

Achieving early detection and diagnosis of cardiovascular disease Activating the manifesto – An advocacy guide



ACHIEVING EARLY DETECTION AND DIAGNOSIS OF CARDIOVASCULAR DISEASE ACTIVATING THE MANIFESTO – AN ADVOCACY GUIDE

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Introduction

Global Heart Hub's (GHH) <u>manifesto on Early Detection and Diagnosis of Cardiovascular Disease</u> (CVD) is a unique call to action – co-created at the <u>3rd Unite Annual Summit</u> in November 2023 by Global Heart Hub's wide community of patient advocates and many other stakeholders, striving for a better future for those at risk of heart diseases, and their families.

This brief advocacy guide is designed to help GHH Affiliate organisations to effectively disseminate the manifesto on early detection and diagnosis in your countries and to use it to support your own policy agenda in a national context. Now is the time to start a powerful campaign for early detection and diagnosis, and to ensure that the manifesto has the reach and influence to stimulate real policy change at global, regional, and crucially, at national level.

Why could this be a win-win and reinforce the work that you are doing on an ongoing basis?

- It can be a hook to contact health politicians and key decision makers and ask them to (re-)consider action in the field of early detection and diagnosis.
- It can link into your existing activities and initiatives as an additional resource and evidence base.
- It can demonstrate the global nature of the challenge and highlight the global response as well as the impetus for real change at national level.

Through the eight well-defined actions, it frames what needs to be done by whom.

Supporting the launch can start at a very simple level and is easy for all Affiliates:

- You can relay messages on social media, re-tweet our messages, and use the other social media tools (see <u>communications pack</u>).
- You can send the manifesto to your key decision-makers.
- You can integrate the manifesto into an event that you are already planning.

Even the smallest action will help to make a difference. If you are keen to do more, we have provided an <u>Advocacy Planning Template and Advocacy Planning Evaluation Template</u> for your advocacy activities in 2024.

Below we outline some steps you may wish to take when considering how to use and promote the manifesto, this year and beyond. We hope that these are helpful and inspiring.

And please do share with us your activities and achievements linked to the manifesto in the weeks and months ahead. We are very keen to understand the impact of our collective work and how we can best accelerate this even further.

On behalf of the GHH team, my warmest thanks and good luck!

Neil Johnson,Executive Director,
Global Heart Hub

Contents of this advocacy and outreach pack

- Advocacy Planning Template
- Advocacy Planning Evaluation Template
- Manifesto Actions
- Elevator Pitch
- <u>Issues and Actions summary Cheat Sheet</u>
- Model Letter
- Model Blog
- Calendar
- WHF Infographic on Global CVD Deaths and Risk Factors
- <u>Communications toolkit</u> launch video, website, social media adverts, editable PowerPoint, template press release, e-newsletter.

USEFUL ADDITIONAL RESOURCES

- 2023 Unite Summit Recording: <u>Influencing Global and Local Policymakers to Improve Early Detection and Diagnosis of CVD.</u>
- 2023 Unite Summit Recording: Focus on Patient Advocacy Role as Catalyst for Action.
- 2022 Unite Summit Recording: Achieving Political Impact.
- 2021 Unite Summit Recording: <u>Influencing Policy The Patient Voice.</u>
- Inspire Speaker Series Recording: Introduction to Patient Advocacy for Patient Organisations.
- Recording: Heart Valve Disease Patient Journey Advocacy Training with Christoph Thalheim.

