

Holding us back?

Tackling inequalities in the
detection and treatment of
structural heart disease in Europe



Health and care

Inequalities

International

Prevention

Life expectancy

Disease and Conditions

Acknowledgements

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About this report

To inform this report, we conducted desk research and interviewed 13 key stakeholders from across the SHD community. We also held a workshop at the 17th World Congress on Public Health in Rome, attended by 10 public health experts. A list of the stakeholders interviewed can be found in the Appendix.

Executive summary

“One of the basic foundations of a good healthcare system is that individuals should have equal access to care.”

Professor Huon Gray, Cardiologist, former National Clinical Director for Heart Disease, NHS England, UK

Structural Heart Disease (SHD) refers to structural abnormalities of the heart that lead to impaired functioning, including the heart valves, walls, muscles and blood vessels. It predominantly affects older people. While effective treatments exist, many people may be lost along the care pathway for SHD: from detection, to diagnosis, to treatment.¹ With populations ageing rapidly and becoming more diverse, certain marginalised populations are at greater risk of this happening.

In an ageing world, SHD is increasing in prevalence. We know that:

- In 2020, 14 million people in Europe were living with SHD in 2020; this will increase to 20 million by 2040².
- Untreated SHD places a heavy burden on both health and care systems, as well as on wider society.
- Without treatment, the mortality rate is around 50% for patients diagnosed with severe forms of SHD two years after the onset of symptoms, which increases to 75% at three years.

Following our 2021 flagship report *The Invisible Epidemic: Rethinking the detection and treatment of structural heart disease in Europe*³, the ILC undertook research on inequalities in the detection and treatment of SHD across Europe. Our research finds that:

Age, socio-economic status, gender, ethnicity, and geographical location can reduce the likelihood of receiving treatment for SHD.

These groups are more at risk of:

1. Poor awareness:

Lack of awareness means people generally don't recognise the signs and symptoms of SHD. This is a particular problem among women, people from less wealthy socio-economic groups and people from ethnic minorities. These groups are more likely have more advanced disease when they first seek help or treatment.

2. Suboptimal detection and referral:

People from these groups can struggle to access primary care, and treatment, especially if they live rurally or come from less wealthy

socio-economic backgrounds. Once they come to primary care, the first step in diagnosis, which is auscultation (a stethoscope check), isn't always carried out by a healthcare professional. SHD can be harder to detect in people with more advanced disease, which further exacerbates inequalities. Women, people from less wealthy socio-economic groups, and people from ethnic minorities are more likely to have advanced disease when they consult their doctor.

3. Suboptimal treatment:

Access to treatment can be hampered if people are diagnosed too late or live rurally. There are differences in outcomes between men and women. Waiting times between regions exacerbate the issue.

4. Lack of visibility due to gaps in data collection:

Incomplete data collection including insufficient representation of different groups in clinical trials means that policy makers and health systems don't fully understand the extent of inequalities among different population groups or how to tailor the treatment pathway for SHD to accommodate them.

The barriers affecting marginalised groups are set against a backdrop of pervasive ageism that affects detection, diagnosis and treatment. Added to this is the ongoing effect of the COVID-19 pandemic, which has resulted in significant delays and disruptions to the diagnosis and treatment of cardiovascular disease (CVD) across the entire population; this issue is intensified for marginalised groups.⁴ These wider structural barriers are increasingly contributing to delayed access to timely care and a further deterioration in quality of life for patients.⁵

Recommendations

Since the ILC 2021 report *The Invisible Epidemic: Rethinking the detection and treatment of structural heart disease in Europe*⁶, there has been meaningful progress at the EU level to tackle the burden of CVD and the early detection of SHD.⁷ However, while there's been some initial interest in the fact that inequalities are driving suboptimal detection, diagnosis and treatment for SHD, tackling these problems hasn't been addressed so far.

If we are to reduce this condition's health and economic burden on countries across Europe, tackling inequalities must be part of the solution. But we can't make meaningful progress towards eliminating inequalities in the approach to SHD without also addressing the barriers

that affect older people. Both are needed to improve health outcomes across the board and close the gap on inequalities.

Improving detection and treatment across the entire population

WHO should:

- **Encourage all countries to update or develop their CVD strategies to include SHD**

WHO should raise awareness of SHD and how inequalities are driving disparities in detection and diagnosis. It should encourage all national CVD strategies to include SHD, to drive investment in detection, diagnosis and treatment services.

The EU should:

- **Develop an EU Cardiovascular Health Plan, emulating the EU Cancer Plan, including an EU wide target for early detection of SHD**

The EU should show leadership by including an early detection target for SHD as part of a Cardiovascular Health Plan. This is a first step to help reduce inequalities by focusing on early detection, to the benefit of women, people from less wealthy socio-economic backgrounds and people from ethnic minorities, who are more likely to be undiagnosed, or diagnosed at a later stage.

National governments should:

- **Prioritise the detection and treatment of SHD to improve outcomes for older people**

As the population in Europe ages, the incidence and prevalence of SHD will grow. However, it's currently significantly under-diagnosed. National governments must prioritise its detection, diagnosis and treatment to improve outcomes for older people. This must begin with a strong approach to detection. ILC reaffirms its recommendation that people aged 65 or over should have the right to an annual check-up that includes an SHD consultation and stethoscope check, and an assessment of risk factors for SHD which could result in more accurate follow up for subjects at high risk.

Health providers should:

- **Explore the use of digital technology, AI, and machine learning to improve diagnosis and support clinicians who are not experts in SHD**

Digital technologies such as smart stethoscopes with AI software – handheld tools that analyse heart sounds digitally to assist with auscultation and identify significant murmurs – could help support SHD detection. Machine learning can be used to generate algorithms for disease prediction and progression using personalised and precision medicine. This may be of particular benefit for women, people from ethnic minorities, and people from less wealthy socio-economic groups who are more likely to have advanced disease when they consult their doctor.

