European Heart Network
Fighting heart disease and stroke

Volume I.

# Empowering individuals with cardiovascular disease (CVD) through advocacy: A comprehensive guide


The 'EHN Patients Advocacy Handbook,' developed by the European Heart Network (EHN), aims at equipping individuals with cardiovascular disease (CVD) with the knowledge and tools to advocate effectively for their rights, better prevention and care, and policy change.

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# Introduction

## Purpose and scope of the handbook

The purpose of this handbook is to empower patients living with cardiovascular disease (CVD) by providing the knowledge, skills, resources, and practical guidance needed to advocate effectively for their rights, quality care, and supportive policies. The ultimate goal is to enable individuals to engage with decision-makers, actively shape policies, and drive positive change in cardiovascular health.

The scope of this handbook includes key facts and figures related to CVD, such as their prevalence, risk factors, and associated inequalities, as well as the economic burden it poses. It outlines key advocacy opportunities at local, national, and European levels, providing guidance on engaging with policymakers, leveraging key health-related events, and navigating institutional processes. Additionally, the handbook offers practical strategies for effective advocacy, including stakeholder mapping, targeted messaging, and post-meeting follow-ups, equipping CVD patients with the tools to drive meaningful change in healthcare policies and patient rights.

## What's advocacy?

Advocacy in healthcare policy is the active effort to inform and influence decisions, policies, and practices to improve health outcomes and equity. It involves amplifying patient and community needs, shaping legislation, and driving systemic change through research, education, and policy engagement.

## Patient advocacy as a force for positive change

At its core, your advocacy efforts serve as a mechanism for translating your patient experiences and needs into tangible policy reforms and legislative actions.

Effective advocacy bridges the gap between evidence and action, ensuring that healthcare systems are fair, accessible, and responsive to public health challenges and reflect the outcomes that matter to patients.

By sharing their experiences and expertise, patients with CVD can encourage researchers, funding bodies, policymakers, and legislators to prioritise initiatives that enhance access to care, increase research funding, and strengthen preventive measures. Advocacy not only empowers individuals but also contributes to a collective movement for systemic change, ensuring better cardiovascular health outcomes for communities worldwide.

# A word from patients

Hearing from those who have firsthand experience of living with chronic conditions can be incredibly valuable for newly diagnosed patients and their families. Below are testimonials from individuals who are actively involved in patient advocacy. Some have chosen to remain anonymous, while others share their names to inspire change and awareness.

"Due to my illness and the lack of resources in the regional healthcare system in the early 2000s, I became an advocate for change. In 2006, we proposed a Non-Legislative Proposal in the Parliament of the Canary Islands to secure economic improvements for patients. This initiative led to the enactment of a Decree, which regulates financial aid and non-contracted patient transportation within the Canary Islands Health Service. My journey has taught me the value of perseverance in achieving systemic change."

Anonymous, Spain

"Through the Diabetes Association of Madrid, I have become more aware of my condition and the importance of patient advocacy. My advice to others is to stay informed and get involved in patient organisations—it makes a real difference."

Anonymous, Spain

"A few years ago, I was diagnosed with ATTR Amyloidosis. On January 19, 2024, we founded AmyBel—the first Belgian association for patients with all types of amyloidosis. In April 2025, we will hold our first Patient Day, and we actively distribute brochures to educate our members about the disease. AmyBel has successfully raised awareness through public and specialised media."

Denis, Belgium

"At 17, my Atrial Fibrillation was misdiagnosed as anxiety, and I was prescribed antidepressants. A decade later, a colleague mentioned needing surgery for symptoms just like mine. That conversation pushed me to seek a second opinion—where I finally received the correct diagnosis and proper treatment. Don't hesitate to ask questions, seek second opinions, or request further tests. Most importantly, share your story—it could save lives."

Mehitabel, Italy

# Part 1:
# Understanding Cardiovascular Diseases (CVD)

## Key Facts and Figures

Before engaging in any discussion, it is essential to understand the broader impact of the topic at hand. In the case of CVD, while personal stories help humanise the issue, numbers provide a clear picture of its scale. The following section highlights key trends at the broader European level. For country-specific data, refer to national observatories and WHO Europe statistics.

## Mortality

- CVD are the leading cause of death in Europe,[1] responsible for 3.9 million deaths – or 45% of all fatalities – annually out of a total population of 748 million people. In the EU, CVD account for over 1.8 million deaths – or 37% of total deaths – every year. To put this into perspective, 1.8 million people are equivalent to the entire population of European cities such as Vienna, Barcelona, Warsaw, Budapest, Milano or Hamburg. This translates to approximately 4,600 deaths per day the across the EU.[2,3]
- The main forms of CVD are Ischemic Heart Disease (IHD) and Stroke, with the former representing the leading single cause of premature mortality under 65 in both men (248,000 deaths, 16%) and women (76,121 deaths, 11%).[4]
- In 2019, CVD accounted for over 10.4 million Disability-Adjusted Life Years (DALYs) in the EU due to dietary risks alone. Additionally, low physical activity contributed approximately 1.08 million DALYs to CVD, while tobacco use was responsible for over 5.25 million DALYs. Alcohol consumption also played a significant role, contributing approximately 1.26 million DALYs to the CVD burden.[5]

