therapies, such as implanting a pacemaker or an implantable cardioverter defibrillator (ICD). By creating opportunities for earlier intervention, genetic testing can reduce the number of deaths related to cardiomyopathy, particularly in young people.
- Genetic testing can help determine the **correct treatment dose**. The European Medicines Agency recommends that people with hypertrophic cardiomyopathy undergo genetic testing to help select the most appropriate treatment dosage (also called pharmacogenetic testing).[12,28] Variants in the gene responsible for metabolising the treatment for hypertrophic cardiomyopathy can result in some people building up elevated levels of the medicine and, consequently, facing an increased risk of heart failure.

'My daughter might still be alive if they had done the genetic test for my niece in 2005, when she survived cardiac arrest.

If I hadn't got the genetic test for my deceased daughter, then my nephew, who had no symptoms, would have never gone to a cardiologist and known that he carried a genetic variant, too.

He was implanted with an ICD. Five years passed with no events, but then he had a ventricular fibrillation and the ICD saved his life.'

Ruth Biller,
ARVC-Selbsthilfe

How does genetic testing protect families with cardiomyopathy and future generations?

- It can **identify undiagnosed relatives who are at higher risk** of life-threatening events. This is vital as undiagnosed cardiomyopathy is the second leading cause of sudden cardiac death, accounting for 15–33% of such deaths.[34-36] Once a person has received a positive genetic result for cardiomyopathy, so called 'cascade screening' involves systematically screening and identifying the relatives who might also be at risk. Where needed, regular monitoring is arranged to detect early signs of cardiomyopathy and provide treatment.[8,33] Post-mortem genetic testing after sudden cardiac death is used to confirm the diagnosis of an inherited cardiomyopathy, which may justify further cascade screening.[1]
- **Genetic-testing facilitates reproductive counselling** to support decision-making around family planning. People who are known to carry a genetic variant associated with cardiomyopathy should receive reproductive counselling.[8,33] This helps them understand the risk that their future children will inherit the condition, and consider pre-natal and

pre-implantation genetic testing. Pre-natal genetic testing is carried out in mothers during pregnancy to detect whether the baby carries the genetic variant. In the case of pre-implantation genetic testing, it can prevent a child from inheriting the genetic variant altogether, as it allows embryo selection in vitro before they are implanted for pregnancy.[1,37]

Building sustainable health systems

How does genetic testing enable the effective use of resources?

- Implementing genetic testing can improve health system efficiency by **ensuring monitoring and treatment are targeted** to the people who need them most. Although misconceptions about high expense persist and have hindered reimbursement in some countries, genetic testing has become increasingly affordable in recent decades and is consistently shown to be cost-effective.[13,14] Clinical guidelines recommend close monitoring of relatives of people with cardiomyopathy to detect early signs of the disease, but this can be resource intensive. However, genetic testing can identify which relatives are genuinely at risk; those with a positive test result will need regular clinical follow-up, and can receive early treatment that reduces costly hospitalisations.[16-19] Clinical monitoring for cardiomyopathy can be safely discontinued for anyone who receives a negative test.[1] Additionally, once the genetic cause is identified in one person, testing their relatives is also less expensive, as it allows a targeted genetic test in other family members.[13,15]

> *'There is still a perception that genetic testing is very expensive, but it is not the case anymore. Costs have gone down really quickly in the past few years.'*
>
> **Ruxandra Jurcut,**
> *Cardiologist*

- By generating wider benefits that extend across generations, **genetic testing also creates long-term value for families and society**. Experts note that most current economic assessments, such as cost-effectiveness analyses, do not account for the broader implications of genetic testing, which are important for decision-makers as well as the families affected.[38] For example, a genetic test can impact future generations, preventing cardiomyopathy through reproductive counselling and pre-implantation genetic testing. It can also support early diagnosis and therefore provide both clinical and psychological benefit for entire families.

How can genetic testing support the strengthening of future health systems?