Tackling inequalities and improving outcomes for marginalised groups

National governments should:

- **Invest in comprehensive data collection, including comprehensive demographic data, SHD registries, and more inclusive clinical trials, to understand inequalities better**

The lack of comprehensive data collection hinders understanding of which groups are most affected by SHD. Better data collection and analysis including clinical trials with more diverse populations, would allow the development of more effective awareness campaigns and detection, diagnosis and treatment services.

- **Pilot screening programmes, which should include an objective to reduce inequalities, to ensure diagnosis at an earlier stage**

SHD is a growing health problem that remains under-diagnosed, particularly among marginalised groups. Population-level screening programmes that target these groups will help to reduce inequalities in detection and diagnosis.

Public health bodies should:

- **Raise awareness of the signs and symptoms of SHD, and develop targeted awareness campaigns that take into account different cultural backgrounds**

Raising awareness of SHD is essential so that people consult primary care if they notice symptoms. For these awareness campaigns to work

effectively, they must be targeted at specific groups. To this end, they should be co-produced to combat assumptions and bias effectively.

- **Develop targeted approaches to address inequalities**

Population-wide awareness campaigns may not be sufficient to reach some population groups. Targeted interventions that aim to improve outcomes for specific marginalised groups, such as SHD screening in rural areas, may be required to ensure everyone is aware of SHD and can undergo screening if required.

Contents

Acknowledgements.....	2
About this report.....	3
Executive summary.....	4
Introduction.....	10
Marginalised individuals are at risk of suboptimal detection and treatment at multiple points in the pathway for SHD	20
Suboptimal policy is driving inequalities in the detection and treatment of SHD	28
Recommendations.....	30
Conclusion	33
Appendix.....	34
References	35

Introduction

When a disease is more prevalent as we grow older, there's a risk that ageism will significantly affect detection, diagnosis and treatment. This is certainly the case with Structural Heart Disease (SHD), a term used to describe a collection of diseases that affect the structure of the heart and the heart valves. SHD is increasing in prevalence. Without treatment, the mortality rate of patients suffering from severe forms of heart valve disease (the most common type of SHD) is around 50% two years after the onset of symptoms, which increases to 75% at three years. Effective treatments exist.⁸ But SHD is significantly under-detected and under-treated across the adult population in Europe, particularly in the older groups that it primarily affects.⁹ It's estimated that 14 million people in Europe were living with SHD in 2020, and that this will increase to 20 million by 2040.¹⁰

In 2021, the ILC report *The Invisible Epidemic: Rethinking the detection and treatment of structural heart disease in Europe*¹¹ highlighted the under-diagnosis and under-treatment of SHD due to ageism and lack of recognition by health services of the need to tackle these diseases. It raised the spectre of inequalities and recommended better data collection and linkage to understand where inequalities arise.

Health inequalities exist, both across Europe and within European countries; these result in worse health outcomes for marginalised groups. For example:

- Life expectancy varies from country to country; it's often worse in Eastern European countries. The country with the lowest life expectancy (Latvia) has a figure nearly nine years lower than that of the highest (Spain).¹²
- The most common cause of death for women across the EU is cardiovascular disease (CVD).¹³ Across 11 European countries, a European heart survey in 2019 found GPs less likely to regularly conduct auscultation on women than men (24.2% compared to 31.3%).
- Incidence of chronic diseases, including CVD, is highest for the least wealthy socio-economic groups across Europe.¹⁴ In England, people from deprived communities are almost four times as likely to die prematurely from CVD compared with those in the least deprived.¹⁵

However, there's been little focus to date on the inequalities that arise within SHD, especially in Europe.

This report aims to address these inequalities and more deeply examine:

1. The inequalities that exist in the detection and treatment of SH
2. How different groups may be at risk of getting lost across the detection, diagnosis and treatment pathway for SHD
3. What can be done to ensure equitable detection and treatment for all

While this paper is intended to identify what must be done at the European level, the ILC draws evidence and has interviewed stakeholders from other regions, to help build evidence on this topic to galvanise action.

Against a background of pervasive ageism, this report finds that further inequalities arise due to gender, socio-economic status, ethnicity and geographical factors. As European research and policy dialogue in general places an increasing focus on inequalities, this paper is an important first step in raising awareness of the inequalities that affect people with SHD across Europe, whether diagnosed or undiagnosed, and calls for change to start to reduce them.

What is structural heart disease?

SHD is a relatively recent term used to describe a number of structural abnormalities of the heart that lead to impaired functioning. SHD can affect different structures of the heart, including the valves, walls, atria, ventricles and blood vessels. It can be congenital, affecting young children, but is most commonly degenerative, primarily affecting older people.

Valvular heart disease (VHD) comprises a large proportion of cases of SHD; it affects how the valves regulate blood flow in and out of the heart. VHD encompasses a range of diseases that include aortic, mitral and tricuspid stenosis and regurgitation.

While people may live for years with mild SHD without any major health issues, once the condition becomes severe, mortality increases dramatically.¹⁶ Left undiagnosed and untreated, SHD will become increasingly debilitating and life-threatening. The condition is also associated with a degeneration of physical function, social and emotional wellbeing, and vitality and general health.¹⁷ Early diagnosis and treatment of SHD is therefore essential. Moreover,

early detection may also result from assessment of risk factors for SHD and more accurate monitoring of those subjects at higher risk.

Signs and symptoms



Fatigue



Difficulty exercising



Palpitations



Chest pain



Shortness of breath



Fainting

Ideal patient pathway

Awareness: An individual notices symptoms and consults their GP or primary care.

Detection: A GP or primary healthcare professional uses a stethoscope to check individual for a heart murmur.

Referral: The individual is referred for an echocardiogram to confirm diagnosis.

Treatment: A decision is made whether the patient is eligible for pharmacological treatment such as beta-blockers, calcium channel blockers or digoxin, which may be used to mitigate the signs and symptoms of SHD (especially for valve diseases) or for heart valve repair or replacement through a surgical or transcatheter approach, or put on 'watch and wait' with close monitoring for any disease progression.

