Cardiomyopathies Matter

Improving cardiomyopathy detection and care in Belgium
Policy recommendations

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Cardiomyopathies Matter

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Executive summary

Cardiomyopathies, a group of diseases affecting the heart muscle, are often neglected despite the significant burden they pose on individuals and society in Belgium and other countries. Unlike most cardiovascular diseases, cardiomyopathies have a strong hereditary component affecting mostly young and active people. However, through enhanced awareness, detection, and healthcare provision, the impact and prevalence of those diseases could be reduced.

Published in 2022, the European Cardiomyopathies Matter Roadmap (accessible on https://cardiomyopathiesmatter.org/) aims to address this issue by raising awareness and ensuring they receive positive policy attention from healthcare system decision-makers and influencers. It is essential to consider that the needs and necessary evolutions in Belgium may vary and require a tailored approach considering, among others, the differences in healthcare policies. **This Roadmap transposes the European priorities to the Belgian context to provide a framework for policy changes in Belgium endorsed by leading experts in the field through the Belgian Cardiomyopathies Matter Network.** The Network is composed of the following experts: Prof. Dr. Bondue (Hôpital universitaire de Bruxelles, Hôpital Erasme, ULB), Prof. Dr. Van Craenenbroeck (Universitair Ziekenhuis Antwerpen) and Prof. Dr. Janssens (Universitair Ziekenhuis Leuven).

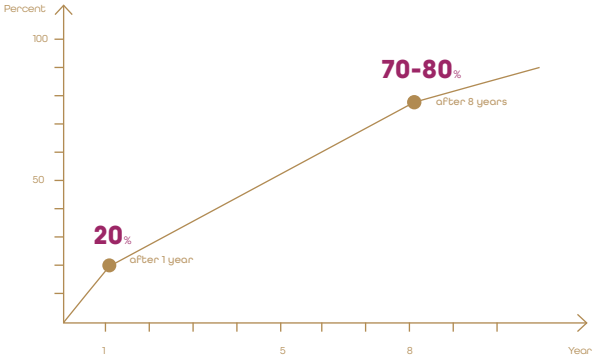
Following the same structure as the European Cardiomyopathies Matter Roadmap, this Roadmap tailored to the Belgian context aims to:

- explain what cardiomyopathies are and how they impact patients, their families, healthcare systems and society in Belgium;
- identify key challenges and unmet needs throughout the patient care pathway;
- provide policy recommendations to address these challenges and improve patient outcomes in Belgium.

1. Introduction

According to scientific estimations, cardiovascular diseases (CVDs) affect about 1 in 15 Belgians, corresponding to 753,740 people.[1] Consequently, it stands as the primary cause of death and is still increasing in Belgium and worldwide.[2],[3] Cardiomyopathies are a specific group of diseases that affect the functioning and structure of the heart muscle, which can lead to significant morbidity and heart failure if not detected in time.[4] The World Health Organization and International Society and Federation of Cardiology define them as "*diseases of the myocardium associated with cardiac dysfunction*".[5] For most patients that develop heart failure, mortality rate sits at 20% after one year and at 70-80% after eight years.[6]

Because of their common clinical manifestations (phenocopies) with multiple underlying causes (ranging from common to rare or very rare diseases), cardiomyopathies are usually not well understood, even in the medical world. Deciphering this heterogeneity, multimodality imaging and genetics play a growing role, allowing a paradigm shift from a global medical approach towards a personalized patient management, up to targeted therapies. Cardiomyopathies can also be clinically silent with the first clinical event being very acute or even fatal: cardiomyopathies (with sometimes "concealed" cardiomyopathies) are now seen as a major cause of sudden cardiac death in young athletes. Despite progress in heart failure management, cardiomyopathies remain also the first cause of advanced heart failure and transplantation in the youth, representing a societal challenge.



The four major types of cardiomyopathies are dilated-, hypertrophic-, restrictive-, and arrhythmogenic right ventricular cardiomyopathy, each with its own specific symptoms and treatment procedure.[7] The risk of developing a cardiomyopathy, like most CVDs, is increased under the influence of an unhealthy lifestyle. There is however also an important yet often understated genetic aspect to cardiomyopathies. In fact, in 20-60% of cases of the four main types of cardiomyopathies, a genetic mutation can be found as a causative factor, as seen in table 1.[8]

Objectives

The Belgian Cardiomyopathies Matter Roadmap aims to raise awareness about cardiomyopathies and to ensure they receive the policy attention they warrant from healthcare system decision-makers and influencers at the Belgian levels.

To this the objectives are to:

- explain what cardiomyopathies are and how they impact patients,
- their families, healthcare systems and society in Belgium;
- identify key challenges and unmet needs throughout the patient care pathway;
- provide policy recommendations to address these challenges and improve patient outcomes in Belgium.

Methodology

This Roadmap was developed based on 1) a review of relevant published and grey literature, and 2) input from expert contributors (see page 3) from the fields of cardiology – gained during an in-person roundtable workshop and reviews of successive drafts.

Despite the high disease burden, ambitious policy actions to tackle CVDs and their impact on people – be it in Belgium or in other countries – tend to be lacking. When implemented, policy initiatives pertaining to CVDs typically prioritize heart attacks and strokes due to their widespread and visible occurrence, significant health ramifications, and preventable nature. However, there is a notable lack

of emphasis on CVDs that are less prevalent and often not preventable, such as those attributed to hereditary factors. Even so, these diseases impose significant burdens on the individuals affected, which could be mitigated through enhanced awareness, improved diagnostic capabilities, and implementation or expansion of appropriate treatment strategies. The psychological impact of CVDs on patients and their families, i.e. when CVDs are of hereditary nature, should be taken into account and addressed as well. If future efforts to prevent CVDs are successful, non-preventable forms such as cardiomyopathies are expected to constitute an even bigger proportion of the overall burden of CVDs.

Type of cardiomyopathy	Characteristic[9,10]	Estimated prevalence in general population[11]	Approximate % of cases in which a genetic pathogenic variant is identified[12]
Hypertrophic	Heart muscle thickens	1 in 500	30 – 60%
Dilated	Dilated heart with impaired contractile function*	1 in 250	20 – 50%
Arrhythmogenic right/ left biventricular	Heart muscle replaced by scar tissue or fat	1 in 2000-5000	30 – 45%
Restrictive	Heart muscle stiffens	Less common	Unclear (may be up to 60%)

Table 1: Features of the main types of cardiomyopathies.
*Can occur towards the end of pregnancy or in the months following delivery (peripartum cardiomyopathy).[13]
Other cardiomyopathies include left ventricular non-compaction cardiomyopathy and Takotsubo cardiomyopathy (which is usually transient and associated with emotional or physical stress).