Preparatory work around the manifesto campaign

- Consider how your organisation could best use and support the manifesto, mobilising your networks.
- Reflect on the specific data / published articles available in your country regarding CVD and its impacts, which you can use in your advocacy work. For instance:
 - » How many deaths from CVD happened in your country last year?
 - » How many people are on sick leave because of CVD, and what is the economic cost in lost productivity?
 - » What is the investment in CVD versus other diseases?
 - » What are the statistics linked to early detection and diagnosis? etc.
- Consider your own planning and prioritisation throughout 2024 where could the manifesto be a helpful addition or support? For instance:
 - » Are you planning a conference or a high-level meeting? Could an international component such as the manifesto be an attractive and useful part of the agenda?
 - » Could the manifesto help you when contacting high level decision makers?
- How will you transpose the manifesto and the eight actions to your country / region in practical terms? For instance:
 - » Could the eight actions be adapted to national reality under your organisation's name, while referring to the manifesto?
- Audiences and target groups: Draw up two lists of key players (people, not just organisations):
 - A very targeted list of the most important decision-makers in your country / region of work
 political decision makers, key opinion leaders, industry partners, patients representatives,
 scientists.
 - » A broader list of stakeholders: experts / organisations / policy makers / companies / industry associations who should know about this manifesto and support it (both lists will grow over time).
 - » NOTE: this last point is critical it defines your key audiences and needs to be considered specifically, even if you have already good lists and databases. It might be worthwhile to reflect on people and organisations BEYOND the usual who are specific to the topic of EARLY detection and diagnosis such as the Ministers for economy, finance, social insurance and pensions, sports, employers organisations, unions' organisations, etc.

Immediate steps to activate the manifesto

This manifesto is a central advocacy tool to push for early detection and diagnosis of CVD. It represents the main output from Global Heart Hub's 3rd Unite Annual Summit, held in Barcelona on 8 and 9 November 2023. The Summit was attended by 125 delegates across 27 countries, including over 40 patient organisation representatives.

What immediate activity could you implement? Options might include:

- Letter (or email) to key decision-makers and influencers see a draft here.
- Article / broadcast in one very influential news medium (with journalist interviewing key decisionmakers on your list) – see <u>cheat sheet</u> and <u>model blog / article</u>.
- Hand over to the Health Minister (with a photo opportunity/ video recording). See cheat sheet and key messages/asks.
- Individual visits to other key decision-makers and influencers. See <u>cheat sheet</u> and <u>key messages / asks</u>.



Using the manifesto throughout 2024 and beyond

- Use the manifesto as a base upon which to develop more specific actions relevant to your local context using data and evidence available for your country.
- Design a specific launch for your country / region: what could the best format be?
 - » A press conference with the Health Minister.
 - » Side event at a scientific / health conference /webinar.
 - » A broader mail-out of the manifesto (especially if translated and if a specific CVD profile for your country / region is added).
 - » A series of visits to key decision-makers, one by one, to explain and hand over the manifesto.
 - » Initiating a (growing) alliance of stakeholders and communicate to decisionmakers the importance of the issue.
 - » Aim at prominent articles and broadcasts in the most influential media, with journalists also interviewing the key decisionmakers.
 - » For European Union countries, link to the campaign for a <u>European Action Plan on Cardiovascular</u> <u>Health.</u>
 - » All this supported by social media activity (see communications toolkit)

Early detection and diagnosis of cardiovascular disease can save lives.



The advocacy planning and evaluation templates

ADVOCACY PLANNING TEMPLATE:

This planning template takes you through a step-by-step process for developing your national Manifesto advocacy plan. You can use it to document the actions which you plan to take in your country over the next year.

Template available to download here

ADVOCACY PLANNING EVALUATION TEMPLATE:

This evaluation template is designed to help you to record the implementation of your national Manifesto advocacy activities. It uses a simple 'traffic light' approach to allow you to monitor progress against your plan and provides space for you to record experiences and lessons learned.

Template available to <u>download here</u>





Urgent action to improve the early detection and diagnosis of cardiovascular disease is essential.



Manifesto Actions

The manifesto outlines eight tangible actions that need to be taken by a united CVD community, including committed policymakers, to achieve early detection and diagnosis. The order of these actions does not indicate their priority. Instead, they cover the entire patient pathway for the detection and diagnosis of CVD as well as broader elements such as research and policy development. Implementing all eight actions is important to foster sustained progress and improved outcomes for people living with CVD. These actions will ensure that fundamental awareness, policies, research and clinical processes are in place, and that new opportunities are capitalised upon to achieve early detection and diagnosis of CVD.



Action 1: Run public campaigns on the risk factors and symptoms of CVD. Launch long-term campaigns to improve understanding of CVD among the general public. These should be tailored to different cultural groups and use diverse media for widespread reach, focusing on empowering individuals to monitor their cardiovascular health and seek timely medical advice.



Action 2: Implement targeted early detection programmes for CVD, at different stages of life. Develop programmes to identify individuals and groups at high risk of CVD, using biomarker testing, clinical support tools and considering risk factors including those related to genetics, metabolism and lifestyle. Collaboration with patient organisations, medical societies and health authorities will help to ensure effective local adaptation of such programmes.



