

The invisible epidemic

Rethinking the detection and treatment of structural heart disease in Europe



Health and care

Community

Prevention

International

Inequalities

Life expectancy

Diseases and conditions

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Executive summary

The problem

In an ageing world, the burden of disease due to preventable illness is steadily rising. This not only has health costs but wider social and economic costs as well.

Structural heart disease (SHD) is one illness that contributes to this burden; it has gone unnoticed for too long. It's imperative that we invest in the detection and treatment of SHD across Europe. ILC's *Prevention in an ageing world programme*¹ has highlighted that it's never too late to prevent ill-health; tackling the SHD burden can get us one step closer to ensuring individuals live longer and healthier lives.

It's estimated that 14 million people throughout Europe are living with SHD.² SHD is an age-related cardiovascular disease (CVD), which has a high mortality rate if not detected and treated early enough. It also decreases quality of life for those living with the condition,³ with severe SHD causing fatigue and shortness of breath even at rest.⁴ Some living with the condition may even be bedbound.⁵ When general population ageing is taken into account, it's estimated that the number of people living with SHD will go up to 20 million by 2040 – a 43% increase.⁶

Untreated SHD can place a heavy burden on both healthcare and social care systems, as well as on wider society. People with the condition often have high health and care needs, and are unable to contribute to society in ways they might otherwise have done. The number of hospitalisations due to SHD has doubled in the last 20 years; there's little doubt that the numbers will increase.⁷ Lack of standardised data means we don't have figures for this disease as a whole. But we know that the number of people aged over 65 who are dying from aortic stenosis (one type of SHD) is increasing – in contrast to the figures for coronary heart disease (CHD), which have recently declined.⁸

But most types of SHD can be successfully treated, removing symptoms and returning life expectancy to normal. New treatment advances are happening all the time.

As well as bringing benefits to the patient, treating SHDs and tackling the related functional decline has been shown to

significantly reduce hospitalisations by up to 50%.⁹ However, there are persistent systematic barriers to detecting and treating this condition – the most important of which is pervasive ageism. Symptoms, such as fatigue and breathlessness, are often dismissed as “usual” signs of ageing, meaning that people fail to seek and receive help.

Barriers to change across Europe

Early diagnosis and treatment of SHD is essential. Mortality rates increase the longer individuals live with the condition. But awareness among the general public and even some medical professionals remains low and varies across Europe. A 2019 European Heart Health survey of people aged over 60 from different European countries found that the highest level of awareness was only 12% (in the Netherlands), with just 2% in Belgium where awareness was lowest.¹⁰

Detection of the disease by health care systems is also poor. A simple stethoscope check of the heart can spot potential SHD with confirmation by echocardiogram. Unfortunately, these stethoscope checks are not routine – a third of respondents to a 2019 European survey of people aged over 60 said their primary care physician checked their heart with a stethoscope “occasionally”; only 28% had their heart checked at every visit. No European country has established a programme for early detection of SHD, and the routine use of digital stethoscopes is yet to be established.

When SHD is detected, a considerable number of people are left untreated, despite the existence of a range of life-saving treatments.¹¹ Evidence suggests that this may partly be due to lack of awareness of treatments, and partly due to clinicians failing to engage patients in decisions about their care, or to use appropriate geriatric assessment tools to determine older people's suitability for treatment. Guidelines for SHD treatment were built around younger people; greater consideration of the needs of older people is required.¹²

Data collection around the condition remains poor; with prevalence estimates across Europe based on studies of limited populations. This means there's little data on any inequalities in treatment or outcome for SHD, which limits how much programmes aimed at specific communities can be adapted.

The COVID-19 pandemic, and the additional pressure this has placed on healthcare systems across Europe, has intensified the burden of SHD. As well as affecting capacity in cardiovascular specialties, COVID-19 appears to have an impact on the heart itself. The reforms that will be necessary to healthcare systems due to the impact of the COVID-19 pandemic will provide an opportunity to ensure that every person with SHD is diagnosed and receives the right treatment.

Understanding and awareness of SHD is growing. More can be done to help patients than ever before, including those who are very frail but pervasive ageism that exists within healthcare systems, and wider society needs to be properly addressed. We must not miss the chance to allow these patients to live healthy, productive lives.

Recommendations

Based on the available evidence, and interviews with five expert stakeholders, we have identified recommendations for how governments, healthcare systems, and patients can ensure better detection and treatment of SHD. These break down into a number of different areas.

Increasing awareness, and improving detection and treatment

Increasing public and healthcare professional awareness:

- **We must improve SHD awareness among the general public**, making people aware of the symptoms so they seek treatment. Policymakers should invest in public awareness campaigns to educate the general population about SHD and its associated symptoms.
- **Primary care physicians must be better educated on SHD**, and given the training necessary for diagnosis, including the knowledge to regularly check the hearts of older patients.

Ensuring early diagnosis with better detection:

- **Investing in early detection must be central to tackling the SHD burden:** EU and national governments should fund early detection programmes and people aged 65 and over should have the right to an annual check-up, which should

include an SHD consultation and stethoscope check. The EU and national governments should also make funding available to establish early detection programmes.

High quality treatment:

- **Clinical guidelines on SHD diagnosis and treatment must be regularly updated**, to capture newest developments in the management of SHD. They must be clear on where and when to diagnose and treat SHD and adopted by European healthcare systems as the gold standard of care.
- **We must create clear care pathways**, and create specialist centres with trained multidisciplinary teams, where all SHD patients are treated.

Inspiring and engaging policymakers, healthcare professionals and individuals

Supporting collaboration and partnership at the European level:

- **We must build stronger cross-country collaboration and a multi-stakeholder approach**, to ensure best practice is shared. We call for a European Joint Action and/or the development of a European Reference Network on SHD.

Engaging politicians and policymakers with the importance of addressing SHD:

- **We need strong political commitment and backing from national politicians and policymakers**: we must demonstrate the cost benefits of detecting, diagnosing and treating SHD earlier. Every country should implement a CVD strategy which includes a comprehensive approach to tackling SHD.

Addressing ageism:

- **Addressing the impact of ageism on diagnosis, referral and treatment must be at the centre of any policy response**, both for SHD policy and wider ageing policy. We call for greater attention to the impact of ageism in follow-up health initiatives to the EU Green Paper on Ageing.

Involving patients in care decisions:

- **Patients of all ages should be empowered and encouraged to come forward for diagnosis and appropriate treatment.**

Each patient should be involved in informed, transparent discussions with clinicians to decide the treatment that best fits their individual needs and situation.