1.1. Overview of policy competence distribution

In Belgium, the competencies in healthcare are divided among different levels of government. At the federal level, the Federal Minister for Social Affairs and Public Health, currently Frank Vandenbroucke (Vooruit), is responsible for setting curative healthcare policies and overseeing various institutions and agencies. These include the Federal Public Service (FPS) Social Security, the administration which assists in developing social policies and conducting research, and the FPS Public Health, Food Chain Safety and Environment, which regulates healthcare, food safety, and animal and plant health. The Minister also supervises entities such as the Control Service for the Health Insurance Funds (OCM-CDZ), the Federal Agency for Medicines and Health Products (FAMHP), the Federal Knowledge Centre for Healthcare (KCE) and the National Institute for Sickness and Disability Insurance (RIZIV/INAMI).[14,15,16]

At the community level, responsibilities are further divided among the Flemish, French-speaking, and German-speaking communities. The French-speaking Community is also known as the Wallonia-Brussels Federation (FWB), as it represents French-speaking Belgians in both Wallonia and Brussels. Each community is responsible for healthcare policies related to preventive healthcare, the recognition of healthcare professions, and care provision. In Brussels, multiple entities, including the Brussels Capital Region, the FWB, the French Community Commission (COCOF), the Joint Community Commission (COCOM/GGC), and the Flemish Community Commission (VGC), share responsibilities on social action and health.[17,18] Generally speaking, the COCOF and VGC are under supervision of the FWB and the Flemish Community, respectively. They do not have legislative power and rather manage their respective unilingual organizations (exclusively French- or Dutch-speaking) in Brussels, in compliance with the decrees from their respective communities.[19,20] However, the FWB legally transferred some of its health competencies to COCOF and the Walloon Region. Thus, for these limited competencies, COCOF has the power to adopt decrees.[21] As for COCOM/GGC, it unites both communities in Brussels and is composed of the same representatives as the Parliament of the Brussels Capital Region. It does not have legislative power.[22]

Provinces and municipalities in Belgium are the levels closest to the citizens, but they have little autonomy and are supervised by the higher authorities (Federal Government, communities, regions).[23,24] In Brussels, the provincial competencies are exercised by the Brussels Capital Region.[25]

Overall, the division of competencies in healthcare in Belgium is complex and involves multiple levels of power. Each level has specific responsibilities, ranging from policy development and regulation to healthcare financing and provision. Since the competencies are highly interdependent, there is consultation between the different levels through the IMC Public Health (Interministerial Public Health Conference) where all responsible Ministers in Belgium meet to discuss protocol agreements.[26]

1.1.1. Emphasis on Cardiomyopathies within the Belgian Political Context

Cardiomyopathies and CVDs in general are currently not a priority in policymaking at the different levels. However, according to the EU's 2021 fact sheet on the state of health in Belgium, in 2018, ischemic heart disease and strokes were the leading cause of death in Belgium: both respectively accounted for 6% of all deaths in Belgium that year.[27] Despite this, in the Flemish policy note Wellbeing, Public Health, Family Affairs and Poverty Reduction for the legislature 2019-2024, CVDs are only mentioned once as an example of the impact climate change has on health, as well as in the policy statement of the Walloon Region.[28,29]

This is also the case when analyzing the Brussels Takes Care Plan (ISSP). It adds environmental noise as the second most important environmental risk factor (after air pollution) leading to, among others, CVDs. Additionally, the Brussels Plan also identifies physical inactivity as the cause of approximately 7.1% of CVD cases in Belgium. The ISSP states that it is important to encourage citizens to move.[30] The policy statements of the FWB and the Federal Government do not mention CVDs, illustrating once again the lack of policy attention to this vital issue.[31,32]

The abovementioned underscores that despite the concerning statistics related to CVDs and cardiomyopathies, there exists a conspicuous dearth of attention from policymakers in Belgium. Experts in the field have consistently emphasized **the urgent need for a comprehensive National Plan dedicated to addressing CVDs.** Most recently, a report authored by numerous leading cardiovascular specialists and healthcare professionals from across Belgium was presented during a round table discussion held in the Federal Parliament in October 2022.[33] This report strongly reinforces the imperative for a National Action Plan, one that establishes a cohesive, resolute, and multifaceted policy framework aimed at improving the overall health of the Belgian population. The initiative gained momentum through the collaborative efforts of several Members of Parliament, as well as representatives from influential organizations including the Belgian Cardiology League, the Belgian Society of Cardiology, the Healthy Heart Fund, and the Belgian Hypertension Committee.

1.2. Ecosystem cardiomyopathies

The two largest Belgian organizations focusing on CVDs are the Belgian Society of Cardiology (BSC) and the Belgian Cardiology League. The BSC serves as the scientific society for Belgian cardiologists, dedicated to advancing research and education in the field of cardiology. Their primary objectives encompass the facilitation of cardiovascular-related inquiries by promoting basic and clinical research, disseminating research findings, fostering scientific collaboration among cardiologists, supporting continuous education in cardiology, and encouraging international cooperation. Additionally, the BSC provides support to various working groups, which conduct specialized meetings and courses throughout the year. Moreover, each year, the BSC organizes the largest cardiology event in Belgium, gathering top experts, industry leaders and company representatives in the cardiovascular field.[34]

The Belgian Cardiology League is Belgium's largest non-profit organization focusing on CVDs. Their goal is the prevention of cardiovascular diseases, both at the level of primary prevention (among the general public and all persons who may be affected by these conditions) and secondary prevention (among patients who have been affected by a cardiovascular disease). Besides various awareness campaigns such as the annual Week of the Heart, the League also organizes conferences and webinars where academics, doctors and experts can exchange views on heart-related topics.[35]

Both organizations are members of the European Alliance for Cardiovascular Health (EACH). EACH is an established collaborative platform that brings together various stakeholders, including healthcare professionals, researchers, policymakers, and patient organizations, with the common objective of improving cardiovascular health outcomes across Europe. The Alliance focuses on fostering cooperation, exchanging knowledge, and promoting evidence-based strategies to prevent, diagnose, and manage CVDs. By facilitating dialogue and collaboration among key stakeholders, the European Alliance for Cardiovascular Health plays a pivotal role in shaping policies and initiatives that address the significant burden of cardiovascular diseases on individuals and societies throughout Europe.[36]

Another major association at the European level is the European Society of Cardiology. This is a not-for-profit medical society whose members include scientists, clinicians, nurses, and allied professionals working in cardiology. [37] The ESC is made up of 57 National Cardiac Societies from across Europe and Beyond. In Belgium, the Belgian Society of Cardiology is member of the ESC.[38] The ESC holds considerable influence, and it frequently publishes guidelines for various cardiovascular diseases. In 2023, the ESC published its new "Guidelines for the management of cardiomyopathies". These guidelines were drafted by an ESC Task Force, which consisted of professionals involved with the medical care of patients with cardiomyopathies. The approved guidelines represent the ESC's official position on cardiomyopathies.[39] Given the ESC's impressive membership, with 57 National Cardiac Societies, these guidelines constitute a solid reference. This roadmap, therefore, refers to these guidelines in some places.

2. Understanding cardiomyopathies

2.1. How common are cardiomyopathies?

The four major forms of cardiomyopathies vary in their prevalence, with some being relatively common.