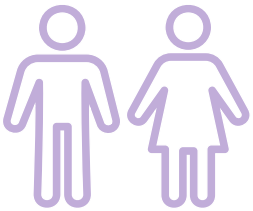
1 https://ehnheart.org/wp-content/uploads/2023/07/CVD-Statistics.pdf
2 https://ehnheart.org/wp-content/uploads/2023/08/CVD-Plan-digital-edition.pdf
3 https://www.flipsnack.com/escardio/eu-27-cardiovascular-realities-2025/full-view.html
4 https://ehnheart.org/wp-content/uploads/2023/07/CVD-Statistics.pdf
5 https://knowledge4policy.ec.europa.eu/health-promotion-knowledge-gateway/eu-burden-non-communicable-diseases-key-risk-factors_en

**CVD is also a major cause of disability and reduced quality of life, impacting the lives of some 60 million people who live with CVD in the European Union.[6]**

# European Cardiovascular Disease Mortality Burden

- Each year cardiovascular disease (CVD) causes **3.9 million deaths in Europe** and over **1.8 million deaths in the European Union (EU)**.
- CVD accounts for **45% of all deaths in Europe and 37% of all deaths in the EU.**

CVD is the **main cause of death in men in all but 12 countries of Europe** and is the **main cause of death in women in all but two countries.**



The main forms of CVD are **ischaemic heart disease (IHD)** and **stroke**.

Death rates from both ischaemic heart disease (IHD) and stroke are generally higher in Central and Eastern Europe than in Northern, Southern and Western Europe.

**CVD mortality is now falling in most European countries**, including Central and Eastern European countries which saw considerable increases until the beginning of the 21st century.



European Cardiovascular Disease Statistics 2017 edition, European Heart Network: https://ehnheart.org/wp-content/uploads/2023/07/CVD-Statistics.pdf

6 https://www.escardio.org/static-file/Escardio/Advocacy/Documents/EHHC-Brochure-2023.pdf

## Prevalence

- Each year, over 6 million new cases of CVD are diagnosed in the EU, with 62 million people living with CVD to date.[7,8]
- In 2021, there were 8.6 million in-patient discharges for diseases of the circulatory system across the EU.[9]

## Risk factors

- Risk factors can be categorised into **biological**, **behavioural**, and **environmental** determinants.
- **Biological determinants**, such as high blood pressure, high cholesterol, and diabetes, are modifiable or non-modifiable physiological conditions that increase risk.
- **Behavioural determinants** include diet, physical activity, smoking, and alcohol consumption. It is worth noting that, while behavioural determinants are often framed as personal choices, they are significantly shaped by the broader environment, including food availability, workplace conditions, urban planning, and social structures, which influence individual decision-making and health outcomes.
- **Environmental determinants** encompass factors such as air pollution, socioeconomic conditions, and workplace exposures.
- The primary causes of death from CVD in the EU include high blood pressure, dietary risks. In 2019, unhealthy diets were linked to 672,923 CVD-related deaths, while smoking contributed to 232,576 deaths. Low physical activity resulted in 92,473 CVD deaths, and alcohol use was responsible for approximately 60,253 deaths. These risk factors collectively contribute to a significant portion of the CVD mortality burden in the EU.[10]
- High blood pressure is a key biological risk factor for CVD but often goes undetected, untreated or uncontrolled.
- Similarly, cholesterol is a critical biological risk factor for CVD that can often go undetected, untreated, or poorly managed. Elevated levels of LDL cholesterol, commonly known as 'bad' cholesterol, can lead to the buildup of plaques in the arteries, increasing the risk of heart attack and stroke.[11]

7 https://research-and-innovation.ec.europa.eu/research-area/health/cardiovascular-diseases_en
8 https://www.flipsnack.com/escardio/eu-27-cardiovascular-realities-2025/full-view.html
9 https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Cardiovascular_diseases_statistics
10 Ibid
11 https://www.ahajournals.org/doi/10.1161/CIRCULATIONAHA.122.061010?utm_source=chatgpt.com

## Inequalities and CVD

- The burden of CVD varies across European countries, with higher mortality rates in Central and Eastern Europe compared to other regions. The highest standardised death rates for CVD are recorded in Bulgaria, Latvia, Romania and Lithuania. By contrast, the lowest rates are recorded in France, Ireland and Luxembourg.[12]

- Over three-quarters of CVD deaths take place in low- and middle-income countries.[13]

- Inequalities in mortality from CVD account for almost half of the excess mortality in lower socio-economic groups in most European countries.[14]

- Despite being the leading cause of death among women in the WHO European Region, CVD has long been under-researched in women, leading to gaps in diagnosis, treatment, and prevention. In Europe, CVD accounts for 45% of fatalities in women and 39% in men,[15] yet much of the medical research and clinical guidelines have historically been based on male-centric data. This has resulted in misdiagnosis, delayed treatment, and a general underestimation of heart disease risk in women.