Amplifying the patient voice:

- **Patient groups should play a key role in raising awareness, highlighting concerns and pushing SHD up the political agenda.** Ensuring the patient voice is heard in health and social care planning decisions means priorities and services will better meet each community's needs.

Addressing workforce capacity and supporting skills training:

- **We must address workforce capacity; we need to plan for the future and ensure healthcare professionals get the necessary training to carry out specialist procedures.** We also need professionals with the skills to undertake echocardiography diagnosis. We need workforce planning across Europe to ensure future workforce capacity to cover increasing demand and evolving treatments and standardisation of emerging specialisms.

More effective technology and data gathering

Better data collection:

- **Each European country should collect robust, standardised SHD data to be shared across Europe for a better understanding of how SHD affects different communities and what inequalities exist in treatment or outcome.** Medical societies and other key stakeholders should advise on the data collected, including type and severity of disease, any treatments given, and outcomes. We should also develop a European registry of SHD patients.

New technology and innovations:

- **Clinicians and healthcare systems must take advantage of innovations in detection, diagnosis and treatment.** The digital stethoscope is one example of an innovation that could vastly improve the detection of SHD. Health planners and policymakers should encourage the uptake of innovative new diagnostic tools and treatment methods that have the potential to improve outcomes for people with SHD.

Funding of research:

- **The EU as a whole, as well as individual countries, must continue to invest in SHD research;** we also need fast rollout and adoption of new treatments that prove cost effective.

Moving from recommendations to action

We recognise that there is already emerging political willingness and commitment to investing in SHD. The EU SHD coalition, launched in March 2021, aims to bring together key opinion leaders, politicians and patients to work together and ensure that policy on SHD is prioritised.¹³ The EU4Health programme 2021-2027¹⁴ - entered into force March of this year - will inject funding worth EUR 5.1 billion into EU countries, health organisations and non-governmental organisations (NGOs). Our recommendations align with its objectives, including health promotion and disease prevention, for which a minimum of 20% of overall funding is reserved. The Next Generation Recovery EU¹⁵ is a recovery plan that will inject EUR 750 billion into member states to boost economic recovery following the pandemic. A significant proportion of these funds will be devoted to healthcare and digital transformation. We believe that these three vehicles represent a crucial opportunity to move from recommendations to action.

Introduction

Structural heart disease (SHD) is a set of cardiovascular conditions that affect the structure of the valves, atria, ventricles and blood vessels in the heart. Though some forms of SHD are congenital and affect young children, the majority are degenerative, primarily affecting older people. These latter forms account for the greatest health and economic impact associated with SHD. It's estimated that 14 million people in Europe were living with SHD in 2020, and that by 2040, this will increase to 20 million.¹⁶

SHD can be both debilitating and deadly for patients, with a worse prognosis than some metastatic cancers. If not treated properly, the mortality rate is around 50% of patients diagnosed two years after the onset of symptoms, which increases to 75% at three years.¹⁷ For patients with severe SHD, symptoms such as fatigue and shortness of breath can be experienced even at rest,¹⁸ limiting their daily activities¹⁹ and their day-to-day life. Some may even be bedbound.²⁰

Early treatment is essential, as the mortality rate increases the longer that individuals live with the disease. Unfortunately, this does not always happen. Left untreated, it has a high mortality rate, yet it can be treated successfully, improving people's life expectancy and quality of life. A lack of public awareness of the symptoms of SHD means that many people are not diagnosed in a timely manner. New treatments are less invasive than traditional treatments, but European member states lack focus on how to improve care and outcomes.

In this report, we consider the impact of SHD in an ageing society. We set out the health and economic case for governments to invest in SHD, followed by the key barriers that contribute to suboptimal detection and treatment. We then present our recommendations, which have been informed by our expert stakeholder interviews, for how governments, healthcare systems and patients can address these issues.

What is structural heart disease (SHD)?

SHD is a relatively new term used to describe a number of structural abnormalities of the heart that lead to impaired functioning.²¹ SHD can affect different structures of the heart including the valves, walls, atria, ventricles and blood vessels.

Valvular heart disease (VHD) comprises a large proportion of cases of SHD; although we don't know the exact figures, this means much existing SHD data refers to VHD specifically. VHD affects how the valves regulate blood flow in and out of the heart, and includes a range of diseases that include aortic, mitral and tricuspid stenosis and regurgitation. In mitral and tricuspid regurgitation, the mitral valve, located between the left atrium and ventricle,²² or the tricuspid valve, situated between the right atrium and ventricle,²³ leaks, as it doesn't fully close. In aortic and tricuspid stenosis, the aortic (between the left ventricle and the aorta) or tricuspid valve doesn't open enough. The risk of these types of SHD increases with age²⁴ and can be classified as mild, moderate or severe. SHD can also be symptomatic or asymptomatic.

Symptoms of SHD include:

- Fatigue
- Shortness of breath
- Palpitations
- Chest pain
- Difficulty exercising
- Fainting

While people may live for years with mild SHD without any major detrimental effects to their health, once the condition becomes severe, mortality increases dramatically.²⁵ Left undiagnosed and untreated, SHD will become increasingly debilitating and life-threatening. The condition is also associated with a worsening of physical function, and social and emotional wellbeing, as well as a loss of vitality and general health.²⁶ Early diagnosis and treatment of SHD is therefore essential.

Treating SHD can prolong and improve quality of life, return survival rates back to that of the general population, and prevent symptoms from worsening, removing the need for care.²⁷ Innovations in treatment have also led to the development of new minimally invasive procedures with swifter recovery times, for example

Transcatheter Aortic Valve Replacement (TAVR). Patients appear to favour these procedures over more invasive forms of surgery because of the reduced procedural invasiveness and the shorter recovery time.²⁸

The health case for tackling SHD

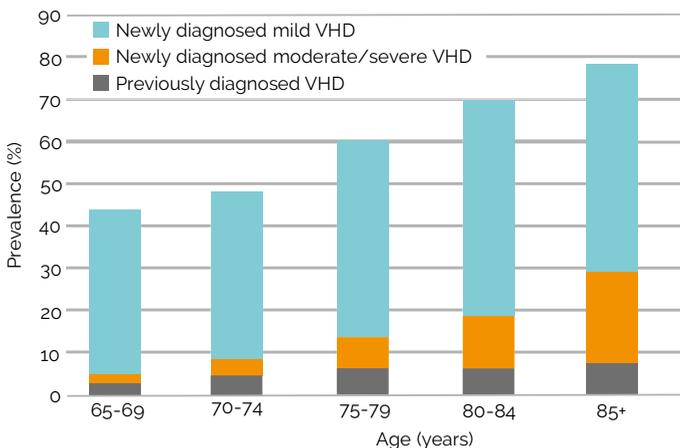
Prevalence is increasing but not systematically recorded

In 2016, nearly one in five Europeans were aged 65 and over – and by 2060, this will be one in three.²⁹ As there's a strong association between SHD and age, clinicians have described this condition as the "next cardiac epidemic". It's estimated that 14 million people in Europe lived with SHD in 2020³⁰, but there's a lack of systematic data on prevalence.

