Strengthening EU cardiovascular health checks

Integrating inherited, congenital and sudden-death-related cardiovascular risk

Evidence annex / position paper in response to the Call for Evidence on the Council Recommendation on health checks for cardiovascular diseases

Initiative	Council Recommendation on health checks for cardiovascular diseases: an EU approach to early detection and screening
Feedback period	21 April 2026 - 19 May 2026, midnight Brussels time
Purpose	To propose a proportionate, evidence-based inherited cardiovascular risk component within EU cardiovascular health checks
Evidence base	European Commission Call for Evidence; ICoN cardiomyopathy genetic testing policy paper; EU recommendations; ESC/EHRA guidance; peer-reviewed evidence
Submitted by	**ERN Guard-Heart** On behalf of **European Coalition for Inherited, Congenital and Sudden-Death-Related Cardiovascular Disease Prevention** with the support of the organisations and experts listed in Annex 1

This submission is made by ERN GUARD-Heart on behalf of the **European Coalition for Inherited, Congenital and Sudden-Death-Related Cardiovascular Disease Prevention**: a voluntary, cross-border collaboration of scientific societies, clinicians, researchers, patient advocates, patients, families and carers from across Europe and beyond. It reflects a shared commitment to ensure that cardiovascular health checks recognise not only cardiometabolic risk, but also the many relevant others that too often remain invisible until a life-changing event occurs.

1. Executive summary

We strongly welcome the European Commission's initiative to develop a Council Recommendation on health checks for cardiovascular diseases as part of the Safe Hearts Plan. The objective of reducing premature cardiovascular mortality by 25% by 2035 is ambitious, necessary and urgent.

Cardiovascular diseases remain Europe's leading cause of death and disability. The Commission's Call for Evidence states that cardiovascular diseases claim 1.7 million lives every year in the EU, affect 62 million people, and generate an economic burden exceeding EUR 282 billion annually.[1,2]

The proposed emphasis on cardiometabolic risk factors - blood pressure, glucose, cholesterol, obesity, kidney health and lifestyle - is essential. However, a cardiovascular health-check model focused predominantly on cardiometabolic risk will miss a significant, actionable and preventable component of cardiovascular disease: inherited, familial, arrhythmic and sudden-death-related cardiovascular risk.

This is particularly important because the Safe Hearts Plan aims to reduce premature cardiovascular mortality within less than a decade. Cardiometabolic prevention is indispensable, but many of its benefits require sustained long-term population change. Europe also needs immediately implementable strategies to identify people and families who are already at high risk but remain undiagnosed.

This document proposes a proportionate genetic cardiovascular disease and sudden-death prevention component within cardiovascular health checks, built around low-cost early actions: identify family-history and symptom red flags, refer to the right pathway, protect relatives, train citizens, equip communities with AED access, and measure outcomes.

Core message: Cardiometabolic prevention is essential, but it is not sufficient. EU cardiovascular health checks should also identify inherited, congenital, familial, arrhythmic and sudden-death-related risk through simple, low-cost, actionable measures.

2. Key data points for policymakers

The table below summarises why the Council Recommendation should include a simple, low-cost inherited, congenital, and sudden-death-related cardiovascular risk component within cardiovascular health checks. The proposed addition is deliberately proportionate: it does not require population-wide genetic testing or complex specialist investigations at screening level. It relies first on low-cost measures - structured family history, warning-sign questions, basic cardiovascular assessment, public CPR/AED education and clear referral to appropriate pathways - while allowing specialist services to determine when ECG, imaging, lipid assessment, genetic counselling/testing or family evaluation is clinically indicated.

