

# **WORLD HEART FEDERATION CHOLESTEROL ADVOCACY TOOLKIT**



# KEY ACRONYMS

- ApoB** – Apolipoprotein B
- ASCVD** – Atherosclerotic Cardiovascular Disease
- CVD** – Cardiovascular Disease
- DALYs** – Disability-Adjusted Life Years
- FH** – Familial Hypercholesterolemia
- HDL** – High-Density Lipoprotein
- HeFH** – Heterozygous Familial Hypercholesterolemia
- HIC** – High-Income Countries
- HoFH** – Homozygous Familial Hypercholesterolemia
- LDL** – Low-Density Lipoprotein
- LMICs** – Low- and Middle-Income Countries
- NCDs** – Non-Communicable Diseases
- NGO** – Non-Governmental Organization
- UN** – United Nations
- WHO** – World Health Organization
- WHF** – World Heart Federation

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# INTRODUCTION

## About this toolkit

The World Heart Federation (WHF) is a leading global advocate for stronger legislation and policies regarding cardiovascular disease (CVD) and its risk factors, including raised cholesterol. The present Cholesterol Advocacy Toolkit 2022 provides WHF member organizations with information as well as practical tools to support cholesterol advocacy at the local and regional levels.

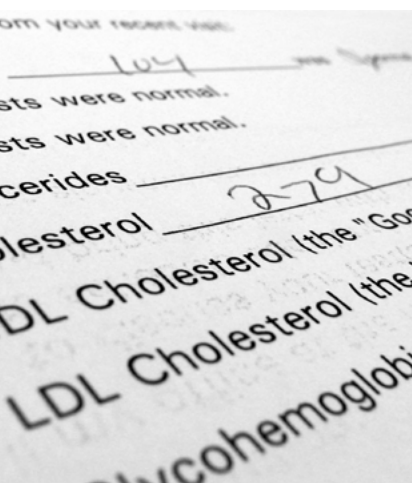
This resource can provide assistance in a variety of ways: from helping your organization develop a cholesterol advocacy strategy to forming successful advocacy partnerships, reaching out to the media, and/or scheduling meetings with key local and national decision-makers. The materials are designed to be adapted to your unique local situation and needs.

This Toolkit also draws from our [White Paper on Cholesterol 2021](#) and [Cholesterol Roadmap 2022](#), which provide frameworks that help identify challenges or roadblocks and suggest potential solutions to achieving cholesterol control. In addition, they also present some background on the critical need for cholesterol-related advocacy.



### Goal

The purpose of the Toolkit is to empower and enable WHF Members, as well as other relevant stakeholders to conceptualize, plan, and carry out a cholesterol-related advocacy campaign on a selected policy call to action.



### Tip

It is important to remember that no advocacy approach is universally applicable. Please adapt the materials and advice of the toolkit according to your local context, needs, and accredited guidelines.

More resources can be found at [worldheart.org](http://worldheart.org)

## Global burden of raised cholesterol

Cardiovascular disease is responsible for an estimated 18.6 million deaths every year and remains the leading cause of mortality worldwide<sup>(1)</sup>. Elevated low-density lipoprotein (LDL) cholesterol is generally considered a major modifiable risk factor for myocardial infarction, commonly referred to as heart attack, and ischemic stroke<sup>(2)</sup>. In fact, a large body of evidence shows that exposures to high levels of LDL cholesterol and apolipoprotein B (apoB) containing lipoproteins significantly increase the risks of atherosclerotic cardiovascular disease (ASCVD)<sup>(3)</sup>. According to the Global Burden of Disease Study, approximately 4.4 million deaths and 98.6 million disability-adjusted life years (DALYs) were attributable to raised LDL cholesterol in 2019<sup>(4)</sup>.

Familial hypercholesterolemia (FH) is a genetic condition that leads to elevated LDL cholesterol from birth<sup>(2)</sup>. Untreated, lifelong exposure to high concentrations of LDL cholesterol results in premature cardiovascular disease morbidity and mortality. Individuals with one inherited mutation develop a condition called heterozygous familial hypercholesterolemia (HeFH), whereas individuals with two abnormal copies of the same gene from both parents develop homozygous familial hypercholesterolemia (HoFH), a particularly rare and severe form of FH. HeFH affects 1 in 311 people or nearly 28 million individuals worldwide<sup>(3,5)</sup>. In contrast, HoFH affects 1 in 300 000 people and generally requires specialized care<sup>(6)</sup>. FH is widely recognized as an underdiagnosed and undertreated condition due to low levels of awareness among the general population, policymakers, as well as healthcare professionals. Data suggest that only 10% of people living with FH are currently diagnosed and adequately treated<sup>(6)</sup>.

In 2015, Member States of the United Nations (UN) adopted the 2030 Agenda for Sustainable Development and pledged to reduce by one-third premature mortality from non-communicable diseases (NCDs), including cardiovascular disease, by the year 2030, through UN Sustainable Development Goal target 3.4. Unfortunately, the public health and economic burdens of cardiovascular disease and raised cholesterol have been shifting from high-income countries (HIC) to low- and middle-income countries (LMICs), negatively impacting existing inequities<sup>(2)</sup>. Undeniably, SDG target 3.4 cannot be realised without properly addressing cardiovascular disease raised cholesterol, as two of the urgent public health priorities.

The World Health Organization (WHO) recommends adopting a Total Risk Approach to the prevention of cardiovascular disease and has acknowledged the critical role of cholesterol control in primary and secondary prevention strategies. In fact, early diagnosis and treatment of raised cholesterol, including a lifetime risk approach, are essential in averting premature cardiovascular disease morbidity and mortality. As such, WHF Members and Partners are encouraged to advocate for the implementation of **primordial, primary, and secondary prevention** strategies as an investment for the future. Exposure to high cholesterol can be reduced through the adoption of relevant health policies, modifying health behaviours, and/or pharmacotherapies. Lastly, universal and cascade screening strategies as well as evidence-based treatments, including statins and other novel cholesterol-lowering medications, need to be made available, accessible, and affordable in all settings.



For more information on the importance of addressing raised cholesterol globally, please read our Cholesterol Roadmap 2022: <https://world-heart-federation.org/cvd-roadmaps/cholesterol/>

## Basic overview of advocacy steps

This Toolkit focuses on the strategies needed to develop a campaign on cholesterol control as a key component of reducing CVD-related deaths. The Toolkit consists of 6 sections that guide the reader through the essential steps of conducting advocacy:

- **Conduct Research**
- **Identify Your Strategy**
- **Identify Your Key Targets**
- **Create Partnerships**
- **Engage the Media**
- **Develop and Disseminate Key Messages**



### Each section features

- Key concepts related to conducting cholesterol-related advocacy
- Critical questions to consider at each stage of advocacy planning
- Useful tips and tools
- Links to relevant material and resources

## Cholesterol advocacy campaign checklist



As you work your way through the steps, keep the following checklist in mind – it will assist you in measuring the progress of your cholesterol-related advocacy campaign. The checklist can and should be adapted to suit your local conditions. Please feel free to add more activities, as you see fit.

### Cholesterol Advocacy Campaign Checklist

- ✓ Conduct research on cholesterol in your setting and identify key stakeholders in NCD, CVD, and cholesterol-related policy decision-making
- ✓ Select your cholesterol-related advocacy issue
- ✓ Develop your cholesterol-related advocacy plan
- ✓ Identify primary targets and corresponding secondary targets
- ✓ Identify and engage key partners from other sectors to add depth to your campaign
- ✓ Write a letter to your Minister of Health or other key decision-makers to request a meeting
- ✓ Engage the media by reaching out to journalists and educate them on the need for CVD prevention and cholesterol control
- ✓ Write Letters to the Editor or Opinion Editorials in leading newspapers to raise awareness on the importance of cholesterol control
- ✓ Use social media to engage a wider audience about the necessity of cholesterol control (e.g., Facebook, Twitter, LinkedIn, blogs, etc.)
- ✓ Publicize your campaign on your organization website and newsletter
- ✓ Engage your membership by including key messages in your newsletters, events, social media, website, and meetings
- ✓ Involve your constituency in your campaign through events and media activities

# STEP 1: CONDUCT RESEARCH



## Know the issue: Understanding the burdens of CVD and raised cholesterol in your setting

The most successful advocacy campaigns are specific and focused. They typically identify a clear and defined problem, raise awareness about it, and provide actionable solutions. Your community is relying on your organization's expertise in confronting CVD and its risk factors, as well as in mitigating its impact on the community. It is therefore crucial that you maintain a comprehensive and up-to-date understanding of the scope of the issue. This knowledge can be obtained from statistics, progress reports, and local research related to:

- The burden of cardiovascular disease in your setting (e.g., local, national, regional, etc.)
- The burden of raised cholesterol in your setting
- The burden of familial hypercholesterolemia, including the screening and diagnosis rates, as well as the treatment coverage in your settings.

### Find more data on NCDs, cardiovascular disease, and raised cholesterol

To understand the burden of NCDs in your setting, please consult the following resources:

- [WHO Non-Communicable Disease Fact Sheet](#)
- [WHO Global Status Report on Non-Communicable Diseases 2014](#)
- [WHO Non-Communicable Disease Progress Monitor 2020](#)

For regional and national level statistics on raised cholesterol, please consult the following resources:

- [WHF World Heart Observatory](#)
- [Global Burden of Disease Study 2019](#)
- [WHO Global Health Observatory](#)

The *World Heart Observatory* is a knowledge hub that curates, aggregates, and visualizes data on cardiovascular conditions, biological risk factors, social determinants of health, and health systems as well as policy responses. The data can be used to inform evidence-based decision-making for health at the population level, identify gaps and research needs, develop capacity for CVD data collection among WHF Members and Partners, and create a forum for research and debate on cardiovascular health.

The next step will be to gather specific information on what action(s) your government is already taking in the areas of CVD and cholesterol control.

We have created a list of key questions to guide your advocacy efforts:

The image shows two screenshots of web portals. The top screenshot is from the WHO Global Health Observatory, displaying a table of 'Mean non-HDL cholesterol (age-standardized estimate)' for various countries from 2010 to 2019. The bottom screenshot is from the WHO Non-Communicable Disease Progress Monitor 2020, showing a search interface for cardiovascular disease causes and risks.