Although data on the prevalence of cardiovascular diseases (CVDs) is collected across Europe, including some specific CVD conditions, data on SHD is not collected systematically. Several studies have screened people to identify SHD prevalence within a particular or local population. These found prevalence in their chosen communities to be higher than the number of people diagnosed, demonstrating that SHD is underdiagnosed. For example, a study in the US in 2006 obtained data for 11,911 randomly selected adults from the general population; from this it estimated the prevalence of moderate or severe VHD in the US population to be 2.5%.³¹

The prevalence of SHD increases with age. A UK study identified the prevalence of all classifications (mild, moderate and severe) of VHD in 2,500 people aged 65 and over in Oxfordshire in 2016 to be 42.4% in those aged 65 to 69, increasing to 76.3% in those aged 85 to 95 (Figure 1).³² Two in ten people aged over 80 had moderate or severe VHD.³³

Figure 1: Population prevalence of VHD according to age³⁴



These UK study³⁵ results were used to predict the prevalence of VHD in the future; it was found there would be “a substantial rise in the clinical impact (and financial consequences) of clinically significant (moderate or severe) VHD within the rapidly expanding elderly population”. These UK figures have subsequently been used to predict the increasing burden across Europe. By 2040, 155 million Europeans will be older than 65. This means that an estimated 20 million people will have SHD, increasing to 23 million by 2050. The stakeholders interviewed for this report also predicted that they would see more SHD patients; one commented that this was already beginning to happen, with the number seen in their clinic doubling year on year.

Mortality rates are increasing

If left untreated, the SHD mortality rate is high. Although more people aged over 65 die from coronary heart disease (CHD) than, for example, aortic stenosis, the percentage of deaths due to aortic stenosis has recently increased, while those due to CHD has declined.³⁶

Untreated, severe symptomatic aortic stenosis has a worse prognosis than many metastatic cancers;³⁷ Figure 2 shows the five-year survival rate compared to some common cancers. The mortality and hospitalisation rate for patients with untreated severe mitral regurgitation is also high (see Figure 3) with a 50% mortality rate after five years.³⁸ The mortality rate for untreated tricuspid regurgitation is similarly high.^{39,40}

In the European Union, CVD is the leading cause of death, accounting for over a third of all deaths and just under a quarter of premature deaths.⁴¹ While great strides were made in reducing CVD deaths in the last century, some EU countries are now reporting an increase in premature CVD deaths for the first time in 50 years.⁴² Recent estimates indicate that every year, close to 50,000 Europeans die from VHD, for example.⁴³ However, as people with SHD can die from heart failure and endocarditis as a result of their condition, it is believed these figures may be an under-estimation.⁴⁴

Figure 2: Prognosis for untreated severe aortic stenosis (AS) compared to the most common metastatic cancers in the UK⁴⁵

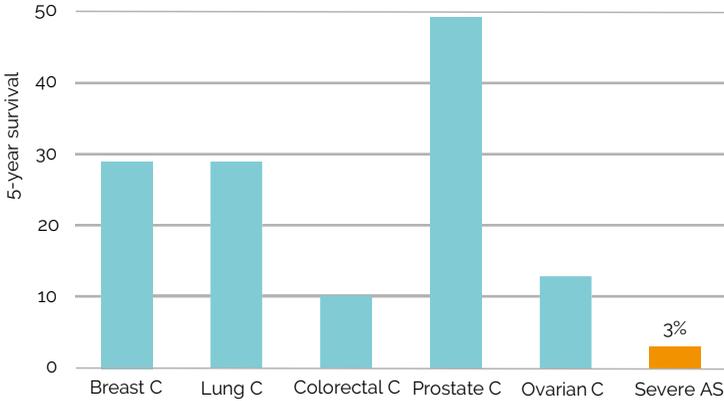
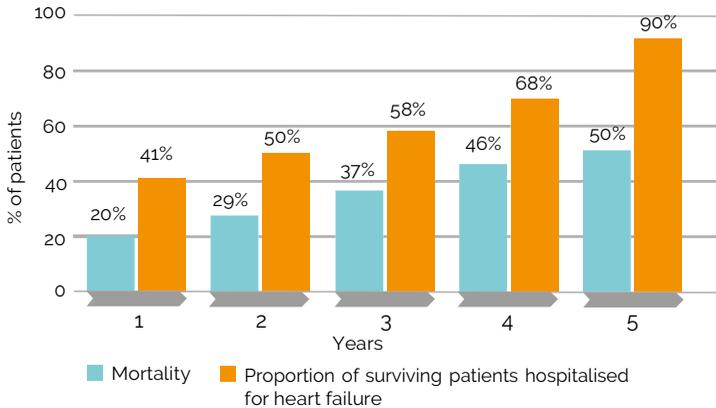


Figure 3: Mortality and heart failure hospitalisation rates for untreated severe mitral regurgitation⁴⁶



Quality of life is poor

As well as having a high mortality rate, SHD affects quality of life for those living with it. People with severe SHD can experience symptoms such as fatigue and shortness of breath even at rest⁴⁷, limiting their daily activities⁴⁸ and day-to-day life. They may become less active, less able to take part in regular exercise, and more dependent on those around them. The most severely affected,

and those with heart failure, are unable to undertake any physical activity without discomfort; they may even become bedridden.⁴⁹

Studies looking specifically at how severe aortic stenosis affects quality of life found quality of life to be lower than the average person living in America.⁵⁰ In addition, all types of SHD can cause complications and lead to other forms of CVD, including heart failure, stroke, cardiac arrhythmia and blood clots, ultimately leading to death.⁵¹

The economic case for tackling SHD

At present, CVD costs the EU EUR 210 billion per year, due to healthcare costs, productivity loss, and informal care by caregivers.⁵² 50% of this cost is healthcare spending and 26% is lost productivity. The economic costs of inaction on CVD are high. For example, the cumulative costs of the predicted slowdown in CVD mortality improvements in England and Wales over 2020-29 is projected to total GBP 47.6 billion⁵³ in terms of health, social and informal care.

The economic impact of SHD across Europe is not yet clear, although studies have shown that earlier treatment leads to cost savings. However, unlike many other chronic CVD conditions, the symptoms of SHD are acute and can be eliminated with treatment. While treatment for other CVD conditions may represent lower upfront costs compared to those associated with SHD, the costs for most other CVDs continue over a longer time period, increasing the overall costs, whereas treatment for SHD is usually time limited.