- Within 30 days of a heart attack, 11.8% of women had died compared to 4.6% of men, and at five years, 32.1% of women had died versus 16.9% of men.[16] While this is partly related to women's longer life span, women are more likely to be misdiagnosed, particularly younger women, which leads to longer delays in receiving appropriate care.[17]

- Gender inequalities are also present in the development of new treatments for CVD, where less than 27% of participants in clinical trials in the EU are women.[18]

12 https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Cardiovascular_diseases_statistics#Deaths_from_cardiovascular_diseases
13 https://www.who.int/news-room/fact-sheets/detail/cardiovascular-diseases-(CVD)
14 https://ehnheart.org/wp-content/uploads/2023/08/CVD-Plan-digital-edition.pdf
15 https://ehnheart.org/wp-content/uploads/2023/07/CVD-Statistics.pdf
16 https://www.escardio.org/The-ESC/Press-Office/Press-releases/Women-more-likely-to-die-after-heart-attack-than-men
17 https://pmc.ncbi.nlm.nih.gov/articles/PMC10945154/
18 https://ehnheart.org/wp-content/uploads/2023/08/CVD-Plan-digital-edition.pdf

## Economic burden of CVD:

In 2017, the annual cost of cardiovascular diseases in the EU amounted to €210 billion, including €111 billion in healthcare costs, €54 billion in productivity losses, and €45 billion in informal care costs.[19] In 2021, this has risen to €282 billion.[20]

### European Cardiovascular Disease Economic Costs

Overall CVD is estimated to cost the EU economy



**€210** billion a year.



Of the total cost of CVD in the EU, around:

**53%** (€111 billion)
is due to **healthcare costs,**

**26%** (€54 billion)
to **productivity losses**, and



**21%** (€45 billion)
to the **informal care of people with CVD.**

European Cardiovascular Disease Statistics 2017 edition, European Heart Network:
https://ehnheart.org/wp-content/uploads/2023/07/CVD-Statistics.pdf

19 https://ehnheart.org/wp-content/uploads/2023/07/CVD-Statistics.pdf
20 https://www.flipsnack.com/escardio/eu-27-cardiovascular-realities-2025/full-view.html

# Part 2:
# Advocacy opportunities

## 2.1 Key advocacy channels: some examples

### At the local and regional level:

**Local and regional politicians**

Engage with city council members, mayors, and regional representatives to advocate for improved funding of awareness campaigns and access to CVD treatments and healthcare services. Additionally, you can support and advocate for educational programs aimed at promoting healthy lifestyles in both workplaces for adults and schools for adolescents and children. These programs can include information on proper nutrition, physical activity, and the importance of regular health screenings.

**Local NCDs stakeholders**

Attend and participate in local health events to spread messages as well as to network and build connections with other NCDs' community representatives, joining forces and identifying common asks to amplify efforts and increase leverage vis-á-vis decision-makers.

**Local communities**

Participate in public information sessions and health screenings to educate communities on CVD prevention and management. Connect with community leaders, schools, and workplaces to promote heart-healthy lifestyles through structured programs and challenges.

**At national level:** in close collaboration with the patient organisation you belong to:

### National politicians

Communicate with members of parliament, congress or national health ministries about the importance of prioritising CVD research, funding, and healthcare policies. Liaising with your national government can impact how resources, including EU funding like Horizon, are allocated and ensure that CVD remains a key focus in public health initiatives.

National food policies and regulations, for example, can play a crucial role in CVD prevention, also considering the rising rates of obesity and diet-related health issues in the EU, where 50.6% of adults aged 16 and over in the EU are considered overweight as of 2022. By implementing measures such as reducing sugar content in everyday products, regulating food marketing, and promoting accessible nutrition education, policymakers can significantly impact public health.