Policy message	Key evidence-based data point	Why it matters for the Council Recommendation
1. CVD is Europe's leading health and economic burden	CVD claims 1.7 million lives every year in the EU, affects 62 million people and generates an economic burden exceeding EUR 282 billion annually.[1,2]	A narrow health-check model risks missing opportunities to reduce preventable mortality, disability, absenteeism, early retirement and long-term healthcare costs.
2. Sudden death is a major and rising European public-health issue	A WHO-based analysis of 26 European countries recorded 2,583,559 sudden-death-attributed deaths from 2010 to 2020 - 5% of all deaths, or **one sudden death every 2.2 minutes**. Age-adjusted **sudden-death mortality increased by about 31% over the last decade**.[27]	SCD/SCA is not a niche specialist concern. The **Recommendation should explicitly connect cardiovascular health checks with SCD prevention and SCA preparedness**.
3. Survival and outcomes after SCA are highly unequal across Europe	EuReCa TWO found bystander CPR rates ranging from 13% to 82% across participating European countries and **only 8% overall survival to hospital discharge**.[16] Sudden-death mortality trends also diverge regionally: Western Europe decreased, while Southern and Eastern Europe increased by +3.3% and +3.4% per year, respectively.[27]	Europe has both "postcode survival" and "postcode prevention" problems. EU added value lies in comparable indicators, benchmarking, best-practice exchange and targeted implementation support.
4. Cardiometabolic prevention is essential, but not sufficient	The Commission proposal rightly emphasises blood pressure, glucose and cholesterol, but also recognises family history, early detection, structured health checks, inequalities and referral pathways.[1]	The **Recommendation should capture both cardiometabolic risk and non-cardiometabolic risk**, including genetic cardiovascular disease, inherited arrhythmias, cardiomyopathies, sudden-death red flags and severe premature disease.
5. Genetic cardiovascular disease is a core preventable gap	Genetic cardiovascular disease includes cardiomyopathies, inherited arrhythmia syndromes, familial aortopathies, familial lipid disorders, and underlies many congenital/complex cardiac disease and families affected by sudden unexplained death. In cardiomyopathy alone, **up to 40% of people have a known family history**.[5] Many **inherited cardiac diseases affect younger people and have immediate implications for relatives**.	This is **not a niche genetic-testing issue**. It is a prevention, equity and personalised-medicine issue: simple family-history and red-flag questions can identify people who need expert assessment before sudden death, heart failure, stroke or disability occurs.
6. Family screening turns one diagnosis into prevention for relatives	In a Copenhagen SCD-family pathway, inherited cardiac disease was diagnosed in 143 of 304 referred families (47%) and in 73 of 695 screened relatives (11%). This means that **nearly one in two SCD families referred for structured evaluation received an inherited cardiac diagnosis, and approximately one relative was diagnosed for every four SCD families evaluated**.[22] Ten-year follow-up showed similar yields: 48% of families	When a cardiogenetic condition or unexplained SCD is detected, **prevention becomes family-based**: relatives can be identified, assessed and protected before a first event. Health checks should therefore trigger pathways for family evaluation when red flags are present.

Policy message	Key evidence-based data point	Why it matters for the Council Recommendation
	and 12% of relatives.[23] In familial hypercholesterolaemia cascade testing, a systematic review found a mean of 1.65 new cases per index case.[26]	
7. Women face under-recognition and delayed care, with worse outcomes	CVD in women remains understudied, under-recognised, underdiagnosed and undertreated.[19] **Sudden-death-attributed mortality increased faster in women than men in Europe** (+3.2% vs +2.8% per year).[27] In HCM, **women present later, with more symptoms and heart failure features, and have worse survival**; female sex has been independently associated with mortality and cardiovascular events.[24,25]	Health checks should include **sex-specific awareness, pregnancy/reproductive history, family history and clear referral criteria**, so that women with inherited or complex cardiovascular disease are not diagnosed only after advanced disease or complications.
8. Actionable family history, warning signs and referral criteria are cheap to collect	A short question set can capture premature sudden death, cardiomyopathy, inherited arrhythmias, aortic disease, familial lipid disorders, unexplained syncope, exertional symptoms, seizure-like episodes and early cardiac device implantation in relatives.[1,5-7]	This is the **low-cost entry point**: no new technology is required at screening level, but missed opportunities are reduced and the right people can be directed to the right pathway.
9. Education, CPR and AED availability improve outcomes	In Denmark, bystander CPR increased from 21.1% to 44.9% and 30-day survival increased from 3.5% to 10.8% after national initiatives.[17] In the Netherlands, AED use almost tripled from 21.4% to 59.3%, and favourable neurological survival in shockable OHCA increased from 29.1% to 41.4%.[18]	**Cardiovascular health checks are a teachable moment.** Adding brief education on warning signs, cardiac arrest recognition, CPR and AED use is inexpensive, scalable and evidence-based.
10. Post-health-check referral pathways and measurement are the implementation levers	Health checks do not need to deliver specialist diagnostics at the point of screening. **Positive findings should trigger defined pathways** to cardiovascular excellence centres (with expertise in rare/complex/inherited cardiovascular disease), or ERN-linked expertise. Systems should also measure registry coverage, bystander CPR, AED use before EMS, ROSC and 30-day survival.[5,12,13,15,27]	**This avoids an expensive universal-testing proposal while ensuring** that ECG, imaging, lipid assessment, genetic counselling/testing, cascade evaluation and psychosocial support **are available for those who need them**, and that Member States can track progress.