There is growing recognition that our increasing longevity could boost economies if we support people to live well and to remain active and contributing for longer. Recent ILC research 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.⁵⁴ Treating older people with SHD is one way this could be achieved. Additional research by ILC and others have shown that older people already contribute to both the formal and informal economy. For example:

- In 2015, people aged 50 and over consumed goods and services worth EUR 3.7 trillion. Consumption for this cohort is expected to grow by approximately 5% per year, rising to EUR 5.7 trillion by 2025.⁵⁵
- Earnings of those aged 50 and over accounted for 14% of GDP and 1/3 of total earnings across the EU in 2014. By 2035 this cohort is projected to generate nearly 50% of all earnings.⁵⁶
- In 2015, about a fifth of people aged 65-74 in the EU participated in formal volunteering.⁵⁷
- In 2010, across Europe, people aged 65 and over spent approximately 50 hours per person, per year, caring in the household.⁵⁸

- European tourists aged 65 and over spend on average EUR 53 per day, and EUR 66 billion per year, accounting for 16% of total tourism expenditure.⁵⁹

Barriers to change across Europe

Lack of awareness among the public and primary care physicians

Across Europe, lack of awareness of SHD is a problem among both primary care physicians and the general public. Our stakeholders highlighted lack of public awareness as a key barrier to people receiving life-saving treatment, especially among older people, who are most at risk.

A 2019 European Heart Health survey of people aged over 60 across 11 European countries found only a quarter claimed to be even familiar with VHD,⁶⁰ and that as few as 6% could correctly describe the condition.⁶¹ Only 4.6% of people said that VHD was their biggest health concern, compared to 34% for cancer and 25% for Alzheimer's disease;⁶² this may reflect the prominence given to these diseases by governments and the media.

Awareness of VHD was consistently low across all countries in the survey, with the highest level being only 12% (in the Netherlands), and the lowest just 2% (in Belgium).⁶³ Action needs to be taken to increase awareness across Europe.

The lack of public awareness of SHD and its associated symptoms means that people dismiss symptoms as a natural consequence of getting older. Unlike cancer, dementia and other forms of CVD, there have been little to no advertising or awareness campaigns by healthcare systems and NGOs to educate the public about SHD, nor does it feature in the media. In addition, the decline in health due to SHD can be gradual, with people incrementally adapting their behaviour and lifestyles to accommodate debilitating symptoms rather than going to the doctor about them. Awareness campaigns across Europe, aimed particularly at older people, are vital to raise awareness so that people go to primary care when they have symptoms.

"Awareness is the problem. But people don't think about it. They think the symptoms are old age and don't recognise deterioration could signal SHD."

Professor Alessandro Boccanelli, Cardiologist, President of the Italian Geriatric Cardiology Association

However, our stakeholders were also concerned about the lack of awareness of SHD among primary care physicians. These physicians are often the first step towards a patient receiving a diagnosis and treatment. Failure to spot that people are living with this condition is a major barrier common to countries across Europe.⁶⁴ Awareness raising among the public must be matched by physicians.

Raising awareness of SHD in primary care in England

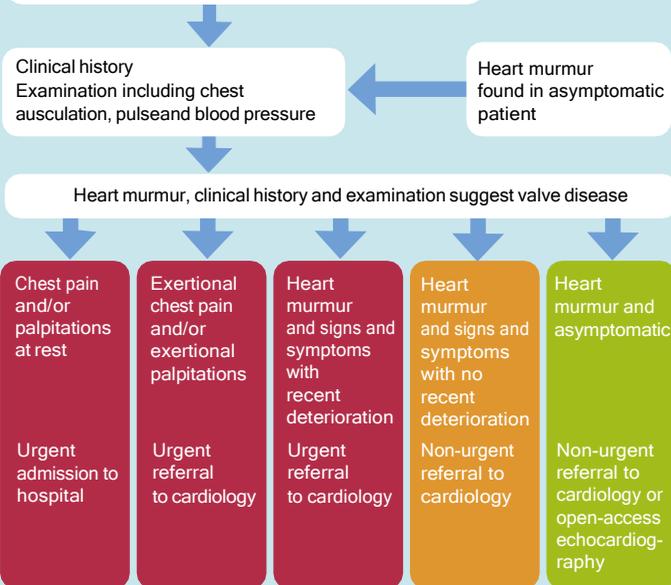
In the UK, the charity Heart Valve Voice has produced a practical primary care guide to VHD. The guide sets out the signs and symptoms GPs should be aware of in patients who may have VHD, the subsequent tests and examinations that should be undertaken, and the various onward referral routes for further care or investigation.

Heart Valve Disease

Diagnosis and Referral

Patient presents with signs and symptoms:

- Shortness of breath on exertion
- Chest tightness and/or pain
- Palpitations
- Fatigue
- Dizziness and fainting



This chart should be read in conjunction with the 'Heart Valve Disease: Practical Guidance for Primary Care' booklet. www.heartvalvevoice.co.uk

Widespread under-detection

One study estimated the prevalence of SHD in the US to be 2.5%, compared to 1.8% of the population diagnosed with the condition.⁶⁵ Moderate and even severe SHD can be asymptomatic, so it's important to proactively check groups that are at risk. Late diagnosis increases the likelihood of severe disease and other comorbidities that will make treatment more risky. Primary care physicians must take a proactive approach to detecting SHD, given low public awareness and the tendency to dismiss symptoms on the basis of a person's age.

"Detection can be difficult because patients modify their behaviour to mask their symptoms, the older population in particular are not aware of symptoms and GPs are not necessarily thinking about valve disease and recognising the red flags (for example they may investigate COPD for breathlessness) and aren't listening to hearts with stethoscopes."