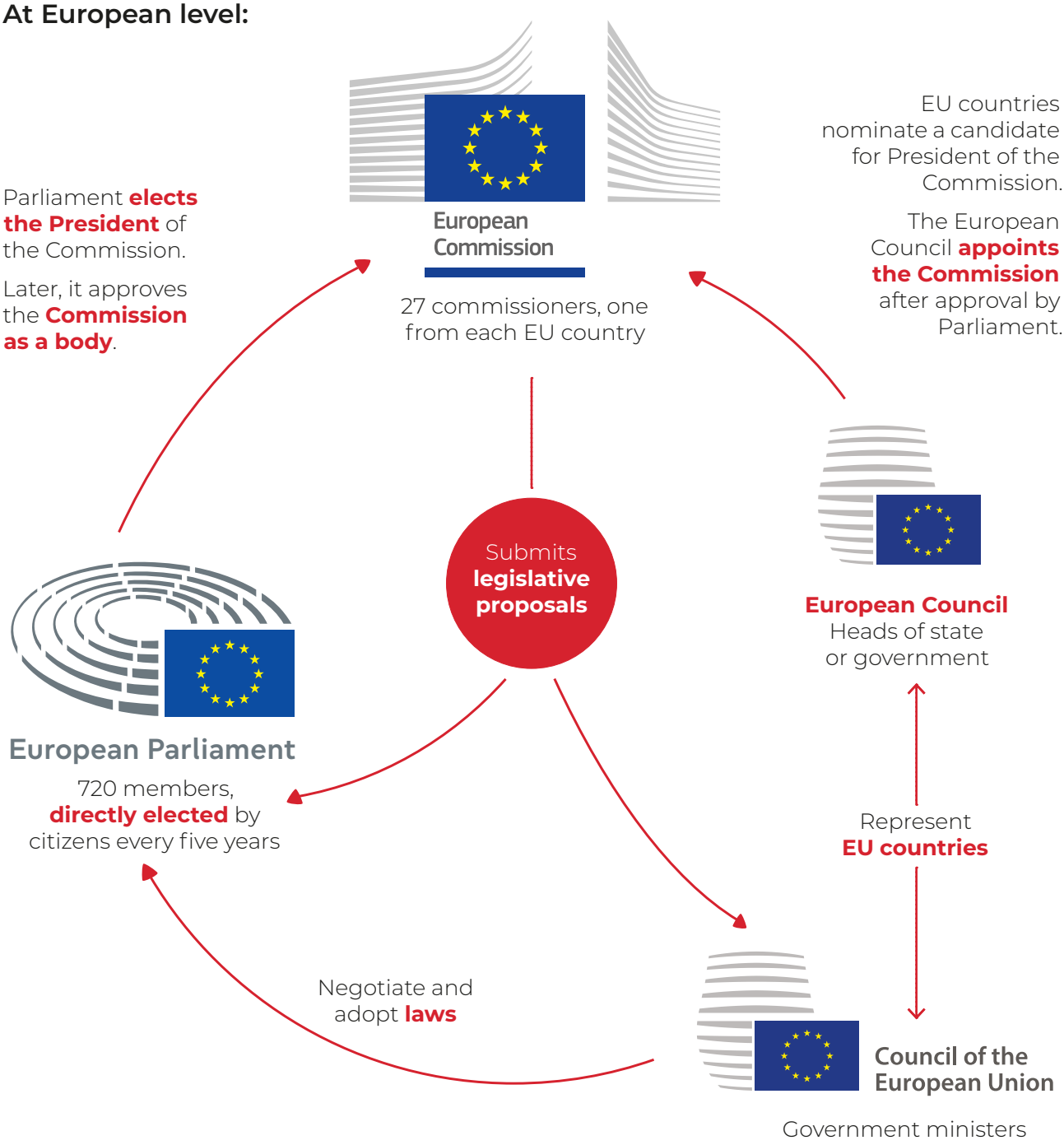
### National public

Leverage opportunities – TV, radio, and online platforms – to inform the public on CVD risks and preventive measures. Leverage social media influencers, patient testimonials, and interactive campaigns to reach broader audiences. Join the organisation of national awareness days (see lists below) to rally support and spark conversations about cardiovascular health.

### Health and Patient organisations

If you are not part of a patient organisation yet, do consider getting involved and participating in their activities in your region, e.g. contribute to their message with your own experience. Organisations have access to a wider network of stakeholders and policymakers and can help you amplify your voice.

## At European level:




European Parliament

*The roles of the main EU institutions and how they interact, European Parliament,* https://www.europarl.europa.eu/topics/en/article/20240524STO21650/what-do-the-eu-institutions-do-infographic

**EHN facilitates patient advocacy at European Union level through its members organisations by identifying opportunities and involving patient advocates in advocacy campaign strategies, and engagement opportunities, to enable you to contribute your unique and invaluable perspectives. The following outlines key European-level institutions and how patient voices can make an impact through EHN coordinated initiatives.**

## European Parliament (EP)

Represents EU citizens and influences legislation. Key interlocutors: SANT (Health), EMPL (Employment & Social Affairs), and AGRI (Agriculture & Rural Development) Committees, which address health policy, social protection, and nutrition-related health factors. Reach out to Members of the European Parliament (MEPs) from your country, especially those on relevant committees, to share patient experiences and advocate for stronger cardiovascular health policies. Participate in public consultations and parliamentary hearings related to health policy.

## Council of the EU

Represents national governments and adopts legislation. Health attachés from Member States negotiate health policies, making them crucial contacts for advocating stronger patient rights. You can submit position papers and recommendations to health attachés and national delegations as well as engaging with national government representatives, particularly health ministry officials, who contribute to EU-level discussions.

### European Commission (EC)

Proposes laws and ensures implementation. DG SANTE (Directorate-General for Health & Food Safety) develops health policies, supports research, and funds initiatives improving patient care. Participate in the European Commission's stakeholder consultations, which seek input when drafting policies and funding priorities. Attend EU health forums, conferences, and expert group meetings where Commission representatives discuss upcoming initiatives.

### Wider EU public

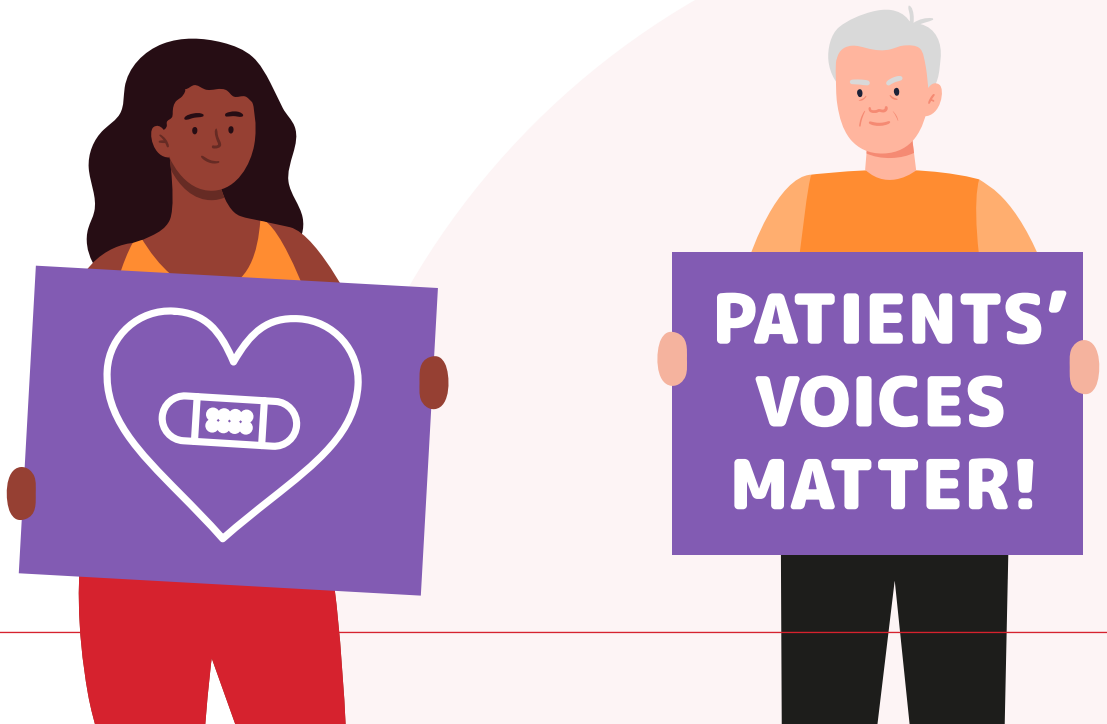
Participate in Europe-wide events in cooperation with key, like-minded stakeholders, encouraging cross-border collaboration in promoting cardiovascular well-being.