- Genetic testing is poised to **provide clinical benefit for people with more complex types of cardiomyopathy**. Our capacity to perform and understand genetic tests is advancing rapidly. While current testing primarily targets cardiomyopathies caused by a single gene with predictable inheritance patterns, experts predict this will expand to conditions caused by multiple gene variants.[30] Studies show that risk assessment tools for cardiomyopathy that take into consideration multiple gene variants can accurately identify people diagnosed with hypertrophic cardiomyopathy who are at higher risk of life-threatening events.[39] Health systems must evolve to harness these developments to benefit people with cardiomyopathy.

- Integrating genetic testing with emerging technologies could **allow more targeted treatment and prevention strategies**. The combination of growing genetic databases and new AI tools could uncover previously unknown disease-causing genes, paving the way for new targeted therapies.[21] This would be a form of personalised and stratified medicine, where interventions are tailored to individual people or specific patient groups.[4] Importantly, early intervention enabled by genetic testing has the potential to prevent the onset of clinical symptoms, especially in younger populations.[25]

'We are going to see a big revolution in cardiomyopathy as we truly integrate clinical, electrical, imaging and genetic information.

We will have a full picture of the patient, we will know why they have cardiomyopathy and how they're going to respond to treatment.

It's not only better for people living with the condition, but it's going to allow us to better use healthcare resources.'

Elena Arbelo,
Cardiologist

'We could find a way of preventing the disease from developing in the first place. That's where the greatest promise lies.

We're uniquely placed to be able to test this in children who haven't developed the condition yet and might benefit the most.

To do this, however, we need to know what the genetic variant of a particular child is and understand how someone goes from carrying the gene to developing cardiomyopathy.'

Juan Pablo Kaski,
Paediatric cardiologist

The three enablers for optimal delivery of genetic testing

- Financing
- Data-sharing systems and infrastructure

- Cardiogenetic services
- A workforce with genetic literacy

- Psychosocial support
- Shared decision-making

System enablers

Financing

Health systems must fully finance genetic testing to ensure universal and equal access to innovation and personalised treatment for families with cardiomyopathy, regardless of their ability to pay. Genetic testing is a gateway for people with cardiomyopathy and their families to receive high-quality care according to clinical guidelines.[1] While its cost has declined, it remains out of reach for many families living in countries where it is not covered by national or private health insurance.[14]

'In Greece, the top priority is the reimbursement of genetic testing. No matter how much we raise awareness of cardiomyopathy and the importance of genetic testing among healthcare professionals, people won't have access to the test unless it is reimbursed.'

Charalambos Vlachopoulous,
Cardiologist

Data-sharing systems and infrastructure

Effective data infrastructure and clear policies are needed for improved access to data for research and innovation. Achieving further breakthroughs requires data-sharing across countries to support innovation and the development of new targeted treatments. To this end, countries must build secure and interoperable data infrastructure and develop clear policies that enable sharing of genomic and health data. This requires balancing privacy concerns with accessibility for improved access to data for research and innovation. Initiatives such as the Global Alliance for Genomics and Health support the multiple sectors involved in developing shared principles for the responsible exchange of clinical and genomic data.[40]

'When clinicians want to collaborate and communicate about genetic profiles, we bump into data regulations.

We encounter the same issues for many conditions. Why can't the EU take action and make sure that we can proceed more swiftly?'

Julie de Backer,
Genetic cardiologist

Capacity building

A workforce with genetic literacy

A healthcare workforce capable of delivering high-quality genetic testing in the future depends on the strength of genetic education and training delivered now. Cardiologists play a central role in coordinating the genetic testing process for people with cardiomyopathy, and must navigate the complexities of selecting an appropriate genetic test and interpreting its results.[30] It is predicted that the role of cardiologists will evolve in the near future, from recognising and managing cardiovascular diseases once symptoms have already established, to integrating genetic data to prevent, diagnose and treat cardiovascular disease.[4,30] For the delivery of this new standard of cardiovascular care, healthcare professionals need to have the knowledge and skills necessary to generate, understand, interpret, communicate and integrate genetic data. Ensuring that the future healthcare workforce possesses these skills requires integrating genetic literacy and training into medical curricula across cardiology, nursing and primary care.[23]

'We live in an era where genetics should be part of the training for all specialists and general practitioners alike.'