3. The Commission initiative is welcome, but cardiometabolic screening alone is incomplete

The Commission's Call for Evidence rightly identifies early detection and screening as crucial tools to prevent cardiovascular disease and reduce inequalities. It highlights the importance of measuring blood pressure, glucose and cholesterol, and of encouraging Member States to develop national screening programmes.[1]

These priorities are essential. However, they do not capture the full spectrum of cardiovascular risk. The Commission document itself recognises family history, cardiovascular indicators, structured health checks, vulnerable groups, referral pathways, digital tools and early diagnosis as relevant components of cardiovascular health checks.[1]

The Council Recommendation should therefore not be limited to measurement of cardiometabolic risk factors. It should also ensure that health checks identify simple warning signs of inherited, familial and sudden-death-related cardiovascular disease.

This is not a proposal for population-wide genetic testing or indiscriminate specialist referral. It is a proposal for better first-line identification: ask structured family-history questions, recognise individual red flags, and refer the right people to the right pathway.

4. Why a genetic and inherited-risk component is necessary

4.1 Rare/complex and familial cardiovascular diseases are collectively significant

Inherited cardiovascular diseases are often described as rare. Individually, many are. Collectively, however, rare diseases are a major public-health and equity issue: the European Commission estimates that 27 to 36 million people in the EU live with a rare disease.[4]

Cardiovascular rare and inherited diseases include cardiomyopathies, inherited arrhythmia syndromes, familial aortopathies, familial lipid disorders, congenital and syndromic cardiovascular conditions, and rare vascular and structural heart diseases.

These conditions frequently affect children, adolescents and adults of working age. They may remain undiagnosed until a major event occurs, including sudden cardiac death, heart failure, stroke, pregnancy complications or severe arrhythmia.

For cardiovascular health checks, the immediate opportunity is not to diagnose every rare condition at the point of screening. It is to identify people and families whose history or symptoms make inherited, familial, arrhythmic or complex cardiovascular disease plausible, and to connect them to the right pathway.

4.2 Genetic cardiovascular disease: early recognition and referral, not broad testing, are the immediate policy opportunity

Genetic cardiovascular disease should be framed broadly and inclusively. It includes cardiomyopathies, inherited arrhythmia syndromes, familial aortopathies, familial lipid disorders, congenital and complex cardiac conditions, and families affected by sudden unexplained death. **These conditions often affect younger people, have implications for relatives, and may present as sudden death, heart failure, stroke, severe arrhythmia, pregnancy-related risk or premature disability**. The immediate policy opportunity is not broad

genetic testing in the health-check setting; it is early recognition of family history and clinical red flags, followed by referral to the right pathway.

The ICoN policy paper provides a strong example within the wider cardiogenetic field: up to 40% of people with cardiomyopathy have a known family history, genetic testing is recognised as part of quality cardiomyopathy care, and yet access to cardiogenetic services and family pathways remains uneven across Europe.[5,12,13] This supports a health-check model that systematically asks the right first-line questions and connects people with positive findings to expert assessment, rather than asking every screening site to deliver specialist diagnostics.

Family-based pathways after sudden cardiac death show why this matters. In a Copenhagen pathway evaluating 304 SCD families and 695 relatives, inherited cardiac disease was diagnosed in 143 families (47%) and in 73 relatives (11%). In practical terms, this means about one affected relative was diagnosed for every four SCD families evaluated, or about one affected relative for every ten relatives screened.[22] Similar family-based logic applies to other inherited cardiovascular diseases; for familial hypercholesterolaemia, a systematic review of cascade testing found a mean of 1.65 new cases per index case, with higher yields when programmes used direct contact, testing beyond first-degree relatives, active sample collection and genetic testing.[26]

For the Council Recommendation, this supports a pragmatic implementation model: **health checks should ask better first-line questions, define red flags, and ensure referral to expert pathways. Genetic counselling and testing should remain downstream, targeted and guideline-based, determined by specialist assessment rather than embedded as universal screening**.