Action 3: Adapt clinical processes to enhance early detection and diagnosis of CVD. Increase access to rapid, on-site point-of-care testing in primary care and community settings. Redesign patient care pathways to ensure potential cardiac symptoms, underlying causes and early indications of CVD are thoroughly and swiftly investigated.



Action 4: Leverage digital technologies to increase access to early detection and diagnosis of CVD. Encourage the use of mobile health interventions, wearable sensors and other tools to monitor risk and support early detection of CVD. Integrate these technologies into clinical practice and train patients and healthcare professionals in their effective use to support early detection and diagnosis.



Action 5: Optimise workforce training and capacity for early detection and diagnosis of CVD. Implement comprehensive multidisciplinary training programmes for primary care physicians and other healthcare professionals to recognise people at high risk of CVD, interpret cardiac symptoms confidently and activate rapid referral pathways. Diversify the skillset of the healthcare workforce to facilitate nurse- or pharmacist-led care, and redesign roles, including the creation of data management and analysis positions.



Action 6: Increase investment in research into early detection and diagnosis of CVD. Boost funding for CVD research and innovation, focusing on developing better personalised risk assessment tools that leverage advanced technologies like artificial intelligence and take into account both magnitude and duration of exposure to CVD risk factors. Involve people living with CVD in the design and conduct of such research, ensuring equitable access among demographic groups.



Action 7: Advance policy development and international partnerships for early detection and diagnosis of CVD. Develop national cardiovascular health plans that include robust, goal-driven strategies for the early detection and diagnosis of CVD to reduce preventable mortality and morbidity, and improve the efficiency of healthcare delivery. These should help reorientate the design of the health system towards early detection and diagnosis of CVD, including multisectoral collaboration and engagement with patient organisations and people living with cardiac conditions.



Action 8: Promote equitable access to early detection and diagnosis of CVD. Implement targeted policies and programmes to improve equitable access to the early detection and diagnosis of CVD. These should aim to reduce inequalities in CVD mortality by addressing social determinants of health as well as gender, socioeconomic, racial and ethnic disparities in early detection and diagnosis of CVD.

Elevator pitch for discussions on the manifesto/ meetings with decision-makers / influencers

(122 words)

- Heart attacks, strokes and other CVD are the biggest killer worldwide / killer no X in our country.
- This is an enormous human price to pay, and it also puts a big economic cost on our economy health system costs, long-term absences from work, disabilities caused by CVD.
- Early detection and diagnosis can avert much of this damage, by alerting people early to improve their lifestyle and by getting them treatment. It then also reduces cost to the health system and the economy.
- We have developed a framework of eight actions, which guide what decision makers need to focus on to implement the solutions, save patients from grave disease, and lower the longer-term cost to the economy.



Issues and Actions – a Summary Cheat Sheet to help prepare for Interviews, Articles, etc.

HEART DISEASE NEEDS TO BE RECOGNISED EARLY - IT SAVES LIVES AT A LOWER COST

A sustained, concerted effort is essential to boost early detection and diagnosis of cardiovascular disease (CVD, commonly referred to as 'heart disease') and to secure investment and innovation. Early detection and diagnosis of CVD can dramatically reduce the burden of illness, improve quality of life for patients and their families, reduce the overall societal burden of chronic disease and substantially enhance population health.

EARLY RECOGNITION OF HEART DISEASE IS LACKING - AND EXPENSIVE

CVD places an enormous pressure on health systems globally. Over the past 30 years, the prevalence of CVD has nearly doubled, reaching over 500 million cases worldwide. This brings significant human and economic cost – currently, CVD accounts for 31% of global deaths annually. The annual number of CVD-related deaths is projected to rise by more than 60% by 2050. A 2023 study estimated CVD to cost the EU \in 282 billion annually, with health and long-term care accounting for \in 155 billion (55%), equalling 11% of EU-health expenditure. Productivity losses accounted for 17% (\in 48 billion), whereas informal care costs were \in 79 billion (28%)\frac{1}{2}.