Location	2010	2011	2016	2018	2019	2020	2021	2022
Algeria	1.92	1.92	1.92	1.92	1.92	1.92	1.92	1.92
Algeria	1.92	1.92	1.92	1.92	1.92	1.92	1.92	1.92
Algeria	1.92	1.92	1.92	1.92	1.92	1.92	1.92	1.92
Algeria	1.92	1.92	1.92	1.92	1.92	1.92	1.92	1.92
Algeria	1.92	1.92	1.92	1.92	1.92	1.92	1.92	1.92

Information Gathering Questions	Answers
Who is responsible for the monitoring and surveillance of cholesterol levels in the Ministry of Health?	<i>E.g., national NCD or CVD focal person</i>
What cholesterol-related goals, targets, and indicators are the government currently tracking?	<i>E.g., prevalence of FH, diagnosis rate of FH patients, etc.</i>
Is there a national NCD surveillance system that tracks cholesterol levels as a CVD risk factor?	<i>E.g., FH registries, etc.</i>
Is there a standard set of guidelines for the management of raised cholesterol?	<i>E.g., national guidelines, international guidelines, etc.</i>
How engaged is your Ministry of Health in cholesterol control?	<i>E.g., national FH guidelines, national FH programmes, etc.</i>
Who funds cholesterol control in your setting?	<i>E.g., governments and/or the private sector</i>
What are funds for cholesterol control primarily spent on?	<i>E.g., primary prevention, secondary prevention, screening for FH patients, etc.</i>
What cholesterol-related information would be helpful to share with ministries?	<i>E.g., latest scientific evidence, awareness-raising material, etc.</i>

## Environmental Assessment: What is the scope of the problem?

**In order to shape your advocacy strategy and develop your key messages, it is important to have a thorough understanding of the policy environment surrounding cholesterol control and CVD management. To create a compelling case for action on cholesterol, it is critical to address overarching questions, such as:**

- Why should policymakers care about the problem?
- What is the medical reality of the cholesterol problem in your country and community?
- What is the policy environment?
- What are the main barriers that patients face in accessing diagnosis as well as preventative care or treatments for raised cholesterol?



## Role of data and evidence

In addition to its central role in public health and clinical decision-making, data also plays a vital role in formulating advocacy strategies. Furthermore, data on health economics (e.g., cost-effectiveness of an intervention, etc.) can also be extremely valuable.

### The role of data in cholesterol-related advocacy

- **Ensuring** that issues are based on patient and population needs and grounded in evidence
- **Illustrating** the problem
- **Supporting** the solution
- **Informing and persuading** decision-makers and their allies
- **Informing** public health campaigns
- **Providing** counterarguments
- **Educating** the general population
- **Changing** perceptions
- **Discrediting** myths and incorrect claims
- **Demonstrating** effectiveness of policies

### What kinds of questions can data help you answer?

- Which populations are most affected by raised cholesterol? What do they say about it? What are the causes of high cholesterol according to people living with raised cholesterol?
- Who or what has an impact on raised cholesterol and strategies to manage it?

- How severe is the issue of raised cholesterol?
- How has the issue changed over time (e.g., The last 1, 5, 10, or 20 years)?

### Essential information and resources on cholesterol

- [WHF Cholesterol Webpage](#)
- [WHF White Paper on Cholesterol 2021](#)
- [WHF Roadmap on Cholesterol 2022](#)

### Essential information and resources on familial hypercholesterolemia

- [WHF Familial Hypercholesterolemia Webpage](#)
- [WHF & FH Europe FH Country Mapping Preliminary Analysis Report](#)
- [FH Global Call to Action](#)
- [FH Europe Website](#)
- [Family Heart Foundation Website](#)
- [EAS Familial Hypercholesterolemia Studies Collaboration](#)

### Other useful resources

- [US Centers For Disease Control and Prevention High Cholesterol Map and Data Sources](#)
- [ESC Atlas of Cardiology](#)



#### Tip

In order to provide a strong rationale for policymakers to support your issue, it is essential to distinguish between evidence and opinion. Clinical, public health, and health economics data are essential in convincing your audience.

For instance, cost-effectiveness analysis can provide you with strong arguments for the prevention, detection, and treatment of raised cholesterol. Additionally, the cost of inaction can also be leveraged.

MS. MAGDALENA DACCORD, CEO, FH EUROPE





# STEP 2: IDENTIFY YOUR STRATEGY

## Defining and selecting your cholesterol advocacy issue

As there are many CVD risk factor-related problems and potential solutions, it is important to focus on an issue that is both meaningful to your organization and feasible as a policy win. The example below, based on the recommendations of the Global Call to Action on Familial Hypercholesterolemia, highlights a cholesterol-related policy problem with potential policy solutions.

### Advocacy issue

- Lowering LDL cholesterol in individuals with FH to prevent premature heart disease and deaths.

### Policy problem

- Familial hypercholesterolemia affects 1 in 311 people or approximately 28 million of individuals worldwide<sup>(5)</sup>. Unfortunately, nearly 90% of individuals with FH remain undiagnosed and untreated. As a result, a significant number of people living with FH are at risk of premature cardiovascular morbidity and mortality.

### Question

- How can we improve the detection, diagnosis, treatment, and management of individuals with FH to reduce the incidence of premature heart disease and deaths?

### Possible policy solutions\*

- Raise awareness of FH by educating the general population and healthcare professionals, especially family doctors, internists, and pediatricians
- Improve screening, testing, and diagnosis of individuals with FH by implementing systematic cascade screening and universal screening of children. Screening programmes should be embedded in national strategies for the promotion of cardiovascular health and prevention of cardiovascular disease
- Treat individuals with FH as early as possible to prevent premature cardiovascular events. Cholesterol-lowering interventions, including statins and other novel medications, should be available, accessible, affordable, of high quality, and patient-centred
- Guarantee care for patients with severe and homozygous FH by establishing specialized guidelines and healthcare centres
- Develop family-based care plans by involving FH patients in the management of their condition, including education for children, support for families, and genetic counselling
- Conduct more research on FH. Develop safe and effective drugs as well as medical interventions for FH
- Establish and maintain registries of patients with FH
- Address genetic discrimination, especially with regard to health insurances.

## Questions to consider when evaluating the different policy solutions

- Can you demonstrate how the solution will impact those most affected?
- Is the solution based on sound evidence and data? Can it be verified by data?
- Is the proposed solution feasible/winnable?
- Is it easy to understand and explain?
- Will it attract support?
- Do established networks based on the issue already exist?



### Tip

**When formulating solutions to your cholesterol-related problem, keep in mind that patients' needs should always be at the centre of any solution. Involving patients in the process both empowers them and lends legitimacy to your campaign.**

\*List in no particular order of action.

## Checklist for selecting an advocacy issue

You can use the checklist below to assess the feasibility of a potential cholesterol advocacy issue.

Criteria for Selection	YES/NO High/Medium/Low
<b>Data:</b> Do you have access to data demonstrating the extent of the problem? Does the data demonstrate that the proposed solution will result in real improvements?	
<b>Scope:</b> Does the issue affect many people? Do enough people feel affected to do something about it?	
<b>Understandable:</b> Is the issue easy to understand and explain? Are you able to frame the issue in such a way that people readily comprehend the issue and its solution?	
<b>Resources:</b> Will you be able to raise enough money to support work on this issue? Do people care enough to donate funds and resources?	
<b>Targets:</b> Are you able to clearly identify the key decision-makers (individuals) to address this issue? Do you have their names and contact information?	
<b>Networks:</b> Do you have existing alliances with other stakeholders or key individuals based on this issue?	
<b>Values:</b> Is the issue consistent with your organization's mission statement and values?	
<b>Winnability:</b> Is the issue and its proposed solution feasible and/or winnable given the current political and social climate?	
<b>Future:</b> Does work on this issue provide the potential for building momentum for campaigns in the future?	
<b>Commitment:</b> Do people care enough about the issue to take action?	
<b>Empowerment:</b> Does the way you have framed the issue offer an opportunity for patient involvement?	

## Elements of an advocacy plan

Once you have selected your cholesterol advocacy issue, the next step is making an advocacy plan that lists your goals, objectives, actions, targets, timeline, partners, and resources. Doing this is a critical part of ensuring success in achieving your long-term goals and short-term objectives.

You need to make sure that your strategy is sound, that you have chosen the right targets, and that the right methods are adopted to reach those targets. A strong advocacy plan should include a goal, strategies for achieving the goal, measurable objectives, and tactics to achieve your objectives.



### Tip

**The difference between successful and unsuccessful advocacy campaigns is seldom the worthiness of the cause, and more often the strength of the plan.**

## Advocacy Planning Tool

The *Advocacy Planning Tool* below can help you organize and plan your cholesterol-related advocacy strategy.

Action Campaign	Partners	Targets	Indicators	Timeline	Budget
<i>E.g., Lipoprotein(a) Awareness Day Campaign</i>	<i>E.g., Family Heart Foundation and FH Europe, sponsors, etc.</i>	<i>E.g., general population, policymakers, etc.</i>	<i>E.g., social media impressions, number of downloads, etc.</i>	<i>E.g., 24 March 2023</i>	<i>E.g., USD</i>

## What are the basic steps of creating a cholesterol-related advocacy plan?

- **Issue:** Select the cholesterol-related advocacy issues, goals, and objectives
- **Data:** Identify appropriate data to support the issues
- **Targets:** Identify appropriate policy audiences (i.e., those capable of making the needed changes happen and those who influence the decision-makers)
- **Messages:** Develop and deliver persuasive advocacy messages
- **Partners:** Build support among constituencies and coalitions
- **Timeline:** Create a work plan with a timeline for advocacy activities
- **Action:** Carry out the work plan
- **Reassess and adapt:** Monitor, evaluate results, and adapt your strategy to learn from successes and failures.

## Defining goals, strategies, objectives, and tactics

- **Goals:** Primary outcomes you would like to achieve
- **Strategies:** Approaches you will take to achieve the goals
- **Objectives:** Measurable steps to achieve your strategies
- **Tactics:** Tools to achieve your objectives.



## What are cholesterol-related advocacy goals?

The first step in creating your advocacy plan is to develop your goals, which are your long-term (i.e., 5-10 years) vision for change. This vision should be far-reaching, in that no one organization working alone could achieve it. Goals address the question of how the long-term policy environment will be changed as a result of your cholesterol-related advocacy efforts. As such, it is important to assess how your goals align with local, national, and regional plans, priorities, as well as budget (e.g., competition with other public health priorities, etc.).