2.1.1. Causes

In general, there is a rising disease burden associated with cardiomyopathies, indicated by an increasing number of cases, rising mortality rates, and the resulting increase in disability-adjusted life years (DALYs) they entail.[40] Cardiomyopathies are underdiagnosed, suggesting that the provided estimated figures represent only a fraction of the actual cases. In an early stage of a cardiomyopathy, patients often do not have symptoms yet. However, an early diagnosis is crucial in order to control and manage the development of the disease, prevent or inhibit the prevalence of symptoms, and prevent undue delays in family screening[41]. These conditions can affect individuals across all age groups, with a predominant diagnosis occurring in young adults. While strokes and heart attacks mainly affect the elderly, certain forms of cardiomyopathies, often the most severe, predominantly impact the younger population, including [42] In the case of hypertrophic cardiomyopathy for example, it has become clear that the disease develops between the ages of 20-40[43]

- Inherited predispositions are a common cause of cardiomyopathies, ranging from rare variants to common variants. Of the main four types of cardiomyopathies, approximately 20-60% of the cases can be attributed to a genetic pathogenic (or likely-pathogenic) variant. Cardiomyopathies are frequently presenting as inherited heart diseases, with nearly 40% of patients in the European Society of Cardiology (ESC) Cardiomyopathy Registry, the European observational study that aims at gathering data on patients with cardiomyopathy and myocarditis[44], having a documented family history of the disease.[45]
- Numerous pathogenic genetic variants have been associated with cardiomyopathies, some of which are consistently linked with poor prognosis (mediated usually by aggressive rhythmic disorders or early progression towards advanced heart failure), while others have an unpredictable relationship with patient outcomes. Despite expanding knowledge of the genetic architecture of cardiomyopathies, it remains not possible nowadays to identify definitive pathogenic genetic variants in many cases, a reducing field called “missed heritability”.[46]
- Cardiomyopathies can also overlap with common or acquired diseases. For example, dilated cardiomyopathies can also be caused by viral infections, endocrine and immune system disorders, cardiotoxic drugs, toxins, and alcohol, with sometimes underlying weaker genetic predispositions. Also, left ventricular hypertrophy can be caused by diseases like amyloidosis, inflammatory disease, glycogen storage diseases, lysosomal storage diseases and even hypertension.

2.1.2. Symptoms and risks

Cardiomyopathies can lead to a reduced pumping ability of the heart, causing organ failure. Regarding the frequency of heart failure, a recent study shows that the cumulative rate of heart failure was 42.8% at 3 years since initial diagnosis of symptomatic obstructive hypertrophic cardiomyopathy (HCM) and increased to 55.4% at 6 years.[47] The severity and progression of the disease can vary. Most diagnosed patients experience cardiac signs and symptoms of heart failure and arrhythmias, which may worsen over time. These symptoms can significantly impact patients’ lives, increase the risk of early cardiovascular

death, and require lifelong treatment. However, some patients may have minimal or no symptoms, and their cardiomyopathy may go undiagnosed unless it leads to a severe complication. The main symptoms of cardiomyopathies are related to heart failure and abnormal heart rhythms. The effects of cardiomyopathies should be seen on a spectrum ranging from, for example, no symptoms and little fatigue to marked signs and symptoms of heart failure at the opposite side of the spectrum.

- Symptoms of heart failure include fatigue, chest pain or discomfort, shortness of breath, palpitations, dizziness and fainting, which can significantly limit patients. Additionally, there might be swelling in the ankles, abdominal congestion, and a loss of appetite. Heart failure has a significant impact on the patient's overall wellbeing, impacting their career, social relations and family life. Over time, the prognosis of patients with heart failure deteriorates, elevating the risk for mortality.[48,49]
- Abnormal heart rhythms, referred to as 'arrhythmias' (such as ventricular tachycardia, ventricular fibrillation, and atrial fibrillation), can lead to palpitations, dizziness, fainting, and sudden cardiac death. Among individuals with cardiomyopathy, abnormal heart rhythms stand as the second leading cause of out-of-hospital cardiac arrests, accounting for 40% of these often fatal incidents.[50] The risk of blood clots that can cause life-threatening complications, particularly strokes, is increased by atrial fibrillation.[51,52]

A key concern of patients is that cardiomyopathies can lead to sudden cardiac death, which could even be the first manifestation of the disease in some patients. It is estimated that almost 50% of patients who suddenly die in childhood or adolescence or who undergo cardiac transplantation at a young age are affected by cardiomyopathies. It is also important to stress that HCM is a common cause of heart failure[53], an important factor for assessing risk and guiding preventive treatment. Sudden cardiac death can occur as the first manifestation of the disease and mostly affects young and active individuals who are asymptomatic.[54,55,56]

- People diagnosed with cardiovascular diseases, including cardiomyopathies, often inquire about the safety and recommended level of exercise or sports participation, as this can greatly affect their quality of life. As cardiomyopathies are predominantly diagnosed in a younger population that is professionally and physically active, the limitations of physical activity and impact on their professional functioning are one of the primary concerns. It is often stated that patients with a cardiomyopathy or CVD in general, cannot exercise anymore due to the severe risks. However, recent research states that this is untrue. Current guidelines recommend patients to exercise low-static/low-dynamic sports such as walking.[57] Furthermore, patients can participate in other more high-intensity sports when individualized and appropriate consultation is provided.[58,59]

2.1.3. Affecting quality of life

The limitations that cardiomyopathies bring to the patient's quality of life and psychological wellbeing should not be neglected. Different studies show that patients with cardiomyopathies suffer from lower mental health, increased anxiety and depression and poor perceived health. Limitations that are often cited are, among others, impact on work and the emotional impact. The burden of patients with cardiomyopathies significantly influences their quality of life.[60]

When a patient requires hospitalization, the impact is particularly considerable, especially when it occurs unexpectedly and is prompted by acute complications.[61,62] Furthermore, invasive treatment with implantable devices, such as Implanted Cardioverter-Defibrillators (ICD), can also have a severe impact on the psychosocial health of patients.[63,64,65]

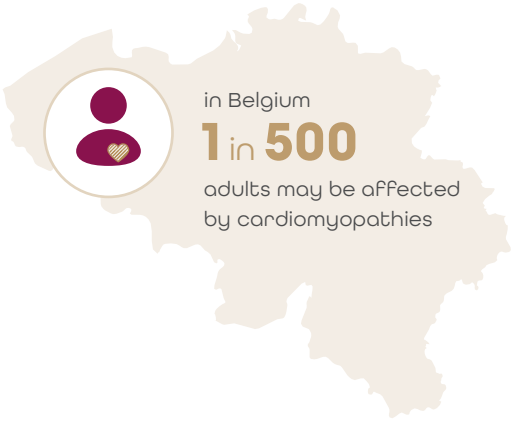
In instances of hereditary cardiomyopathy, patients are additionally confronted with the potential genetic inheritance of the condition by their children, thereby imposing a supplementary burden upon them. The ESC guidelines recommend pre-pregnancy risk assessment as well as counselling on the risk of disease inheritance. Additionally, the psychological aspect and fear of the hereditary aspect of cardiomyopathies compounds the challenges faced by patients.[66]