POLICY MAKERS CAN ACT NOW TO PREVENT THE ESCALATION OF CVD AND RELATED ECONOMIC COST

Enduring system pressures, lack of infrastructure and more significantly the absence of comprehensive government-led strategies to tackle CVD have resulted in inadequate access and availability of diagnostics tests and technologies. Governments and policy makers need to prioritise the early detection and diagnosis of cardio-vascular disease (CVD).

This manifesto focuses on eight critical actions:

ACTION:	
1. INFORM	Run public information campaigns on risk factors and symptoms of CVD.
2. DETECT	Implement early detection programmes for CVD, at different stages of life.
3. TEST	Enhance early CVD detection through rapid, onsite (point-of-care) testing.
4. GO DIGITAL	Increase access to timely detection and diagnosis of CVD through digital technologies (mobile health apps, wearable sensors).
5. TRAIN	Optimise workforce training and capacity for early detection and diagnosis of CVD.
6. RESEARCH	Increase investment in research into the early detection of CVD.
7. GUIDE	Advance policies and international partnerships for early detection and diagnosis of CVD.
8. ACCESS	Promote equitable access to early detection and diagnosis of CVD, with respect to gender, socio-economic, racial and ethnic disparities.

¹ European Heart Journal (2023), https://academic.oup.com/eurheartj/article/44/45/4752/7251239

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ADVOCACY RESOURCE

Model letter to top decision makers / influencers

Your Excellency/ Madam / Sir,

Cardiovascular diseases (CVD) place enormous pressure on our national health system. This is true worldwide as much as in our country– over 500 million people were affected by CVD last year and xxxx million at home. They are the leading cause of death globally, taking an estimated 17.9 million lives each year, according to WHO.

There is clearly an ethical as well as an economic imperative to act. My organisation is a proud member of the Global Heart Hub, an international platform of over 100 organisations representing xxxxxx patients with CVD. We have joined forces with GHH and health experts from around the globe to develop a succinct and workable approach to lowering the risk of CVD and its very negative human and financial impacts.

Achieving early detection and diagnosis of cardiovascular disease: A manifesto for change sets out eight actions that health decision makers, system managers and stakeholders such as industry need to take and sustain to achieve real world results in lowering the risk of CVD.

The stress lies on **EARLY**: to prevent CVD from happening or aggravating, early detection and diagnosis is critical. The sooner a possible CVD case is discovered the more effective the treatment and management will be, with far better outcomes for patients and society at large.

The eight Actions to achieve this are:

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Your Excellency / Madam / Sir, we would like to submit this manifesto to your consideration. We are aware that it represents a global view and needs to be tailored to the specific opportunities and needs in our domestic context.

We therefore seek a personal meeting with you and your team to discuss the detailed measures and actions needed in our country. We stand prepared to support your team in designing the appropriate national / regional response.

OR ALTERNATIVELY:

We stand prepared to support your team in designing the appropriate national / regional response. We therefore ask you to consider the eight Actions as a framework for improving our country's / region's pro-active measures to reduce the occurrence and gravity of cardio-vascular disease and to lower its cost to our national / regional community.

We look forward to your reply and thank you very much for your attention.

Sincerely,

XXXX

Model blog / article

This blog/article provides the key information which you may wish to use as a basis for your own blog/article at national level – adding country specific data and stories.

(734 words)

Death and disease lead many news stories anywhere on the globe – homicide, accidents, cancer, infectious diseases are part of the daily drip we receive in our news channels.

Yet heart attacks, strokes, high blood pressure, and other cardiovascular diseases (CVD) kill more people every day than any other medical condition. Over 500 million people were affected by CVD last year and xxxx million in our country / region. This is the leading cause of death globally, taking an estimated 17.9 million lives each year, according to WHO².

A 2023 study estimated CVD to cost the EU €282 billion annually, with health and long-term care accounting for €155 billion (55%), equalling 11% of EU-health expenditure. Productivity losses accounted for 17% (€48 billion), whereas informal care costs were €79 billion (28%)³.

The annual number of CVD-related deaths is projected to rise by more than 60% by 20504.

Misleadingly, CVD are still seen as a problem for industrialised societies only but in reality the opposite is true: the global burden of this type of disease has expanded strongly into the developing world. In fact, countries worst hit by CVD are now more likely to be found in Africa, and Eastern Europe, where the reduction of disability-accounted life years (DALYs) because of CVD is highest. This estimates not just life lost due to premature mortality but also years lived with disability because of CVD. For example, Ischemic heart disease caused by poor blood flow to the heart caused 9,5 million deaths globally in 2021 but life years lost through long-term disease and disability amounted to 185 million⁵.