**Example:** Increase the national diagnosis rate and treatment coverage of individual with FH to 90%.

## What are cholesterol-related advocacy objectives?

Advocacy objectives are specific, short-term (i.e., 1-2 years), measurable, action-oriented targets that help you take incremental steps towards achieving your vision of change. They describe what you want to change, who will make the change, by how much, and by when.



**Example:** Establish a national registry for HeFH as well as HoFH patients, in collaboration with relevant partners, by the end of 2024.

## What are advocacy campaign tactics?

While cholesterol advocacy activities can be more general in scope, advocacy tactics are more specific tools that always require some measure of power. Tactics are:

- Influencing activities
- Steps in carrying out your advocacy plan
- Actions done to decision-makers to make them give you what you want
- Actions that involve showing or demonstrating real power (e.g., numbers of supporters, support of influential people in the community, etc.)

Advocacy tactics should demonstrate how broad your base of support is for your cholesterol-related issue. You might consider bringing together the largest number of supporters in one place in order to rally supporters and secure media coverage. Almost anything can be a tactic, as long as it actually puts pressure on a decision-maker either directly or through the media.

### Examples of Tactics

- **Face-to-face meetings**
- **Consultation responses**
- **Public meetings or conferences**
- **Turnout events**
- **Petition drives**
- **Letter writing**
- **Traditional and social media advocacy**
- **E-advocacy**
- **Public hearings**
- **Marches**
- **Town hall meetings, technical meetings, EU Presidencies meetings, etc.**

### Example from the field

**The Japanese Association for Patients with Refractory Familial Hypercholesterolemia (JAPRFH) regularly conducts advocacy campaigns to improve the conditions of people living with FH in Japan.**



1. JAPRFH members and partners advocated for the financial support of care for HoFH patients by the government. Following 3 years of collaboration and negotiations with the Ministry of Health and Welfare, medical costs of HoFH interventions are nowadays covered by the Japanese government.
2. JAPRFH has been organizing gatherings of FH patients to educate and empower patients as well as their families. Over a hundred patients and/or family members have attended the meetings since 2017.
3. JAPRFH, in partnership with the Japanese Atherosclerosis Society, advocated for the reimbursement of genetic tests for FH in 2018. Following 4 years of collaboration and negotiations with the Ministry of Health and Welfare, genetic tests for FH are nowadays covered by health insurances in Japan.

**PROF. MARIKO HARADA-SHIBA, OSAKA MEDICAL AND PHARMACEUTICAL UNIVERSITY**

## Sample Strategy Planning Tool: goal, strategy, objectives, and tactics

The *Sample Strategy Planning Tool* below provides examples of how to select and plan tactics that are in line with your objectives, strategy, and overall goal.

- **Goal:** Reduce by one-third national premature mortality from cardiovascular disease by 2030
- **Strategy:** Secure governmental support and funding for primordial, primary, and secondary CVD prevention strategies.

Objectives	Tactics	Tactics	Tactics
Gain support of the Ministry of Health on improving the prevention and control of raised cholesterol	Identify CVD and cholesterol control leaders with connections to the Ministry of Health	Develop and circulate policy briefs, as well as other resources, on the need for better prevention and control of raised cholesterol	Secure meeting with Minister of Health
Get an Op-Ed article published in leading newspapers to support the prevention and control of raised cholesterol	Meet with Op-Ed Board	Letter to the Editor on the need for more actions to prevent and control raised cholesterol	Hold a widely reported press conference to announce the launch of a campaign to raise awareness on raised cholesterol and familial hypercholesterolemia
Gain multi-sectoral support for improved cholesterol prevention and control	Develop outreach materials aimed at gaining support from relevant partners	Set up meetings with key stakeholders to share information and gain support	Identify CVD leaders with connections to key allies in other sectors



# STEP 3: IDENTIFY YOUR TARGETS



## Understanding your advocacy audiences

It is important to identify who the key decision-makers are in your country or setting. After people living with CVD and/or raised cholesterol, decision-makers are likely to be your most important cholesterol advocacy stakeholders. These are the people with the power to bring about change and usually work in places of influence, such as government departments, leading hospitals, or successful businesses. Some of your important stakeholders might include, depending on the national context, members of the following non-exhaustive list:

- **Donor agencies**
- **Community groups**
- **Business leaders**
- **Pharmaceutical and medical devices industries**
- **Medical, cardiologists, lipidologists, pediatricians, family doctors, pharmacists, and nursing associations**
- **Academics and universities**
- **Ministry of Health officials**
- **United Nations agencies**
- **Celebrities**
- **Politicians (local, provincial, and national)**
- **CVD patient groups**
- **CVD, FH, and Rare Diseases communities**
- **International agencies**

**These audiences can be divided into “primary” and “secondary” targets.**

### Primary targets

A primary target is a person who has the most power to give you what you want to advance your campaign or fulfil your requests. It is always a person and not an institution (e.g., the Minister of Health rather than the government or departments). You can use the table below to plan your approach to identify and reach your primary targets.

### Sample target strategy chart

**Objective:** National government supports reducing by one-third premature mortality from cardiovascular disease by 2030.

Primary Target	Position on Issue	Tactics to Reach Primary Target
<i>E.g., Minister for Health</i>	<i>E.g., supportive, unaware, etc.</i>	<i>E.g., letter to the Ministry of Health, etc.</i>

## Secondary targets

Secondary targets are individuals with strong influence over your primary target. Therefore, it is important to include them in your advocacy strategy. Secondary targets can be widely variable and multi-sectoral (e.g., the leading national newspaper or your primary target’s personal physician, etc.). Take the time to research and identify the actors that have the greatest impact on your primary targets. You can use the table below to plan your approach to identify and reach your secondary targets.

### Sample target strategy chart

**Objective:** National government supports reducing by one-third premature mortality from cardiovascular disease by 2030.

Secondary Target	Relationship to Primary Target	Tactics to Reach Secondary Target
<i>E.g., name of secondary target</i>	<i>E.g., personal physician of Minister for Health</i>	<i>E.g., secondary target is a member of the national society of cardiology or heart foundation</i>



#### Tip

Be creative and turn to your own professional and social networks to see if you have existing connections to both primary and secondary targets.

### Once you have identified your primary and secondary targets, you can assess each target based on the following factors:

- **Familiarity with your organization:** Have they interacted with you before? What type of interaction?
- **Knowledge about your advocacy issue:** How well-informed are they about your issue?
- **Position on your advocacy issue:** Do they support or oppose it? Or are they neutral?
- **History of support for your advocacy issue:** Is there a history of support for your issue?
- **Potential benefits of supporting your advocacy issue:** What’s in it for your target? How would your target benefit from supporting your issue? What are their interests and concerns related to supporting your issue?



# STEP 4: CREATE PARTNERSHIPS



## What is a multi-sectoral approach?

The challenges posed by CVD and its risk factors – including cholesterol control – require the meaningful engagement of various stakeholders through a whole-of-society approach. Multi-sectoral collaboration is the partnership that results when civil society (i.e., patient groups, community organizations, medical and professional societies, insurance companies, health technology assessment bodies, etc.), the business and private sectors, governments (i.e., all the different key sectors), academia, the media, and individuals come together to solve problems.

As you prepare your cholesterol-related advocacy strategy, be prepared to reach out to people who work in related health fields (e.g., experts in non-communicable diseases, nutrition, maternal and child health, prevention, etc.), sectors other than health e.g., experts in non-communicable diseases, nutrition, maternal and child health, prevention, etc., and those with experience working on international agreements.

### Example of a multi-sectoral partnership

WHF has designed a series of CVD-related roadmaps to translate existing knowledge of best practices, barriers, and solutions into practical strategies to meet the target set by the United Nations to reduce by one third premature deaths from NCDs, including cardiovascular disease, by 2030.

In order to create these roadmaps, WHF has convened global advisory groups of experts in CVD prevention in various sectors, including specialists in health policy, health systems, health economics, and patient advocacy. In 2022, the Cholesterol Roadmap was updated to include the latest evidence on the prevention and management of

raised cholesterol, as well as lessons learnt from the original Cholesterol Roadmap 2017 <sup>(3)</sup>.

WHF has developed the roadmaps as models for advocates to assess roadblocks and potential solutions to improving CVD care in their own country situations. In other words, WHF Roadmaps need to be adapted for different settings. To this end, WHF envisions that **national CVD Roadmaps** should be developed and implemented within “multi-sectoral” partnerships, including inter-governmental organizations, heart health advocacy foundations, cardiovascular scientific organizations, healthcare leaders, providers from primary and specialized care, private-sector partners, and people affected by CVDs (e.g., patients and caregivers).

### Find more details on our WHF Roadmaps

- [WHF Roadmap on Atrial Fibrillation](#)
- [WHF Roadmap on Chagas Disease](#)
- [WHF Roadmap on Cholesterol 2022](#)
- [WHF Roadmap on Digital Health 2022](#)
- [WHF Roadmap on Diabetes](#)
- [WHF Roadmap on Heart Failure](#)
- [WHF Roadmap on Hypertension 2021](#)
- [WHF Roadmap on Rheumatic Heart Disease](#)
- [WHF Roadmap on Secondary Prevention](#)
- [WHF Roadmap on Tobacco Control](#)

### Expert Advice

#### How Working in Partnership Can Help You Overcome Challenges to Cholesterol Advocacy:

In September 2021, the Heart and Stroke Foundation South Africa, the South African Heart Association, the Lipid and Atherosclerosis Society of Southern Africa, the Global Alliance for Patient Access, and a group of South African experts in cardiovascular disease partnered to launch the campaign “*Know Your Risk, Treat Your Numbers*” to raise awareness of the dangers of raised cholesterol as well as other risk factors for heart disease and strokes.

*“Before the COVID-19 pandemic, our country was already grappling with a dangerous combination of many life-threatening epidemics. The increasing rate of heart disease and strokes over the years and risk of patients having worse COVID-19 outcomes indicate that we have to mobilize to prevent and manage the complex burden of co-morbidities”*

**PROF. PAMELA NAIDOO, CEO, HEART AND STROKE FOUNDATION SOUTH AFRICA**



## Needs assessment: Partnerships

Both within the CVD community and beyond, strong partnerships will be essential to achieve Sustainable Development Goal target 3.4 and conduct successful advocacy related to cholesterol control. You can begin evaluating which groups have the potential to be appropriate advocacy partners by answering these core questions:

- Do you have an existing partnership working on cholesterol-related issues or other CVD risk factors?
- Is there a common goal that will bring the organizations together?
- Do your staff and volunteers have connections with organizations, academia, or the private sector that you want to involve?