Julie De Backer,
Genetic cardiologist

THE ROLES OF HEALTHCARE PROFESSIONALS INVOLVED IN GENETIC TESTING

- **Cardiologists** must be able not only to perform standard clinical assessment, but also to coordinate the process of genetic testing – from selecting an appropriate test to choosing an accredited laboratory and interpreting the results.[30]
- **Genetic counsellors** play a key role in delivering care that addresses the medical, genetic and psychological aspects of genetic testing.[41]
- **Specialist nurses** can bridge the gap between cardiology and clinical genetics, while providing person-centred care for families affected by cardiomyopathy.[42]

Importantly, the multidisciplinary team, including psychosocial professionals, also plays a key role in providing person-centred care for people with cardiomyopathy.[25,27]

Cardiogenetic services

The accreditation of laboratories staffed by skilled professionals is vital to the delivery of high-quality genetic testing. Over the past two decades, the number of clinical laboratories offering genetic tests has increased; however, the volume of testing provided varies widely.[43] Accreditation of laboratories has not kept pace with this growth.[43] Ensuring quality across the genetic testing process requires adherence to standards at each stage, including referral, analysis, interpretation and reporting.[43] Several frameworks already provide guidance in this area. The European Molecular Genetics Quality Network, for example, has established guidelines stating that laboratories testing for inherited cardiac conditions should be accredited by a national or international body, participate in external quality assessment schemes, and involve appropriately skilled professionals in the test analysis. Additionally, the European Board of Medical Genetics offers standards and a curriculum for clinical laboratory geneticists, supporting workforce competence alongside laboratory accreditation.[44]

WHICH OTHER PROFESSIONALS ARE INVOLVED IN GENETIC TESTING?

Laboratories that offer genetic testing and interpretation of results employ a wide range of professionals, including clinical laboratory geneticists, variant scientists and analysts, as well as laboratory technicians.[45,46] While their main responsibilities are variant classification and interpretation, they are often also involved in data management and sharing. Despite these being highly technical roles, there are currently limited training programmes and accreditation options available.[45]

'The quality of genetic tests in labs is an issue in Germany. We had eight patients in our community with a negative genetic test result which were not negative when they got tested at an experienced lab.

Some people live far from the cities where the big labs are, so they have to travel long distances. It would be great if genetic counselling were offered more often.'

Ruth Biller,
ARVC-Selbsthilfe

'A major problem in Romania now is being aware that you need genetic testing. We received a letter from someone who has known for 10 years that he has hypertrophic cardiomyopathy.

He lives 500 km away from the capital, where there is more expertise. His cardiologist didn't know that he should have a genetic test. He doesn't know what gene variant he has and what it means for his family.'

Carmen Balan,
CardioGen Patients Association

More equitable access to genetic testing can be supported through care that is well organised and coordinated across the health system. Formal reference centres, expert centre networks and standardised care pathways can support more consistent care for people with complex conditions such as cardiomyopathy, especially in rapidly evolving fields such as genomics.

- Networks of expertise mean that best practice can be exchanged across regions and countries.[23]
- At the national level, reference centres for cardiomyopathy can provide multidisciplinary care,[47] involving cardiology, paediatrics, nursing, genetics, genetic counselling, psychology, imaging, pathology and primary care.[1]
- Finally, experts highlight that clear care pathways, referral criteria and clinical leadership are needed to ensure access to genetic testing.