**Important Organisations at EU level which EHN works with:**

EPF European Patients Forum

EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

ESC European Society of Cardiology



## 2.2 Key moments for advocacy

**European Level:** in close collaboration with EHN

### Official sittings:

- **The European Parliament** convenes regularly into public meetings both at committee level – in Brussels, roughly twice a month- and in plenary sittings – in Strasbourg, usually once per month -. MEPs are usually rather approachable before and after such meetings, representing an interesting opportunity to connect with them and connect your asks to the topics being discussed in the session. Find 2025 programme for the EP here. The European Parliament also holds public hearings within its committees, where experts, stakeholders, and patient organisations are often invited to present their views on relevant issue.
- **The Council of the EU** convenes regularly to discuss health-related matters in the EPSCO configuration **(Employment, Social Policy, Health and Consumer Affairs Council).** Such meetings, partly public, are attended by health attachés representing each of the 27 EU Member States, offering an opportunity to follow key discussions and communicate messages.

**Council Presidencies**: Every semester a different EU Member State holds the **rotating presidency** of the **Council of the EU**. The presidency country **sets priorities, chairs meetings, and drives negotiations** on legislative files and policy initiatives. Each presidency prepares a **work programme** outlining its key focus areas, which significantly influence policy discussions, including those on **health and patient rights**. Engaging early with upcoming presidencies is crucial to ensure cardiovascular disease policies are prioritised in their agenda. A list of future presidencies can be found here.

**Stakeholders Consultations:** Stakeholder consultations conducted by the European Commission are an essential part of policymaking, allowing for input from a wide range of interested parties. These consultations can take two main forms: written consultations, such as calls for feedback or evidence on specific policy proposals, and events like workshops or public hearings. Selecting the right consultations and actively participating in them is crucial for ensuring that the views and needs of the CVD patients' community are heard, ultimately helping to inform and shape the Commission's work to create more effective policies.

**Multi-stakeholders' events:** Both in Brussels and at national level, it is very common to hold multi-stakeholders events where European decisionmakers are invited to participate as speakers. Such events provide a platform to approach policymakers and communicate your messages, potentially linking them with their intervention at the given event.

**Bilateral meetings:** European decision-makers are usually open to take meetings with stakeholders, especially when these represent their constituency/country. Bilateral meetings can be set up to discuss strategies in line with the policymaker's agenda and national priorities in the context of CVD. Such meetings necessitate preparation to understand the policymaker background and position and deliver asks in a compelling way. Ask your national health organisation if they have templates you could use.

## Regional, national and local levels:

Similar advocacy efforts can be tailored to national, regional, and local contexts, leveraging pertinent dates and occasions to maximise outreach and impact. This may include:

- Support local health authorities and/or your organisation of affiliation to conduct awareness events or workshops.
- Engaging with community leaders and influencers to advocate for policy changes or initiatives that promote cardiovascular health.

### Tip!

Beyond the widely recognised World Heart Day on 29 September, EU member states observe additional national awareness days or months dedicated to cardiovascular health. Check for such initiatives in your own country with the EHN national member and take the opportunity to participate in activities, share your experiences, and raise awareness on social media to amplify the message.

# Part 3:
# Effective advocacy strategies

Please find here some tips and advice for effective communication with policymakers, including how to articulate personal experiences and concerns:

## 3.1 Find your representative(s): get to know your legislators

Map the stakeholders who work on health and healthcare in the municipality, the region, national or at European level. EHN member organisations, which are present in your country, will help you in this excercise.

Understanding the priorities and advocacy channels of your representatives can help tailor your messaging to align with regional healthcare agendas. Map out their affiliations, legislative priorities, and key stakeholders can guide your advocacy strategies.

European Representatives: For advocacy efforts spanning beyond national borders, it's essential to engage with MEPs and other EU officials who influence healthcare policies at the European level. Researching their committee assignments, policy interests, and participation in cardiovascular health initiatives can inform targeted advocacy campaigns within the European Union.

**Mapping exercise**

Before approaching decisionmakers, make sure you have the answers to the following questions:

- What are their current interests and priorities?
- Do they have a role in committees that oversee health policy?
- What are their positions?
- Where do they stand on the issue/problem and on the solutions you are proposing?
- What aspects of your proposal are they likely to question?
- What will motivate them to support your proposal?
- How could they benefit from your proposal?
- Are they facing an election this year?

