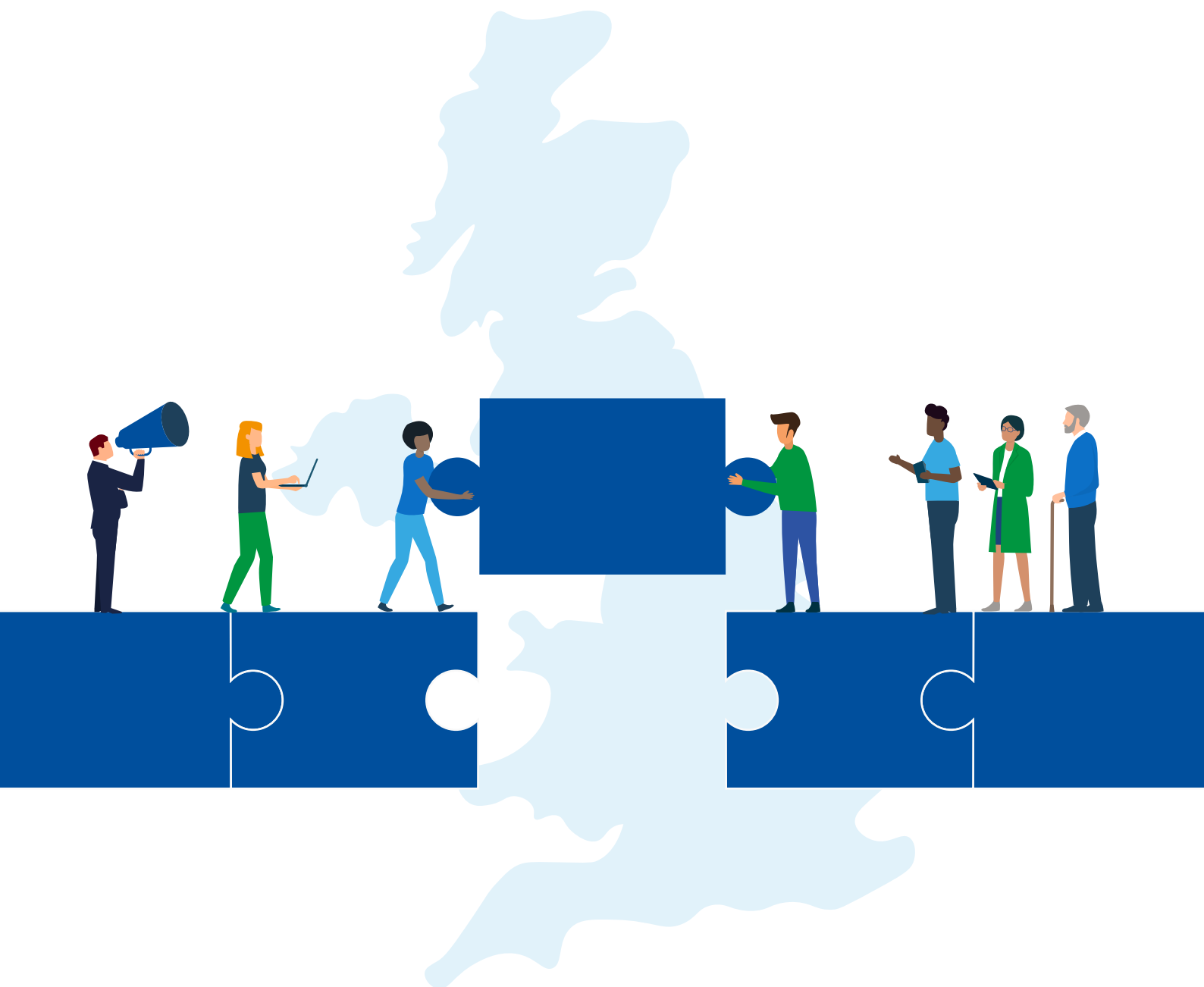


Closing the cholesterol gap

Putting high cholesterol at the heart of action on health inequalities



Daiichi Sankyo UK Ltd, working with HEART UK have produced this report and related materials. The project was initiated and funded by Daiichi Sankyo UK Ltd.

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Foreword

Jules Payne, Chief Executive, HEART UK



As the UK's only cholesterol charity, at HEART UK our vision is to prevent early disease and premature death from high cholesterol – a major factor in cardiovascular diseases including coronary heart disease (CHD), heart attack, and stroke. Every year, we campaign to enable everyone with high cholesterol to access a proper diagnosis and the best possible care, while supporting those who contact us for help and advice about their cholesterol health.