Person-centred care

Shared decision-making

High-quality shared decision-making ensures that people with cardiomyopathy understand the purpose of genetic testing and its potential implications.
It is essential that people understand the possible implications of genetic testing, so they can provide informed consent.[1,48] Genetic counsellors play a vital role in explaining the rationale and anticipated benefits of testing, while enabling the person to make an informed decision that reflects their personal values and circumstances.[25] Motivations for consenting to genetic testing often extend beyond medical expediency, including resolving uncertainty for the person and their relatives, and planning for the future or a pregnancy.[49] Healthcare professionals must therefore communicate results in ways that clearly explain their meaning and implications for prognosis and care.[26,27] Implementing consistent, high-quality shared decision-making depends on good communication, active engagement of families and adequate resources (such as time, funding, staff, space), workflows, incentives, policies and guidelines.[50,51]

'We are moving away from a paternalistic approach to genetic testing that tells people what to do towards shared decision-making with parents and the child.

We see these families for many years, so it's an ongoing process. It's really important that we build a good relationship with them. That's a key aspect of what we do.'

Juan Pablo Kaski,
Paediatric cardiologist

'Knowledge is power, but somebody must be able to make it valuable. Having the information and not knowing what to do with it actually creates a bigger burden. I have a broken gene – what does that mean? What should I do with the result? Is it a matter of the future? Should I get treatment? Should I get married? Should I have children?'

Anargyros Vasilakis,
Nikos Protonotarios Association for Rare Cardiovascular Disease Care and Prevention

Psychosocial support

Psychosocial support is a core component of person-centred care for people with cardiomyopathy. People who have received a diagnosis may experience a wide range of emotional responses, from difficulty accepting their diagnosis in the absence of obvious symptoms to ongoing anxiety or depression related to disease-associated risks.[26,27] While genetic counsellors provide support during the genetic testing process, psychologists offer longer-term psychosocial care that families may need, as genetic test results can impact other aspects of life, including social relationships, education and employment.[25,27] Communication about genetic testing must address concerns such as the potential psychological burden for individuals, their children and other relatives.[15,26,27] Mental healthcare professionals and social workers play a key role in supporting person-centred care, addressing the long-term psychological wellbeing and practical daily needs of people with cardiomyopathy.[52] Patient organisations also play an important role in providing psychological support to families affected by cardiomyopathy.[26]

'Fear can be worse than the disease itself. The first time I felt the arrhythmias, I thought that in ten seconds I would be on the floor and never get up.

Fifteen years later, I can hike in the mountains and I really enjoy life. But that came after spending a lot of time thinking, judging and deciding how I want to deal with my condition.'

Anargyros Vasilakis,
Nikos Protonotarios Association for Rare Cardiovascular Disease Care and Prevention

'Some people with cardiomyopathy live like they have a sword above their head, knowing that they may die at any moment. Most people would benefit from psychological counselling. Whether the diagnosis affects you only a little, or you live in anxiety, it's a turning point in your life. It changes everything.'

Carmen Balan,
CardioGen Patients Association

Current gaps in genetic testing

Uneven systems, uneven access

Despite efforts to improve access to genetic testing, there are wide inequalities in its delivery across Europe. According to the European Cardiomyopathy Registry, only 37% of adults diagnosed with cardiomyopathy undergo genetic testing, and only 62% of their relatives then also receive testing.[22] There are significant differences in the use of genetic testing between different centres and countries. Higher rates are noted in southern and western European countries,[22] with striking differences in the number of tests per year; while the majority of centres report no or fewer than 10 genetic tests, a minority report more than 100.[24] In surveys and interviews, experts report that access to genetic testing for people diagnosed with cardiomyopathy varies widely, with access to genetic counselling lagging behind in some countries (*Table 1*).

Table 1. Access to genetic testing and genetic counselling for people living with cardiomyopathy and their relatives in European countries

Country	Access to genetic testing	Access to genetic counselling from trained professionals
Belgium	III	IIII
Czechia	III	III
Estonia	IIII	IIII
Finland	I	I
France	IIII	IIII
Germany	IIII	IIII
Italy	III	III
Malta	IIII	III
The Netherlands	IIII	IIII
Portugal	III	II
Romania	III	I
Spain	IIII	IIII

KEY		
	I - Less than 25% accessibility	III - Between 50% and 75% accessibility
	II - Between 25% and 50% accessibility	IIII - More than 75% accessibility

