EU SHD Coalition Proposal for an EU Joint Action on Structural Heart Diseases under the 2022 EU4Health Work Programme

The EU Structural Heart Disease (SHD) Coalition represents a European network that brings together key experts, medical professionals, politicians, patients, NGOs and industry. The Coalition collaborates at EU and in Member States to ensure that structural heart diseases is recognised and prioritised in policy, with the aim of decreasing the burden of the disease and improving patients' quality of life.

The EU SHD Coalition strongly welcomes the European Commission's targeted stakeholder consultation on the 2022 EU4Health Work Programme. To complement the targeted consultation and to follow-up on the meeting held with representatives from the European Commission's EU4Health Task Force in July 2021, the EU SHD Coalition is pleased to share **concrete topic suggestions focused towards enhancing cooperation between Member States through a dedicated Joint Action to improve the health and treatment of patients suffering from structural heart diseases**.

These suggestions are in line with the EU4Health general objectives, and more particularly in the framework of disease prevention (DP), health promotion and prevention of non-communicable diseases and related risk factors, as well as the challenge of demographic change on to health systems.

POLICY CONTEXT

Structural Heart Diseases are structural abnormalities of the heart leading to impaired functioning.[1] They are forms of cardiovascular disease and include heart valve diseases such as aortic stenosis and mitral or tricuspid regurgitation that require valve repair or replacement. The disease is age-related, and therefore primarily affects the elderly. They **cannot be prevented** as such through lifestyle measures.

It is estimated that Structural Heart Diseases affect **14 million Europeans** today, a significant proportion of whom are also suspected to be suffering from heart failure. In the last 20 years the number of hospitalisations due to SHD has doubled, and these numbers will continue to increase. [2] [3]

With a rapidly ageing EU population, this also means that such age-related diseases will grow exponentially: In 2050, **23 million people** across the EU are projected to potentially suffer from a form of structural heart disease.[4]

Structural heart disease can be deadly, and highly debilitating. The difference between having structural heart disease and being disease-free lies in being able to live a fully independent life, and contribute to society and the economy[5], and not being able to make it up a flight of stairs.

[1] Daniel H. Steinberg, Stephan Staubach, Jennifer Franke, Horst Sievert, Defining structural heart disease in the adult patient: current scope, inherent challenges and future directions, *European Heart Journal Supplements*, Volume 12, Issue suppl_E, 1 September 2010, Pages E2–E9, https://doi.org/10.1093/eurheartj/suq012

[2] J. d'Arcy et al. (2016) Large-scale community echocardiographic screening reveals a major burden of undiagnosed valvular heart disease in older people: the OxVALVE Population Cohort Study. https://www.ncbi.nlm.nih.gov/pubmed/27354049#

[3] International Longevity Centre – UK**,** The invisible epidemic: Rethinking the detection and treatment of structural heart disease in Europe, June 2021. ILC-The-invisible-epidemic-1.pdf (ilcuk.org.uk)

[4] J. d'Arcy et al. (2016)

[5] Recent research found that found that across 27 European countries, older people in better health (i.e. those who have better cognition, are less limited in daily activities and/or report being in good health) are more likely to be in work, volunteer more often, and spend more. Source: International Longevity Centre, 2020. Health equals wealth. Available at https://ilcuk.org.uk/healthequalswealth/

Severe aortic stenosis, one of the main types of the disease, has a worse prognosis than some metastatic cancers. If not treated properly, 1 out of 2 diagnosed patients will die after 2 years. After 3 years, this increases to 2 out of 3 patients.[6]

The European Commission is committed to support Member States in **reducing premature mortality** from non-communicable diseases, to support an active and healthy ageing, whilst meeting the United Nations Sustainable Development Goals including Goal 3.4 on non-communicable diseases.

For that, it set up **a holistic approach** to address non-communicable diseases, including exchange and transfer of best practices on health promotion and disease prevention, monitoring of policy developments, and supporting EU countries in their efforts to reduce premature mortality.

Within this framework, the focus often lays on those CVDs that could be prevented through targeted lifestyle or environmental factors. However, there is a subset of cardiovascular diseases that cannot be prevented, such as structural heart diseases **that are linked to ageing.**

Today, **several barriers** to the detection and treatment of the Structural Heart Diseases continue to persist across the EU. These include **lack of EU data, understanding of prevalence and impact of the disease, public and medical awareness, under-detection[7], unequal access to treatment and age discrimination[8], leading to premature mortality, and limiting successful healthcare delivery or healthcare policies**. [9]

Even if some Member States have included the importance of early detection, diagnosis and treatment of structural heart diseases, in other countries concrete policy action is completely absent with primary focus of CVD strategies being on preventative measures tackling other types of CVDs. In other Member States, people do not get their heart checked regularly despite the existence of national rules. [10] [11]

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[6] Thaden JJ, Prog Cardiovasc Dis. 2014 May-Jun;56(6):565-71. Orlando R, Health Technol Assess. 2013 Aug;17(33):1-86. Carabello BA, Lancet. 2009 Mar 14;373(9667):956-66.