In our work, we have a strong interest in the relationship between high cholesterol and health inequalities. For too long, poorer cardiovascular outcomes have been closely associated with deprivation, with poorer communities having considerably higher premature death rates from heart disease. However, not enough has been done to understand – and tackle – the causes driving these disparities.

As the UK continues its recovery from the COVID-19 pandemic, there is rightly a strong focus on the urgent need to address the significant health inequalities facing our society, which the pandemic has both brought to light and further entrenched. In light of the long-recognised inequalities in the nation's heart health, any action on health inequalities must not only put cardiovascular disease (CVD) front and centre, but the risk factors that drive these diseases.

This report brings together the existing evidence base on variation in cholesterol management and outcomes from across the four nations. While in some areas the data can be patchy, the report demonstrates the need for governments and health systems in all four nations to take a new approach to delivering cholesterol care that is both more joined-up and more equitable. The CVDPREVENT audit in England¹ is a welcome development that will continue to enhance our understanding of where the challenges lie, particularly regarding variation and inequalities. As a result of this information, we can work together to address these challenges, improving health outcomes across all communities.

As we move forwards, I am eager to see ongoing policy initiatives – such as the journey towards integrated care in England – leverage the opportunities to place cholesterol health at the heart of the health inequalities agenda. I hope that this report will go some way in informing policymaker thinking across the UK on the actions that can be taken to improve cholesterol care. In the meantime, HEART UK stands ready to work in partnership with the whole system to make our recommendations a reality.

Executive summary

The COVID-19 pandemic has brought the far-reaching challenge of health inequalities into sharp focus, putting those facing existing structural inequalities in society at higher risk of serious illness and death from COVID-19. This issue is not unique to the pandemic, however: the strong association between deprivation and CVD has been acknowledged for many years.² Those communities hit hardest by COVID-19 are those who have long been disproportionately impacted by poorer cardiovascular health, as well as a myriad other serious illnesses and comorbidities.³

Sitting at the heart of inequalities in CVD outcomes are inequalities in the risk factors that contribute to its development. In 2010, the Marmot Review highlighted that behaviours such as smoking, physical activity and obesity follow a steep social gradient,⁴ contributing to an uneven distribution of risk factors such as high cholesterol – a condition associated with over a quarter of CVD deaths in the UK.⁵

Whilst the inequalities in CVD outcomes are well recognised, the picture on cholesterol itself is more difficult to ascertain. While all four national governments in the UK have made welcome policy commitments to enhance CVD prevention efforts, an absence of data on the nation's cholesterol health means it is difficult to understand the true scale of the challenge and where progress is most needed. Policy initiatives on CVD prevention, including targeting high cholesterol, are yet to demonstrate success in severing the link between societal inequality and poorer CVD outcomes.

As we recover from the impact of the COVID-19 pandemic, we have a critical opportunity to definitively take action on health inequalities, a decade on from Sir Michael Marmot's landmark review. While policymakers recognise the huge imbalances in the UK and have committed to pursuing a 'Levelling Up' agenda which reduces health disparities⁶ – it is important that heart health is now recognised as a key building block for a fairer, more equal society. The four health systems across the UK must be empowered to play a key role in the journey moving forwards.

This report aims to contribute to this discussion by providing a snapshot of the current approach to managing high cholesterol across the four nations, and the extent of inequalities in outcomes. However, while metrics on cardiovascular outcomes are well-established, data gaps do exist in the prevention stages of the pathway. To deliver meaningful improvement, enhanced mechanisms for collecting data on high cholesterol will be required. In England, the recent CVDPREVENT audit⁷ is an encouraging new approach that should be monitored by health systems in the rest of the UK. Expanding the scope of this initiative will be key to understanding where health inequalities within the cholesterol pathway lie, and it will become increasingly important that its data sources and indicators are regularly reviewed to ensure an accurate understanding of where improvements are needed.

Despite the data challenges, in each nation, the findings are evident: we see clear inequalities in cholesterol-related outcomes, with certain regions – including North West England, South Scotland and South West Scotland, and South Wales – consistently experiencing a greater burden of morbidity and mortality. Variations are not limited to environmental or lifestyle-induced raised-cholesterol: people living with familial hypercholesterolaemia (FH), a relatively common genetic condition causing very high cholesterol from birth, face disparities in access to diagnosis and treatment both within and between nations.

