Cardiomyopathies Matter: a multistakeholder European initiative to improve patient outcomes through effective health policies

Teofila (Tootie) Bueser,[1] Ester Costafreda,[2] Tomás Fajardo,[3] Stefan Janssens,[4] Hugo Katus,[5] Stellan Mörner,[6] Iacopo Olivotto,[7] Matteo Pinciroli,[8] Sean Taylor,[9] Maria T. Tome Esteban,[10] Patricia Tiramani,[11] Jean-Noël Trochu,[12] Rogier Veltrop[13]

[1]South East Genomic Medicine Service Alliance, Guy's & St Thomas' NHS Foundation Trust and North Thames Genomic Medicine Service Alliance, Great Ormond Street Hospital NHS Foundation Trust, London, UK; [2]Asociación para Pacientes y Familiares con Síndromes Arrítmicos relacionados con la Muerte Súbita (SAMS), Spain; [3]Cardioalanza, Spain; [4]Department of Cardiovascular Diseases, University Hospitals Leuven, Leuven, Belgium; [5]Department of Internal Medicine III—Cardiology, Angiology, and Pulmonology, Heidelberg University Hospital, Heidelberg, Germany; [6]Department of Public Health and Clinical Medicine, Umeå University, Umeå, Sweden; [7]Department of Experimental and Clinical Medicine, University of Florence and Meyer University Children Hospital, Florence, Italy; [8]Cardiomyopathy Patient Council, Global Heart Hub and Italian Association for the study and research of Cardiomyopathies (AICARM), Italy; [9]World Heart Federation, Geneva, Switzerland; [10]Cardiovascular Clinical Academic Group, Inherited Cardiac Condition Service, St George's Hospital NHS Foundation Trust and St George's University of London, London, UK; [11]Global Heart Hub, Galway, Ireland; [12]Thorax and Nervous System Institute and Heart Failure and Cardiomyopathies Unit, University Hospital, Nantes, France; [13]LMNA Lab Mechanobiochemistry and Cardiac Cell Signalling, Cardiovascular Research Institute Maastricht, Maastricht University, and LMNAcardiac Foundation, Maastricht, The Netherlands

Purpose

Cardiomyopathies are common, affecting up to 1:250 of the population. Despite conferring a risk for sudden cardiac death and substantial disease burdens that could be reduced through better awareness, detection and care, specific considerations for cardiomyopathies are rarely incorporated in health policies.

New European Society of Cardiology cardiomyopathy guidelines[1] could substantially benefit patient care but need to be supported by effective policies.

Cardiomyopathies Matter (*cardiomyopathiesmatter.org*) is a Europe-wide, multistakeholder initiative aiming to raise awareness about cardiomyopathies and to ensure they receive the policy attention they warrant from European Union (EU) and national decision-makers.

Methods

Cardiomyopathies Matter's participants include experts from the fields of cardiology, cardiac nursing, and patient advocacy, coordinated by a secretariat (Dentons Global Advisors, Brussels).

Participants in the EU-level initiative include representatives from 10 countries, seven centres and six patient advocacy or multistakeholder groups.

A Policy Roadmap and other publications were co-created based on:

- *reviews of published and grey literature*
- *input from participants through group workshops, individual consultation meetings, and a modified nominal group technique reviewing successive drafts toward consensus approval.*

The Policy Roadmap was launched at an event in the European Parliament (November 2022) with formal support from three Members of the European Parliament.

Publications and updates are published via the website *cardiomyopathiesmatters.org*.

National Cardiomyopathies Matter initiatives are currently underway or in development in various countries.

Results

EU Policy Roadmap

The Roadmap[2] identifies unmet needs and challenges throughout the patient care pathway and offers holistic EU and national policy recommendations to address these and improve patient outcomes.

A Cardiovascular Health Action Plan is needed at EU and national levels, giving specific attention to cardiomyopathies based on the priority areas in **Figure 1**.

These include policy measures to support early and accurate diagnosis, access to expert, multidisciplinary, patient-centred care, guidelines-led disease investigation and management, holistic support and empowerment of patients and carers, and research and innovation.

Key aspects for nurses and allied health professionals include:

- *the need for improved knowledge and awareness to promote early diagnosis*
- *rapid referral systems to multidisciplinary care*
- *access to care provided by specialist cardiomyopathy or heart failure nurses, including genetic counselling (index cases and cascade/family screening) and care coordination.*
- *holistic support of patients and families.*

Building on existing examples of good practice at national expert centre networks (e.g. France, Spain, UK), Cardiomyopathies Matter published updated policy recommendations for the EU mandate focusing on inherited cardiomyopathies[3].

In 2023, the initiative helped include genetically inherited diseases and the importance of secondary prevention in a European Parliament report on non-communicable diseases.

Cardiomyopathies Matter will further deliver its recommendations and an overview of the national policy landscape across Europe in an article submitted to the *European Heart Journal* Cardiopulse section.

National initiatives

National Cardiomyopathies Matter initiatives are underway or in development in Belgium, Hungary, Italy, Netherlands, Poland, Romania, and Spain (**Figure 2**).