Cardiomyopathies also represent challenges within a societal context. Financially, patients may experience problems to obtain life insurance and mortgages, especially if the patient survived a sudden major adverse event as a result of a cardiomyopathy according to experts in the field. They also have to pay for travel costs to the clinics and aspects of care that insurance does not cover (e.g. diagnostic tests, recommended supplements). As for education and professional life, research shows that children and adolescent patients may have reduced educational attainment, and adults may see their options for vocational training and employment limited.[67]

Not only are there limitations on the quality of life of an individual living with a cardiomyopathy, but the disease also affects the families and informal caregivers of the patients. For instance, they may be limited in their ability to work due to caring for the patient. The diagnosis of the disease could put the patients and their families under financial pressure, and without doubt, sudden cardiac death experiences profoundly impact the families.[68]

2.1.4. What are the related costs for Belgian healthcare system?

According to scientific estimates, up to 1 in 500 adults may be affected with cardiomyopathies.[69,70] In Belgium, there are 9.361.224 people above 18 years old as of 1 January 2023.[71] It's crucial to highlight that many cases of cardiomyopathies often remain undetected or are misdiagnosed as general heart failure, contributing to the substantial burden on healthcare resources.



It is complicated to give a detailed overview of the total costs for Belgian healthcare, because to obtain a comprehensive overview of the estimated costs for the healthcare sector, it is essential to also factor in expenses that are not directly linked to a hospitalization such as consultations, medicines, etc. Additionally, the opportunity costs should also be considered. These consist for example of the income lost to society because the patient is unable to work (fulltime) or the additional costs for mental wellbeing. These costs are not fixed and depend on a multitude of variables.

As mentioned, cardiomyopathies tend to affect the younger, active population more than other CVDs (such as ischemic heart disease and strokes). Young people want to work and exercise, and for some jobs they are crucial. Which is why authorities need to take special care of them. An early and correct diagnosis and treatment will help avoid hospital stays and avoid the need for patients to quit working. This will benefit the patients, who can work and therefore receive an income, and social security, which sees its health expenses reduced. Taking into account all these potential expenditures and the fact that cardiomyopathies affect younger people more, it becomes apparent that early detection and prevention play a pivotal role in mitigating its financial burden on public funds.

3. Addressing challenges and unmet needs

In this section, the Belgian Roadmap provides policymakers with tangible policy advice and recommendations, in each case motivated by current policy shortcomings and alarming figures that call for action in Belgium. Considering the repartition of policy competences in Belgium, policy measures should always be coordinated with the respective regional and community governments and their competent organizations to guarantee the most sustainable and efficient impact putting patients first.

3.1. Challenges for Belgium

The overall health of the Belgian population is notably positive, marked by an increasing life expectancy.[72] Despite Belgium's rankings falling below the European average for overweight, the substantial prevalence of overweight individuals (50%)[73] continues to exert a significant influence on the occurrence of CVDs in patients. Concerning alcohol consumption, the average consumption in Belgium was in 2019 recorded at 10.3 liters per capita per year. This is above the European average of 9.2 liters per capita in 2019 and implicates a disease burden in the country related to alcohol.[74] Furthermore, it is imperative to take into account the sedentary lifestyle, which impacts more than one in three Belgians and effectively doubles the occurrence of cardiovascular diseases.[75] Overall, it is also important to maintain a balanced lifestyle as excessive physical exertion can also potentially aggravate symptoms of patients with cardiomyopathies.[76]

Reducing socioeconomic inequalities also remains a challenge and prevention policies could be further

We call **on Belgian federal and regional decision-makers to implement** the following recommendations within **Cardiovascular Health plans**, and existing policies and initiatives.

A strong ecosystem for R&D, innovation and clinical trials

- Support R&D in the field of cardiomyopathies
- Encourage the development of precision medicines

Patient support: holistic approach

- Multidisciplinary approach
- Promote patient organisations
- Include PREMs and PROMs in healthcare policy

Screening, early detection and prevention

- Family screening
- Public awareness
- Cardiovascular health checks
- Genetic testing after cardiac arrest/sudden cardiac death
- Professional education and decision-support tools for HCPs to facilitate diagnostic precision and ensure timely referrals
- Develop a framework to inform families about the diagnosis of cardiomyopathies

Data collection and data sharing

Facilitate evidence-based policy through:

- Data collection specifically on cardiomyopathies
- Cardiomyopathies Registry including information about MRI results, genetic testing...
- Framework for molecular autopsy and post-mortem analyses

Raising awareness, social inequality and access to specialist care

- Prioritize accessible, affordable and qualitative care
- Raise awareness of cardiomyopathies among HCPs that do not specialize in cardiovascular health and in the general public
- Empower people to recognize symptoms

Lifestyle

- Encourage healthier lifestyle choices

strengthened. Besides unhealthy lifestyle as a driving factor, there is also a crucial but lesser-known genetic aspect, which is particularly relevant for cardiomyopathic diseases. It is imperative to raise awareness of this genetic aspect among the general population, and to step up efforts in targeted preventive genetic screening. There are currently 8 genetic centers in Belgium that meet the requirements.77 The significance of aftercare and social support towards patients and their families also play pivotal roles to boost their resilience and ability to cope with cardiomyopathies.

3.1.1. Screening, early detection and prevention

Despite significant diagnostic and therapeutic advances in cardiology, prevention and early detection are still the most important elements of a significant and sustainable reduction in cardiovascular morbidity and mortality. As it stands, cardiomyopathies oftentimes remain undiagnosed, especially among younger, apparently healthy patients (please see 2.1.2 Symptoms and risks).[78] Moreover, a significant portion of patients often go very late to specialized healthcare facilities for adequate treatment. It is, therefore, necessary to increase awareness-raising efforts, as it has been demonstrated that early diagnosis and adequate treatment substantially lower mortality and morbidity rates.[79]

The methods used to diagnose cardiomyopathies include an electrocardiogram (ECG), echocardiography, Holter recording, an exercise test, Cardiac Magnetic Resonance (CMR) (a type of Magnetic Resonance Imaging (MRI)), nuclear imaging and a biochemical or genetic test. These tests are necessary in order to rule out other causes such as high blood pressure or valvular or infiltrative heart diseases, but also to raise or confirm the possibility of a cardiomyopathy for a given patient. For the detection and follow-up of certain heritable heart defects, such as hypertrophic and dilated cardiomyopathies, CMR is used as a key phenotyping exam, together with genetic testing. CMR is considered a safe and comprehensive imaging modality for assessment of heart and blood vessels, which is of great importance, most notably for patients with complex congenital heart disease, requiring recurrent scans.[80] Nevertheless, it is imperative to emphasize that even among healthcare professionals with specialized expertise, the task of assessing the patient's condition and determining the precise treatment continues to pose considerable challenges according to the field.