Based on our findings, our recommendations pave the way for a cholesterol pathway that is responsive to data, digitally-led, easily and equitably accessible, and joined-up. As we see from the case studies included in the report – covering cholesterol management and beyond – it is possible to put in place services that deliver on these ambitions. Across the UK, ongoing policy developments and reforms provide a timely opportunity to replicate this best practice, delivering optimum pathways for every person living with high cholesterol.

Key definitions

High cholesterol: Cholesterol is a fatty substance, naturally produced by the liver and found in the blood. While everyone needs some cholesterol, over half of adults in the UK have too much non-high-density lipoprotein (non-HDL), or 'bad' cholesterol, in their blood. High levels of non-HDL stick to the inside wall of arteries, causing blockages and making it harder for blood to flow through the body. Throughout this report, we define 'high cholesterol' as high levels of non-HDL (typically above 4mmol per litre of blood).⁸

Familial hypercholesterolemia (FH): An inherited condition – affecting around 1 in 250 people – that causes very high cholesterol levels from birth, independent of lifestyle factors, creating increased risk of cardiovascular morbidity and mortality at a younger age.⁹

Cardiovascular disease (CVD): A general term for diseases affecting the heart and/or blood vessels (vascular system). High cholesterol is a key risk factor for CVD, due to the blockages it can create in arteries, alongside blood pressure and atrial fibrillation (known as the 'ABC' of heart health').¹⁰

Coronary heart disease (CHD): The most common cause of CVD, CHD occurs when blockages in the arteries interrupt or block the flow of blood to the heart. It puts increased strain on the heart, and can be a catalyst of other conditions such as heart attack and heart failure.¹¹

Note on methodology

The heatmaps in this report present data on outcomes for patients living with CHD, used as an indicator of cholesterol-related outcomes. Although high cholesterol can contribute to a range of cardiovascular conditions, the report focuses on CHD as the most common form of CVD,¹² affecting 2.3 million people across the UK.¹³

Deprivation data are also provided to allow for comparison between deprivation levels and related health outcomes. In England, data on uptake of NHS Health Checks – a key mechanism to detect high cholesterol – are also explored, but comparable data are not available from elsewhere in the UK, with such programmes no longer funded in Scotland, for example.¹⁴

In England, data on deprivation and CHD outcomes are provided at the Clinical Commissioning Group (CCG) level, with boundaries correct as of July 2020/21.^{15,16,17,18} Data on NHS Health Checks are provided at the local authority level – the commissioner for these services.¹⁹ In England, data on FH prevalence and uptake of lipid lowering therapies are provided by the CVDPREVENT audit to March 2021 at the CCG level, with boundaries correct as of January 2022.^{20,21} In Scotland and Wales, data are provided by local authority and health boards,^{22,23,24,25,26,27,28,29,30} and in Northern Ireland, at the Health and Social Care Trust level.^{31,32,33,34,35}



Summary of recommendations

Recommendations for each of the UK nations, and the UK as a whole, are set out below.

England



1. NHS England should consider working in partnership with the Office for Health Improvement and Disparities (OHID) to develop a national framework for CVD prevention, which encourages the adoption of best practice models for reducing the association between high deprivation and poorer outcomes. In developing this framework, policymakers should consider a national target for average cholesterol levels to 'level up' England's cholesterol health, and examine re-introducing national incentives for local health services to measure cholesterol
2. In developing the forthcoming White Paper on Health Disparities, the Department of Health and Social Care should consider prioritising CVD prevention as a matter of urgency, given the strong association between CVD and inequalities. The White Paper could set out action to reduce inequalities in access to preventative measures for all groups, including women, deprived communities, and people from ethnic minority backgrounds, particularly those of African and Caribbean heritage
3. NHS England should consider working in partnership with OHID, Integrated Care Systems (ICSs), and NHS Genomic Medicine Service Alliances to ensure consistent implementation of AHSN-led programmes for the detection and management of FH and cascade testing of family members,³⁶ underpinned by a national database
4. The NHS should consider steps to swiftly evaluate and implement digital tools that can support case-finding, detection, and management of people with cholesterol, particularly those that can support ambitions of empowering patients to take greater control of their health
5. As ICSs become statutory bodies, ICS leaders should consider mechanisms for improving the management of high cholesterol, in line with NHS England's CVD prevention ambitions. ICSs could explore:
 - a. Appointing 'cholesterol champions' within each locality
 - b. Incentivising primary care, including community pharmacy, to drive system action on the detection and management of CVD risk factors, including high cholesterol
6. In developing their Health and Wellbeing Strategies, ICS boards may consider steps to understand the association between deprivation and CVD in their footprints, and develop targeted strategies to address gender and ethnic inequalities
7. ICS leaders may consider exploring how integrated care and virtual care models can be developed to improve the FH pathway
8. Following the publication of the CVDPREVENT audit,³⁷ which has highlighted opportunities for improvement in CVD prevention and management, NHS England should consider ensuring that local systems are incentivised to measure a broader range of outcomes – including in cholesterol management – that can further enhance our understanding of existing gaps and opportunities for improvement within the clinical pathway
9. In reforming the NHS Health Checks programme, the Office for Health Improvement and Disparities should consider opportunities to reduce inequalities in access to heart health checks, such as utilising opportunities to carry out health checks digitally and in community settings to improve detection in underrepresented groups