### Next steps include:

- Making a list of organizations, volunteers, and community leaders to reach out to about joining the campaign
- Developing outreach materials that include background information, the goals of the campaign, and how the organizations can be involved
- Holding face-to-face outreach meetings to discuss the campaign and your common issues and goals

Once you achieve a critical mass of partnerships, consider forming a coalition or network to come together specifically on a cholesterol-related campaign. The network can be formal or informal, according to your needs. A strong coalition allows advocates to pool resources, extend their outreach, and increases the power of their voice.

### Expert Advice



The Iraqi Lipid Clinics Network regularly conducts awareness-raising campaigns on familial hypercholesterolemia and the importance of early screening. Awareness of the dangers of raised cholesterol remains low among the general public and healthcare professionals in Iraq. As such, the Network collaborated with several institutions, including the Ministry of Health, the Ministry of Education, and civil society organizations, to educate the general population and healthcare professionals. In addition, the Network also collaborated with several international organizations to provide training for medical professionals.

The Iraqi Lipid Clinics Network was also successful in launching a pediatric FH screening initiative, raising awareness of FH on official TV channels, developing a premarital FH screening strategy, establishing an FH patient advocacy group, and setting up an FH electronic consultation centre.

**DR MUTAZ AL-KHNIFSAWI, PRESIDENT, IRAQI LIPID CLINICS NETWORK**

## How can you identify potential partners for cholesterol advocacy actions?

Partner mapping tools can help you identify appropriate partners to engage as allies for cholesterol-related advocacy. Here are some examples of partner mapping tools that can walk you through this process. The *Profile of Potential Partners* Tool below can be used to map, analyse, and assess stakeholders who might be interested in working with you.

Potential Partner Details				Sphere of Influence			
Organization	Name	Contact Details	Position	Expertise	Position on Issue	Influenced By	Influence On
<i>E.g., Family Heart Foundation, FH Europe, etc.</i>	<i>E.g., contact name</i>	<i>E.g., email address, phone number, etc.</i>	<i>E.g., CEO, etc.</i>	<i>E.g., FH and patient advocacy</i>	<i>Supportive</i>	<i>E.g., member organizations, etc.</i>	<i>E.g., American and European organizations</i>

## Sample partnership list

The *Sample Partnership List* below can help you organize and keep track of potential partners for specific roles in your advocacy campaign.

Potential Partner	Key Contact & Relationship	Mutual Interest	Role in Campaign
<i>E.g., European Atherosclerosis Society</i>	<i>E.g., member of EAS</i>	<i>E.g., familial hypercholesterolemia</i>	<i>E.g., raise awareness of FH among healthcare professionals</i>

## Strategies to engage partners

When forming strong partnerships, face-to-face conversations are key. However, virtual meetings have also become a popular alternative. Look for opportunities to engage potential cholesterol advocacy partners through already scheduled CVD-related conferences and events.

### Calendars of global events to facilitate partners engagement

- [World Heart Federation – Events Calendar](#)
- [European Society of Cardiology – World Cardio Agenda](#)
- [American Heart Association – International Events Calendar](#)
- [NCD Alliance – Events Calendar](#)
- [Elsevier – Events List](#)

### World Heart Federation and WHF member-partner congresses

- [World Heart Summit](#)
- [World Congress of Cardiology](#)
- [American Heart Association Scientific Sessions](#)
- [American College of Cardiology Scientific Sessions](#)
- [European Society of Cardiology Congress](#)
- [Brazilian Society of Cardiology Congress](#)
- [Japanese Circulation Society Annual Scientific Meeting](#)
- [Pan-African Society of Cardiology Congress](#)

Additionally, **other like-minded organizations** may host events that are relevant to cholesterol advocacy, such as those focused on promoting physical activity and healthy eating, that may help you further communicate your messages and gain supporters.



**Be on the lookout for such events!**

# STEP 5: ENGAGE THE MEDIA



Engaging the media is a key component of most advocacy campaigns. Mass media is the quickest way to reach a large number of people. The media plays a significant role in shaping current debate around key issues, beyond raising awareness and information sharing. The media can also put pressure on policymakers to take action, educate and motivate the public, help dispel myths, and clarify key points around your cholesterol advocacy issue.

Although the media may run stories on heart disease, the scale of the burdens of CVD and/or raised cholesterol is not enough of a story on its own. It is a better strategy to approach the media with a specific “angle”, event, or piece of research to base their story on.



## Tips on media engagement

### Monitor News Coverage

- How are CVD and its risk factors, including raised cholesterol, being covered in your country?
- How much news coverage has the issue received (e.g., number of articles, mentions on TV, etc.)?
- Who has been covering the issue? Which newspapers, blogs, and TV stations have had stories about cholesterol and/or familial hypercholesterolemia? Has a specific journalist been writing about it? Do you have a relationship with the journalists covering the issue?
- How has CVD and high cholesterol been portrayed in the media? What are the main arguments and concerns? Are there any public misconceptions, especially with regard to inherited and/or lifestyle causes of high cholesterol?

Consider setting up an online email alert to inform your network on news around cholesterol and any related policy goals. One option is using Google Alerts. Please find hereafter, a step-by-step guide on how to set up a Google Alert.

[www.wikihow.com/Use-Google-Alerts](http://www.wikihow.com/Use-Google-Alerts)

## Consider the different ways to get your message heard



- Special events
- Press conferences
- Letters to the Editors
- Meeting with Editorial Boards
- Paid media advertisements
- Social media

**Develop and cultivate relationships with journalists:**

Further develop any existing relationships with journalists covering local and national health issues. Be proactive in seeking out major media actors and establish yourself as an expert on CVD and its risk factors, including raised cholesterol. Find out who covers topics related to CVD and cultivate relationships with them.

**Be opportunistic:** As you monitor the media, look for opportunities to promote your message. For instance, the best time to submit an editorial may be immediately after an article has been published on CVD and other risk factors or after a major health event or meeting. Breaking research on cholesterol can also be a great opportunity to link the research back to the larger issue of health systems strengthening and SDG target 3.4.

**Be proactive:** Don't wait for the media to come to you or to start covering the issue. You need to be proactive and

reach out to the media. Provide them with key background information and establish yourself as a valued source. Try to find out what information they need and provide it in a timely manner. Write press releases in the style of articles and stories of your local newspaper in order to help journalists do their jobs.

**Activate your social media network:** The effective use of social media (e.g., Twitter, Facebook, LinkedIn, blogs, etc.) can help spread your campaign message, engage the traditional media, and recruit people for your cholesterol advocacy agenda. Consider using Instagram and TikTok to engage with younger generations of advocates and ambassadors. These tools give you access to millions of users from around the world. While you should be active within multiple social media communities to maximize your reach, determine which platforms are most popular among your key targets and prioritize those.

**Expert Advice****Tips from the Iraqi Lipid Clinics Network on working with the media:**

- Use a range of different media! We broadcasted our messages through official and non-governmental TV channels, official and non-governmental radio stations, social media, etc
- Be creative! We used a range of materials and resources to convey our messages, including cartoons to boost the appeal
- Avoid jargon! We used easy to understand messages for the general population
- Do not assume that you will need a lot of money for a media campaign! We capitalized on our relationship with journalists and government officials to air our messages.

**DR MUTAZ AL-KHNIFSAWI, PRESIDENT, IRAQI LIPID CLINICS NETWORK**

**Engaging the Media: 'Do's'****The Mexican Organization Paco's top tips for working with the media:**

- **Make it newsworthy:** Make your media event compelling by bringing together a large number of people. Highlight a celebrity or well-known spokesperson or tie the event into the launch of a new resource, program, campaign, or breaking story related to cholesterol
- **Make it visual:** Envision how your event will look and make it interesting for video
- **Make it emotive:** Emphasize the art of storytelling
- **Use a catchphrase or hashtag:** Make sure that a consistent theme anchors the event and that speakers use the same quote as an effective "sound bite"
- **Use lay terms:** Make your messages easy to understand and compelling
- **Make it about real people:** Showcase patients and other individuals affected by CVD and raised cholesterol, by empowering them to tell their own stories.

# STEP 6: DEVELOP AND DISSEMINATE KEY MESSAGES



Now that you have identified your cholesterol advocacy goal, the evidence that supports it, and partners to help you achieve it, you can focus on shaping your advocacy messages and how you are going to get these messages across to a variety of audiences. Developing and delivering effective advocacy messages is an intrinsic part of building support for your campaign, and it flows directly out of the research that you did on identifying key decision-makers in the policy process, determining who your primary and secondary targets are, and understanding the general framework of the decision-making process.

## Strategic communications for Cholesterol Advocacy

- A planned communications strategy seeks to inform, persuade, motivate, and move a designated policy audience to take action
- It involves expertise to formulate compelling arguments to achieve advocacy objectives
- It considers target characteristics and preferences
- It always features a clear call to action.

## Framing messages for greatest support

Successful advocacy is contingent upon your organization's ability to move decision-makers into taking action. It requires strategic communication – formulating and articulating arguments in a compelling way – to achieve your advocacy objectives.

Effective advocacy is based on the message you are delivering, how you deliver the message, and the audience you are intending to reach. How you frame the issue will depend on who you are talking to and their personal as well as professional experience.

## Position your issue

Getting others on board, especially government officials, will require you to position your issue in a way that makes it relevant to them. In environments with limited resources and many competing priorities, often those who are most effective in communicating a problem and presenting cost-effective solutions are the ones who will be heard. Familiarise yourself with existing programmes and priorities in order to identify how you could fit your objectives or how decision-makers could achieve their goal by supporting your campaign.

Ensure that your asks are easy to endorse. For example, emphasizing the financial implications of raised cholesterol and the impact of this burden on your community may help get the attention of decision-makers. Emphasize the links between national policy and international policy and development. As CVD and its risk factors remain a development issue – one leading to and resulting from poverty – all countries have a stake in addressing it.

## Tailoring messages to different audiences

Tailoring your messages to the audience will allow you to leverage their interests and increase their engagement. Different audiences will have different availability, modality, levels of understanding, needs, expectations, and aspirations. It is important to translate scientific data regarding raised cholesterol and other CVD risk factors into messages that motivate government officials, the media, and potential advocacy partners to take action.

On the following pages, we have included examples of tailored messages for various audiences. The most effective messages use local data. Please include local data and information wherever possible.