Reimbursement remains a major barrier to accessing genetic testing. One survey indicated that the cost of routine genetic testing is covered either by the person or by private insurance for over 25% of people with cardiomyopathy in Europe.[24] Most countries in Europe fully reimburse genetic testing for people diagnosed with cardiomyopathy, but fewer cover genetic testing for first-degree relatives and post-mortem genetic testing. Four of twelve surveyed countries in Europe did not fully reimburse genetic testing for first-degree relatives of people diagnosed with cardiomyopathy, while four of twelve did not reimburse post-mortem genetic testing, with families having to pay out of pocket or through private health insurance (*Table 2*).

Table 2. Reimbursement of genetic testing for cardiomyopathy in Europe

Country	All people with cardiomyopathy	First-degree relatives of people diagnosed with cardiomyopathy	Post-mortem genetic testing
Belgium	III	II	II
Czechia	III	II	I
Estonia	III	III	II
Finland	III	III	III
France	III	III	II
Germany	III	III	I
Italy	II	II	I
Malta	III	III	III
The Netherlands	III	III	III
Portugal	III	III	III
Romania	III	I	I
Spain	III	III	III

KEY | I – Not reimbursed | II – Partially reimbursed | III - Fully reimbursed

Existing regulations for data-sharing hinder communication and collaboration within and between countries. Healthcare professionals often experience difficulties in understanding and navigating data regulations, which can be outside of their scope of work and may require long processes for approval.[23] Even when individuals consent to their data being shared, restrictive or inconsistent regulations across regions and countries may halt the process.[23,53] These difficulties in data-sharing may hinder innovations in cardiomyopathy care and reflect a broader challenge affecting cardiovascular disease and other areas. While survey data indicated that most of the 12 European countries have established guidelines for data management and privacy, these remain limited and inconsistent, and post-mortem data management is not legally defined in many countries.

Limited access to a prepared workforce

Gaps in workforce capacity and genetic expertise continue to limit access to genetic testing for cardiomyopathy. Limited availability of cardiogenetic expertise and services remains a major barrier to accessing genetic testing in several countries.[24] Low levels of genetic literacy among cardiologists persist, reflecting the historical absence of cardiovascular genetics in traditional training.[30] Beyond laboratory capacity, effective genetic testing requires dedicated units for inherited cardiac disease or specialist clinical teams, as the skills needed to order, interpret and act on genetic test results often exceed those available in regular cardiology practice.[54] There is a clear gap here, as more than 35% of survey participants did not have a dedicated cardiogenetic service or genetic lab, and almost 22% rely on sending genetic samples abroad because local services or genetic counselling are unavailable.[24] Formal, structured training with certification for cardiogenetic professionals remains rare, with availability reported in only a small number of countries (*Table 3*).

'I know that in other countries there are genetic counsellors, but in Romania, while there is formal education in genetic counselling, that role is not integrated in clinical practice.'

Carmen Balan,
CardioGen Patients Association

'In Belgium we are in a transitional stage, I hope, where genetic testing is requested by many people who are not always very well-educated to correctly interpret its results.'

Julie De Backer,
Genetic cardiologist

The uneven distribution of expert centres and the lack of national expert networks exacerbate the poor access to a skilled workforce, leading to inequalities in outcomes. Gaps persist in formal guidance, clear referral and care pathways for genetic testing. Although most countries report having cardiomyopathy or inherited cardiac condition centres, the remainder have no centres in place or have centres that remain in the early stages of development. Even where specialist centres exist, the absence of structured national network in some countries results in geographical inequalities in access to genetic testing.[54] Expertise is typically concentrated in academic centres in larger cities, limiting access for individuals living further away.[13,26]

While financial support for transport may partially address these barriers, genetic tests may not be offered at all in some settings due to limited awareness or their insufficient integration into routine care.