Scotland

1. In line with the Scottish National Party's 2021 manifesto commitments to reduce health inequalities and prevent ill health,³⁸ the Scottish Government should consider exploring how the link between deprivation and increased prevalence of CVD risk factors can be tackled
2. The Scottish Government should consider convening a CVD Prevention Taskforce to monitor progress against the 2021 Heart Disease Action Plan,³⁹ and work with local health boards to facilitate consistent delivery of commitments across Scotland
3. The Scottish Health Survey should consider re-introducing routine cholesterol measurement, and the findings should be considered by health services as part of risk stratification efforts
4. NHS Scotland should consider steps to swiftly evaluate and implement digital tools that can support case-finding, detection, and management of people with cholesterol, particularly those that can help people with more complex needs look after their health
5. Health boards responsible for more deprived populations should consider exploring opportunities for targeted outreach to identify and protect people with risk factors for developing CVD, such as high cholesterol
6. To support delivery of the 2021 Heart Disease Action Plan commitments on FH,⁴⁰ NHS Scotland should consider undertaking a review of access to lipid services for patients in more rural health boards, and explore how remote or virtual lipid services, or expanded provision in primary care, can be put in place to support better case-finding and management of people living with FH



Wales

1. In line with Welsh Labour Party's 2021 manifesto commitments to reduce health inequalities and prevent ill health,⁴¹ the Welsh Government should consider exploring how the link between deprivation and increased prevalence of CVD risk factors and premature mortality from CVD can be tackled
2. In line with Welsh Labour Party's 2021 manifesto commitments to extend the use of new technologies to engage with patients and carers, the Welsh Government should consider commissioning pilots to boost the use of digital tools in the primary and secondary prevention of CVD – including in cholesterol management – particularly in more deprived communities
3. The Welsh Government should consider reviewing the data it is collecting on all aspects of the nation's cardiovascular health to track and support patients at risk of developing CVD. Where data are not currently being collected – for example on cholesterol levels– the Government should consider introducing, and incentivising where appropriate, the collection, analysis and publication of additional metrics
4. The All Wales Familial Hypercholesterolaemia Service⁴² should consider working in partnership with Local Health Boards (LHBs) to review gaps in FH services in rural areas, and consider the use of peripatetic, virtual, and primary care models to facilitate equitable access across Wales
5. LHBs responsible for more deprived communities should consider developing holistic strategies to reduce the association between premature CVD mortality and deprivation, including through primary and secondary prevention initiatives, and remote and community-based support for patients
6. LHBs could consider how remote and peripatetic services could be utilised to better identify and support those at higher risk of CVD in remote and rural areas, including those with high cholesterol