According to Belgian government data, more than 1.6 million people per year have an echocardiography performed.[81] Ideally, people suspected of having hypertrophic cardiomyopathy should undergo both CMR and echocardiography, as recommended by experts.[82] The ESC recently included CMR in the diagnostic work-up of all patients with cardiomyopathies in its recommendations as published in its cardiomyopathy guideline of 2023.[83]

Given the significant genetic component associated with cardiomyopathies, the role of genetic testing becomes pivotal in identifying individuals with hereditary cardiomyopathies, even if they initially appear asymptomatic. Genetics play a major role in identifying the precise underlying cause for a given patient (allowing improved prognostic stratification and appropriate or targeted management), but also in allowing risk stratification for relatives. Indeed, equally important is the identification of potential risks for relatives if the cardiomyopathy turns out to have a hereditary factor.[84] Further research in this field holds promise for future precision medicine interventions such as disease modifiers or gene editing. There are currently ongoing trials of gene editing in cardiomyopathy patients which is an initiative that can only be supported and should be further elaborated as indicated by experts.

When a cardiomyopathy is diagnosed, it is crucial that first-degree relatives are offered genetic testing ("pedigree analysis") as well to identify those who could also suffer from that condition. Furthermore, it is important that primary healthcare professionals are adequately trained to recognize underlying symptoms and predispositions for cardiomyopathies and refer patients to a specialized center at an early stage. Especially in the context of the recent emergence of 'long COVID', which has certain similarities in terms of symptoms, leading to an additional risk of misdiagnosis.[85,86]

According to the field, the hereditary aspect of cardiomyopathies emphasizes the importance of prioritizing the dissemination of information to the family members of the diagnosed patient. However, the question of who bears the responsibility for conveying this information to the relatives can be a subject of discussion. In Belgium, the patient is typically responsible to inform his or her relatives. Conversely, in some other countries, a legal framework exists that empowers geneticists to directly contact the relatives and provide them with the necessary information (e.g. Australia). Unfortunately, such a framework is not as well-developed in Belgium. Experts indicate that the development of a framework

could benefit the patient and their relatives in navigating the various potential implications of cardiomyopathies as well as receiving early support. Developing a framework does bring ethical and legal questions to the table, which should be considered by policymakers in order to have clear procedures that eventually benefit patients and their relatives.[87]

As earlier discussed, sudden cardiac death can be the first manifestation of the disease often impacting younger, active persons. Preventing cardiomyopathies presents a significant challenge, yet early disease detection through screening can save lives. When specialists and patients are informed about their condition, personalized medical interventions can be implemented to manage the disease. Studies indicate, for example, that an ICD is notably effective in averting sudden cardiac death.[88]

Policy Recommendations

To address cardiomyopathies effectively, it is crucial to e**mphasize screening and early detection of the disease, as well as timely identification of patients at high risk.**

- This includes **promoting better targeted check-ups and intervention through risk assessment, relevant tests, and guidance** on maintaining a healthy lifestyle even for seemingly healthy individuals. Regular checkups provide an opportunity for healthcare professionals to assess risk factors, conduct relevant tests, and offer guidance on maintaining a healthy lifestyle while allowing earlier detection of cardiomyopathies.
- Particular attention should be paid to **prevention and screening among the younger population at risk.** They tend to be more affected by cardiomyopathies. Increasing prevention and screening among the younger populations can help avoid hospital stays and get more people at work. This will benefit both the patients and social security, as they both will see their expenses reduced.
- To increase prevention, it is also important that **relatives of patients with a cardiomyopathy are empowered to be followed-up.** They may, for instance, be offered counselling, or they may be empowered and encouraged to get screened. Increasing data collection of genetic testing and screening, implementing a life-course approach to genetic screening, and enhancing cardiovascular symptom recognition among healthcare providers are key actions to improve awareness and tackle the disease. Additionally, it is crucial for the governments to tackle waiting times and access thresholds to specialist care.
- Explore the possibility of **developing a framework to inform the families of patients** with cardiomyopathies When considering the familial dimension, it becomes evident that ensuring that relatives of patients with cardiomyopathies receive appropriate information is of great significance.
- Given the multitude of diverse symptoms associated with cardiomyopathies, obtaining an exact diagnosis presents a formidable challenge. Consequently, it is advised by experts **that primary healthcare practitioners receive enhanced training in the field of cardiomyopathy, to facilitate diagnostic precision, and ensure timely referrals to specialist centers.** Additionally, it is imperative that cardiomyopathy patients are referred as early as possible to specialized healthcare centers for adequate treatment without delay.

3.1.2. Data collection and data sharing

Data collection, data sharing, and open access to databases, while abiding by all relevant privacy laws and regulations, play crucial roles in informing effective health policy, particularly in the context of cardiomyopathies. The availability of comprehensive and up-to-date data is essential for understanding disease patterns, evaluating interventions, and developing evidence-based policies. Belgium has made significant strides in developing a well-functioning system for heath data collection and sharing. The central eHealth portal serves as a crucial platform that connects all healthcare services in the country, enabling seamless data sharing among health professionals and scientists.[89] Additionally, governmental scientific organizations, such as Sciensano, actively gather data on general health status and infectious diseases.[90] However, when it comes to non-communicable diseases like cardiovascular diseases and genetically predisposed conditions such as cardiomyopathies, the available data remains very limited and outdated. This scarcity of accurate and up-to-date figures regarding cardiomyopathies poses a significant challenge for the healthcare system, as experts rightfully highlight. In the EU registry on cardiomyopathies by the ESC, Belgium is absent due to the scattered data caused by the complex distribution of competencies.

Efforts are being made in Belgium to establish a Health Data Agency (HDA), which will facilitate the secondary use of health data. One of the key tasks of the HDA will be to create a comprehensive data catalogue, classifying data sources based on factors like quality, age, origin, and openness. This systematic approach aims to streamline data accessibility and ensure transparency. Moreover, the HDA is envisioned to serve as a primary resource for individuals seeking health-related data, providing assistance and guidance for data inquiries. Through the HDA, data standardization and simplification will be implemented, presenting information in a user-friendly manner for the convenience of end users.[91]

Additionally, experts highlight the need for a framework on including molecular autopsy and post-mortem genetic analyses in data. As sudden cardiac death, especially in young people, could be explained by conducting these analyses and could offer valuable insights and data on the disease. However, policymakers should be aware of the ethical, privacy and legal hurdles. Creating a framework that takes all aspects into account ensures a better understanding of the disease which will eventually benefit the patients and our society.

Policy Recommendations

It is essential **to establish robust systems for data collection, analysis and surveillance in the healthcare sector to optimize evidence-based policymaking and qualitative care**.