## Type of audiences and messages

Audience	Interest	Messages
<p><b>Ministers of Health &amp; Government Officials</b></p>	<p><b>Roles of the Ministers for Health &amp; Government Officials</b></p>	<ul style="list-style-type: none"> <li>• Develop national guidelines on the diagnosis and management of raised cholesterol and FH</li> <li>• Implement cost-effective screening strategies, such as systematic cascade screening and universal screening for children, for raised cholesterol and FH</li> <li>• Integrate key cholesterol control interventions in national health systems and programmes to achieve SDG target 3.4</li> <li>• Monitor and collect relevant data on individuals with high cholesterol and FH</li> <li>• Establish national care centres for screening and management of people living with raised cholesterol and FH, including individuals with HoFH</li> <li>• Implement primordial, primary, and secondary CVD prevention strategies to preserve health instead of treating disease</li> <li>• Enact public health policies that enable healthy lifestyles.</li> </ul>
	<p><b>Financial Implications</b></p>	<ul style="list-style-type: none"> <li>• Cardiovascular disease as well as its risk factors have significant impacts on the health and economic burden of a country. They are responsible for considerable amounts of morbidity, mortality, and medical expenditures. In addition, CVD and raised cholesterol also affect the productivity and economic growth of a population</li> <li>• Screening, diagnosing, and treating raised cholesterol are cost-effective interventions. The price of inaction is considerable and furthers existing inequities</li> <li>• Cholesterol-lowering therapies, such as statins, need to be available, accessible, and affordable.</li> </ul>
<p><b>Media</b></p>	<p><b>Why Does Raised Cholesterol Matter?</b></p>	<ul style="list-style-type: none"> <li>• Cardiovascular disease remains the number one killer worldwide, causing approximately 18.6 million deaths annually<sup>(1)</sup>. Evidence shows that elevated blood cholesterol is one of the major modifiable risk factors for CVD<sup>(2)</sup>. Approximately 4.4 million deaths and 98.6 million DALYs were attributable to raised LDL cholesterol in 2019<sup>(4)</sup></li> <li>• Familial hypercholesterolemia affects 1 in 311 people or approximately 28 million of individuals worldwide<sup>(3,5)</sup>. In spite of the high prevalence, only 10% of people living with FH are diagnosed and treated<sup>(6)</sup></li> <li>• Most people remain unaware of their cholesterol levels or their overall cardiovascular risk. Lifelong exposure to elevated concentrations of LDL cholesterol leads to premature cardiovascular morbidity and mortality. Therefore, raised cholesterol and FH should be diagnosed and treated as early as possible</li> <li>• For patients who have already developed CVD, reducing cholesterol is central to preventing recurrent cardiovascular event. However, a large treatment gap exists in the proportion of patients achieving national targets for cholesterol lowering, despite the overwhelming evidence that statins reduce CVD risk and improve life expectancy</li> <li>• The United Nations Sustainable Development Goals have set targets to reduce by one-third premature deaths from non-communicable diseases, including cardiovascular disease, by the year 2030. Reducing the risk of cholesterol-related CVD has an essential role to play in achieving the goal</li> <li>• People are not receiving the appropriate prevention and treatment services they need to lower cholesterol and prevent CVD death and disability</li> <li>• Raised cholesterol is a major cause of disease burden in both the developed and developing world. Heart disease and stroke are not diseases of the rich and affluent. The burdens of cardiovascular disease and raised cholesterol have been shifting from high-income countries to low- and middle-income countries. In fact, most deaths from heart disease and stroke occur in low- and middle-income countries.</li> </ul>

Audience	Interest	Messages
<b>Heart Health Community</b>	<b>Role of the Heart Health Community</b>	<ul style="list-style-type: none"> <li>• Urgent actions are needed. Reliable monitoring of non-HDL cholesterol or apoB levels are essential to tackling the burden of cardiovascular disease. In addition, lipoprotein(a) should also be measured in routine lipid profiles</li> <li>• It is the heart health community's responsibility to generate and secure the political backing necessary to ensure that CVD and its risk factors, including raised cholesterol, are a top priority on the political agenda</li> <li>• The heart health community need to identify windows of opportunities to convince governments and international bodies to devote appropriate resources to curb the rise of non-communicable diseases, including CVD and raised cholesterol.</li> </ul>
	<b>Priorities of the Heart Health Community</b>	<ul style="list-style-type: none"> <li>• Increase access to health facilities among poor or remote populations for cholesterol testing, with inexpensive and easy to use technologies (e.g., cholesterol test strips)</li> <li>• Ensuring that the UN Sustainable Development Goals target 3.4 on NCDs is considered and included in all national plans</li> <li>• Increase access to cholesterol treatment for patients, with an emphasis on affordability and availability of statins, through free or subsidized drug provision, insurance schemes, and generic drugs.</li> <li>• Campaign to raise awareness among health professionals and the public about the importance of screening for elevated cholesterol and possible FH. In addition, the CVD and FH communities should promote FH Awareness Day on 24 September and World Heart Day on 29 September</li> <li>• Explore the use of Fixed-Dose Combinations strategies (combination pill including a beta-blocker, a statin, an ACE-inhibitor, and sometimes aspirin) among certain high-risk groups</li> <li>• Develop simplified national guidelines on the diagnosis and management of CVD and dyslipidemia.</li> </ul>

## Expert Advice



### Tailoring Cholesterol Advocacy Messages to Different Audiences

FH Europe is a European Patient Network that actively strives to improve awareness, understanding, and access to diagnosis as well as treatment for inherited lipid conditions across Europe. FH Europe conducts a range of different advocacy activities and campaigns so that all those impacted can receive optimal treatment and support.

- In 2020, FH Europe conducted, in collaboration with the World Heart Federation, an international survey to map the state of FH around the world. A preliminary analysis report was published by both organizations in April 2022
- In 2020, FH Europe joined forces with the European Atherosclerosis Society and MEDizzy, on FH Awareness Day, to raise awareness and educate young generations of healthcare professionals on FH
- In 2022, FH Europe, in collaboration with ANHET.F and other stakeholders, published an open letter, in French, addressed to President M. Emmanuel Macron to advocate for universal FH pediatric screening
- In September 2022, FH Europe successfully advocated for the endorsement of the Prague Declaration on Universal FH Pediatric Screening in Europe by the Czech Government. FH Europe invited national and regional policymakers, medical societies, patient and public health organizations, as well as individual experts to support the Declaration

For each and every activity or campaign, FH Europe had to tailor its messages and language to the audience – from the general population to young healthcare professionals, researchers, decision-makers, etc.

**MS. MAGDALENA DACCORD, CEO, FH EUROPE**



## Strong messages

The best cholesterol advocacy messages are evidence-based, with clearly cited facts and statistics. They effectively translate dry data into compelling messages that motivate decision-makers to take action on cholesterol control. When appropriate, consider supporting your argument using visual materials, such as disease burden maps (e.g., from the World Heart Observatory) and WHF infographics, to capture your audience's attention.

## Developing effective messages

- Use clear, concise, and compelling language
- Keep sentences and paragraphs short and punchy to catch and keep attention
- Avoid jargon, dry bureaucratic language, and acronyms
- Use facts and statistics that mean something to the audience
- Illustrate your messages with human-interest case studies or success stories.

## Selecting effective messengers

Your message can have a very different impact depending on who is delivering it. Who is the most appropriate person to deliver the message? Who will the target respond to best? Who will the target find credible?

You should choose your messengers strategically and you may wish to have different messengers for different forums or audiences, and at different geographical or political levels. For example, a well-known celebrity could be very effective at delivering your message to the general public, whereas a scientific expert on cholesterol control could bring credibility in a political forum.

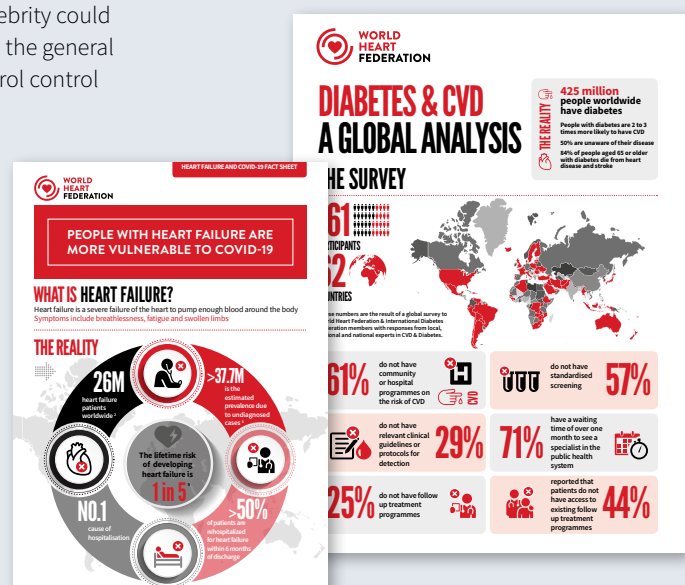


## Patient Ambassadors: Patients as spokespeople and patient engagement

The patient voice is a valuable tool for health advocacy. Although patients are experts on the lived experience of their disease, their potential to engage in advocacy often remains untapped. It can be a powerful strategy for a person who will be affected by your proposed policy change to present the advocacy message.

When people affected by CVD and its risk factors bring personal experiences to the attention of decision-makers, they put a “human face” on complex societal problems. Communications from the patient perspective are an especially important vehicle for helping your audience connect with your messages on an emotional level (to balance compelling facts and statistics). Your organization can harness the power of the human story to educate decision-makers by establishing and maintaining a cadre of patient spokespeople. Patients can be especially effective as advocates because they can:

- Speak to the media and decision-makers to help change public opinion and advocate for systems-level changes
- Serve as role models for others touched by CVD and its risk factors
- Put a human face and story to a cause
- Add credibility to your advocacy efforts
- Become an advocate for healthy lifestyles and wellbeing.





## Tips for developing effective Cholesterol Advocacy messages

- Use credible data to support the message
- Who cares? Offer a human element by using real life examples and featuring the patient voice and experience
- The messenger can be as important as the message
- Keep it simple, concise, persuasive, and positive
- Invite the audience to join their peers in supporting your issue
- Be familiar with opposing arguments and prepare counter-arguments
- Why now? Create urgency
- Involve an expert for credibility
- Involve a big name, someone the audience cares about.