Wil Woan, CEO, Heart Valve Voice UK

The first step in detecting or diagnosing SHD is a stethoscope check (auscultation) of the heart in primary care, before referral to secondary care for echocardiography if an abnormality is detected. It is recommended in the clinical guidelines set out by the European Society of Cardiology (ESC) and the European Association for Cardio-Thoracic Surgery (EACTS) that patients have their heart checked regularly via auscultation.⁶⁶ Unfortunately, auscultation of the heart doesn't appear to be happening routinely across Europe; no European countries are funding early SHD detection programmes, an approach recommended by the European Heart Network to benefit people at risk of CVD.⁶⁷

A third of respondents to the 2019 European Heart Health survey said their primary care physician only checked their heart with a stethoscope occasionally; just 28% had their heart checked at every visit. Once again, this varied among European countries.⁶⁸ France showed the best record, with 76% of respondents checked at every visit, compared to the Netherlands, where only 5% were checked every time.⁶⁹ Only 4% of those aged 60 and over reported never being checked in France, whereas this rose to 37% in the UK and 35% in the Netherlands.⁷⁰ The UK charity Heart Valve Voice found that primary care physicians use auscultation routinely in less than two fifths of patients whose symptoms suggest VHD.⁷¹

Heart checks could be added to existing healthcare programmes targeted at those aged 65 and over, such as annual flu vaccinations or as part of atrial fibrillation screening, though attendance for such medical checks or treatments varies from country to country. A recent report by the European Heart Network highlighted the benefits of approaches such as these, which target screening at populations likely to be at greater risk of CVD.⁷²

Digital stethoscopes are an innovation that could vastly improve detection of SHD in primary care. Their introduction provides an opportunity for health professionals to be better trained at detecting SHD and offer more reliable patient assessments. One stakeholder advocated abandoning the standard stethoscope, replacing it with the digital version in order to detect SHD. This would require training doctors on how to read results and spot abnormalities. With training, healthcare professionals can learn to use either standard or digital stethoscopes to identify concerning sounds or readings, and can then refer the patient on for further imaging for diagnosis.

Ageism in diagnosis and treatment

Ageism is one of the most prevalent forms of discrimination in society, with 40% of EU residents reporting they perceive age discrimination as widespread in their country.⁷³ The age discrimination that exists in healthcare systems can have a significantly detrimental impact on older people, as it can mean the difference between living or dying. This is particularly true in the case of SHD: as it's a degenerative disease, it's disproportionately likely to affect older people.

Ageism in healthcare systems can affect diagnosis, referral or treatment. For example, our stakeholders were concerned that a lack of awareness among medical professionals may mean that SHD symptoms are dismissed as a consequence of old age and not investigated.

Research suggests that younger people are more likely to receive proper cardiological investigations, from echocardiography to measuring cholesterol levels.⁷⁴ Moreover, there may also be a problem of under-treatment, with medical professionals not using the right equipment to assess older people, leading them to overestimate the risk of treatment, while failing to fully take account of the potential benefits to the patient, their family and wider society. Indeed, data collected from patients with severe aortic stenosis

across nine European countries between 2015 and 2017 found that symptomatic patients were being referred for further treatment late in the course of the disease.⁷⁵ Our stakeholders expressed further concern that too many older people with SHD are being placed on palliative and end-of-life care pathways, rather than being referring for treatment. One interviewee stated that with the advent of less invasive and risky treatment even those aged over 90 could undergo successful life-improving treatment.

Internalised ageism can lead individuals to dismiss their own symptoms as a consequence of ageing, preventing them from seeking treatment. The 2019 European Heart Health survey showed that older people were less likely to seek medical help about the symptoms of SHD.⁷⁶ Without addressing ageism at all levels, it's unlikely that there will be a reduction in SHD morbidity and mortality.

Recent progress on tackling ageism, such as the UN Global Report on Ageism published in March 2021,⁷⁷ is a welcome step towards spotlighting its detrimental effects. We must use this as a framework to ensure that the issue remains at the forefront of any SHD or wider policy response on ageing.

Difficulties obtaining a referral for echocardiography

If auscultation leads to a possible SHD diagnosis, the patient should be sent for echocardiography. This is the main diagnostic technique for SHD, usually carried out in secondary or tertiary care.

However, echocardiography is not sufficiently widespread across Europe. It requires appropriate equipment and qualified sonographers: some European countries are experiencing a shortage of people with sonography skills. For example, in 2018 the British Heart Foundation reported that UK GPs were struggling to access echocardiograms for their patients, partly due to a shortage of sonographers.⁷⁸

Our stakeholders were also concerned that there may be reluctance among some primary care physicians to refer patients on for further diagnostic tests, such as echocardiography, and that ageism may be creeping into referrals in the belief that nothing can be done to help older patients.

Echocardiography

An echocardiogram is a test that uses ultrasound to show how the heart muscle and valves are working. The sound waves make moving pictures of the heart, allowing its size and shape to be assessed.

Variable standards and unequal access to treatment

Despite the existence of a range of treatments, including minimally invasive procedures that require less recovery time for the patient, a significant proportion of people with SHD are left untreated. Different European countries also show variation in the choice of treatments available. This suggests a lack of appropriate decision making at both patient and national health system level, as well as failure to implement clinical guidelines.

Treatment for SHD most often involves the repair or replacement of a damaged heart valve, either via surgery or catheter-based interventions, both of which have been shown to improve survival rates and quality of life.^{79,80} Catheter-based approaches are relatively new, but are becoming increasingly common.⁸¹ The introduction and widespread acceptance of transcatheter aortic valve replacement (TAVR) has led to a significant boost in survival among patients with severe aortic stenosis; the median survival period has doubled (>11.5 years vs. 6.8 years; $p < 0.0001$).⁸² Surgical techniques are evolving towards minimally invasive procedures, which tend to be preferred by patients, although in some cases open-heart surgery is still needed.⁸³

Patients not deemed ready or eligible for intervention are put on active surveillance, with a “watch and wait” approach taken. They may be given medication to help alleviate their symptoms and comorbidities during this time. Medication does not, however, halt disease progression.^{84 85} In situations where the risks of intervention outweigh potential benefits for a person with SHD, palliative options are considered.

Evidence suggests there is under-treatment. In the UK, a report by Heart Valve Voices suggests 30% of people with VHD are left untreated.⁸⁶ Another review suggested that 42% of patients with severe symptomatic aortic stenosis didn't undergo surgical aortic valve replacement;⁸⁷ a review of tricuspid regurgitation patients in France found that only 10% received a tricuspid valve intervention.⁸⁸

A study in the Netherlands⁸⁹ examined the reasons why some patients with severe symptomatic aortic stenosis were not given aortic valve replacement: 56% were given medical, as opposed to surgical, treatment. The reasons given were: patients were perceived as having high operative risk (34%), symptoms were regarded as mild (19%), stenosis was perceived as non-severe (14%), and patient preference (9%). In 5% of cases the decision was pending at the time of the analysis and in 20% of cases the reason was other/unclear.

Determining the best treatment option for a patient should be carried out by a heart team, taking into account each patient's preferences, situation and overall health. Our stakeholders were concerned that this was not always happening, particularly for older patients. One commented that the guidelines underpinning SHD treatment had been built around younger people and that it should take the needs of older people into account, including the incorporation of equipment required for geriatric medicine. They also pointed out that it would be increasingly useful to have input from geriatricians in care and treatment decisions, and for cardiac surgeons and cardiologists to make use of assessment tools such as a gait speed test⁹⁰ (which tests speed taken to walk a defined distance) to determine fitness for surgery, rather than relying on the age of the patient.