[7] A recent survey under almost 13,000 Europeans above 60 years in 11 European countries showed a general lack of awareness of age-related heart diseases, such as structural heart disease, and 67.2% of surveyed being auscultated occasionally, never, or only when the ask. European heart health survey 2019 - Gaede - 2020 - Clinical Cardiology - Wiley Online Library

[8] Age-discrimination in heart disease has been documented and the absence of systematic heart check and access to SHD treatment can be linked to structural ageism, that leads to the dismissal of symptoms of treatable conditions in older people both by clinician and patient, late diagnosis and referral, as well as delayed, suboptimal or denied treatment. Source: International Longevity Centre – UK**,** The invisible epidemic: Rethinking the detection and treatment of structural heart disease in Europe, June 2021. ILC-The-invisible-epidemic-1.pdf (ilcuk.org.uk)

[9] International Longevity Centre – UK**,** The invisible epidemic: Rethinking the detection and treatment of structural heart disease in Europe, June 2021. ILC-The-invisible-epidemic-1.pdf (ilcuk.org.uk)

10 European Heart Health Survey 2019.

[11] For example, the Spanish Senate has approved in November 2020 an updated cardiovascular health strategy with an overall objective to incidence, morbidity and mortality, and prevent disability to achieve improvements, in the quality of life and well-being of patients and their families. The strategy also includes heart valve disease, a form of structural heart disease, including various recommendations for improving early diagnosis. Source : Ministerio de Sanidad Consumo y Bienestar Social (2020). El Ministerio de Sanidad traslada a las CCAA el borrador de la Estrategia en Salud Cardiovascular del SNS. https://www.mscbs.gob.es/gabinete/notasPrensa.do?id=4993

Similarly, the newest Scottish heart disease plan, issued in 2021, takes a disease pathway approach, looking beyond primary prevention and lifestyle factors towards ensuring equitable and timely access to diagnosis, treatment and care for people with suspected heart disease in Scotland, and including particular attention to non-preventable diseases such as structural heart diseases. Source: Scottish Government (2021). Heart Disease Action Plan 2021. https://www.gov.scot/publications/heart-disease-action-plan/

A Joint Action on Stuctural Heart Diseases aims to contribute to a better understanding of the disease, better awareness on effective policy and measures already in place in Member States, and suggestions to improve the detection, treatment and management of the disease at Member State level and EU level.

As such the Joint Action also contributes to supporting the policy objective of reducing the burden of non-communicable diseases and implements the EU4Health Programme's general objective of improving and fostering health in the Union (Article 3, point (a)) through the specific objectives defined in Article 4, points (a) and (i) of Regulation (EU) 2021/522).The award of a direct grant as referred to in Article 13(5) of Regulation (EU) 2021/522 is duly justified because this action can only be carried out by Member States authorities that have the required competence and responsibility to implement the Union policies at national level.

OBJECTIVES, SCOPE AND ACTIVITIES

The aim of this Joint Action is to improve the understanding of, and the early detection of age-related structural heart diseases and therefore to reduce mortality and incidence. This is in line with the objectives of the UN SDGs, the EU Green Paper on Ageing, and complements the objectives of the European Health Union as well as the Commission holistic approach to NCDs.

By enhancing cooperation and exchange between Member States, the Joint Action will focus on:

- improving data collection on and access to information on structural heart diseases. This will include data on prevalence, impact, inequalities, as well as barriers and solutions to the tackling of the disease. Digital means will be prioritized, for example through digital patient registries, and online repositories.
- increasing and strengthening the exchange and transfer of best practices between Member States
- supporting networks for knowledge-sharing and mutual learning
- supporting capacity-building actions to strengthen strategic planning and awareness.

Activities will include (digital) data collection, transfer and implementation of best practices on topics including data collection, early detection, and facilitating access to regular diagnostic and heart checks**.** The work will be divided in several work packages based on a timetable and concrete deliverables.

EXPECTED RESULTS AND IMPACT

This Joint Action is expected to result in:

a) **An open-access repository,** available in various EU languages, to ensure better understanding on the burden of the disease and actions needed to address the disease
b) **A toolbox**, including validated best practices to support Member States in their national efforts to improve early detection of age-related heart diseases
c) **A blueprint** to enable the extension of the benefits of these best practices to the participating Member States

The expected impact is a **better scientific understanding of SHD**, **enhanced public awareness** of the disease, as well as an **increased capacity of national authorities** to design and implement

approaches to improve the early detection of structural heart diseases, and ultimately improve health outcomes for European citizens.