- Gathering **data specifically on cardiomyopathies** is crucial to provide information on the prevalence, risk factors, treatment outcomes and evolution of this disease as part of a broader cross-border EU data-sharing system, potentially by the development of a registry on cardiomyopathies. While strictly abiding by all relevant laws and regulations, such an initiative would provide critical information on the prevalence, risk factors, and treatment outcomes of these conditions. This wealth of data would serve as a foundation for evidence-based policymaking and allow for the monitoring of progress over time.
- The **information gained from tracking data pertaining MRI, echocardiography and genetic testing** is essential in developing a complete understanding of the current situation regarding cardiomyopathies in Belgium. When combined with the future plans for centralized data collection and secondary data sharing, a comprehensive and accurate picture of the landscape can be formed, facilitating informed decision-making and targeted interventions.
- Additionally, explore the possibility of developing **a framework on molecular autopsy and post-mortem analyses**. To achieve a more comprehensive understanding of the disease, conducting analyses following instances of sudden cardiac death can provide vital information for research purposes and offer valuable insights for the affected family members.

Data is the basis for developing evidence-based optimalisations and solutions and is therefore crucial in tackling cardiomyopathies in a targeted manner.

3.1.3. Raising awareness, social inequality and access to specialist cardiology care

As outlined by the World Health Organization (WHO), CVDs rank as the primary contributors to global mortality and impairment, with a substantial portion of these instances being preventable through the management of behavioral risk elements such as smoking, unhealthy diet, physical inactivity, alcohol consumption, and stress.[92] Nevertheless, not all individuals possess an awareness of these risk factors or their own vulnerability to CVDs. Research underscores that a solid comprehension of behavioral risks and a heightened perception of personal susceptibility are pivotal drivers for embracing a health-conscious way of life and diminishing the likelihood of CVD development.[93,94] Consequently, the significance of screening and early detection of CVDs becomes evident, serving to apprise individuals of their health status and inspiring affirmative modifications in their conduct.

While data regarding this issue in Belgium is limited, a study conducted in the city of Antwerp revealed a substantial lack of knowledge among a portion of the population regarding CVDs. Specifically, in Antwerp, 65.9% were not aware of the familial predisposition to CVD. Furthermore, individuals with higher household incomes displayed greater intentions to adopt a healthy diet. Conversely, individuals of non-European origin exhibited lower intentions to maintain a healthy diet compared to their European counterparts. The level of education was significantly linked to CVD knowledge scores, risk perception, intention for physical activity, and intention for a healthy diet.[95] These findings are largely confirmed by similar studies conducted in other countries.[96,97]

Another observation is that, despite the very low level of economic inequality, there are still certain groups struggling financially to get out-of-pocket costs in terms of health expenditure. Due to Belgium's excellent social security care system, the cost of taking an MRI scan or genetic test is no impediment to patients covered by the obligatory single payer health insurance scheme.[98] Nonetheless, a recent analysis from the Belgian Health Care Knowledge Center (KCE), funded by the European Union, shows that Belgium exhibits one of the highest proportions of households experiencing catastrophic health spending compared to other Western European countries. According to the analysis, catastrophic health spending in Belgium is more heavily driven by out-of-pocket payments for medical products (hearing aids, glasses, dentures, and prostheses), outpatient medicines, diagnostic tests and outpatient care. In 2020, approximately 5.2% of Belgian households encountered such financial burdens. However, this percentage increases significantly to 8% for households headed by unemployed individuals and rises even further to 12% for households belonging to the poorest quintile of the population.[99]

Awareness raising campaigns to inform citizens and general practitioners about the urgency of a potential cardiomyopathy diagnosis could encourage individuals to consult a specialist in time. Additionally, HCP that do not specifically specialize in the field of CVD might be lacking information on cardiomyopathies which could lead to misdiagnosis.

Policy Recommendations

Improving policy: Raise early awareness of the risk factors (including genetics) and prevention measures on the disease promoting early diagnosis and adequate surveillance of relatives.

- The government must **empower individuals to recognize potential symptoms** by disseminating information through different channels in a way that reaches as many layers of society as possible. Through raising awareness among the general public, people are encouraged to recognize the disease and seek medical council. The early diagnosis resulting from this approach is beneficial in the treatment of the disease, potentially avoiding severe risks.
  - Health knowledge and literacy are not equally distributed among different education and income classes, leading to health inequalities. It is essential to prioritize initiatives aimed at diminishing these health inequalities associated with cardiomyopathies. **Government-led awareness initiatives must be designed to target and bridge this knowledge gap**, ensuring that individuals from all socioeconomic backgrounds have equal access to information on cardiomyopathies, prevention measures, diagnosis options and treatment services.
- **Enhanced training and awareness of the disease for all HCPs that do not specialize in the CVD field** is crucial in the timely recognition and diagnosis of the disease. This could potentially avoid misdiagnosis and by identifying the disease more quickly, it benefits the treatment options.
- Continue to closely monitor **policy initiatives** such as the reduction of screening costs and ensure that they achieve their intended goals, without getting drained in negotiations and/or implementation at lower power levels.

3.1.4. Patient support: holistic approach

Cardiomyopathies can exert a wide range of effects on patients' health and significantly impact their overall quality of life. The complex nature of these conditions often leads to evolving and multifaceted needs.[100,101] In order to address these needs effectively, it is crucial to conduct a comprehensive assessment of both patients and caregivers, taking into account their holistic well-being. By providing access to supportive care services, along with relevant information and tools, healthcare professionals can offer the necessary assistance to meet these diverse and evolving needs.

In recent years, patient-centered healthcare approaches have become increasingly popular and appear to be more effective. A strongly advised practice is the implementation of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). By PREMs, we mean instruments that measure a person's experience with healthcare or healthcare services such as waiting time, the quality of communication with staff, the involvement of the patient in making decisions, etc. PROMs are questionnaires about a person's perception of his or her state of health in which aspects such as symptoms, functional capacities, and self-reliance are evaluated.[102] PROMs enable clinicians to better understand how patients perceive the impact of the disease and treatment on their lifestyle and quality of life. As for PREMs, they enable patients to holistically reflect on the inter-personal elements of their healthcare experience, they can be used as a common measure for public reporting and benchmarking of institutions and healthcare plans, and they can provide patient-level information which is useful in driving service quality improvement strategies. [103,104] Pilot studies and working groups have been created in Belgium to explore the possibilities of PROMs and PREMs.[105,106] Those projects can only be encouraged and should shortly evolve into concrete plans of action to implement these ideas.

A second pillar in holistic support is the empowerment of patients, and the facilitation of shared decisions. Patient empowerment is understood as a joint process whereby patients and providers work in partnership to enhance patients' involvement in their health and health care. This can be done through increased information sharing between patients and physicians, simpler explanations of symptoms, treatment, and medicinal aspects, and empowering patients to weigh the costs and benefits to make decisions for themselves.[107] A fluid and accessible way to provide the patient with all information, costs and benefits in a bite-sized and understandable way is through a digital tool or, if necessary, an app.[108] A

similar interactive tool already exists in Belgium, created by the Federal Health Care Knowledge Centre (KCE) to help consider whether to take statin drugs after cardiovascular problems.[109]

Lastly, research demonstrates that social support and having a strong social environment significantly reduces the risk of cardiovascular diseases and alleviate symptoms in patients.[110,111] It is therefore crucial that the government prioritizes the provision of support groups, (online) discussion forums, meeting places, and similar resources for cardiovascular patients to provide them with a sense of community and additional psychological support.