Northern Ireland

1. The Northern Ireland Executive should consider commissioning a new national strategy to improve the prevention, detection, and management of CVD following the expiration of the 2014 Service Framework for Cardiovascular Health and Wellbeing⁴³
2. Ahead of the 2022 Northern Ireland Assembly elections, the governing parties should consider committing to a new public health framework prior to the expiry of the 'Making Life Better' strategy in 2023, with tangible commitments to tackle inequalities in cholesterol health and factors which can increase the risk of poor cardiovascular health
3. The Northern Ireland Executive could consider reviewing the data it is collecting on all aspects of the nation's cardiovascular health, to ensure it is able to fully track and support patients at risk of developing CVD. Where data are not currently being collected – for example on cholesterol levels – the government should consider introducing, and incentivising where appropriate, collection, analysis and publication of additional metrics
4. Health and Social Care Trusts could consider taking steps to improve targeted primary and secondary prevention of CVD to support individuals living in more deprived communities to better manage their health, through lifestyle and medical interventions where necessary
5. Health and Social Care Trusts with more rural and/or older populations may consider how existing community-based outreach (such as satellite clinics in rural areas) can be utilised to make every contact count in encouraging patients to look after their cardiovascular health to support the prevention of CVD
6. Health and Social Care Trusts with higher admissions rates for circulatory admissions and responsible for more geographically disperse populations (such as Northern), should consider how remote and peripatetic services can be utilised to enhance detection and management of high cholesterol in the community
7. For patients living in more remote areas with further distances to travel to their local lipid clinic, Health and Social Care Trusts should consider how they can build on existing provision for rural populations (for example remote or peripatetic services and enhanced primary care services) to strengthen case-finding and management of people with FH



Across the UK

1. Health systems across the UK should consider sharing learnings on the collection and analysis of data on high cholesterol and other CVD risk factors. NHS England may consider collecting learnings from the development and roll-out of the CVDPREVENT audit in England,⁴⁴ a model which Scotland, Wales and Northern Ireland could look to introduce and implement
2. The UK four health systems should consider convening a steering group to compare and share learnings on CVD health checks, and make recommendations so that communities across the UK have standardised access to these programmes, the digital and data infrastructure is in place to monitor progress, and the potential for these programmes to be highly cost-effective is maximised⁴⁵
3. The four UK health systems should consider exploring opportunities to develop a UK-wide model for case-finding and diagnosing people with FH, sitting above national and local models, to support cascade screening beyond borders and provide extra resource in those areas where lipidology and genetic testing capacity is limited

What does 'good' look like for cholesterol management?

These recommendations are designed to support the implementation of an optimal prevention pathway for cholesterol management, that:



Routinely collects and evaluates data on cholesterol levels and management, particularly in higher risk and vulnerable groups, with findings guiding identification of challenges and opportunities for improvement



Embedding digital tools into clinical practice to enhance the detection of those with high cholesterol – for example, through AI-led risk stratification – and monitor the success of interventions



Ensures that services for detection and management of high cholesterol – both face-to-face and digital – are easily accessible to everyone in the community, no matter their circumstances, and are guided by principles of shared decision making⁴⁶



Supports streamlined, joined-up pathways that are integrated around the patient, mobilising the wider workforce, including community pharmacy, and enable the transition from primary to secondary care when more specialist care is required

Introduction:

What is high cholesterol, and why does it matter

High cholesterol is a primary cause of cardiovascular disease (CVD), the leading cause of death worldwide,⁴⁷ and responsible for over 160,000 deaths across the UK every year – or one death every three minutes. Of these CVD deaths, CHD is responsible for 64,000 (around 40%).⁴⁸

Cholesterol is a fatty substance, naturally produced by the liver and found in the blood. While everyone needs some cholesterol, over half of adults in the UK⁴⁹ have too much non-high-density lipoprotein (non-HDL), or ‘bad’ cholesterol, in their blood. High levels of non-HDL stick to the inside wall of arteries, causing blockages and making it harder for blood to flow through the body. If left untreated, or not managed optimally, high cholesterol can cause life threatening conditions, such as coronary heart disease, heart attack, and stroke.⁵⁰

High cholesterol can be caused by behavioural factors – including obesity, smoking and alcohol – and can also be inherited through families. While it can often be managed through lifestyle, some people – especially those with familial hypercholesterolaemia (FH) will need to take medicines to help control their cholesterol levels and reduce their risk of developing CVD.⁵¹

Explainer: familial hypercholesterolaemia (FH)



FH is an inherited condition – estimated to affect around 1 in 250 people – that causes extremely high cholesterol levels from birth. Only around 8% of people in the UK with FH are currently diagnosed,⁵² despite the availability of cascade testing which can detect and diagnose people in early life. This leaves thousands of people at risk of heart disease, and even death, at a very young age: **the risk of developing CHD is up to 13 times higher in people with untreated FH than the general population.**^{53,54}

Despite the availability of interventions – medical and non-medical – that can help manage cholesterol levels, **non-HDL cholesterol is still associated with 25% of all CVD deaths in the UK, and 44% of deaths from CHD.**⁵⁵