**Tip!**

You can also check on their personal history: Do you have anything in common? If you can't identify the right person, contact your mayor, local MP or MEP and ask to refer you to the competent colleague.

## 3.2 Target your message to the specific person/ organisation you are engaging with

Don't lose sight of your value and authority as an advocate. **Make sure you establish your credibility when engaging with those you seek to inform – ideally at the very onset of your conversation.**

**Ask yourself: Why should they listen to you? Your authority comes from the legitimacy you hold in the eyes of the person you are trying to inform.**

- **Expertise and knowledge-based legitimacy**: in your case, developed through firsthand experience of living with a condition and managing it daily. This lived experience provides deep, practical insights that are invaluable in understanding the real-world challenges and needs associated with the condition.
- **People-based legitimacy:** gained through working with the people affected by a given issue.
- **Cause-based legitimacy:** your legitimacy may come from a cause or mission which resonates with your interlocutor(s) priorities or which, according to the results of your research, they have been a longstanding supporter of.

**Tip!**

Prior to an advocacy meeting, practice introducing yourself in 20 seconds in a way that establishes your legitimacy and credibility. Practise answering the question: Who are you and why should I listen to you?

## 3.3 Reach out

After identifying their email or phone number, which you can normally find on their institutional webpages, **establish first contact, sending them a message to introduce yourself/the organisation you are part of.**

**Tailor your advocacy message to your target audience**! This will depend on the person or institution you are meeting. The language and the amount of detail you use will likewise depend on your interlocutor:

- Are you communicating your message in public to ordinary citizens or in the media? Keep the message short and snappy.
- Are you communicating the message to a civil servant in a private meeting?
  - Are they already quite well-versed in the topic (e.g. based on their education/professional background)? Skip the basic concepts and go straight to the reason why you are meeting them, avoiding "lecturing" them on a topic they are already familiar with. Make sure you acknowledge their experience and share yours as additional knowledge to inform their work.
  - Are they rather new to the topic (e.g. no previous educational/professional experience)? Make sure you provide them with some brief, concise background information, contextualising the issue and the solutions you are proposing.

**Tip!**

Focus on opportunities for collaboration, even if you don't align on every issue. If a policymaker is willing to support a cause you care about, take the win and use it as a chance to build bridges. Finding common ground can help create momentum for positive change.

However, be mindful that in some countries, certain parties or politicians may not be suitable partners due to scandals, highly controversial positions or legal disputes. In such cases, it's best to avoid engagement—local advocates will have the best insight into these dynamics.

## 3.4 What should an advocacy message contain?

An advocacy message must capture:

- **The problem:** Analyse and research the problem you want to address so that you are clear about the root causes of the problem and the blockages to change.
- **The solution(s):** Understand the changes needed to secure the long-term goal.
- **The action you want your target audience to take:** Have a clear "ask" – a specific action you will request from the legislator, such as voting for a particular piece of legislation. Be prepared to answer questions and to listen to your policymaker's perspectives on the issue.

Have ready a lightning-fast message to convey your message quickly (ideally in less than a minute). Include: What is the problem and how can change be achieved? What do you want from the person you're speaking with? It could simply be an opportunity to meet and discuss further in detail.

**Tip!**

Pick your battle. It is better to focus each meeting on one issue than to "bombard" them with several asks on multiple topics.

Do not hesitate to propose a meeting with the staff if the elected official is unavailable. At times, speaking directly with assistants or advisors may have a greater impact, as they are often responsible for discussing the technical details of files and initiatives and may have a hands-on perspective on the topics you wish to discuss.

Practise your talking points, show up ten minutes early and be understanding if the legislator or staff are late.

## 3.5 Follow up of a meeting or campaign

Leave a brief summary of the organisation you belong to and the issues you are discussing. One-pagers with bullet points work best, as policymakers and their staff often do not have time to review lengthy handouts.

## Post-meeting to-dos:

- Always send a brief thank-you email within a day or two (See the *Meeting Follow Up* section for a helpful template).
- Did they commit to take any actions? In the same email, reiterate the commitment they took and express your enthusiasm in supporting them and anticipation of next steps.
- Send a digital copy of the documents you provided during the meeting (if you were not able to send them beforehand) and offer to answer any additional questions.
- In case of event participation or in-person meetings, make sure you take pictures and share them on social media!

**Tip!**

Ask in writing if you have permission to share a group photo or a short note about your meeting on social media. This can help spread your message effectively and provide more visibility to your campaign.

# Part 4:
# Effective social media communication and campaigning

Social media communication is a powerful tool for patient advocacy. It allows patients to engage with a wide range of audiences, including policymakers, healthcare professionals, and the broader public—groups that might otherwise be difficult to reach.

By using social media effectively, you can amplify your voice, raise awareness about cardiovascular health, and connect with others who share your experience.

Whether you want to inform or impact EU and national policies, share your personal experiences, or mobilise support for better cardiovascular care, social media provides a platform to **make your voice heard and drive meaningful change**.

This section will guide you through selecting the right platforms, crafting impactful messages, and using storytelling and visual content to strengthen your advocacy efforts.

## Choosing the right social media platform based on your goal

Selecting the appropriate social media platform is crucial for maximising engagement and impact:

- **X (Twitter), Bluesky** → Ideal for microblogging and engaging with policymakers.
- **LinkedIn** → Best for engaging with a professional audience, including healthcare professionals, industry experts and some policymakers.
- **Facebook, Instagram** → Effective for reaching a broader audience, including civil society and patient communities.