Inequalities affect certain demographic groups

Emerging evidence suggests that inequalities arise for older people, between men and women, across socio-economic groups and geographical locations, and for ethnic minorities.

“There’s definitely attrition between initial visit, referral to a specialist to confirm diagnosis, and then intervention. If you consider the estimated population of people living with heart valve disease, then see the estimates of those treated; and then explore further to see how many received less-invasive treatment options, the numbers go down at different points along the way. It’s clear that both lack of awareness and structural health inequities play prominent roles.”

Lindsay Clarke, Senior Vice President for Education and Advocacy and Lead for Heart Valve Awareness Day, Alliance for Aging Research, USA

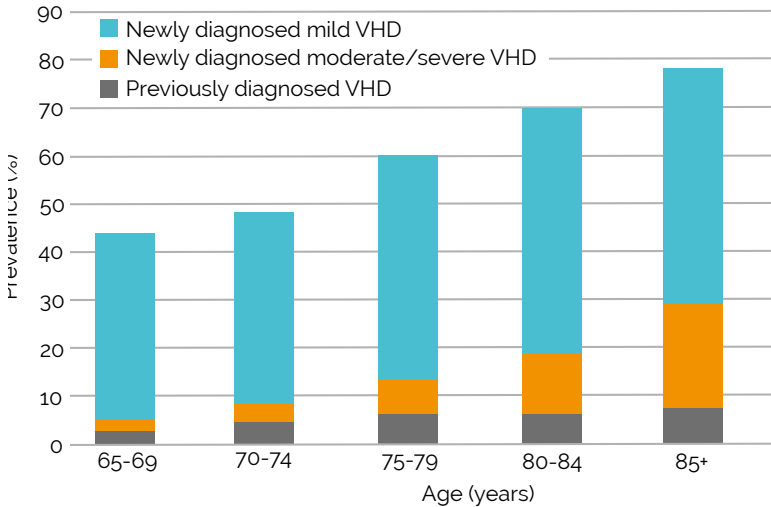
How inequalities affect older people

“Patients and healthcare providers often dismiss the early signs of heart valve disease, such as fatigue or shortness of breath, as “normal” signs of ageing. We need to stop using ageist assumptions because if heart valve disease is detected and treated in a timely manner, people can recover and enjoy a good quality of life.”

Ellen Ross, Managing Director, Heart Valve Voice Canada

The prevalence of SHD increases with age. A 2016 UK study of 2,500 people aged 65 and over in Oxfordshire found that 42.4% of those aged 65 to 69 suffered from VHD of any classification (mild, moderate or severe), increasing to 76.3% in those aged 85 to 95.¹⁸ Two in ten people aged over 80 had moderate or severe VHD.¹⁹

Figure 1: Prevalence of VHD in the population by age



Older people can dismiss the signs and symptoms of SHD as a normal part of ageing and fail to seek help from primary care. Primary care practitioners don't always proactively conduct auscultation of older people. Even once older people are on the treatment pathway, some may believe that it isn't worth undergoing treatment because of their age.

“Structural heart disease is most common in older people. We're not detecting or treating enough affected individuals and people will be dying as a consequence. Our failure to pay enough attention to this could be construed as age discrimination; we would never think such an oversight acceptable if the affected person were in their 30s or 40s.”

Professor Huon Gray, Cardiologist and former National Clinical Director for Heart Disease, NHS England, UK

How inequalities affect people of lower socio-economic status

“In Germany, among higher socio-economic groups, we have approximately 20% privately insured patients, and their access to the health care system is faster than other patients, especially for the initial appointment. Awareness of SHD is higher among well educated groups compared to people with a lower educational level. So if people don't have a high school

diploma or academic education they are typically less likely to find information on these diseases. This lack of awareness means patients from lower socio-economic groups present later, they come with more severe disease and they typically have less access to specialist cardiology services."

Professor Ralph Stephan von Bardeleben, Head of the Centre of Structural Heart Disease Interventions and the Heart Valve Centre in Mainz, Germany

Where studies have examined prevalence of SHD in different socio-economic groups, they have found that people of lower socio-economic status are more likely to have SHD. A population study using a data collection register in Sweden found that deprived neighbourhood status was associated with a slight increase in diagnosis of Aortic Stenosis (AS). Analysis of a separate group that had undergone echocardiography found the association with less wealthy socio-economic groups was higher, potentially indicating underdiagnosis of AS in underserved groups.²⁰ This follows the pattern found in CVD across Europe more generally, where the association between socio-economic status and CVD mortality is independent of major risk factors and comparable to the association with tobacco use, insufficient physical activity, raised blood pressure, obesity and diabetes.²¹

People of lower socio-economic status are also less likely to be diagnosed. The OxValve study in the UK found double the level of undiagnosed VHD in the two most deprived socio-economic quintiles than in the most affluent quintile.²²

People from less wealthy socio-economic groups may also be diagnosed later, with more advanced disease. An observational study in Czechia found that people with lower educational status required procedures at an earlier age and were more likely to require an urgent procedure than people of higher educational status, but that outcomes post-procedure were the same.²³ Urgent procedures can be more costly than elective procedures and have worse outcomes.

The stakeholders we interviewed agreed that people from less wealthy socio-economic groups may be more likely to be diagnosed later or not diagnosed at all. They might also be lost during the treatment pathway. They might be reluctant to consult their primary care doctor with symptoms, and if they're still working, to take time off from work to do this. If they live rurally, this can also be a barrier to undergoing detection, diagnosis or treatment, if travel to primary care or treatment

centres is long and expensive and requires significant time away from employment.

How inequalities affect women

“Women’s symptoms can be much more subtle, and not always taken seriously. Fatigue is a very common one, and can be attributed to many different things in the ageing process. It can be under recognised. Women frequently have stiff left ventricles, which can lead to this low flow, low gradient state. And it can be very much under recognised by those not part of the valve team as being severe aortic stenosis.”