"We need to ensure the patient receives the best treatment for them, not the best treatment for the physician."

Professor Martine Gilard, Director, Department of Interventional Cardiology at Brest University Hospital and former President of the French Society of Cardiology

Access to treatment also varies within some European countries. For example, one study showed wide variation across England in access to transcatheter procedures for patients who require this intervention.⁹¹ Similar variation has been shown between different regions of France in the numbers of people hospitalised for VHD.⁹² Some of our stakeholders expressed concern that hospital capacity may affect the ability to treat patients, and that funding prevented some countries from using minimally invasive procedures. They predicted that new devices will continue to be developed, for the treatment of SHD with fewer associated complications. It is important that new devices and procedures are adopted and funded by healthcare systems so that everyone can benefit from minimally invasive procedures.

"Every country can improve. It is difficult to compare countries. Germany is treating more patients than the UK but reimbursement and the system is different."

Professor José Zamorano, Head of Cardiology at the University Hospital Ramon y Cajal Madrid

Steps to ensuring high quality treatment across Europe are in their infancy

There are further steps that can be taken to ensure high quality treatment for everyone. Treatment at specialist centres by well-trained staff, rolling out specific care pathways, and updating clinical guidelines all have a part to play in the delivery of high quality treatment.

Guidelines for clinical practice are a useful tool to share evidence and standardise good practice among clinicians and across borders. They help to ensure all patients receive the best treatment and care. In 2017, the ESC and EACTS produced guidelines setting out how SHD should be detected, diagnosed and treated. Our stakeholders agreed that these guidelines now need to be updated and, even more importantly, adopted in all European countries.

For some diseases, such as cancer, care pathways have been introduced to ensure that care is streamlined and effective, from diagnosis to treatment, to discharge and aftercare. Care pathways do not yet exist for SHD. People should be treated at specialist centres by well trained multi-disciplinary teams, but it is not clear if this always happens; clear care pathways would help.

With the growth in the number of specialist SHD treatment procedures available, individual healthcare professionals may not have adequate training or experience in every technique. The 2017 guidelines recommend that "a heart valve centre should have structured training programmes" and that "surgeons and cardiologists performing any valve intervention should undergo focused training as part of their basic local board certification training".

Increasing specialisation has implications for the workforce, as trends in retention and demographics can affect the availability of specialists. One stakeholder commented that more medical schools were creating specialisms which sit between surgery and

cardiology, to provide the specialists needed to undertake these procedures. It's important that there is workforce planning across Europe, both to ensure sufficient workforce capacity in the future and agreement on, and standardisation of, this new emerging specialism.

"The biggest challenge is we find more disease but there is no additional capacity to do more. That is the biggest challenge for people to grasp and understand."

Keith Pearce, Consultant Cardiac Scientist, immediate past President for the British Society of Echocardiography

Lack of systematic data collection and reporting

We can only estimate the prevalence of SHD across Europe, based on studies of the disease in certain populations. Routine SHD data collection would allow healthcare systems to plan care, provide a better understanding of how SHD affects different communities, and illuminate any inequalities in treatment or outcome. France is running a registry of SHD patients including gathering data on outcomes, which will allow them to understand the long-term outcomes of different treatments. Other countries should follow suit and ensure data is collected on people with SHD. Standardising data collection among countries would also allow the sharing and comparison of data.

Poor understanding of the savings associated with treatment

Treating older people with SHD allows them to live longer with fewer debilitating symptoms. This helps them continue to contribute to society and the wider economy, whether through childcare, unpaid care, volunteering or paid work. However, the cost effectiveness of treatments and the wider economic benefits are not well recognised.

Studies have consistently shown the cost effectiveness of treating aortic stenosis.⁹³ A study looking at the costs of SHD in the US found that individuals with the disease had significantly higher healthcare expenditure than similar individuals without it. For example, healthcare expenses for patients with severe symptomatic aortic stenosis are on average 3.4 times higher than those of the average person.⁹⁴ Another study found that those with medically managed severe symptomatic aortic stenosis are intensive users of healthcare resources, with a high rate of rehospitalization (1.9 admissions per patient-year) and prolonged lengths of stay (11.5 hospital days per patient-year).⁹⁵

In addition, less invasive methods of treatment, which tend to be preferred by patients, are less costly to healthcare systems because of reduced lengths of stay and reduced numbers of patients requiring rehabilitation.

"Innovation and technology will push on and people will develop new products, new valves and less lengthy procedures and quicker ways of doing things. Procedures will be easier to do in lower co-morbidity groups which may release capacity."

Keith Pearce, Consultant Cardiac Scientist, immediate past President for the British Society of Echocardiography

However, despite these cost savings, all our stakeholders highlighted funding as a key barrier preventing people receiving treatment for SHD. They felt more needed to be done to demonstrate the cost benefits of detecting, diagnosing and treating SHD earlier to politicians and commissioners.

Lack of political action

Over the last decade, many other diseases, such as cancer, have been receiving increasing levels of attention from policymakers compared to CVD and SHD, ultimately resulting in national plans for cancer and the recently published EU Beating Cancer Plan.⁹⁶

While CVD receives some political and policy attention in certain countries, and European policymakers acknowledge that action should be taken to address the disease, the reality is that there is no streamlined policy approach and action at either the EU or national level. When they do mention CVD in policy, most countries tend to include it within overall health strategies, and to focus on primary prevention, which is not applicable to diseases like SHD. In France, the 2018–2022 National Health Strategy calls for reducing cardiovascular risks by supporting lifestyle habit changes⁹⁷, while Italy's 2020–2025 National Plan for Prevention focuses on the health, societal and environmental factors that contribute to CVDs. Specific regional projects in Italy – such as Cardio50 – are piloting screening programmes for CVDs.⁹⁸

Only a very few countries dedicate specific policy attention to CVD, and few of those include SHD as a priority:

- In Spain, a new CVD strategy is expected in 2021 which will include SHDs⁹⁹

- In the UK, the NHS 10-year plan¹⁰⁰ devotes a chapter to CVD and highlights the importance of early detection and treatment, as well as the importance of better support from heart teams for SHD patients specifically
- The Scottish government released a Heart Disease Plan in March 2021,¹⁰¹ setting out a long-term programme of reforms to cardiac services in Scotland. The plan recognises VHD, along with heart failure and atrial fibrillation, as one of its key current long-term priorities. The National Heart Disease Taskforce will implement this plan, which sets out non-disease-specific commitments to improve heart disease care, centred around prevention; access to diagnosis, treatment and care; the cardiac workforce; and data. Though non-disease-specific, there are complementary plans to introduce national, condition-specific pathways. With VHD as a key priority within the broad action plan for all CVD care, long-term action on these diseases is expected.