## Tips for successfully delivering messages to decision-makers during face-to-face meetings

- Make a plan: Before the meeting, review your key points, your requests, and each person's role, including who will be the primary spokesperson
- Get consensus: Make sure that everyone agrees on the message, how it will be presented, and who will be the messenger
- Stay on message: Keep the focus of the meeting on your issue. Convey your most important points first in case you run out of time
- Get to the point: Present your message clearly and consistently. Make sure you tell them why they should care by connecting your issue to their interests. Tell them what you want them to do
- Provide details in writing: Leave a fact sheet with your policy "asks"
- Be a good listener: Listen carefully to the responses you receive. Give the decision-maker time to talk
- Provide additional information: Answer questions as they arise. Offer to provide further information
- Counter arguments respectfully: Respond to opposing arguments in a direct but principled way. If you know that the decision-maker opposes your position, make sure to point out areas of commonality
- Cultivate an ongoing relationship: Meetings are part of developing an ongoing relationship with decision-makers, so treat them respectfully, convey flexibility, and thank them before you leave
- Follow-up after the meeting: Send a thank-you letter, and any further information that was requested. This reminds policymakers about your issue and is an important step in relationship-building
- Evaluate and track process: Review what happened in the meeting. Track the progress of your request. Involve an expert for credibility.

# APPENDICES

## Appendix 1: Sample letter to minister of health or other key decision-makers to request a meeting to discuss cholesterol control

Once you have identified your advocacy targets, it is important to connect with them and raise the issue of cholesterol control as a key strategy for reducing CVD-related death and disability. One easy first step to take is to write a letter. When writing a letter, it is good to be clear, concise, and back up your claims with local statistics. Try to include the following information:

- Who you are and what your organization does
- Key messages about CVD and its risk factors, including raised cholesterol

- What the local CVD and raised cholesterol burdens are in your setting
- What you are asking the decision-maker to do
- How you can support the decision-maker
- Your availability for a face-to-face or virtual meeting to follow up the conversation

We have provided the following text as a template letter to your national Ministry of Health, to urge them to meet with you and address raised cholesterol.

### Your Excellency Minister {Name},

I am writing on behalf of {insert name of organization} to request your support in addressing the burdens of cardiovascular disease (CVD) and raised cholesterol in {insert name of country} and across the world.

As you are aware, cardiovascular disease is responsible for over 18.6 million deaths every year and remains the leading cause of mortality worldwide. Raised cholesterol is widely recognized as a major risk factor for myocardial infarction and ischemic stroke. Evidence shows that early diagnosis and treatment of people living with elevated cholesterol are critical to preventing premature cardiovascular disease morbidity and mortality.

Of particular concern, the public health and economic burdens of CVD and raised cholesterol have been shifting from high-income countries to low- and middle-income countries, disproportionately affecting the most vulnerable populations and furthering existing inequities. In {insert name of country}, the impact of cardiovascular disease and high cholesterol, includes {insert local data on CVD and raised cholesterol} [...].

The United Nations and the World Health Organization are committed to reducing by one-third premature mortality from non-communicable diseases by 2030, through the UN Sustainable Development Goal target 3.4. Undeniably, the aforementioned target cannot be reached without properly addressing cardiovascular disease and raised cholesterol as public health priorities.

We believe that accelerated and collaborative efforts from the government and the civil society are essential to achieving SDG target 3.4. Therefore, we would like to request a meeting at your earliest convenience, either in person or virtually, to discuss potential avenues of collaboration and how the CVD community could best support your efforts in addressing the burdens of cardiovascular disease and raised cholesterol.

Thank you again for your time, consideration, and leadership in the fight against cardiovascular disease.

We look forward to hearing from you.

Sincerely,

{Insert Name}, {Insert Title}

## Appendix 2: Open letter to Head of State President Emmanuel Macron – English version

Association ANHET.F  
 1 rue de Pouilly  
 02000 Chéry les Pouilly  
 anhet.f@anhet.fr  
<https://www.anhet.fr>

Mr. Emmanuel Macron  
 President of the French Republic  
 and of the Council of the European Union  
 Palais de l'Élysée  
 55 rue du Faubourg Saint-Honoré  
 75008 Paris

### **Subject: Paediatric screening for familial hypercholesterolemia - an urgent and solvable public health problem in France and Europe**

#### **Mr. President of the Republic and of the Council of the European Union,**

As the only French association of patients with familial hypercholesterolemia, Anhet.f is writing to you today, supported by FH Europe, a European network of 29 national associations of familial hypercholesterolemia, of which Anhet.f is a member. Our organizations represent the interests of patients and citizens affected by an inherited genetic disease called Familial Hypercholesterolemia (FH) in France and in Europe. This letter is also co-signed by international and national organizations and experts in the field (see signatures).

Homozygous Familial Hypercholesterolemia is a rare and extremely serious disease (1-9:1,000,000) affecting children as young as 4 years of age and with death due to heart attacks by the age of 20. It occurs when both parents pass on to their child the genes for Familial Heterozygous Hypercholesterolemia, which is one of the most common genetic diseases affecting one in 250 to 300 people in France and Europe. It is an urgent and potentially fatal public health problem. We are convinced that the prognosis of this disease in its two forms can be improved with your support.

It should be noted that heterozygous FH is the most common genetic and inherited risk factor for cardiovascular disease (CVD). CVD is the leading cause of premature death in France and Europe! Undetected and therefore untreated heterozygous FH leads to heart attacks, strokes and consequently to avoidable premature death, independently of gender, age and lifestyle. One in sixteen (1:16) people diagnosed with a heart attack have FH. In France, between 225,000 and 270,000 people are affected, and one in five (1:5) of these people will suffer a heart attack, according to data from the global FH registry published in The Lancet in 2021.

Paradoxically, FH is poorly identified in the French general population and in addition very late. Only 10% of patients are screened. Estimated 50,000 children are born with FH in France and only 5% of them are diagnosed. At the European level, a few countries such as Holland and Slovenia have implemented early screening to increase the detection rate to more than 70%, showing that this objective is realistic. In view of the increased risks, early detection for these patients is essential and vital.

Whatever the form, Familial Hypercholesterolemia from birth can only lead to cardiovascular complications and even premature death in these children and/or their parents. However, this fatality and loss of life can be avoided by a simple blood screening because effective and inexpensive treatments exist.

The European Commission emphasizes the importance of prevention in the context of cardiovascular disease (CVD). Faced with these increasing costs, both financial and human, during the last Slovenian Presidency of the European Union, this country organized, with the support of FH Europe, on October 11, 2021 a high level Technical meeting on the issue of paediatric screening for Familial Hypercholesterolemia.

On the occasion of this meeting, various elected officials and representatives of European member states were present. Recognized European scientists as well as patient associations were able to underline the importance of screening this frequent genetic disease as early as possible in order to prevent early atherosclerosis in children, and thus avoid neuro-cardio-vascular complications in young adults. Given the unequivocal scientific and political consensus reached at the technical meeting and in light of the current French presidency of the EU, we believe it is essential that France follow Slovenia's lead and implement a paediatric HF screening program for its citizens, of whom more than 225,000 are affected.

Finally, the EU4Health 2022 work program published in January 2022, as well as the EU initiative on noncommunicable diseases (NCDs) "Healthier together" launched in December 2021, show concrete political momentum and financial resources for specific actions such as HF screening in France and in Europe.

We kindly request a meeting as soon as possible to discuss how we can move this issue forward with you and your departments, as well as with representatives of the scientific and FH patient communities in Europe.

We thank you for your attention to our request and for the important contribution this action will make to the improvement of the health of French and European citizens. Please accept, Mr. President of the Republic, the expression of our highest consideration.

**Letter signed by Anhet.f, FH Europe, World Heart Federation, European Heart Network, European Atherosclerosis Society, International Atherosclerosis Society, NSFA, Inserm, and EAPC**

## Appendix 3: Sample article about the launch of the updated WHF Roadmap on Cholesterol

### Cholesterol Risks and Remedies: A Roadmap to Improve Cardiovascular Health

Increasingly, evidence is equipping us with ways to manage our blood cholesterol levels that can mitigate or prevent dangerous cardiovascular conditions. The updated World Heart Federation Cholesterol Roadmap 2022 delves into the epidemiology, diagnosis, treatment, and policies for better outcomes and highlights implementation case studies. The Roadmap focuses on approaches to reduce atherosclerosis and atherosclerotic cardiovascular disease (ASCVD) from cholesterol plaque that causes arteries to become thick or stiff. The 2022 Roadmap identifies challenges to prevention and management of cholesterol while providing evidence-based solutions.

As much as 85% of the 18 million cardiovascular deaths annually is due to ASCVD. Left untreated, elevated levels of unhealthy cholesterol (low-density lipoproteins or LDL-C) can lead to atherosclerosis. Advancing quietly, symptoms of atherosclerosis can erupt suddenly and often fatally. Premature death, disability and high healthcare expenditure are attributed to ASCVD which drives heart disease, stroke, and other complications of the circulatory system – our blood vessels.

*"We have effective and inexpensive therapies to target atherosclerosis. We have identified solutions for implementing adequate therapies tailored to different models of care to ensure success,"* said Raul D. Santos from

the University of Sao Paulo and Hospital Israelita Albert Einstein, co-chair WHF Cholesterol Roadmap.

### Lifestyle and genetics

Globally, raised total cholesterol ( $\geq 5.0$  mmol/L) affects approximately 39% of adults. Lifestyle plays a key role in cholesterol levels. A diet high in saturated fat and trans-fats combined with physical inactivity and smoking can cause cholesterol levels to soar. Lifestyle-impacted metabolic conditions including type 2 diabetes and obesity also increase unhealthy cholesterol in the blood stream.

Heredity can play a partial role in the amount of cholesterol our bodies produce. Moreover, a genetic disorder called Familial Hypercholesterolemia (FH) affects approximately 28 million people worldwide (one in 311 people), a figure possibly much higher due to low awareness and under-diagnosis. Only 5-10% of those affected by FH know about their condition and less than 3% are adequately treated.

Most patients globally do not have a low-enough level of LDL-C that would minimize their risk of ASCVD. Obstacles to managing cholesterol often include lack of health awareness and education, insufficient or delayed screening, poor access to health facilities and health professionals, and unaffordability and unavailability of essential treatments.

Inadequate management of cholesterol can also be partly due to the under-use of effective doses of potent statins as first-line therapies, low use of combination therapies and

poor adherence to lipid lowering regimens. Cultural biases often persist and include patients' fear of side effects of treatments such as statins.