Local actions include multistakeholder roundtables and events, national Roadmap publications, educational activities and media outreach.

Further information and updates can be found at *cardiomyopathiesmatter.org*

Figure 1. Cardiomyopathies Matter policy priorities

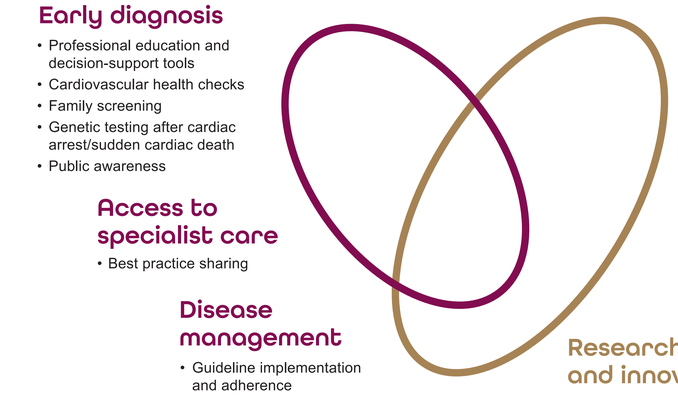
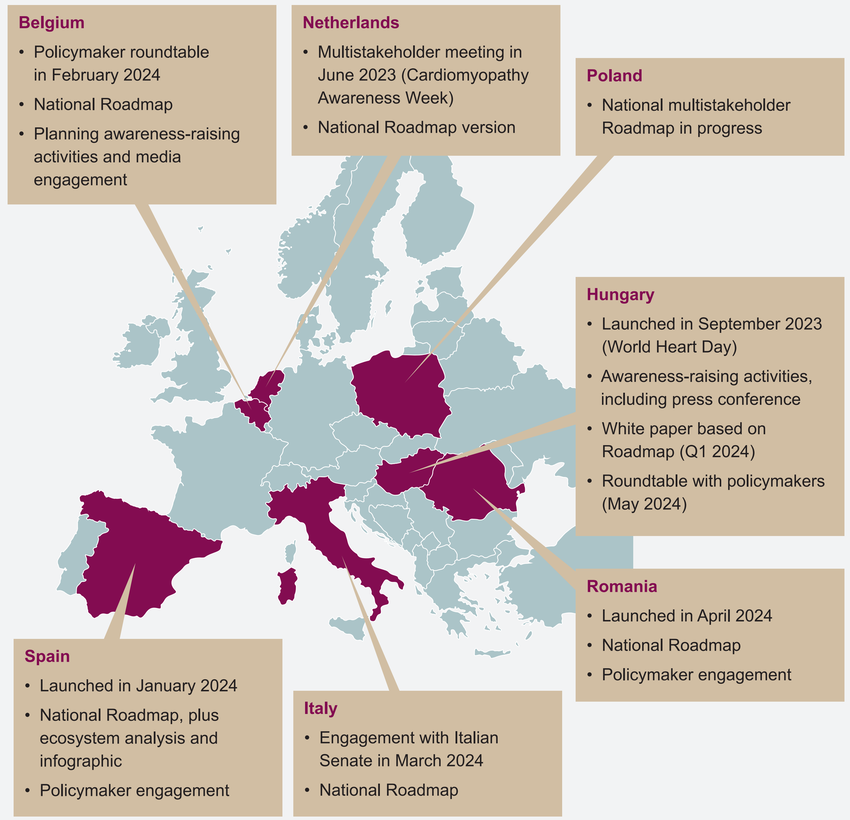


Figure 2. National Cardiomyopathies Matter initiatives



Conclusions

EU and national Cardiovascular Health Action Plans are needed, with specific attention to cardiomyopathies and other inherited cardiovascular diseases.

Cardiomyopathies Matter fosters collaboration between healthcare professionals, patient advocates, and policymakers to promote national and EU policies that ensure all patients and families have access to guidelines-led care.

Annual Congress of the Association of Cardiovascular Nursing and Allied Professions (ACNAP) 14–15 June 2024, Wrocław, Poland

References

1. Arbelo E, et al. 2023 ESC Guidelines for the management of cardiomyopathies. Eur Heart J 2023;44:3503–26

2. Cardiomyopathies Matter: a Policy Roadmap to improve cardiomyopathy detection and care in Europe. 2022. https://cardiomyopathiesmatter.org/wp-content/uploads/2022/11/Cardiomyopathies_Matter_Policy_Roadmap_Nov_2022.pdf

3. Cardiomyopathies Matter. Family matters: tackling inherited cardiomyopathies in the next EU policy mandate. 2023. https://cardiomyopathiesmatter.org/wp-content/uploads/2023/09/Cmatter_Family-matters_Report_23-online_1.pdf

Declaration of interest

Cardiomyopathies Matter is funded by Bristol Myers Squibb. Nothing contained herein is intended, nor should be interpreted, to promote BMS nor any BMS product or agent. Editorial control for this poster rests with the authors. Cardiomyopathies Matter is currently working to extend its funder base to involve additional partners.

Cardiomyopathies Matter