Dr Angela Lowenstern, Interventional Cardiologist, Vanderbilt University, USA

Prevalence of SHD is similar in men and women, but evidence suggests that women tend to consult their doctor later and have more comorbidities than men.²⁴ They also have worse outcomes after surgery. More needs to be done to understand the drivers of the inequity in outcomes between men and women.

A range of factors appear to be at play. Our stakeholders confirmed that women tend to consult their doctor later than men, as they don't recognise the symptoms in themselves, assume CVDs are more prevalent in men, and can have caregiving responsibilities that hinder them from seeking help. A European Society of Cardiology study found that women were significantly more likely to be late going to hospital (defined as waiting 12 hours or longer after symptom onset).²⁵

Symptoms in women may also be more subtle. There appears to be a lack of understanding regarding how SHD presents in women, compared to men.

When women do consult their doctor, they appear to be referred less or referred later.²⁶ If they do access treatment, they may not receive valve repair.²⁷ Outcomes can be worse compared to men. A US study found greater mortality compared to men, and an Italian study found that women are more likely to die after procedures and are more likely to be older and frailer at the time of procedure.^{28 29}

This trend is also visible across Europe. A French cohort study looking at severe AS diagnoses between 2000 and 2017 found that women were diagnosed at a later age than men (74 vs 79). It also found that there was less (and later) use of aortic valve replacement as a treatment for women, irrespective of age. Ultimately, the study showed that women

had a lower five-year survival rate than men. This suggests that late diagnosis and more conservative disease management leads to worse outcomes for women, despite their symptoms.³⁰

Gender inequality may also be driven by other factors. Women's hearts are generally smaller and surgery guidelines have biological cut-offs for valve sizes that don't take this into account.³¹ And historically, women haven't been well represented in clinical trials, which can affect the decisions made by both healthcare professionals and female patients regarding diagnosis and treatment, as well as the development of clinical guidelines. A report by Heart Valve Voice Canada called for more research and clinical trials, to help identify changes to the care pathway that would improve longevity and quality of life for women living with heart valve disease.³²

"...when they [women] do present, and when they do get to a treatment pathway, they get there later, they get there sicker. And then because of that they don't do as well after treatment, because there is a point where, obviously, the sicker you are going into treatment, you don't necessarily have the same recovery."

Dr Janine Eckstein, Assistant Professor of Cardiology, University of Saskatchewan, Canada

How inequalities affect people from different ethnic backgrounds

"Unfortunately, there's a deadly disconnect between the number of people who have an initial concern about their heart health and those who pursue diagnosis from a specialist and are ultimately treated. We focus on the urgency of timely diagnosis and treatment so that people understand how potentially serious structural heart disease can be. These issues are especially critical for communities of colour, who experience higher rates of heart valve disease risk factors at younger ages, but there is inequitable access to specialty care."

Lindsay Clarke, Senior Vice President for Education and Advocacy and Lead for Heart Valve Awareness Day, Alliance for Aging Research, USA

Our stakeholders told us there are inequalities for ethnic minorities. However, there's also a paucity of data in this area, driven by lack of representation in clinical trials. In the UK, the King's Fund has found that South Asian and Black people are at higher risk of CVD than White people.³³ A study in The Hague identified that people from Surinamese

or Antilles backgrounds were more likely to have CVD.³⁴ Migrants to Europe face a range of barriers when accessing healthcare, including language skills, lack of insurance, lack of information and knowledge about the health system, and inability to pay for healthcare.³⁵

“There’s a lack of data on how SHD affects different ethnic groups. White males are predominantly entering trials. There is a paucity of other ethnic groups - Black, Asian, Latino and native groups like native Indigenous groups in the US and Canada - in trials and consequently a lack of data.”

Professor Ralph Stephan von Bardeleben, Head of the Centre of Structural Heart Disease Interventions and the Heart Valve Centre in Mainz, Germany

There’s emerging evidence that people from ethnic minorities may be consulting their doctor about SHD at a younger age. Studies in the US suggest that Black people undergo treatment significantly less frequently than White people.³⁶

In the UK, the South East London Cardiovascular Network ran a project to explore attitudes to SHD among Black people aged over 50.³⁷ They found that people from Black communities had a mistrust of NHS services, informed by historical race scandals, but these could be overcome through interaction with peers. The report recommended sensitivity training for NHS professionals. There was consensus among our stakeholders that to be most effective, communications and services need to be designed to take different cultural backgrounds of different marginalised populations into account.

“Translating awareness into Urdu does not suddenly solve the problem of inequalities of Asian people accessing health. It has to be more culturally sensitive. That’s why we’re working to co-design awareness programs. It took six months to develop a video for the Jewish Community using a series of patient engagement sessions and reviews and then an outreach to deliver that. It’s been watched over 300,000 times. There’s an appetite to watch health communication if it is tailored to each community.”

Will Woan, CEO, Heart Valve Voice UK

The ongoing effects of the COVID-19 pandemic has resulted in significant delays and disruptions to the diagnosis and treatment of SHD and CVD.³⁸ In England, deaths in 2022 exceeded the 2015-2019 average by 6%: CVD was a major contributor to this.³⁹ And several

studies have also found that the pandemic may have contributed to a widening of inequalities. For instance, people from ethnic minorities had disproportionately poorer cardiovascular outcomes than their White counterparts. Coupled with higher infection and mortality rates for COVID-19, this group has experienced a double burden. It's also worth noting that similar trends were found in women and people with the highest levels of socio-economic deprivation. These groups saw a decline in general practice health checks for key CVD risk factors.⁴⁰

Variation across geographies

There are also differences between countries in terms of recorded figures, not only for incidence and prevalence, but also for detection and provision of treatment,⁴¹ which means that prevalence and incidence figures may be inaccurate.