Policy Recommendations

This discussion relates to mental health. Especially in the case of hereditary cardiomyopathies, there is a psychological burden associated with the knowledge of having a cardiomyopathy. People with hereditary cardiomyopathy have to cope with the stress of passing it on to their children, on top of dealing with the disease itself.

Due to all these different aspects, patients should receive qualitative long-term care that is aligned with their individual needs. Similarly, to a MOC (Multidisciplinary Oncology Consultation) in oncology[112], a multidisciplinary consultation could be beneficial in centering the patient in his or her treatment in collaboration with experts within different domains, as also recommended by the ESC guidelines on cardiomyopathies.[113] In this consultation, specialists from the relevant disciplines will review all tests and results, and then discuss a future treatment plan. This approach can provide the necessary expertise and standardize the follow-up and data management. This consult should include the cardiologist, geneticist, first line HCP, etc. To support HCPs as much as possible, the responsibility of the government is to facilitate this consult as much as possible.

Putting the patients and their families at the center is key to delivering optimal care and securing adherence to it in treating cardiomyopathies.

- Proactive measures should be taken to guarantee that individuals diagnosed with a cardiomyopathy can access comprehensive long-term care and rehabilitation services. Authorities should **invest in a multidisciplinary approach to cardiomyopathies that has the patients and their family at heart, as recommended by the new 2023 European guidelines for the management of cardiomyopathies.** Authorities should also **guarantee that patients and their families are able to refer to multidisciplinary teams**[114]. This approach requires coordination between health experts for diagnosis, assessment, and management of patients with cardiomyopathy, in order to provide the patient with an "*individualized pathway that delivers optimized care and lifestyle advise by a multidisciplinary and expert team*".[115] The concept of 'individualized pathway' implies that the composition of the multidisciplinary team can vary, depending on the patient's and the family's needs.[116]
- It is fundamental **to incorporate PROMs and PREMs in the healthcare system taking into account the patient experience**. By funding and supporting platforms for patients to connect, local support groups and patient advocacy organizations, the patient effectively engages in his/her journey. Additionally, the patient is supported through a network that provides, among others, the needed emotional support.
- Initiatives that **support the creation of online platforms or directories that connect individuals** with similar experiences, local support groups, or community resources must be encouraged. Additionally, the governments can allocate additional funding to support patient advocacy organizations that provide emotional support, educational resources, and opportunities for individuals to connect with others facing similar challenges.
- The population needs to be proactively **educated about the benefits of social support networks** and individuals should be encouraged to seek and maintain strong social connections. Family, friends and community support can be instrumental in ensuring early diagnosis, especially when dealing with a hereditary cardiomyopathy.
- **Implement digital health tools** to empower self-care and foster collaborative decision-making.

3.1.5. A strong ecosystem for R&D, innovation and clinical trials

With the objective of achieving the Europe 2020 targets[117], specifically to increase the share of research and development (R&D) expenditure in Global Domestic Product (GDP) to 3%, the Belgian government has implemented robust tax incentives to promote R&D activities starting from 2005. These measures have proven effective, particularly due to the spillover effect that positively impacts other sectors.[118] Today, Belgium ranks among the top countries, along with Sweden, with the largest expenditure on research & development (R&D) in the European Union, when considering the percentage of gross domestic product at 3.5%.[119] In light of this success, Belgium should keep following that path to foster a strong R&D ecosystem. Belgium should consider healthcare as an investment, and not as a cost. It should acknowledge the significance of innovative therapies that have a clear added value, including those therapies that target CVDs.

As CVDs are the leading cause of death in Belgium, additional research in the field of cardiomyopathies in Belgium could yield numerous benefits. Firstly, it would stimulate advancements in understanding the causes, prevention strategies, and innovative treatment options for these diseases. Such research has the potential to result in reduced economic burdens associated with cardiovascular conditions, improved health outcomes for patients, and increased well-being within their social environment, especially as cardiomyopathies affect a young population with therefore major societal impact.

Moreover, the spillover effects of supporting research in cardiomyopathies can extend beyond the immediate healthcare sector. By investing in R&D activities focused on cardiomyopathies, knowledge and innovations can permeate other related fields, leading to advancements in medical technology, pharmaceuticals, and healthcare services. This, in turn, would contribute to overall societal progress, improved patient care, and increased happiness among individuals affected by cardiomyopathies.

Furthermore, clinical trials, a domain in which Belgium excels as one of the top-tier countries in the European Union thanks to its world-renowned expertise, high-quality staff and centers of excellence, can help reach those objectives. They can also ensure that patients have fast(er) access to innovative therapies in Belgium. Cardiogenetics and precision medicines also represent great opportunities related to cardiomyopathies and cardiovascular diseases in general which should be further explored in Belgium, so that Belgium plays a leading role in that field.

Additionally, it is important to acknowledge the significance of reimbursement policies for medicines targeting cardiomyopathies. It is essential to prioritize the maximization of support and reimbursement for innovative treatments, including those that tackle CVD's. Thanks to that, Belgium can also further bolster its position as a frontrunner in research and development, particularly in the realm of cardiomyopathies and cardiovascular diseases. Such efforts would ultimately foster a comprehensive approach to tackling these conditions, benefiting both patients and the overall healthcare landscape.

Policy Recommendations

Resources should be allocated to **support research and development in the field of cardiomyopathies.** This can facilitate the discovery of innovative treatments, diagnostic tools, and preventive interventions. Collaborations between academia, industry, and healthcare providers can be fostered to accelerate progress in CVD and cardiomyopathy research. Improved understanding of cardiomyopathy enables healthcare professionals to implement more effective interventions, resulting in better patient outcomes and an overall reduction in disease burden.

- The **development of precision medicines** is strongly encouraged, intensifying efforts in tailoring healthcare to the needs and genetic profiles of patients with cardiomyopathies. By identifying specific genetic mutations and physiological factors driving these conditions, precision medicines can target the root causes more effectively.

3.1.6. Lifestyle

Lifestyle measures are important to ensure that cardiomyopathy patients stay as healthy as possible while encouraging adherence to disease-modifying drugs. It is well documented that unhealthy dietary patterns, tobacco use, excessive alcohol consumption, and chronic stress contribute to an increased risk of developing a cardiovascular disease[120,121] and worsen the manifestation of cardiomyopathies. As previously mentioned, it is crucial for patients with cardiomyopathies to manage the intensity of sport activities by seeking appropriate counsel as well as closely monitor the hereditary aspect of the disease. Lifestyle can have an impact on the disease, however, in many cases, the hereditary aspect takes the upper hand, emphasizing the need for screening and early detection.

Policy Recommendations

Public health initiatives, education, and policy interventions are essential in promoting awareness and fostering environments that **encourage healthier lifestyle choices**, ultimately leading to a decrease in the incidence and burden of cardiomyopathies in society.