With these exceptions, SHD does not appear to have a strong focus within EU health policies or those of member countries, despite attempts by patient groups and NGOs to push it up the agenda. This affects funding for both research and care, as well as data collection, detection, diagnosis and treatment. When MEPs have raised questions about SHD in the European Parliament, the European Commission has responded that it's working to strengthen individual healthcare systems, working on policy around non-communicable diseases (NCDs) and funding research projects through Horizon 2020.

The EU4Health programme aims to decrease the impact of NCDs on both individuals and society; its goal is to reduce premature mortality due to NCDs by a third by 2030. There are calls among stakeholders, including the EU SHD Coalition, formed in March 2021, for a European Joint Action on SHD as part of the EU4Health programme with a need for greater awareness and earlier treatment of SHD.¹⁰²

"There is a need to Influence commissioners and policy makers - show them that earlier treatment is cheaper in the long run."

Wil Woan, CEO, Heart Valve Voice UK

The impact of COVID-19 disruption on cardiovascular treatment

The COVID-19 pandemic, which hit European countries during the spring of 2020, has affected the diagnosis and treatment of SHD. In the first wave of the pandemic, vast numbers of people across Europe were told to stay at home to reduce transmission of the disease and demand on healthcare systems struggling to cope with large numbers of seriously ill COVID-19 patients.

Patients coming to their primary care physicians with symptoms for all sorts of conditions fell dramatically and have not fully recovered, as have subsequent referrals on to specialist services – and subsequent waves of the pandemic have seen both fall further. People with cardiovascular symptoms have also been reluctant to call an ambulance or go to the hospital. The pandemic has seen a 50% decrease in the number of people presenting at hospitals and other healthcare facilities with symptoms of heart attacks or stroke.¹⁰³ This is particularly worrying as data suggests patients with SHD may be at particular risk during from COVID-19,¹⁰⁴ as 95% of all COVID-19 deaths have at least one underlying condition, with CVD being the leading comorbidity (65%).¹⁰⁵ Data from China also confirms that pre-existing heart conditions increase the risk of death by more than 10% in COVID-19 patients.¹⁰⁶ In another study, up to 40% of patients admitted to intensive care units with COVID-19 had pre-existing congestive heart failure.¹⁰⁷

Our stakeholders were very concerned about the long-term consequences of “missing” patients, with one clinician describing the impact of the pandemic on cardiology services as a disaster. They concluded that more people will die from SHD as a consequence of not being diagnosed, or will be diagnosed later with a more severe stage of the disease, meaning both poorer outcomes for the patient and more demand on health and social care systems. One clinician was aware of a patient who had chosen not to undergo treatment for SHD due to the risk of COVID-19 and had died as a consequence. They also worried about a backlog in demand and an influx of patients coming forward once the pandemic ends, causing pressure on diagnostic and cardiac services. The increased pressure on healthcare professionals during the pandemic also means there's a real risk of burnout in the coming months and years, which could affect workforce capacity.

COVID-19 has also forced a reshaping of the way healthcare systems, care delivery and hospital capacity is organised. Early and innovative treatments can keep patients healthy and therefore out of hospital, reducing the burden on hospitals and broader care systems. Some of our stakeholders had seen such a shift in care for SHD patients as a result. Anecdotal evidence suggests less invasive treatments have been favoured to reduce the risk for patients and the length of stay, releasing needed capacity. There's also been a move to remote digital appointments and monitoring, to reduce the transmission of COVID-19.

What needs to change?

SHD has a high mortality rate if left untreated and is debilitating for people who live with it. But it can be successfully treated, reducing symptoms and improving survival. Large numbers of people across Europe remain undiagnosed, the majority of whom are older people. There is a lack of data on SHD and the various forms of VHD that comprise it.

When asked which European countries were doing the best in diagnosing and treating SHD, our stakeholders consistently stated that no country in Europe is doing well enough. All countries could be doing better.

Many of those at risk of SHD are older people who could be living more active lives, and contributing more to society, if they had treatment. A lack of awareness of the condition, failure to regularly screen for it, under-diagnosis and few treatment options has meant that many people have died unnecessarily from SHD. People may be unaware that their decline in health is due to the condition and families may be equally unaware they have lost a loved one prematurely. The condition itself may well be dismissed as a consequence of ageing prohibiting people from receiving treatment.

There is a lack of demand for action, coupled with the additional pressures COVID-19 has placed on health and social care services, which could further exacerbate this invisible epidemic. However, with the advent of more treatment options, some of which are less invasive or more suitable for people at higher risk from surgery, and a growing understanding of the high prevalence within the older population, we have an opportunity to improve people's quality and length of life. This could lead to cost savings, both within health services and the wider economy as a whole. We must take action to address this growing health burden by improving the numbers of people diagnosed and given treatment that suits their condition and needs.

Recommendations

Based on the available evidence and interviews with our five expert stakeholders, we have identified the following recommendations for how governments, healthcare systems and patients can ensure better detection and treatment of SHD.

Increasing awareness, and improving detection and treatment

Increasing public and healthcare professional awareness

We must improve SHD awareness among the general public.

SHD can be successfully treated to both alleviate symptoms and drastically improve survival rates. Yet lack of awareness is still widespread, including some living with SHD dismissing symptoms as the consequence of ageing. It's imperative that we make people aware of the symptoms so they seek treatment.

Awareness programmes for other diseases, such as cancer and stroke, have highlighted common symptoms and what people should do to seek help. Policymakers should invest in public awareness campaigns to educate the general population about SHD and its associated symptoms.

Primary care physicians must be better educated on SHD. Public awareness measures must be matched by actions to increase awareness among physicians, as they're often the first step towards diagnosis and treatment. Without awareness of the disease, too many medical professionals may dismiss SHD symptoms as a consequence of old age. Equipping primary care physicians with the necessary training is crucial, including the knowledge to regularly check the hearts of older patients.

Ensuring early diagnosis with better detection

Investing in early detection must be central to tackling the SHD burden.

Early detection significantly reduces mortality, enables older adults to live well and be active members of society for longer, and reduces the economic burden on healthcare systems.

People aged 65 and over should have the right to an annual check-up, which should include an SHD consultation and stethoscope check. The EU and national governments should also make funding available to establish early detection programmes.

High quality treatment

Clinical guidelines on SHD diagnosis and treatment must be regularly updated, to capture newest developments in the management of SHD. They must be clear on where and when to diagnose and treat SHD and adopted by European healthcare systems as the gold standard of care.