The median age-standardised prevalence estimates per 100 000 people for degenerative Mitral Valve Disease (MVD), one form of SHD, were nearly five times as high in middle-income countries as in high-income countries. Incidence rate estimates per 100 000 people varied widely, ranging from <1.0 in Belgium, Cyprus, Iceland, and Portugal to >30 in Croatia, Czechia, Hungary, Italy, Norway, Poland, Slovenia, Bosnia and Herzegovina, Republic of Georgia, and Serbia. Given that in 2019, there were an estimated 284,200 new cases of degenerative MVD in the 57 countries that are members of the European Society of Cardiology, SHD is a significant problem across Europe. It's not clear what's driving these variations: it's possible that they're due to under-detection.

Overall CVD mortality rates vary significantly among EU countries, with rates in Central and Eastern European countries being significantly higher than those in Northern, Southern and Western countries.⁴² This is driven by differences in health systems as well as different cultural backgrounds.

Geographical inequalities also exist within countries. Public Health France conducted trend analysis between 2006 and 2016: it found differences in incidence rates of patients hospitalised for rheumatic and non-rheumatic heart valve disease. Across the country, there were higher incidence rates for rheumatic disease in Île-de-France, French overseas territories and the south-east of France. Incidence rates for non-rheumatic disease were higher in the west of France compared with the east, with three areas where rates were particularly high being close to Rouen, Toulouse and Clermont-Ferrand.⁴³

Marginalised individuals are at risk of suboptimal detection and treatment at multiple points in the pathway for SHD

Our stakeholders told us that there are multiple points in the SHD treatment pathway where people can be lost, from consulting their GP, to referral, to making decisions about treatment. These points can all be affected by someone's age, socio-economic status, gender, ethnicity and location.

Inequity in awareness and attitudes about SHD

The first essential part of the pathway is awareness. Poor awareness of SHD and assumptions about CVDs and ageing, as well as caring and employment status and health literacy levels, can all affect people's decision-making and health-seeking behaviour. Levels of SHD awareness appear to vary between different groups of patients and between countries, which may be affecting how likely people are to consult primary care. Awareness of the signs and symptoms of SHD is vital to ensure that those with symptoms understand that they should get checked.

A 2019 European Heart Health survey across 11 European countries of people aged over 60 found that only a quarter claimed to be familiar with heart valve disease in general.⁴⁴ Only 6% could correctly describe the condition.⁴⁵ Men were most concerned about cancer, and women were most concerned about Alzheimer's disease.⁴⁶ Older people were more likely to say that they wouldn't consult primary care if they had symptoms (80+ years: 10.0%; 60-64 years: 6.9%).⁴⁷ The survey also found differences in awareness between countries: while only 12% of people were aware of valvular disease in the Netherlands (the highest level of awareness), just 2% were aware in Belgium (the lowest level).⁴⁸

As already described, there are also differences in awareness and behaviour due to sex. Our stakeholders confirmed that women tend to consult their doctor later, as they don't recognise the symptoms in themselves, assume CVDs are more prevalent in men, and can have caregiving responsibilities that act as a barrier to seeking help. Women may also have slightly different presentations of symptoms, and may not exercise as much, meaning that they don't experience symptoms relating to physical exertion.

“Cancer is well understood by the general public. Everyone knows cancer, fears cancer. Yet untreated severe heart valve disease has a similar or worse prognosis than cancer. We need greater awareness of heart valve disease and that there are effective treatments.”

Dr Marta Sitges, Director, Cardiovascular Institute, Hospital Clinic, University of Barcelona, Spain

There is also the complication of internalised ageism. The decline in health due to SHD can be gradual, with people adapting their behaviour to accommodate for debilitating symptoms. The risk is that the lack of awareness of SHD and its associated symptoms among the general population means that people assume symptoms are the natural consequences of getting older. Instead of going to the doctor, they may make changes to their lifestyles to compensate. This can have consequences later, when they present with more advanced disease.

“Currently, there is low awareness of heart valve disease and its symptoms, even among those most at risk and this leads to under detection. Heart valve disease is a complex condition, and the signs and symptoms may be difficult for people to recognise, and many people may be asymptomatic, in other words not showing symptoms. More funding is needed to build awareness, especially those most at risk, to improve early detection.”

Ellen Ross, Managing Director, Heart Valve Voice Canada

One solution might be to invest in public health campaigns for SHD. Health systems and governments run these campaigns for other conditions, for example, the signs and symptoms of cancer and heart failure. In some countries the voluntary sector and other partners work together to deliver awareness days.⁴⁹ Our stakeholders felt that awareness campaigns would have most success when targeted at specific population groups, including marginalised ones, so the messages could be tuned to each group’s particular cultural background. For example, campaigns could be targeted at women or people from different ethnic groups to challenge assumptions or bias. Co-producing such campaigns with the targeted groups would help ensure they are most effective.

“This Heart Valve Disease Awareness Day, we worked with more than 120 partners, including several organisations in countries outside the US, to help them create targeted resources that would resonate with their communities.”

Lindsay Clarke, Senior Vice President for Education and Advocacy and Lead for Heart Valve Awareness Day, Alliance for Aging Research, USA

Inequitable detection and diagnosis of SHD

There appear to be inequalities in the detection and diagnosis of SHD. Incidence of SHD increases with age and suitable treatments exist, yet detection and diagnosis of the disease is not prioritised by health systems.

Detection via auscultation is flawed

Detection of SHD currently relies on people consulting primary care about symptoms, or on GPs proactively conducting auscultation on patients who they suspect could have SHD based on symptoms or age profile and conducting those checks effectively.

There are variations in the rates of auscultation across Europe: they're lower in Spain (16.3%) compared to France (76.1%) and the rest of Europe (28.2%).⁵⁰ There's also regional variation within Spain, ranging from a third (31.3%) in Extremadura, to less than 9% in the Valencian Community.⁵¹ More widespread auscultation across Europe would result in better detection of SHD and reduce inequalities between countries. Sex-based inequalities exist too. The 2019 European heart health survey found GPs less likely to regularly conduct auscultation on women than men (24.2% compared to 31.3%).⁵²

If GPs and other primary care professionals are stretched, they may be less likely to conduct proactive auscultations on people at risk of SHD.