5. Sudden cardiac death prevention should be part of cardiovascular health checks

Sudden death and sudden cardiac arrest are among the most devastating presentations of cardiovascular disease and remain a major European public-health and equity challenge. A WHO-based analysis of 26 **European countries recorded** 2,583,559 sudden-death-attributed deaths between 2010 and 2020, representing 4.8% of all deaths - **approximately one sudden death every 2.2 minutes**. Age-adjusted sudden-death mortality increased by about 31% over the decade, with sharper increases among women and in Southern and Eastern Europe.[27]

Not all sudden cardiac deaths are preventable. However, a meaningful proportion are preceded by warning signs, family-history red flags, abnormal findings or familial disease patterns that can be detected earlier. Health checks should therefore include simple questions on sudden death in relatives, unexplained syncope, exertional symptoms, seizure-like episodes, early ICD or pacemaker implantation, cardiomyopathy and inherited arrhythmia syndromes.

Health checks should also be used as a teachable moment for sudden cardiac arrest preparedness. Public awareness of cardiac arrest recognition, emergency activation, CPR and AED use should be embedded in cardiovascular health education, especially in schools, workplaces, sports settings and community health programmes.

6. Genetics is also relevant to common cardiovascular diseases

Familial and inherited risk should not be seen only as a rare-disease issue. Common cardiovascular diseases can present earlier and more severely when genetic susceptibility interacts with cardiometabolic and environmental risk factors.

Familial hypercholesterolaemia is a clear example. It affects about 1 in 300 people worldwide and, if untreated, lifelong exposure to high LDL cholesterol increases the risk of premature atherosclerotic cardiovascular disease.[9] Its diagnosis has direct implications for treatment intensity and cascade screening of relatives.

Common coronary artery disease also has a genetic component. The EHRA/HRS/APHRS/LAHRS consensus statement notes that monogenic predisposition to familial hypercholesterolaemia is a powerful predictor of premature coronary artery disease and that polygenic risk contributes to coronary artery disease susceptibility, although polygenic scores are not yet routinely used in clinical practice.[7]

The practical implication for health checks is clear: family history, premature disease, very high LDL cholesterol, early severe presentation and clustering of cardiovascular disease within families should be systematically captured.

7. Early detection can save lives and reduce health-system and societal burden

Inherited, familial and sudden-death-related cardiovascular diseases are especially important for policy because they often affect younger people and families. Preventing a cardiovascular event in a young or middle-aged person avoids not only acute healthcare costs, but also decades of disability, productivity loss, informal care, psychological burden and reduced quality of life.

The Commission's Call for Evidence recognises that implementation costs may be offset by lower healthcare spending and improved productivity due to reduced disease burden.[1] This logic is particularly strong for inherited cardiovascular disease because one diagnosis can prevent harm in multiple relatives.

The same logic applies to inherited and familial cardiovascular disease more broadly. The most cost-effective first step is to avoid missed opportunities: capture family history, recognise warning signs and refer the right people. Expert services can then target monitoring, treatment, genetic counselling/testing and family evaluation to those most likely to benefit.

This is a high-value prevention model: identify one warning sign, reach the right pathway, protect the family, reduce uncertainty and prevent avoidable events across generations.

8. Proposed policy asks for the Council Recommendation

Policy ask 1: Include structured family history in cardiovascular health checks

- Premature sudden unexplained death, particularly before age 50.
- Sudden infant death, unexplained drowning or road traffic accidents possibly related to syncope.
- Cardiomyopathy, inherited arrhythmia syndromes, familial aortic disease, congenital or syndromic cardiovascular disease.
- Familial hypercholesterolaemia, very high LDL cholesterol or markedly elevated lipoprotein(a).
- Early pacemaker or ICD implantation, recurrent syncope, seizure-like episodes or unexplained collapse in relatives.

Policy rationale: Family history is low-cost, immediately implementable and already recognised by the Commission as part of cardiovascular risk assessment.[1]

Policy ask 2: Add individual red-flag symptom questions

- Unexplained syncope, especially during exertion, emotion or swimming.
- Exertional chest pain, palpitations or breathlessness.
- Seizure-like episodes without clear neurological explanation.
- Documented arrhythmia, abnormal ECG or very high LDL cholesterol.
- Known family history of inherited cardiovascular disease or sudden cardiac death.

Policy rationale: Red flags can identify people who need clinical assessment before a catastrophic event occurs.

Policy ask 3: Define referral pathways to expert services

- Primary care should know when and where to refer.
- Pathways should connect general cardiology, inherited cardiac disease clinics, electrophysiology, cardiovascular genetics, paediatric cardiology and sports cardiology.
- For rare and complex cases, Member States should make use of European Reference Networks and expert centres where appropriate.