- International best practices solve this by reorienting their health systems towards health promotion and disease prevention, **integrating lifestyle assessment and intervention into the practice of primary care professionals** (and linking it to community resources). Examples include Spain's "prevention and health promotion strategy of the Spanish National Health Service"[122], and France's "National sports and health strategy 2019-2024"[123].

4. Summary of the policy recommendations

The large and steadily rising number of Belgians suffering from differing forms of CVD calls for an ambitious Interfederal Cardiovascular Health Action Plan implemented in consultation and cooperation with the regions and with all relevant stakeholders. Improvements and extra attention should be considered at every stage of treatment: prevention and awareness, correct and prompt diagnosis, access to the best possible treatment, and qualitative aftercare. However, cardiomyopathies in particular deserve extra attention given the vast underdiagnosis of these diseases and the sometimes-underexposed genetic aspect underlying them. Additionally, cardiomyopathies affect, unlike most CVDs, mostly people that are young and active, resulting in a significant burden for our society.[124,125]

4.1.1. Screening, early detection & prevention

To address cardiomyopathies effectively, it is crucial to **emphasize screening and early detection of the disease, as well as timely identification of patients at high risk**.

- This includes **promoting better targeted check-ups and intervention through risk assessment, relevant tests, and guidance** on maintaining a healthy lifestyle even for seemingly healthy individuals. Regular checkups provide an opportunity for healthcare professionals to assess risk factors, conduct relevant tests, and offer guidance on maintaining a healthy lifestyle while allowing earlier detection of cardiomyopathies.
- Particular attention should be paid **to prevention and screening among the younger population at risk.** They tend to be more affected by cardiomyopathies. Increasing prevention and screening among the younger populations can help avoid hospital stays and get more people at work. This will benefit both the patients and social security, as they both will see their expenses reduced.
- To increase prevention, it is also important that **relatives of patients with a cardiomyopathy are empowered to be followed-up**. They may, for instance, be offered counselling, or they may be empowered and encouraged to get screened. Increasing data collection of genetic testing and screening, implementing a life-course approach to genetic screening, and enhancing cardiovascular symptom recognition among healthcare providers are key actions to improve awareness and tackle the disease. Additionally, it is crucial for the governments to tackle waiting times and access thresholds to specialist care.
- Explore the possibility of **developing a framework to inform and support the families** of patients with cardiomyopathies. When considering the familial dimension, it becomes evident that ensuring that relatives of patients with cardiomyopathies receive appropriate information is of great significance.
- Given the multitude of diverse symptoms associated with cardiomyopathies, obtaining an exact diagnosis presents a formidable challenge. Consequently, it is advised by experts that **primary healthcare practitioners receive enhanced training in the field of cardiomyopathy, to facilitate diagnostic precision, and ensure timely referrals to specialist centers**. Additionally, it is imperative that cardiomyopathy patients are referred as early as possible to specialized healthcare centers for adequate treatment without delay.

4.1.2. Data collection and data sharing

In general, it is essential **to establish robust systems for data collection, analysis and surveillance in the healthcare sector to optimize evidence-based policymaking and qualitative care**.

- Gathering **data specifically on cardiomyopathies** is crucial to provide information on the prevalence, risk factors, treatment outcomes and evolution of this disease as part of a broader

cross-border EU data-sharing system, potentially with the development of a registry on cardiomyopathies. While strictly abiding by all relevant laws and regulations, such an initiative would provide critical information on the prevalence, risk factors, and treatment outcomes of these conditions. This wealth of data would serve as a foundation for evidence-based policymaking and allow for the monitoring of progress over time.

- The **information gained from tracking data pertaining to MRI, echocardiography and genetic testing** is essential in developing a complete understanding of the current situation regarding cardiomyopathies in Belgium. When combined with the future plans for centralized data collection and secondary data sharing, a comprehensive and accurate picture of the landscape can be formed, facilitating informed decision-making and targeted interventions.
- Additionally, explore the possibility of developing **a framework on molecular autopsy and post-mortem analyses**. To achieve a more comprehensive understanding of the disease, conducting analyses following instances of sudden cardiac death can provide vital information for research purposes and offer valuable insights for the affected family members.

Data is the basis for developing evidence-based optimalisations and solutions and is therefore crucial in tackling cardiomyopathies in a targeted manner.

4.1.3. Raising awareness, social inequality and access to specialist cardiology care

Raise early awareness on the risk factors (including genetics) and prevention measures on the disease promoting early diagnosis and adequate surveillance of relatives.

- The government must **empower individuals to recognize potential symptoms** by disseminating information through different channels in a way that reaches as many layers of society as possible. Through raising awareness among the general public, people are encouraged to recognize the disease and seek medical counsel. The early diagnosis resulting from this approach is beneficial in the treatment of the disease, potentially avoiding severe risks.
  - Health knowledge and literacy are not equally distributed among different education and income classes, leading to health inequalities. It is essential to prioritize initiatives aimed at diminishing these health inequalities associated with cardiomyopathies. **Government-led awareness initiatives must be designed to target and bridge this knowledge gap**, ensuring that individuals from all socioeconomic backgrounds have equal access to information on cardiomyopathies, prevention measures, diagnosis options and treatment services.
- **Enhanced training and awareness of the disease for all HCPs that do not specialize in the CVD field** is crucial in the timely recognition and diagnosis of the disease. This could potentially avoid misdiagnosis and by identifying the disease more quickly, it benefits the treatment options.
- Continue to closely **monitor policy initiatives** such as the reduction of screening costs and ensure that it achieves its intended goals, without getting drained in negotiations and/or implementation at lower power levels

4.1.4. Patient support: holistic approach

Putting the patients and their families at the center is key to delivering optimal care and securing adherence to it in treating cardiomyopathies.

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- **Implement digital health tools** to empower self-care and foster collaborative decision-making.

4.1.5. A strong ecosystem for R&D, innovation and clinical trials

Resources should be allocated to **support research and development in the field of cardiomyopathies.** This can facilitate the discovery of innovative treatments, diagnostic tools, and preventive interventions. Collaborations between academia, industry, and healthcare providers can be fostered to accelerate progress in CVD and cardiomyopathy research. Improved understanding of cardiomyopathy enables healthcare professionals to implement more effective interventions, resulting in better patient outcomes and an overall reduction in disease burden.

- The **development of precision medicines** is strongly encouraged, intensifying efforts in tailoring healthcare to the needs and genetic profiles of patients with cardiomyopathies. By identifying specific genetic mutations and physiological factors driving these conditions, precision medicines can target the root causes more effectively.

4.1.6. Lifestyle

Public health initiatives, education, and policy interventions are essential in promoting awareness and fostering environments that **encourage healthier lifestyle choices**, ultimately leading to a decrease in the incidence and burden of CVD and avoiding the worsening of cardiomyopathy symptoms in society.

- International best practices solve this by reorienting their health systems towards health promotion and disease prevention, **integrating lifestyle assessment and intervention into the practice of primary care professionals** (and linking it to community resources). Examples include Spain's "prevention and health promotion strategy of the Spanish National Health Service"[129], and France's "National sports and health strategy 2019-2024"[130].

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