We must create clear care pathways. Healthcare planners must establish specialist centres with appropriately trained multidisciplinary teams, and ensure that all SHD patients are treated at them.

Inspiring and engaging policymakers, healthcare professionals and individuals

Supporting collaboration and partnership at the European level

We must build stronger cross-country collaboration and a multi-stakeholder approach at the EU level to ensure best practice is shared, with a strong commitment to reducing the burden of SHD. Such an approach can open avenues to funding more research and development, data gathering, hospital planning and awareness raising.

We call for a European Joint Action and/or the development of a European Reference Network on SHD.

Engaging politicians and policymakers with the importance of addressing SHD

We need strong political commitment and backing from politicians and policymakers at the national level. This can create a domino effect leading to greater awareness and clearer care pathways. We must demonstrate to politicians and commissioners the cost benefits of detecting, diagnosing and treating SHD earlier, including informing on the cost-effectiveness of new procedures.

We need the same level of political commitment to CVD as we have for cancer. At the national level, every country should implement a CVD strategy which includes a comprehensive approach to tackling SHD.

Addressing ageism

Addressing the impact of ageism must be at the centre of any policy response. Without addressing the pervasive ageism that

can act as a barrier to diagnosis, referral, or treatment, we cannot reduce SHD morbidity or mortality.

We must ensure that addressing ageism is not only core to the SHD policy response but also the wider ageing policy response, to embed tackling ageism within society at all levels. We begin by calling for greater attention to the impact of ageism in follow-up health initiatives to the EU Green Paper on Ageing.

Involving patients in care decisions

Patients of all ages should be empowered and encouraged to come forward for diagnosis and appropriate treatment.

Age should not be a barrier to treatment. Each patient should be involved in discussions about what they want from treatment and what procedure would best meet their individual needs and situation. Clinicians should take these wishes into consideration, presenting treatment options in a fair and transparent manner, setting out the short and long-term opportunities and risks.

Amplifying the patient voice

Patient groups should play a key role in raising awareness, highlighting concerns and pushing SHD up the political agenda.

Ensuring the patient voice is heard in health and social care planning decisions means priorities and services will better meet each community's needs.

Addressing workforce capacity and supporting skills training

We must address workforce capacity; we need to plan for the future and ensure healthcare professionals get the necessary training. With a growing number of specialist SHD treatment procedures available, healthcare professionals don't have the right specialist skills and experience. Too many patients are unable to get the right care. This needs to change. They must receive the training to carry out these specialist procedures. We also need professionals with the skills to undertake echocardiography diagnosis.

We need adequate workforce planning across Europe to ensure sufficient future workforce capacity to cover increasing demand and evolving treatments. As more medical schools create specialisms to provide the healthcare professionals, it's important that there is agreement on, and standardisation of, these emerging specialisms.

More effective technology and data gathering

Better data collection

Each European country should collect robust, standardised SHD data to be shared across Europe for a better understanding of how SHD affects different communities and what inequalities exist in treatment or outcome. The gathering and dissemination of more robust real-world data would allow better understanding of the condition, its impacts and the success of any measures taken to address it.

Medical societies and other key stakeholders should advise on the data that clinicians and healthcare systems should be regularly collecting about their SHD patients. This data should include type and severity of disease, any treatments given, and outcomes. Further clinical guideline updates are an additional opportunity to be more detailed and structured on data gathering.

To help facilitate more systematic data collection and a better understanding of the disease and its impact across society, we need a European registry of SHD patients.

New technology and innovations

Clinicians and healthcare systems must take advantage of innovations in detection, diagnosis and treatment with the potential to improve outcomes for people with SHD. The digital stethoscope is one example of an innovation that could vastly improve the detection of SHD; new treatment approaches are likely to lead to fewer associated complications than traditional surgery will continue to be developed. Artificial intelligence will potentially provide further ways to improve SHD detection and diagnosis. Health planners and policymakers should encourage the uptake of innovative new diagnostic tools and treatment methods that have the potential to improve outcomes for people with SHD.

Funding of research

The EU as a whole, as well as individual countries, must continue to invest in research to improve treatment and outcomes for people with SHD. The last decade has already seen major innovations, allowing patients to undergo less invasive forms of treatment. The development of prosthetic (mechanic or biological) valves has also continued to evolve and improve. Such research and innovation can only occur with investment in research, as well

as the fast rollout and adoption of new treatments that prove cost effective.

Moving from recommendations to action

We recognise that there is already emerging political willingness and commitment to investing in SHD. The EU SHD coalition, launched in March 2021, aims to bring together key opinion leaders, politicians and patients to work together and ensure that policy on SHD is prioritised.¹⁰⁸ The EU4Health programme 2021-2027¹⁰⁹ - entered into force March of this year - will inject funding worth EUR 5.1 billion into EU countries, health organisations and non-governmental organisations (NGOs). Our recommendations align with its objectives, including health promotion and disease prevention, for which a minimum of 20% of overall funding is reserved. The Next Generation Recovery EU¹¹⁰ is a recovery plan that will inject EUR 750 billion into member states to boost economic recovery following the pandemic. A significant proportion of these funds will be devoted to healthcare and digital transformation. We believe that these three vehicles represent a crucial opportunity to move from recommendations to action.

Conclusion

The SHD burden is expected to rise significantly over the next 20 years. Without the right action to prevent its spread, SHD will continue to place not only a health burden, but a social and economic burden on society. In an ageing society this needs to change.

We need both the public and healthcare professionals to have greater awareness of both SHD symptoms and the importance of early detection. We also need clearer care pathways, that place patients at their heart, and specialist treatment centres.

We must make politicians and policymakers aware of the cost benefits of the early detection, diagnosis and treatment of SHD. They must commit to greater funding and better cross-country and multi-sector collaboration. We need better data collection to understand the impact of SHD on different communities, and we must continue to invest in research and innovation to improve treatment outcomes for people with SHD.

Only by implementing these solutions will we be able to properly tackle the pervasive ageism that has contributed to the unnecessary SHD burden. This includes ensuring that the patient's voice is heard at every level, including being active in their own care decisions.

The COVID-19 pandemic has further increased the urgency of investment in the prevention of ill health. As countries begin to repair the damage the pandemic has had on health and healthcare systems, including its disruption of cardiovascular treatment, we must use this opportunity to ensure SHD is part of the European and national response to pandemic recovery.

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About the ILC

The International Longevity Centre UK (ILC) is the UK's specialist think tank on the impact of longevity on society. The ILC was established in 1997, as one of the founder members of the International Longevity Centre Global Alliance, an international network on longevity.

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