### Prevent, detect, manage

Primary prevention is about treating risk factors to prevent ASCVD; primordial prevention is about avoiding the development of risk factors in the first place – those that arise from environmental and social conditions present from birth and that continue depending on lifestyle.

Awareness and education campaigns, food labelling and regulation, tobacco legislation, and taxing unhealthy commodities are some concrete steps that must be ramped up. Reinforcing ASCVD risk assessment processes, screening, genetic testing such as for FH, and national monitoring of outcomes are part of a robust package to promote healthy societies and end premature loss of life from treatable causes.

Timing matters for interventions to take effect. For example, started early, population-level screening can identify at-risk individuals and is important for a full picture of total blood fats such as cholesterol: LDL-C, non-HDL-C as well as triglycerides and lipoprotein (a), another type of blood fat or lipid. Increased health literacy for both public and healthcare providers is essential and can help promote patient adherence to therapies once risks have been identified.

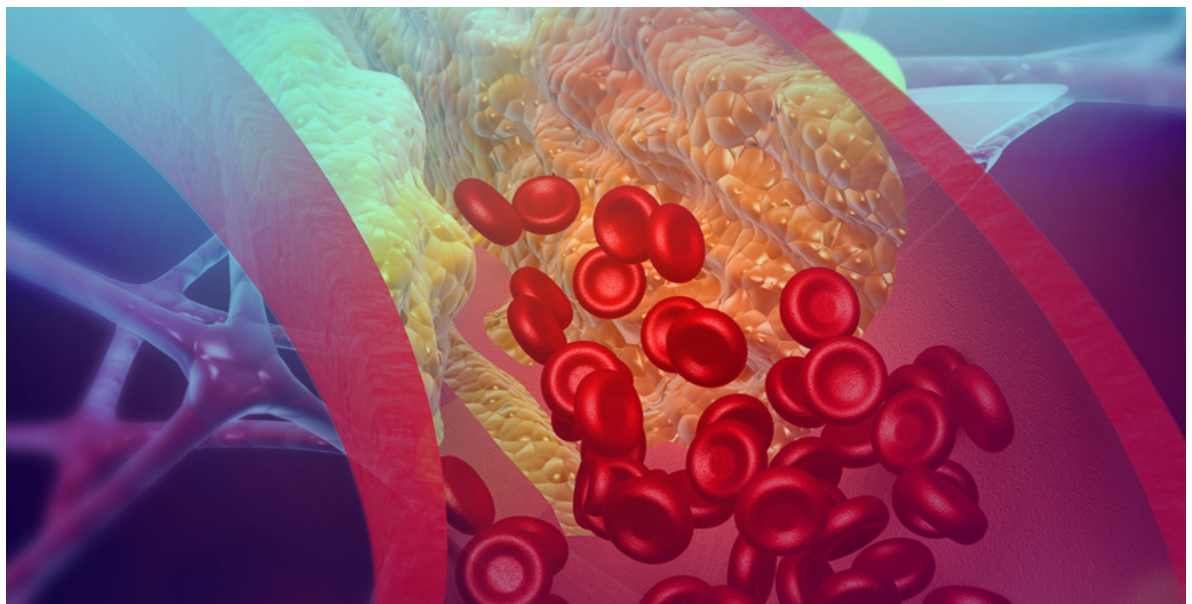
*“Our goal is to work together to reduce deaths from atherosclerotic cardiovascular diseases, and to curb human suffering and societal and fiscal costs. The knowledge gathered helps us provide pragmatic solutions via the WHF Cholesterol Roadmap, including a lifetime cholesterol-lowering approach,”* said Professor Kausik K Ray of Imperial College London, co-chair WHF Cholesterol Roadmap.

### Global implementation, national commitment

In tandem with clinical approaches are the critically important enabling health policies. Strong national policy is the bedrock that allows for implementation of increasing knowledge and evidence, effective drug treatment, and modified lifestyles so that all who need care get care.

From Europe to Asia, efforts have been underway to roll out guidelines in lipid management. In Belgium, a National Stakeholder Roundtable was convened leading to agreement for more systematic screening for FH in EU countries. Collaboration with the Colombian Society of Cardiology and Cardiovascular Surgery led to priorities including implementation of cholesterol clinical guidelines in all healthcare settings in the country. A National Roundtable in the Philippines resulted in a plan of action for patient screening, better education and guidelines, and access to health facilities by poor or remote populations. Similarly, Saudi Arabia identified a series of country-specific roadblocks to better CVD management at patient-, clinician- and healthcare system- levels, a precursor to proposed solutions for submittal to the national health council.

We have increasing knowledge, more drug therapies, and the proof that lifestyle modifications can tackle ASCVD. As the Cholesterol Roadmap 2022 shows, preventing the risks of cardiovascular disease due to cholesterol plaque build-up that cause atherosclerosis is a goal with possibly even more solutions than obstacles to achieving it.



## Appendix 4: Sample letter to the Editor or Op-Ed to leading newspapers for FH Awareness Day

**Dear {Name},**

I am writing on behalf of **{insert name of organization}** to call on the support of your newspaper to raise awareness around familial hypercholesterolemia on **FH Awareness Day on 24 September**.

Familial Hypercholesterolemia or FH is a genetic disorder that causes high levels of cholesterol from birth. The condition affects 1 in 311 people or approximately 28 million of individuals worldwide. Untreated, lifelong exposure to elevated concentrations of low-density lipoprotein (LDL) cholesterol leads to premature heart disease and deaths. In 1998, the World Health Organization (WHO) formally recognized FH as a global public health issue and published a set of recommendations to address its burden. Two decades later, implementation of the WHO recommendations has remained largely insufficient in many countries and regions. In fact, nearly 90% of individuals living with FH remain undiagnosed and therefore untreated, despite the fact that established evidence shows that early diagnosis and treatment of FH are critical to averting further premature cardiovascular disease morbidity and mortality.

In 2020, representatives from the global FH community launched a **Global Call to Action** and issued a set of revised recommendations to reduce the clinical and public health burden of familial hypercholesterolemia globally. On **FH Awareness Day**, the World Heart Federation (WHF) urges governments, the World Health Organization, and the global health community to:

- **Raise awareness** of FH as a global public health issue
- Actively **screen, test, and diagnose** for individuals with FH by implementing systematic cascade screening or universal screening for children
- Manage and **treat FH** patients to prevent further premature heart disease and deaths
- **Guarantee care for severe and homozygous FH** patients since they require specialized guidelines and care
- **Develop family-based care plans** for people living with FH and ensure opportunities for patient involvement as well as shared decision-making
- Establish and **fund FH registries** to collect relevant data, identify gaps, inform best practices, and monitor progress
- Conduct **research and implement** FH programmes to improve care
- **Understand the value and costs** of FH interventions
- **Advocate** for the implementation of the above recommendations!

In light of the continued need to raise awareness of FH and identify gaps as well as opportunities, the World Heart Federation has conducted, in partnership with FH Europe, an international survey to map the state of FH around the world. The **preliminary analysis of the data** concurred with well-established evidence: FH remains a widely underdiagnosed and undertreated condition across all countries and regions. Fortunately, the initial findings also suggest that many countries have initiated more actions to address FH at the national level.

We encourage you to publish more information in future editions of the newspaper on familial hypercholesterolemia, its impact on premature heart disease and deaths, and the importance of early diagnosis and treatment for people living with FH. If we, the heart health community, can be of any assistance, or if you require any additional information, please feel free to contact us at **{insert contact information}**.

Thank you again for your consideration.

We look forward to hearing from you.

Kind regards,

**{Insert Name} {Insert Title}**

## Appendix 5: Selected global challenges and policy recommendations

### Cholesterol Control: Selected global challenges

- **Raised cholesterol** is largely a silent disease, which generally causes no visible symptoms. As a result, it often remains undetected. Even when diagnosed, high cholesterol is not systematically treated and often remains poorly controlled. Low physician and healthcare workers awareness is also a reality, in particular with regard to familial hypercholesterolemia.
- **Eight risk factors** – high cholesterol, high blood pressure, tobacco, high glycemia, unhealthy diet, physical inactivity, obesity, and alcohol – account for 61% of all cardiovascular disease deaths. Raised cholesterol can be prevented by adopting intersectoral approaches that reduce exposure to the above risk factors.
- **The World Heart Federation** urges governments to enact policies that ensure an environment that is conducive to healthy living. Governments can do so through legislative action, policies, programmes, and campaigns that encompass CVD risk factors.
- **High cholesterol** often remains undiagnosed. For FH, the situation is even more dramatic, as it is estimated that

only 10% of individuals affected are diagnosed. The lack of facilities to measure cholesterol is another hurdle to detection as facilities to analyse blood samples are not universally available at the primary care level.

- **Although high cholesterol** can be easily reduced or treated with inexpensive and cost-effective medications, these treatments remain inaccessible to a broad segment of the world’s population. Despite the fact that statins – the most commonly prescribed drug to treat raised cholesterol – have been included in the WHO Lists of Essential Medicines for over a decade, their availability and affordability continue to be a major hurdle for some populations.
- **Psychological barriers** to long-term treatments are not to be under-estimated: patients lack health literacy, do not realize the importance of treatment adherence or have misconceptions about their medications, and therefore stop taking them.
- **Measuring and tracking** progress are key elements to defining priorities, adapting strategies, programmes, and projects, controlling progress towards desired outcomes, identifying what works and what doesn’t, justifying the allocation of resources, etc.

### Cholesterol Control: Selected policy recommendations



inform

#### Inform

- Conduct campaigns to raise awareness among the general public as well as healthcare professionals of the importance of screening for raised cholesterol and possible FH
- Conduct campaigns to provide balanced information to the public and healthcare professionals on the safety and efficacy of cholesterol treatments, including statins
- Foster the use of novel technologies, such as mHealth apps or text messaging, to remind and support patients toward treatment adherence
- Raise awareness of the importance of severe hypercholesterolemia and FH as a global public health issue – by targeting the general public, educational institutions, the medical community, and healthcare delivery systems.