INDICATIVE TIMETABLE, BUDGET, IMPLEMENTATION AND PROCEDURE TYPE

Call topic/sub-topic	Estimated call publication	Budget
Improving detection of age-related structural heart diseases	Q4 2022	5- 7 000 000 EUR
Procedure type	**Implemented by**	**Types of applicants targeted**
Direct grant to Member States (Joint action) in accordance with Article 195(c) of Regulation (EU, Euratom) 2018/1046	HaDEA	Member States authorities

ANNEX – BACKGROUND INFORMATION

As part of the Joint Action, following work packages could be considered:

1. Data collection:

To find the right policy options to tackle the disease, a detailed understanding of the impact of the disease is key. Today, however, there still is a tremendous lack of detailed data and information on structural heart diseases.

Data collection around the condition remains poor; with prevalence estimates such as the figures mentioned above, across Europe based on studies of limited populations. This means there is little data on any inequalities in treatment or outcome for SHD, which limits successful or tailored healthcare delivery or healthcare policies.[12]

The Joint Action could contribute in the following ways:

a. **Landscape analysis on** (the effectiveness of) early detection policies and guidelines in Member States and at EU level relevant for structural heart diseases. [13]
b. **Identification of barriers and challenges** that result in the lack of early detection, and access to heart checks. In some Member States, for example, people do not get their heart checked regularly despite the existence of national rules. [14]

[12] International Longevity Centre – UK**,** The invisible epidemic: Rethinking the detection and treatment of structural heart disease in Europe, June 2021. ILC-The-invisible-epidemic-1.pdf (ilcuk.org.uk)

[13] Recent evidence suggests that evidence-based, targeted case-finding in selected settings and to specific population groups known to be at high risk are more likely to be effective for reducing CVD. Such specific population groups could include people above 65 years, who may develop age-related heart diseases, linked to functional decline.
New EHN paper on CVD Risk Assessment Programmes (ehnheart.org)

[14] A recent survey under almost 13,000 Europeans above 60 years in 11 European countries showed a general lack of awareness of age-related heart diseases, such as structural heart disease, and 67.2% of surveyed being auscultated occasionally, never, or only when the ask. European heart health survey 2019 - Gaede - 2020 - Clinical Cardiology - Wiley Online Library

c. **Development of cross-border structural heart patient registries** to **s**upport the collection and comparison of accurate data to effectively identify unmet needs in the detection and treatment of SHDs. This would help to tackle healthcare inequalities and shift services to where they are needed most.
d. **Supporting research** into the impact of ageism on age-related heart diseases detection and access to treatment.

Linkage with existing European Reference Networks, such as the ERN GUARD-HEART could be explored.

2. Exchange and extensions of Best Practices to improve early detection:

Member States may have identified, developed or already introduced tailored approaches to improve early detection and access to heart checks. Such best practices could be further elaborated and shared with other Member States, with the aim to facilitate the implementation best practices on early detection and preparedness in national policies and improve cooperation mechanisms between EU Member states
Such best practices could include, but are not limited to:

a. **Awareness campaigns** aimed at targeted populations (people above 65 years, families, caregivers)
b. **Campaigns** to facilitate auscultation to improve early diagnosis, for example checks during vaccination campaigns (eg influenza)
c. **Digital tools** to facilitate checks at primary care level, such as digital stethoscopes, or monitoring applications.
d. **Training and/re-upskilling activities** to recognize symptoms and optimize early detection (aimed at professionals such as general practitioners, nurses, echocardiographers, cardiologists, long-term carers)

3. EU-wide conference on Structural Heart Disease

Through an EU-wide conference on Structural Heart Disease, a first EU level action towards a common approach in detecting and managing SHD will be ensured. This conference will bring together policy-makers and relevant experts and stakeholders in the field to explore gaps, opportunities and solutions to improve the lives of people suffering from SHD.

4. Blueprint for action to improve early detection at Member State and EU level.

Based on work packages 1,2 and 3, a Blueprint for Action, including recommendations to improve early detection at Member State and assessing the added-value for EU action, in line with the objectives set in the European Health Union and with the goals of the EU NCD strategy.

5. Coordination, Dissemination and Evaluation

As part of the Joint Action, work packages on coordination (management, reporting, budget control), as well as dissemination (online communication, awareness raising on the Joint Action) and evaluation should be anticipated.
An expert panel would need to be set up, in order to drive the work of the Joint Action. Targeted stakeholders include, but are not limited to:

- **Representatives of the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases** to be involved in the development and implementation of the Joint Action
- **National experts** focusing on early detection, NCDs.

- **NGOs and patient groups**: Structural heart disease patient representatives | Heart foundations | elderly and care organisations
- **Healthcare professionals and care facilities**: primary care (GPs, GP nurses), echocardiographers, cardiologists and surgeons.
- **Researchers and academia** with an interest in early detection, heart disease, and health equities.
- **Start-Ups and Companies:** providing the (digital) tools to facilitate early detection