Policy rationale: A health check only saves lives if detection leads to timely assessment and action. For inherited, familial, arrhythmic and complex cardiovascular disease, the main implementation need is a clear pathway from first-line red flags to appropriate expertise.

Policy ask 4: Use expert pathways to determine further testing, including genetic counselling/testing when clinically indicated

- Genetic counselling and genetic testing should be available when clinically indicated, but they should sit downstream of the health check within specialist pathways. Referral should be triggered by a compatible phenotype, family history of inherited disease or sudden death, premature or severe cardiovascular disease, unexplained arrhythmia or cardiomyopathy, suspected familial hypercholesterolaemia, or sudden unexplained death in a young person.
- Countries should ensure that genetic testing is available and accessible to patients in terms of costs, distance, and ease of referral.
- Further testing should be accompanied by appropriate counselling, expert interpretation and shared decision-making. Depending on the pathway, this may include ECG, imaging, lipid assessment, genetic counselling/testing, post-mortem evaluation or family-based clinical evaluation.
- This is not universal genetic testing; it is targeted specialist assessment according to clinical indication.

Policy rationale: This protects Member States from a broad and costly testing obligation while ensuring that people with red flags are not lost before reaching the correct pathway.

Policy ask 5: Promote cascade screening and family-based prevention

- When an inherited or familial cardiovascular condition or sudden-death risk is suspected or identified, relatives should have access to appropriate clinical evaluation, psychosocial support, and prevention pathways. Genetic testing should be considered when a familial pathogenic variant or clear clinical indication exists.
- Member States should support family communication, cascade evaluation workflows and data systems that track whether relatives have been offered assessment.

Policy rationale: Familial cardiovascular risk is often a family diagnosis. One diagnosis, or even one recognised red flag, can prevent multiple events across generations.

Policy ask 6: Include sudden cardiac arrest preparedness in cardiovascular health education

- Health checks should include basic education on warning signs, recognition of sudden cardiac arrest, calling emergency services, bystander CPR and AED use.
- This should be linked to schools, workplaces, sports settings and community programmes.

Policy rationale: Prevention and emergency preparedness are complementary. When sudden cardiac arrest occurs, survival depends on rapid recognition, CPR and defibrillation.

Policy ask 7: Use digital tools and interoperable data systems

- Electronic health records and health-check tools should include structured fields for family history, red flags, abnormal ECG, suspected FH, genetic testing status and cascade screening status.
- Member States should support interoperable data systems for clinical care, quality improvement and research while ensuring privacy and appropriate governance.
- All patients should be ensured access to their own patient data, including but not limited to test results, patient history, etc. This access should be free and not subject to any further limitations. In cases where patients are underage this access should be granted to their parents or custodians.

Policy rationale: The Commission Call for Evidence highlights fragmented health data as a limitation, and ICoN recommends EU action on genetic data infrastructure and interoperability.[1,12]

Policy ask 8: Involve patient associations and families

- Patient associations should be involved in designing health-check materials, red-flag questions, awareness campaigns and evaluation metrics.
- They can provide evidence on delayed diagnosis, missed warning signs, psychological burden, family impact, inequities in access and barriers to genetic testing.

Policy rationale: Patient organisations bring lived experience and can help design materials that are understandable, acceptable and effective. ICoN emphasises person-centred care, shared decision-making and psychosocial support.[5,12]

9. Suggested wording for the Council Recommendation

Member States should ensure that cardiovascular health checks include a short, structured assessment of family history and individual warning signs suggestive of inherited, familial, arrhythmic, congenital or otherwise complex cardiovascular disease. These should include

premature sudden cardiac death, premature cardiovascular disease, cardiomyopathy, inherited arrhythmia syndromes, familial hypercholesterolaemia, aortic disease, congenital or complex cardiac disease, unexplained syncope, exertional symptoms, seizure-like episodes, and early cardiac device implantation in relatives.

Individuals identified through such red flags should have access to clear referral pathways for appropriate cardiovascular assessment. Specialist pathways should determine the need for ECG, imaging, lipid evaluation, genetic counselling, genetic testing, post-mortem evaluation or family-based assessment according to clinical indication and national guidelines.

Cardiovascular health checks should also be used as an opportunity for health education on cardiac warning signs, sudden cardiac arrest recognition, CPR and AED use.