Prevent

#### Prevent

- Support food reformulation efforts, in particular with regard to eliminating artificial trans-fats. The WHO REPLACE action package and technical support in-country should be leveraged by policymakers to protect their populations from the health harms of trans fatty acids (TFA)
- Embed TFA elimination in a broader and coordinated approach to improve diet and nutrition as well as reduce NCDs
- Advocate for the taxation of unhealthy products, such as unhealthy foods, unhealthy non-alcoholic beverages, tobacco, and alcohol. Allocate the revenues to advancing the prevention and control of NCDs
- Implement primordial, primary, and secondary CVD prevention strategies to reduce exposure to high concentrations of LDL cholesterol throughout the life-course.





dEct

## Detect

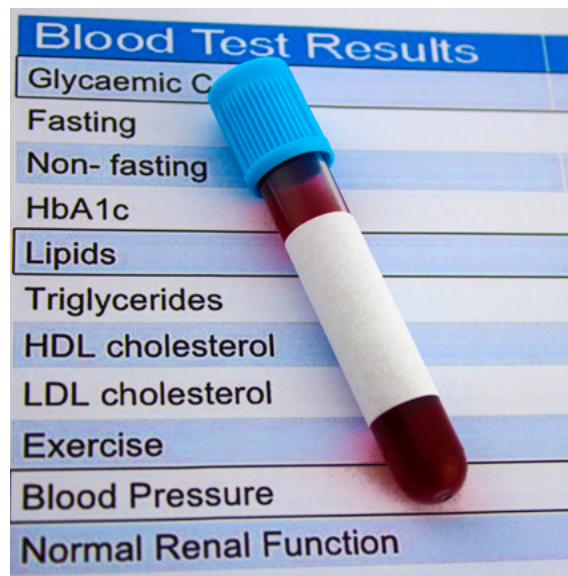
- Develop simplified national guidelines on whom and how to screen for CVD risk factors, including recommendations on cholesterol measurement
- Adapt existing risk score charts to ensure appropriateness for specific populations
- Set up point-of-care testing with inexpensive and easy-to-use technologies (e.g., cholesterol test strips, etc.)
- Support screening for FH based on country-specificities and guidelines. Screening may be based on cholesterol levels or positive genetic tests. Governments are encouraged to consider, in particular, universal child-parent screening and cascade testing of first- and second-degree relatives.



tReAT

## Treat

- Support continuing medical education for general practitioners and nonlipid specialists to improve skills and confidence in prescribing statins and other cholesterol-lowering drugs
- Support a greater clarification on statin regimens to avoid misconceptions surrounding dose and cholesterol-lowering efficacy
- Ensure affordability of statin and non-statin therapies through free or subsidized drug provision, the elimination of duties and taxes on medicines, and/or generic drugs
- Ensure availability of cholesterol-lowering medications in pharmacies and health facilities through local generic drug manufacture
- Support the use of fixed-dose combinations (i.e., combination pill including a beta-blocker, a statin, an ACE inhibitor, and sometimes aspirin) among certain high-risk groups (e.g., post-MI, diabetics, etc.) as well as statin/non-statin drug combinations in a single pill where available
- Engage pharmacists, as well as non-physician health workers, in patient support and counselling for treatment adherence.



mEasure

## Measure

- Monitor and collect relevant epidemiological data on CVD and raised cholesterol. In time, apoB should become the reference measure for total atherogenic lipid burden. In addition, lipoprotein(a) should be measured at least once in a lifetime
- Develop reliable health information systems to monitor health behaviours, risk factors, morbidity, and mortality
- Implement the WHO Global Monitoring Framework
- Financially support the establishment of FH registries to quantify current practices, identify knowledge-practice gaps, facilitate FH awareness-raising and screening, etc.



## Top Tips for CVD and risk factors advocacy

- **Put people living with CVD and its risk factors at the center of your advocacy efforts:** Involve people living with CVD and its risk factors in all aspects of advocacy planning and strategies
- **Develop and follow an advocacy plan:** Careful planning is critical to success
- **Know your policy audience:** Study your policy audience systematically and ask yourself “*Who has the decision-making authority? Who has the power to influence decision-makers? What are the main views held by decision-makers related to my issue?*”
- **Form strategic alliances:** Seek out alliances with a variety of actors – including patient groups, medical and healthcare professional societies, domestic, regional or international organizations, other health constituencies, government bodies, public health systems, parliamentarians, the private sector, etc.
- **Cultivate the media:** Develop productive relationships with the media. Make sure that the media is educated about raised cholesterol as well as other CVD issues and solutions. Involve patients in media exposure to share their stories
- **Know your facts:** Do your research to get appropriate data to support your position. Use data strategically to support your messages
- **Involve key CVD stakeholders throughout the advocacy process:** Draw upon the opinions and energy of a wide range of stakeholders at all phases of your advocacy efforts. Incorporate a wide range of experience and expertise to further your agenda and make a strong, persuasive case.

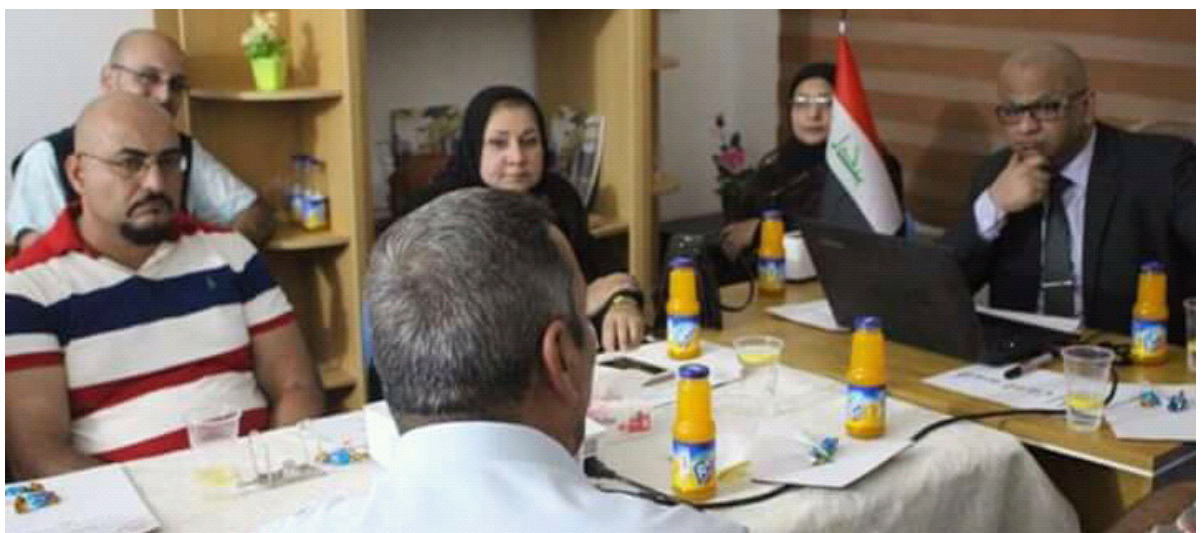
## Expert Advice



### Tips from the Iraqi Lipid Clinics Network for Carrying Out Cholesterol Control Advocacy

- Use the voice of patients! The chair of our patient advocacy group was able to dialogue with representatives from the Ministry of Health and deliver strong messages as someone with lived experience.
- Select your spokespeople carefully! The spokesperson of our Network was chosen carefully to deliver our tailored messages.
- Use a range of different channels! We promoted our activities on TV, the radio, and social media to reach a larger and international audience.
- Partner up! We collaborated with a range of relevant stakeholders, including the government, civil society, academia, international organizations, and the pharmaceutical industry for our advocacy efforts.

**DR MUTAZ AL-KHNIKAWI, PRESIDENT, IRAQI LIPID CLINICS NETWORK**

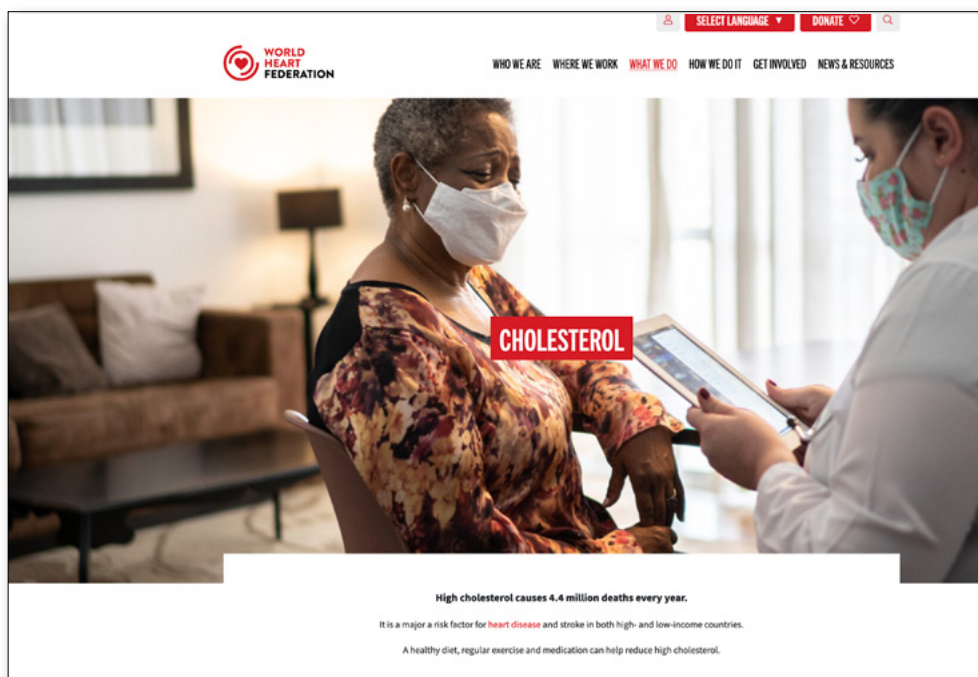


## Appendix 6: Resources on raised Cholesterol

- [WHF Cholesterol Webpage](#)
- [WHF White Paper on Cholesterol 2021](#)
- [WHF Roadmap on Cholesterol 2022](#)
- [World Heart Observatory](#)

## Appendix 7: Resources on Familial Hypercholesterolemia

- [WHF Familial Hypercholesterolemia Webpage](#)
- [WHF & FH Europe FH Country Mapping Preliminary Analysis Report](#)
- [Global Call to Action on FH](#)
- [FH Europe Website](#)
- [Family Heart Foundation Website](#)
- [EAS Familial Hypercholesterolemia Studies Collaboration](#)
- [Public Policy Background and Recommendations for Paediatric FH Screening in Europe](#)
- [The Prague Declaration on Paediatric FH Screening Across Europe](#)



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# CHOLESTEROL ADVOCACY TOOLKIT

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