## Engaging audiences around key dates and events

Strategic communication campaigns can be timed to coincide with key dates and cardiovascular health-related awareness events. Aligning advocacy efforts—whether at the European, regional, national, or local level—with significant campaigns can substantially enhance visibility and impact. See over the page.

## February

**Heart Month**

**14 February:** Valentine's Day

## March

**4 March:** World Obesity Day

**8 March:** International Women's Day

**14 March:** European Day for Prevention of Cardiovascular Risk

## May

**International Hypertension Month**

**5–11 May:** Heart Failure Awareness Days 2025

**31 May:** World No Tobacco Day

## September

**29 September:** World Heart Day

## October

**29 October:** World Stroke Day

## November

**Diabetes Awareness Month**

**14 November:** World Diabetes Day

## The power of storytelling: how to make your experience speak for many

As someone with lived experience of CVD, the strength of your message lies in sharing **your personal story**. A story that is impactful and engaging resonates deeply because it appeals to human emotions. This is a powerful pillar of communication—one you should embrace and harness as much as possible.

While opening up about your experience can feel vulnerable, remember that your voice has the power to inspire others and drive real change. Your story can motivate people to take action, raise awareness, and push for better care and policies.

## The art of crafting the perfect social media post

A well-structured post should include:

- **Context:** Provide background information to ensure clarity and relevance.
- **Personal Opinion:** Share your perspective to add authenticity and credibility.
- **Call to Action:** Encourage engagement, whether it is signing a petition, attending an event, or sharing the message.

## Sample posts

### LinkedIn post (personal story & advocacy-oriented)

International Women's Day is a crucial time to call for gender equity in cardiovascular care.

*A few years ago, I started experiencing unexplained fatigue, chest discomfort, and shortness of breath. When I finally went to the doctor, I was told it was anxiety and given antidepressants. I knew something wasn't right, but I trusted the system. Months later, I suffered a serious cardiovascular event that could have been prevented if my symptoms had been taken seriously from the start.*

*I later learned that I wasn't alone. Women's symptoms are often misdiagnosed because cardiovascular research has historically focused on men.*

## The facts

- Women comprise only one-third of CVD clinical trial participants.
- 50% of cardiovascular trials fail to report gender-specific results, even when including men and women equally.
- Many treatment guidelines are still based primarily on male data.

**It's not that women have 'atypical' symptoms—it's that 'typical' symptoms have been defined based on men.**

This needs to change. We need:

- More funding for gender-sensitive cardiovascular research.
- Mandatory gender-specific data reporting in clinical trials.
- More women in research leadership and decision-making.

Women shouldn't have to fight to be believed when it comes to their heart health. If you've experienced something similar, share your story. The more we speak up, the harder it is to ignore.

#InternationalWomensDay #CVDResearch #GenderEquity #HeartHealth

### *X/Bluesky post (concise & engaging)*

*On International Women's Day, I want to share my story as a woman and CVD patient. A few years ago, I was told my chest pain & fatigue were 'just anxiety.' I was given antidepressants instead of proper care. Months later, I had a heart attack.*

🚨 *Women's heart symptoms are often misdiagnosed. Why?*

🔹 *1/3 of CVD trial participants are women*

🔹 *50% of trials don't report gender-specific data*

🔹 *"Typical" symptoms? Defined by men's experiences.*

*Women's heart health matters. We need:*

🔹 *More research on women's CVD*

🔹 *Gender-specific trial data*

🔹 *More women in research leadership*

*Have you faced misdiagnosis? Share your story. Let's push for change.*

*#HeartHealth #GenderEquity #InternationalWomensDay*

**Interactive engagement:** Like, share, and comment on your legislators' posts to increase visibility and build rapport. Tag them in your advocacy-related posts to draw their attention.

## Visual content creation

It is important to accompany your written content with visual elements whenever possible. Visuals can make your message more engaging, memorable, and impactful.

This can take the form of:

- **Live photos** – Captured by you at relevant events, initiatives, or even moments from your daily life that help illustrate your advocacy. If you speak at events or meet policymakers, be sure to capture these real-life moments of advocacy in action!
- **Graphic design visuals** – Infographics, quotes, or key statistics that reinforce your message in a clear and compelling way.

Canva is a great, user-friendly tool for creating professional-looking graphics, even with no prior design experience. Additionally, many organisations provide **social media kits** or **shareable content** for key events and campaigns, making it easy to personalise and amplify important messages.

# Part 5:
# Advocacy tools and resources

## Sample advocacy letters and emails for meetings with policymakers

Below there is an example of messages used in the past for reaching out to MEPs for the EACH Summit 10–13 December 2023:

Dear MEP Olekas,

As the European Heart Network, we are writing to request a meeting with you during the week of December 11th at the Swan area to discuss the biggest killer in Europe. (Lithuania Stats)

From 11–14th an exhibition dedicated to cardiovascular health will take place in the European Parliament in Strasbourg in the Swan area.

We believe that policymakers should not need to choose between electability and taking action on what is demonstrably the biggest threat to public health in the EU today.

We, as leaders of the European Alliance for Cardiovascular Health, representing scientific societies, patient organisations, industries and foundations are coordinating our social media and media activities to ensure that those MEPs who make serious commitments to CVD reach as many people as possible at a local level. For our organisation, we are pushing for an EU Cardiovascular Health Plan because it can provide a much needed policy framework for action.