In more advanced disease, murmurs can be hard to hear, meaning they are missed. Our stakeholders were concerned about the ability of practitioners to identify murmurs. Since women, people from less wealthy socio-economic backgrounds, and people from ethnic minorities are more likely to consult their doctor at a later stage, this could further entrench inequalities.

Using technology to enhance detection

Digital technologies and AI could be used to aid detection of murmurs, as they could enable more accurate detection as well as auscultation

by a wider range of healthcare practitioners. This approach was piloted at a pharmacy in Farnborough, UK: it has had significant success in tackling under-detection and reducing waiting times for onward referral.⁵³

“We need more effective methods for detecting valve disease. Developments such as Artificial Intelligence offer opportunities. Doctors also need better education, but we need to recognise that sometimes it is not easy to pick up murmurs. There can be a weak sound, and this can be the case for more advanced disease, which it is crucial to detect.”

Dr Marta Sitges, Director, Cardiovascular Institute, Hospital Clinic, University of Barcelona, Spain

Machine learning could help with SHD prediction and progression by developing an algorithm. This process is a way to combine several different types of data (clinical, imaging and old and new biomarkers) from personalised and precision medicine. The algorithm can be continuously improved by adding more data as it's generated. Machine learning can help with better planning of regular medical checks and therapeutic decisions. If the data used for the process includes relevant demographic factors, it could also improve detection and treatment of SHD in marginalised groups.

Inequitable access to primary care for detection

Another barrier to detection and diagnosis is lack of access to primary care. Once people have identified they have symptoms, they need easy access to primary care. This can be affected by location, and by pressure on health systems, especially following the Covid-19 pandemic. Our stakeholders also confirmed that people from less wealthy socio-economic backgrounds might be less likely to attend primary care appointments if they have to take time off from work or if they live in a rural area. The OxValve study demonstrated under-diagnosis in people from less wealthy socio-economic groups.

Stakeholders talked about the importance of making screening and detection more accessible, by taking screening programmes to local shopping centres or making digital stethoscopes available in community centres such as libraries, so people could undertake screening themselves.

“One of our big ambitions is to get digital stethoscopes into primary care. We’ve been doing some pilots in libraries, so people can access digital stethoscopes and it doesn’t have to be done by a healthcare professional. If you have a clinically significant murmur that warrants a referral, you can take that to your GP.”

Will Woan, CEO, Heart Valve Voice UK

Screening programmes to aid detection

Screening programmes are a potential solution for improving detection in older people and improving outcomes for people from marginalised groups. There aren’t currently any systematic screening programmes for SHD across Europe. The EU SHD coalition has called for their introduction across Europe.⁵⁴ Programmes that involve everyone over a certain age would encompass everyone eligible and lessen the need for individuals to be aware of SHD symptoms. They could involve being invited to auscultation or, more rigorously, for an echocardiogram. This could potentially reduce inequalities for women and those from less wealthy socio-economic groups. Heart Valve Voice Canada has called for everyone over 60 to have regular stethoscope checks and Heart Valve Voice UK has called for the same for those aged over 65.^{55 56}

In addition, identification of risk factors for SHD could result in more accurate follow-ups for high-risk individuals. This might include people with comorbidities such as arterial hypertension and dyslipidaemia, along with certain biomarkers such as high plasma lipoprotein(a), which has been linked with greater risk of AS.

“We have prophylactic programmes for woman with discovering breast cancer, for example. I see people that are 90 years old, that didn’t have an echo in their life, they have severe aortic stenosis. If we had discovered this 10 years ago, they could have other options. It is a political decision [not the screen], but the health system has to help in the implementation of this.”

Dr Mohammad Sherif, Deputy Chief Physician and Head of interventional cardiology and angiology, Charité – Universitätsmedizin Berlin, Germany

Some screening pilots have been undertaken. An Italian pilot was conducted in 2022-23 in 10 small regions (where residents struggle to access bigger hospitals) with people aged over 65. The pilot provided education in prevention and guaranteed access to screening for rural communities.⁵⁷ In the same year, the Republic of San Marino announced

implementation of a cardiovascular health (including SHDs) screening campaign for those over 50 years old.⁵⁸

Case study: Screening pilots for SHD in rural villages in Italy

Pilot SHD screening sessions were established in ten small rural villages across Italy during 2022 and 2023. Consultant cardiologists worked with the local GPs for those villages to invite people aged over 65 to attend screening sessions in local community buildings. The villages selected had poor access to local hospitals and were in different parts of Italy, including Lazio, Tuscany and Campania.

Each village had a population of about 2,000, with about 200 older people invited to attend. Posters were used to raise awareness, with help from the local mayors and word of mouth.

As well as identifying cases of SHD, these sessions diagnosed people with atrial fibrillation and heart failure. Many of those screened have never had a consultation with a cardiologist before, and had dismissed or failed to recognise symptoms. It's estimated that the screening pilots cost 20 Euros per person. Results are expected to be published later this year.

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

"A lot of cancers have different formal screenings. And that's shown a huge reduction in later presentations of malignancy. So, if you have a screening program, we know from cancer research that it gets picked up early."

Dr Janine Eckstein, Assistant Professor of Cardiology, University of Saskatchewan, Canada

Once a murmur has been detected, the next step is diagnosis. Our stakeholders thought the use of AI and digital technologies could help with diagnosis. For example, echocardiogram results don't currently lead to automated recommendations for investigation and treatment, unlike those set up for Computed Tomography (CT) scans. Automating recommendations would reduce errors and missed diagnoses.

“AI could be very helpful for a second reading in imaging. It could support diagnosis, treatment and decision making, in my area imaging is helpful for a scan reading.”