10. Implementation route: simple, scalable and proportionate

Find the warning signs. Refer the family. Save the life.

This can be captured in a simple implementation package: Identify - Refer - Protect for SCD prevention, and Train - Equip - Measure for SCA preparedness.

Prevention:

- **Identify:** include family-history and individual red flags in cardiovascular health checks, primary care and digital health-check tools.
- **Refer:** define clear routes from primary care and health checks to appropriate expert cardiovascular pathways.
- **Protect:** ensure that relatives can access counselling, clinical evaluation and follow-up when genetic cardiovascular disease or SCD risk is suspected or confirmed.

SCA preparedness:

- **Train: use health checks and community programmes to promote warning-sign awareness, cardiac-arrest recognition, CPR and AED use.**
- **Equip: improve AED mapping, accessibility and integration with dispatch and first-responder systems.**
- **Measure:** registry coverage, bystander CPR, AED use before EMS arrival, ROSC, survival to discharge or 30-day survival, and completeness of post-SCD family referral pathways.

Health-check element	What it requires	Why it is proportionate

Family-history module	A short standardised question set in primary care or digital forms.	No new equipment; captures high-risk families.
Red-flag symptoms	Brief questions on syncope, exertional symptoms, palpitations and seizure-like episodes.	Targets further assessment to those with clinical suspicion.
ECG/further evaluation when indicated	ECG and clinical assessment only for people with warning signs or family history.	Avoids indiscriminate testing while enabling early detection.
Expert referral pathway	Defined routes to cardiology, inherited cardiac disease, electrophysiology, lipid, aortopathy, congenital heart disease and other expert services.	Improves efficiency and reduces missed referrals without requiring specialist testing at the first contact.
Specialist testing when clinically indicated	ECG, imaging, lipid assessment, genetic counselling/testing or other investigations after phenotype/family-history assessment.	Not universal testing; targeted, guideline-aligned and decided within expert pathways.
Cascade screening	Clinical and/or genetic evaluation of relatives when a familial diagnosis is made.	One diagnosis can protect multiple relatives.
CPR/AED education	Basic health education integrated into public-facing health-check materials.	Low cost and high public-health value.

11. Conclusion

We fully support the Commission's ambition to strengthen cardiovascular prevention and reduce premature cardiovascular mortality by 25% by 2035. Cardiometabolic prevention is indispensable. However, it is not sufficient.

A modern EU cardiovascular health check should also capture inherited, familial, arrhythmic and sudden-death-related cardiovascular risk. These conditions are *often detectable through simple clinical information*, *affect younger people and families*, and can l*ead to preventable death, disability, productivity loss and psychological harm*.

The Council Recommendation should therefore include a proportionate inherited cardiovascular risk component based on structured family history, individual warning signs, referral criteria, expert pathways, access to genetic counselling and testing when indicated, cascade screening, patient association involvement, and CPR/AED education.

This would make the Recommendation more complete, more equitable and more aligned with the Safe Hearts Plan objective of preventing premature cardiovascular death across Europe.

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Annex 1. Endorsing organisations and experts

This evidence annex is submitted on behalf of the **European Coalition for Inherited, Congenital and Sudden-Death-Related Cardiovascular Disease Prevention**, an ad hoc coalition of scientific societies, patient organisations, clinical experts and advocates supporting the inclusion of inherited, congenital, familial, arrhythmic and sudden-death-related cardiovascular risk within EU cardiovascular health checks.

The organisations and individuals listed below have endorsed the overall objectives and policy asks of this submission. Endorsement indicates support for the direction and core recommendations of the document, while recognising that each organisation may have its own governance processes, national context and detailed policy positions.