That cardio-vascular diseases are such an enormous problem and yet often overlooked has two principal consequences: it affects the livelihoods of a vast number of people who may die but more likely will be affected with long-term, serious health problems and reduced quality of life. And it bears a huge economic cost, directly for the health systems and indirectly through productivity losses and the cost of informal and social care.

But the world does not have to accept this situation – double benefits are possible

The Global Heart Hub, its network of over 100 Affiliate organisations, and its partners around the world are on a mission to improve early warning systems for CVD around the globe. Based on a 3-day conference in 2023, the GHH and a host of science, health system, and policy advisors have developed a manifesto to outline what needs to be done to prevent CVD from wreaking havoc with our health, health systems and wider societies.

The manifesto presents eight actions – all comprehensive and straightforward to implement – that a country and/or administration should undertake to tackle the biggest killer of our times. **Achieving early detection and diagnosis of cardiovascular disease: A manifesto for change** addresses health decision makers, system managers and stakeholders such as industry and shows what they need to do to achieve real world results in lowering the risk of CVD.

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ADVOCACY RESOURCE

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For CVD, the early warning system is extremely effective, both in saving lives and increasing quality of life, but also in lowering the economic burden of cardio-vascular disease. The eight Actions captured in the manifesto, taken together and implemented sustainably over the next few years, will reap the **double benefit** – improving the life of patients and lightening the economic burden of CVD.

⁵ Vaduganathan, M, Mensah, G, Turco, J. et al. The Global Burden of Cardiovascular Diseases and Risk: A Compass for Future Health. J Am Coll Cardiol. 2022 Dec, 80 (25) 2361–2371. https://doi.org/10.1016/j. jacc.2022.11.005



² WHO https://www.who.int/health-topics/cardiovascular-diseases#tab=tab_1

³ European Heart Journal (2023), https://academic.oup.com/eurheartj/article/44/45/4752/7251239

⁴ World Heart Federation. 2022. World Heart Vision 2030: Driving policy change. Geneva: World Heart Federation

Health Awareness Day Calendar 2024

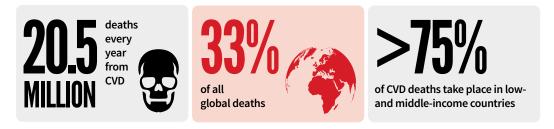
DATE	EVENT
MARCH 24	LP(A) AWARENESS DAY
MONTH OF MAY	HEART FAILURE AWARENESS CAMPAIGN
MAY 4	HOFH RARE DISEASE DAY
MAY 17	WORLD HYPERTENSION DAY
MAY 31	WORLD NO TOBACCO DAY
MONTH OF JUNE	CARDIOMYOPATHY AWARENESS MONTH
SEPT 16 - 22	HEART VALVE DISEASE AWARENESS WEEK
SEPT 24	FH AWARENESS DAY
SEPT 29	WORLD HEART DAY
OCTOBER	CHOLESTEROL MONTH
OCT 10	WORLD MENTAL HEALTH DAY
OCT 29	WORLD STROKE DAY
NOV 14	WORLD DIABETES DAY

Graphic on global CVD deaths and risk factors to support your advocacy messaging

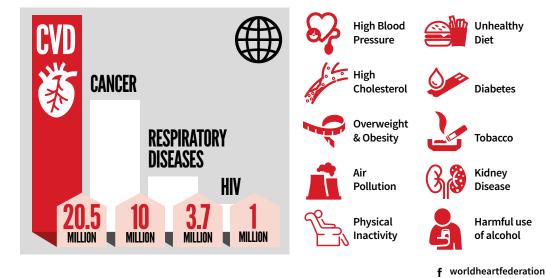


CARDIOVASCULAR DISEASE THE WORLD'S NUMBER 1 KILLER

Cardiovascular diseases are a group of disorders of the heart and blood vessels, commonly referred to as **heart disease** and **stroke**.



GLOBAL CAUSES OF DEATH RISK FACTORS FOR CVD



Sources: World Health Organization; IHME, Global Burden of Disease

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■ worldheartfed

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