Professor Riemer Slart, Professor in Cardiovascular Multimodality Imaging, University Medical Center Groningen, Netherlands

Inequitable access to treatment

Waiting times for treatment are an issue. In Canada, some provinces have waiting times that are three times longer than others, and Scotland sees significant differences in waiting times between regions.^{59,60} There are also differences in waiting times between different types of hospitals in Ireland (where a lack of cardiac physiologists also hinders diagnosis).⁶¹

Geographical inequalities are likely to affect access to SHD treatment in Europe. The wider literature suggests that suboptimal healthcare infrastructure, including an overstretched and under-resourced healthcare workforce, is a global underlying barrier affecting timely access to healthcare.⁶²

“There are issues with access to treatment in our area in that we don't have enough capacity to meet demand, which will mean some people die before they can have surgery.”

Dr Raj Chelliah, Consultant Cardiologist, Hull University Teaching Hospitals, UK

Access to treatment can be affected by whether people live rurally or in urban centres, particularly in the US and Canada, where travel times from homes in rural areas to urban treatment centres can be three to four hours. This may be less of an issue in certain parts of Europe. Ensuring easy access to treatment centres would help reduce inequalities.

“In East Yorkshire, people from rural areas and more deprived areas tend to present later and this can mean they have more advanced disease. We also have very small numbers of people from Black or Asian backgrounds coming through for treatment, which could mean they are not being diagnosed in time or not presenting to primary care.”

Dr Raj Chelliah, Consultant Cardiologist, Hull University Teaching Hospitals, UK

The drop off that occurs along the pathway from awareness, to diagnosis, to referral, could also affect access to treatment.

Previous research on inequalities in vaccination uptake by ILC finds that in Europe, people from urban areas could actually be more likely to be locked out of the health system than those in rural areas. This is especially true for individuals with physical or mental disabilities, as in some urban areas transport may not be accessible or healthcare facilities may be more dispersed.⁶³ Moreover, ILC's initial 2021 report⁶⁴ showed that there isn't enough access to echocardiography across Europe due to shortages of the right equipment and of sonographers. There's also a shortage of specialists with the proper training and experience in valve interventions. Such issues could quite possibly be contributing to geographical inequalities.

One stakeholder from England said that they have personally only observed a very small number of Black and Asian people presenting for treatment. Our stakeholders felt that clinical guidelines should be updated to reflect more recent data and clinical practice, particularly taking into consideration the differences in the presentation of the disease between men and women.

For CVD generally, more men are admitted to hospital across Europe than women (30% more on average), but women have greater length of stays.⁶⁵ For CVD as a whole, women spent 12% longer in hospital than men; for heart failure (which can be a consequence of SHD), women spent on average 13% longer in hospital than men.⁶⁶ This may be due to the previously outlined inequity in diagnosis and treatment – if men are diagnosed sooner and given treatment sooner, they're likely to require less serious treatment that requires a shorter hospital stay.

Suboptimal policy is driving inequalities in the detection and treatment of SHD

As this report has shown, there are significant inequalities in awareness, detection, diagnosis and treatment of SHD. Improving awareness, diagnosis and detection of SHD is crucial to improving outcomes for marginalised groups. Our stakeholders said that governments and health systems were not giving enough attention to the disease and that there are problems throughout the pathway, which are exacerbated by inequalities.

Health systems don't prioritise SHD. Different European countries vary in how much they prioritise it, which affects service provision. France doesn't have a CVD plan, leading to a lack of resources and services for CVD in some areas of the country.⁶⁷ In Spain, the Strategy of Cardiovascular Health has a focus on SHD and includes SHD screening for everyone aged over 65.⁶⁸ It also recommends that healthcare professionals are trained about gender inequalities. The 2019 NHS Long Term Plan for England mentions heart valve disease and commits to ensuring better patient access to multi-disciplinary teams and echocardiography in primary care.⁶⁹

“Those countries who have a heart-health strategy, like Spain, they are already in a good position. But it can't be done alone by one country. Joint efforts across countries, which will provide solutions, like we've seen with COVID-19. We have to think about cardiovascular disease globally and then it needs to be translated and implemented at national level.”

Birgit Beger, CEO, European Heart Network

There's also a lack of SHD data collection in most health systems, and very little data on how SHD affects different communities. The US holds an SHD registry that collects patient data from hospitals enrolled in the registry. There's no systematic SHD data collection in European countries, apart from in France. England has recently established a register for transcatheter mitral and tricuspid valve procedures.⁷⁰

Establishing systematic data collection, including demographic information, would enable health systems to obtain more data and conduct analysis to identify variations between population groups and understand inequalities better.

“We need to collect data on the different aspects of socio-economic status of our patients, where they’re coming from, how they’re accessing the healthcare system, where there are problems in this system, whether people are not getting treated or not getting treated in an expedited manner. Even if a patient does get their appropriate treatment, but it’s six months later than it should have been, that increases their risk of adverse outcomes, because they’re now sicker than they were. Collecting data at all those different steps would help us as a team to identify how to help people.”

Dr Angela Lowenstern, Interventional Cardiologist, Vanderbilt University, USA

Recommendations

Recommendations

Since the ILC 2021 report *The Invisible Epidemic: Rethinking the detection and treatment of structural heart disease in Europe*⁷¹, there has been meaningful progress at the EU level to tackle the burden of CVD and the early detection of SHD.⁷² However, while there's been some initial interest in the fact that inequalities are driving suboptimal detection, diagnosis and treatment for SHD, tackling these problems hasn't been addressed so far.

If we are to reduce this condition's health and economic burden on countries across Europe, tackling inequalities must be part of the solution. But we can't make meaningful progress towards eliminating inequalities in the approach to SHD without also addressing the barriers that affect older people. Both are needed to improve health outcomes across the board and close the gap on inequalities.

Improving detection and treatment across the entire population

WHO should:

- **Encourage all countries to update or develop their CVD strategies to include SHD**

WHO should raise awareness of SHD and how inequalities are driving disparities in detection and diagnosis. It should encourage all national CVD strategies to include SHD, to drive investment in detection, diagnosis and treatment services.