Endorsing organisations

Organisation	Country / Scope	Representative / contact person
ERN Guard-Heart	Europe *European Reference Network*	Arthur A. Wilde *Coordinator*
European Patient advocacy group of ERN GUARD-Heart	Europe *European Patient Advocacy Group of ERN GUARD-Heart | Europe / European Patient Advocacy Group*	Ruth Biller and Simone Louisse *Co-chairs*
Spanish Society of Cardiology	Spain *Professional society*	Ignacio Fernández-Lozano *President*
Portuguese Society of Cardiology	Portugal *Professional society*	Cristina Gavina *President*
Società Italiana di Cardiologia	Italy *Professional society*	Gianfranco Sinagra *President*
Belgian Society of Cardiology	Belgium *Professional society*	Rik Willems *Chair* Antoine Bondue *Chair-elect*
Polish Cardiac Society	Poland *Professional society*	Prof. Marek Gierlotka *President*
Maltese Cardiac Society	Malta *Professional society*	Maryanne Caruana *President*
Belgian Council on Cardiovascular Genomics (BELCARGEN)	Belgium *Professional Working Group*	Tomas Robyns *Chair*
Cardiogenomics Council of the Polish Cardiac Society	Poland *Professional Working Group*	Prof. Elżbieta Katarzyna Biernack *Chair*
The Lancet Commission on Sudden Cardiac Death	International *Healthcare expert collaboration*	Eloi Marijon *Chair*
Hospital Sant Joan De Deu Servicio de Cardiologia Pediátrica	Spain *Hospital*	Georgia Sarquella *Chief of Department*
Hospital Universitari Bellvitge	Spain *Hospital*	Javier Tapia Martínez *Medical subdirector*
Global Heart Hub	International *Patient association*	Neil Johnson *Executive Director*
HCM Patient Foundation	Europe *Patient association*	Emil Tsenov *Founder and managing director*
Asociación SAMS – Síndromes Arrítmicos Relacionados con la Muerte Súbita	Spain *Patient association*	Ester Costafreda *Managing director*

ARVC-Selbsthilfe e.V.	Germany *Patient association*	Ruth Biller *Chair*
Hart4Onderzoek / Heart4Research	The Netherlands *Patient association*	Simone Louisse *Board member / treasurer*
Friends' Association for the Care and Prevention of Rare Cardiovascular Diseases "Nikos Protonotarios"	Greece *Patient and professional association*	Antigoni Eleni Tsatsopoulou *President*
Asociación Española de Miocardiopatía Hipertrófica	Spain *Patient association*	Antonia Cascales Martínez *International ambassador* Susana Portela *Chair*
LMNA Cardiac Diseases Network	International *Patient association*	Stefan Bassant, Founder / Director
Asociația CardioGen	Romania *Patient association*	Carmen Bălan *President*
Asociación Española contra la Muerte Súbita José Durán #7	España *Patient association*	José Durán *President*
Asociación Española de Enfermos con Displasia Arritmogénica de VD (DAVD-DAI)	España *Patient association*	David Flores Ayestarán *President*
Fundación Carme Chacón *for patients with congenital heart disease*	International *Patient Association*	Esther Piqueras Liras *President*

Endorsing individual experts

Name	Affiliation	Role	Country
Assoc. Prof. Elena Arbelo	Hospital Clínic de Barcelona, University of Barcelona	Coordinator, Familial Cardiomyopathies and Sudden Cardiac Death Syndromes Programme ERN GUARD-Heart European Coordinator for rare and inherited arrhythmias in adults and children *Drafting coordinator for the document*	Spain
Dr. Ahmad S. Amin	Amsterdam University Medical Centers	MD-PhD, Cardiologist, Coordinating member of ERN GUARD-Heart	The Netherlands
Assoc. Prof. Ruxandra Jurçut	University of Medicine and Pharmacy "Carol Davila". Emergency Institute for Cardiovascular Diseases	Coordinator, Centre of Expertise for Rare Genetic Cardiovascular Diseases	Romania
Assoc. Prof. Michelle Michels	Erasmus Medical Center, Rotterdam	Head, Centre of Expertise for Inherited Cardiovascular Disease	The Netherlands
Assoc. Prof. Georgia Sarquella-Brugada	Hospital Sant Joan de Deu	Chief of Paediatric Cardiology, Hospital Sant Joan de Déu ERN GUARD-Heart European lead for special electrophysiology conditions in children	Spain
Prof. Lucie Carrier	University Medical Center Hamburg-Eppendorf	Professor of Functional Genomics of Cardiomyopathies	Germany
Prof. Eloisa Arbustini	IRCCS Foundation Policlinico San Matteo, Pavia	Director, Centre for Genetic Cardiovascular Diseases	Italy
Prof. Giuseppe Limongelli	Inherited and rare Disease Centre, Monaldi Hospital, University of Campania "Luigi Vanvitelli"	Director, Inherited and Rare Cardiovascular Disease Centre	Italy
Assoc. Prof. Lia Crotti	University Milano Bicocca, Milan,	Inherited arrhythmias and sudden cardiac death genetics specialist;	Italy