If you look to tackle a major public health issue for your manifestos, then look no further than the biggest killer in the EU and worldwide. If you look to tackle gender imbalances, take note that today more women than men will die of CVD and yet it is still treated as a "men's disease". If you are concerned about disparities between east and west, it is important to note that you have a 70% chance in Bulgaria of dying of CVD today compared with 24% in Denmark.

Action to promote cardiovascular health is the fight for gender, generational and geographical equity. It is the fight against ageism and structural inequalities.

It is the means to enable a silver economy and keep our systems sustainable. It is the public health campaign of this generation.

Would you have 30 minutes during Strasbourg to come down to meet with us to discuss the impact of cardiovascular disease in our country and if you are willing, have a short interview?

If you would like to discuss this, we are more than happy to set up a short call.

Thank you for your time and we look forward to hearing from you.

Best regards,

## Sample follow-up thank you email

**New Message**

Recipient Cc Bcc

Thank you for your time on [date of the meeting]_[Topic of the meeting]

Dear [MP's Name],

I sincerely appreciate the time you took to meet with me today to discuss the progress of the National Cardiovascular Health Plan. It was encouraging to hear your insights, and I'm grateful for your support on this critical issue.

I also appreciate your commitment to [reiterate their specific commitment, e.g., advocating for increased funding, raising the issue in Parliament, supporting policy implementation]. Your leadership on this will make a real difference for people affected by cardiovascular disease.

As promised, I've attached a digital copy of the documents we discussed for your reference. Please don't hesitate to reach out if you have any further questions—I'd be happy to provide any additional information.

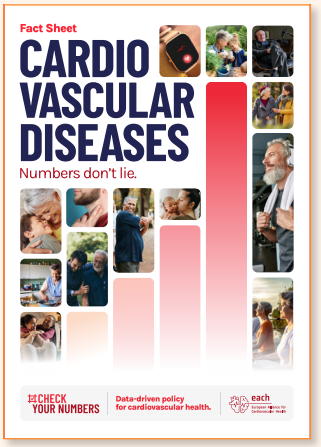
Additionally, would you be comfortable with me sharing a short note or our photo together on social media?

Thank you again for your time and commitment. I look forward to staying in touch and continuing this important conversation.

Best regards,
[Your Name]
[Your Contact Information]
[Your Organisation, if applicable]

Send

## Templates for creating advocacy materials such as fact sheets or infographics



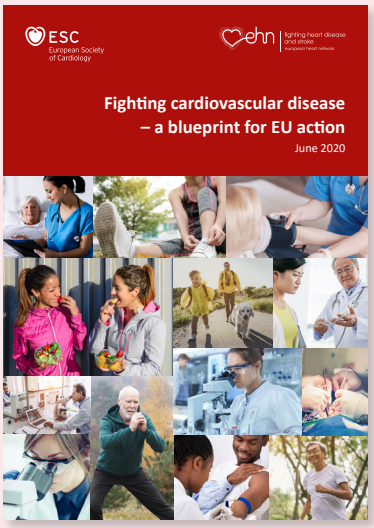

Other templates available:

- Burden of Disease
- Geographical inequalities
- Stroke
- Gender Inequalities
- Chronic Kidney Disease

## List of relevant websites, organisations, and resources for further information and support

- List of MEPs in Public Health Committee
- MEP Cardiovascular Health Group

## Additional resources, such as relevant research studies or policy documents


# EHN Members Representing Patients

A comprehensive list of EHN member organisations actively working with patients. We highly recommend reaching out to them for support in your national advocacy efforts.

| Country | Organisation | Contact name | Contact information |
|---|---|---|---|
| **Belgium** | Belgian Heart League | Mr Rik Vanhoof | rik.vanhoof@liguecardioliga.be |
| **Denmark** | Danish Heart Foundation | Ms Anne Kaltoft | annekaltoft@hjerteforeningen.dk |
| **Finland** | Finnish Heart Association | Prof Marjaana Lahti-Koski | Marjaana.lahti-koski@sydanliitto.fi |
| **Germany** | German Heart Foundation | Mr Martin Vestweber | vestweber@herzstiftung.de |
| **Ireland** | Irish Heart Foundation | Ms Tracy Egan | tegan@irisheart.ie |
| **Israel** | Israeli Heart Association | Mr Gil Meltzer | gil@israeli-heart.org |
| **Netherlands** | Harteraad | Mr Peter de Lange | peter.delange@harteraad.nl |
| **Portugal** | Portuguese Heart Foundation | Dr Manuel Carrageta | fpcardio@fpcardiologia.pt |
| **Romania** | Romanian Heart Foundation | Prof Dan Gaita | dgaita@cardiologie.ro |
| **Slovenia** | Slovenian Heart Foundation | Ms Nataša Jan | drustvo-zasrce@siol.net |
| **Spain** | Spanish Heart Foundation | Dr José Luis Palma | jlpalma@secardiologia.es |
| **Sweden** | Swedish Heart and Lung Association | Ms Ulrica Sundholm | ulrica.sundholm@hjart-lung.se |
| **Switzerland** | Swiss Heart Foundation | Dr Robert Keller | keller@swissheart.ch |
| **United Kingdom** | British Heart Foundation | Dr Charmaine Griffiths | Griffithsch@bhf.org.uk |

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