The EU should:

- **Develop an EU Cardiovascular Health Plan, emulating the EU Cancer Plan, including an EU wide target for early detection of SHD**

The EU should show leadership by including an early detection target for SHD as part of a Cardiovascular Health Plan. This is a first step to help reduce inequalities by focusing on early detection, to the benefit of women, people from less wealthy socio-economic backgrounds and people from ethnic minorities, who are more likely to be undiagnosed, or diagnosed at a later stage.

National governments should:

- **Prioritise the detection and treatment of SHD to improve outcomes for older people**

As the population in Europe ages, the incidence and prevalence of SHD will grow. However, it's currently significantly under-diagnosed. National governments must prioritise its detection, diagnosis and treatment to improve outcomes for older people. This must begin with a strong approach to detection. ILC reaffirms its recommendation that people aged 65 or over should have the right to an annual check-up that includes an SHD consultation and stethoscope check, and an assessment of risk factors for SHD which could result in more accurate follow up for subjects at high risk.

Health providers should:

- **Explore the use of digital technology, AI, and machine learning to improve diagnosis and support clinicians who are not experts in SHD**

Digital technologies such as smart stethoscopes with AI software – handheld tools that analyse heart sounds digitally to assist with auscultation and identify significant murmurs –could help support SHD detection. Machine learning can be used to generate algorithms for disease prediction and progression using personalised and precision medicine. This may be of particular benefit for women, people from ethnic minorities, and people from less wealthy socio-economic groups who are more likely to have advanced disease when they consult their doctor.

Tackling inequalities and improving outcomes for marginalised groups

National governments should:

- **Invest in comprehensive data collection, including comprehensive demographic data, SHD registries, and more inclusive clinical trials, to understand inequalities better**

The lack of comprehensive data collection hinders understanding of which groups are most affected by SHD. Better data collection and analysis including clinical trials with more diverse populations, would allow the development of more effective awareness campaigns and detection, diagnosis and treatment services.

- **Pilot screening programmes, which should include an objective to reduce inequalities, to ensure diagnosis at an earlier stage**

SHD is a growing health problem that remains under-diagnosed, particularly among marginalised groups. Population-level screening programmes that target these groups will help to reduce inequalities in detection and diagnosis.

Public health bodies should:

- **Raise awareness of the signs and symptoms of SHD, and develop targeted awareness campaigns that take into account different cultural backgrounds**

Raising awareness of SHD is essential so that people consult primary care if they notice symptoms. For these awareness campaigns to work effectively, they must be targeted at specific groups. To this end, they should be co-produced to combat assumptions and bias effectively.

- **Develop targeted approaches to address inequalities**

Population-wide awareness campaigns may not be sufficient to reach some population groups. Targeted interventions that aim to improve outcomes for specific marginalised groups, such as SHD screening in rural areas, may be required to ensure everyone is aware of SHD and can undergo screening if required.

Conclusion

Two years ago, the ILC drew attention to the under-detection and under-treatment of SHD across Europe. In this report we have extended our attention to the underlying inequalities contributing to the problem.

We know that global populations are ageing rapidly, but they're also becoming more demographically diverse in ways that can widen health inequalities. This means an urgent and growing need to prioritise the tackling of health inequalities, including those arising from SHD.

Ageism is the overall inequity driving the problem. This may not be conscious or overt, but the lack of attention and action by governments and health systems regarding diseases that predominantly affect older people is clear. Against this backdrop, there are also issues of under-diagnosis and late diagnosis of women, people from less wealthy socio-economic groups, and people from ethnic minorities.

To tackle the inequalities and improve outcomes for marginalised groups, there needs to be investment in improving under-diagnosis and under-treatment across all of Europe. Health services need to improve patient pathways so that all parts take the needs of different groups into account. This will require strong political drive and targeted action, not a one-size-fits-all approach. This will help to improve outcomes and save more lives, and enable everyone better access to healthcare.

While countries like the US and Canada are further down the line in building an evidence base and identifying solutions, Europe is lagging behind. This report aims to galvanise action and ensure that inequity is central to the discussion on SHD moving forward. This will allow optimal outcomes to be enjoyed by the entire adult population, not just the privileged few.

Appendix

The following stakeholders were consulted to inform the findings of the publication.

- Professor Ralph Stephan von Bardeleben, Head of the Centre of Structural Heart Disease Interventions and the Heart Valve Centre in Mainz, Germany
- Birgit Beger, CEO, European Heart Network
- Professor Alessandro Boccanelli, Cardiologist, President of the Italian Geriatric Cardiology Association
- Dr Raj Chelliah, Consultant Cardiologist, Hull University Teaching Hospitals, UK
- Lindsay Clarke, Senior Vice President for Education and Advocacy and Lead for Heart Valve Awareness Day, Alliance for Aging Research, US
- Dr Janine Eckstein, Assistant Professor of Cardiology, University of Saskatchewan, Canada
- Professor Huon Gray, Cardiologist, former National Clinical Director for Heart Disease, NHS England, UK
- Dr Angela Lowenstern, Interventional Cardiologist, Vanderbilt University, USA
- Dr Mohammad Sherif, Deputy Chief Physician and Head of interventional cardiology and angiology, Charité – Universitätsmedizin Berlin, Germany
- Dr Marta Sitges, Director, Cardiovascular Institute, Hospital Clinic, University of Barcelona, Spain
- Professor Riemer Slart, Professor in Cardiovascular Multimodality Imaging, University Medical Center, Groningen, Netherlands
- Ellen Ross, Managing Director, Heart Valve Voice Canada
- Wil Woan, CEO, Heart Valve Voice UK

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64

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About 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. We have unrivalled expertise in demographic change, ageing and longevity. We use this expertise to highlight the impact of ageing on society, working with experts, policy makers and practitioners to provoke conversations and pioneer solutions for a society where everyone can thrive, regardless of age.



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