		EHRA representative to the ESC Council on Cardiovascular Genomics	
Prof. Philippe Charron	Sorbonne University. Faculty Hospital Pitié-Salpêtrière	Coordinator Reference Centre for Inherited Cardiac Diseases ERN GUARD-Heart European Coordinator for rare and inherited cardiomyopathies in adults and children	France
Assoc. Prof. Iacopo Olivotto	University of Florence	Cardiomyopathy Programme lead	Italy
Prof. Stefan Kääb	Ludwig-Maximilians-Universität München	Chair of the ESC Council of Cardiovascular Genomics	Germany
Prof. Adalena Tsatsopoulou	Nikos Protonotarios Medical Centre	Director, Nikos Protonotarios Medical Centre	Greece
Prof. Antonia Cascales Martínez	Universidad de Murcia	Professor, Universidad de Murcia Patient advocacy representative in hypertrophic cardiomyopathy	Spain
Prof. Nikola Kozhuharov	University Hospital Bern – Inselspital	Consultant cardiologist electrophysiologist; invasive electrophysiology and cardiac device specialist	Switzerland
Dr. Rita Reig Viader	Hospital Clínic de Barcelona	Secretary to the Hospital Clínic Rare Disease Programme	Spain
Prof. Jacob Tfelt-Hansen	The Heart Centre, Copenhagen University Hospital	Director of Inherited Arrhythmia Clinic	Denmark
Assoc. Prof. Bo Gregers Winkel	The Heart Centre, Copenhagen University Hospital	Leader of Cardiac Arrest Diagnostic Work-up Clinic	Denmark
Prof. Eloi Marijon		Chair of the Lancet Commission for the prevention of Sudden Cardiac Death	France
Prof. Jolanda van der Velden	Amsterdam University Medical Center (Amsterdam UMC)	Head Departments of Physiology and Experimental Cardiology	The Netherlands
Prof. Antoine Bondue	Hôpital universitaire de Bruxelles, Hôpital Erasme, Université libre de Bruxelles	Chair-elect of the Belgian Society of Cardiology Chair-elect of the ESC Council of Cardiovascular Genomics	Belgium
Assoc. Prof. Luis Lopez	University College London. St Bartholomew's Hospital	Liaison officer for the ESC Council of Cardiovascular Genomics Consultant Cardiologist in inherited cardiovascular disease	United Kingdom
Assoc. Prof. Agnieszka Zienciuk-Krajka	Medical University of Gdańsk. University Clinical Center, Gdańsk, Poland	Cardiogenetics / inherited arrhythmia specialist	Poland
Assoc. Prof. Ruben Casado	Université Libre de Bruxelles; Hôpital Erasme, Brussels	Director, Cardiac Electrophysiology Laboratory	Belgium
Assoc. Prof. Cordula Wolf	German Heart Center Muenchen Technical University of Munich	Director, Centre for Rare Congenital Heart Diseases	Germany
Prof. Cristina Basso	Cardiovascular Pathology, Azienda Ospedaliera di Padova; Department of Cardiac, Thoracic and Vascular Sciences and Public Health, University of Padua	Director, Cardiovascular Pathology Unit Full professor of Pathology	Italy
Dr. Efstathia Prappa	Evangelismos General Hospital Athens, Cardiomyopathy and Imaging unit	Cardiologist, Cardiomyopathy and Imaging Unit	Greece
Prof. Julie de Backer	Ghent University Hospital; Ghent University	Head, Adult Congenital Heart Disease Clinic; aortopathy and HTAD specialist	Belgium

Prof. Elżbieta Katarzyna Biernack	Cardinal Wyszyński National Institute of Cardiology	Head of the Outpatient Department of Genetic Arrhythmias and Congenital Heart Diseases Chairperson of the Cardio-Genetics Section of the Polish Cardiac Society	Poland
Dr. Mauro Toniolo	University Hospital S. María della Misericordia, Udine	Cosultant cardiologist, arrhythmia expert	Italy
Dr. Roberto Barriales-Villa	Complexo Hospitalario Universitario A Coruña	Coordinator, Familial Cardiomyopathies Unit	Spain
Prof. Maciej Sterlińsk	National Institute of Cardiology, Warsaw	Professor of Cardiology; electrophysiology and cardiac device therapy expert	Poland

Endorsements were collected by email between May 13th, 2026, and May 19th, 2026 (noon). Additional organisations and experts may submit aligned individual or national contributions to the European Commission call for evidence.