Table 3. Availability of national training, certification, reference centres and expert networks to support the high-quality delivery of genetic testing for cardiomyopathy in Europe

Country	National training programmes or formal certificates for cardio-genetic professionals	National reference centres for genetic testing for cardiomyopathy	National reference network for genetic testing for cardiomyopathy
Belgium	III	IIIII	IIIII
Czechia	IIIII	IIIII	IIII
Estonia	III	II	IIII
Finland	I	IIIII	I
France	IIIII	IIIII	IIIII
Germany	IIIII	IIIII	IIII
Italy	III	IIIII	IIIII
Malta	III	II	IIII
The Netherlands	III	IIIII	IIIII
Portugal	I	I	I
Romania	III	IIIII	IIII
Spain	IIIII	IIIII	IIII

KEY		
	I - None	IIII - Yes, but needs further development
	II - Under development	IIIII - Yes
	III - Training, but no formal certificates	

Lack of person-centred care

The absence of structured shared decision-making models further constrains person-centred genetic testing. While clear, tailored communication is essential to supporting shared decision-making, patient empowerment and an accurate understanding of the risks involved, formal processes and tools to enable this approach are not consistently in place across countries and care settings.[25,26] Where shared decision-making is insufficiently embedded, people with cardiomyopathy and their families may have limited involvement in genetic testing and treatment decisions, particularly in ways that reflect their preferences, values and personal circumstances.

> *'Once I was told by a healthcare professional that she didn't want to do the genetic test for my child because she wouldn't be able to deal with the result. She told me that I wouldn't be able to look my child in the eye without bursting into tears, thinking that they might die one day. That was quite shocking.'*
>
> **Anargyros Vasilakis,**
> *Nikos Protonotarios Association for Rare Cardiovascular Disease Care and Prevention*

Gaps in communication and access to psychosocial support continue to limit person-centred genetic care for cardiomyopathy in some health systems. In several European countries, communication about the inherited nature of cardiomyopathy remains inconsistent, with limited awareness among healthcare professionals of how and when to discuss genetic risk.[26,27] As a result, many individuals and families have an unclear understanding of what a diagnosis of cardiomyopathy means, and may not be aware that clinical guidelines recommend genetic testing.[1] Even when this information is effectively communicated to the person diagnosed, barriers arise in informing their family members about their potential risk, as healthcare professionals are generally unable to contact relatives directly.[23] Additionally, people with cardiomyopathy often face fears and anxieties after receiving the diagnosis or their genetic test results, yet access to appropriate psychosocial support remains limited in many countries.[26,27]

Final call to action

Genetic testing has already begun to reshape the future for families affected by cardiomyopathy, but access to this progress remains uneven. Genetic testing offers clarity where uncertainty once prevailed, and the possibility of prevention where, for generations, risk was inherited in silence. But too many families still depend on where they live or what they can afford to receive care that should be routine. This inequity is not merely a gap in provision; it is a failure of health systems to keep pace with scientific reality.

The challenge is also an opportunity. Other fields – oncology foremost among them – have shown how rapidly care can be transformed when genetics is embedded into clinical pathways and supported by coherent policy. Cardiomyopathy is now poised to follow suit. With the right investment, it could become one of the first cardiovascular conditions where personalised medicine is not an aspiration but the norm, and where high genetic risk no longer predetermines a lifetime of uncertainty.

Realising this future requires action at every level. Global, European and national decision-makers must address the structural barriers that slow progress. These obstacles are solvable problems – but only if they are treated as priorities rather than peripheral ambitions.

The prize is considerable. A health system that embraces genetic testing for cardiomyopathy can deliver earlier diagnosis, targeted treatment and, in some cases, the possibility of preventing disease altogether. It can also offer something less tangible but equally vital: reassurance for families who have lived too long with unanswered questions.

The science is ready. The tools exist. What remains is the political will to ensure that no family is left behind as cardiomyopathy care enters a new era.

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Please cite as: Elliott P, Lorenty K, Harding E. *Genetic testing in cardiomyopathy: ensuring our future health systems leave no family behind*. London: International Cardiomyopathy Network and The Health Policy Partnership.