Although the UK has made significant progress in reducing the mortality burden of CVD since the second half of the twentieth century – with death rates falling by over 75% since the 1960s¹² – improvements have plateaued since 2010, leaving death rates stubbornly high.^{56,57,58} A recent study has found that CVD caused 46 per 100,000 UK deaths in 2015, considerably higher than other nations including Japan and France (both 20 per 100,000) (2014 data), Spain (30 per 100,000), and Italy and Norway (both 35 per 100,000) (in 2015).⁵⁹ In the past two years, the COVID-19 pandemic has further exacerbated this precarious situation, with **almost 6,000 more CVD deaths than would usually be expected in the first year of the pandemic alone.**⁶⁰

High cholesterol and health inequalities

CVD is strongly associated with health inequalities, with some communities in the UK facing the brunt of severe disparities in CVD outcomes: in England, those living in the most deprived areas are **almost four times more likely** to die prematurely from CVD than those in the least deprived areas,⁶¹ while black people are **almost twice as likely** to have a stroke than white people.⁶²

The lifestyle factors often behind high cholesterol levels are also associated with deprivation. The likelihood of smoking, for example, is four times higher in the most deprived areas than in the least.⁶³ Whilst the underlying inequalities in these 'social determinants of health'⁶⁴ are multifaceted and complex to solve, quicker wins do exist in tackling health inequalities and high cholesterol.

However, at present, the lack of data available on cholesterol means it is difficult to ascertain the true picture of cholesterol management. As a result, it can be challenging to identify clear opportunities for regional and local improvement. In this report, we explore the available data on cholesterol management and outcomes in all four nations, before making recommendations for improvement.

Key stats: the burden of CVD in the UK⁶⁵



7.6m

people are living with CVD in the UK – with numbers set to rise even further as the population ages



25%

of all deaths in the UK are still down to CVD, with around **46,000** premature CVD deaths per year in the under 75s



£9bn

CVD costs the UK's health system **£9 billion** every year, with wider costs to the economy totalling **£19 billion**

The most common type of CVD is **coronary heart disease (CHD)**, which occurs due to a build-up of atheroma (a fatty material) in the arteries providing blood supply to the heart – which is often caused by high cholesterol. CHD is the most common cause of premature death in the UK, causing around **175 deaths each day, or 64,000 each year**



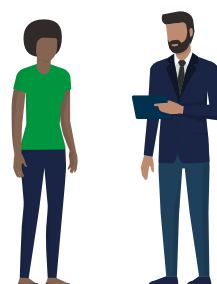
1 in 8 men
and
1 in 15 women
in the UK will die from CHD

High cholesterol: where are we now?

CVD prevention policies across the UK

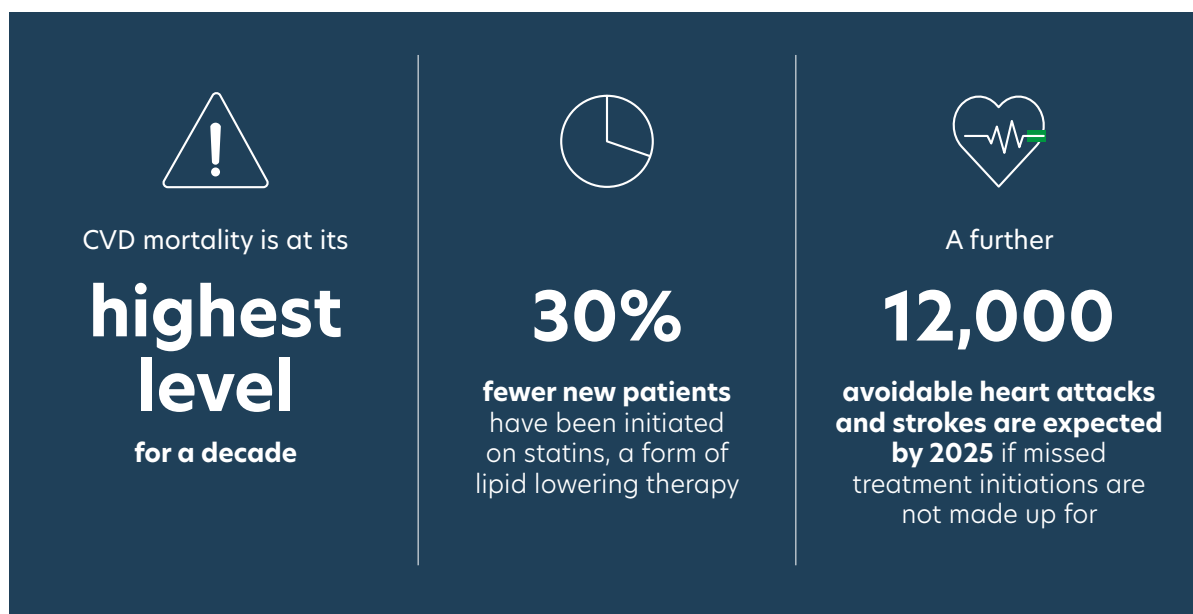
CVD has a huge impact on the overall health of the UK. However, the majority of CVD is preventable – through early detection of risk factors, lifestyle and behavioural changes and treatment – meaning there is a tangible opportunity to improve cardiovascular outcomes across the UK.¹⁹ Throughout the UK, governments and the NHS have long prioritised the prevention of CVD, with policy initiatives currently in place in the four nations:

- In **England**, the **NHS Long Term Plan (2019)**⁶⁶ includes CVD as a clinical priority, describing it as the ‘single biggest area where the NHS can save lives’. The plan pledges to prevent up to 150,000 heart attacks, strokes, and dementia cases by 2028/29, including by:
 - Supporting people to have improved knowledge of their ‘ABC’ (atrial fibrillation, blood pressure and cholesterol) through better use of digital technology and multidisciplinary working
 - Improving diagnosis rates for FH to 25% through expanded genetic testing and the NHS genomic programme
- In **Scotland**, the **Heart Disease Action Plan (2021)**⁶⁷ pledges to minimise preventable CVD through improving the detection, diagnosis, and management of risk factors, including through community-based care models, telemonitoring and a standardised approach to diagnosing and managing FH. This will be underpinned by improved data collection for high cholesterol, high blood pressure, and atrial fibrillation, to support quality improvement and the reduction of regional variation. Also in 2021, the **Women’s Health Plan** prioritised women’s heart health, pledging to reduce gender inequalities in health outcomes related to CVD⁶⁸
- In **Wales**, the **Quality Statement for Heart Conditions (2021)**⁶⁹ puts efficient and effective detection, diagnosis, and management of high-risk conditions at the heart of desired quality attributes of cardiovascular services in Wales. This should be supported by a national approach to informatics systems that enables greater integration of care and provides relevant, high quality, standardised data to drive service improvement
- In **Northern Ireland**, the **Service Framework for Cardiovascular Health and Wellbeing (last updated 2016)**⁷⁰ introduces standards for CVD prevention, including a patient registry of high cholesterol to identify risk, and improved identification and management of people with FH. However, the most recent iteration of the Framework expired in March 2017,⁷¹ and extended until 2018,⁷² with no new strategy having yet been published



The impact of COVID-19

In the aftermath of the COVID-19 pandemic, the UK faces a challenge of worsening CVD outcomes in the future unless action is taken:⁷³



At the same time, the reduction in face-to-face GP primary care service will have led to missed opportunities for opportunistic detection of risk factors, while increased high-risk alcohol consumption and purchasing of processed food has also been reported. Encouragingly, however, more people report doing more physical exercise than usual and attempting to quit smoking.⁷⁴

Without urgent prioritisation, we are likely to see an increase in adults in the UK - particularly those from already deprived and marginalised communities - living with undiagnosed and untreated high cholesterol, and at risk of developing CVD.

It is more important now than ever that policy commitments on CVD prevention are honoured, and that efforts to get the nation's health back on track prioritise cardiovascular health. At the heart of this should be detection and management of those with high cholesterol, and tackling the health inequalities associated with this common risk factor.



The burden of high cholesterol in England

Nationwide challenges in the cholesterol pathway in England

The NHS Long Term Plan has made welcome commitments on detection and management of high cholesterol in England. However, even before the challenges of COVID-19, several systemic challenges existed:

- **Many patients with high cholesterol are not diagnosed:** In England, the NHS Health Check programme seeks to measure and identify a range of CVD risk factors in people over 40, including high cholesterol. However, its impact is limited by low uptake: in the five years between April 2013 and March 2018, 82.5% of the eligible population was offered a check, with an uptake rate of just 48.4% with huge variation across the nation.⁷⁵ During the pandemic, NHS Health checks saw even lower uptake⁷⁶
- **Even when patients with high cholesterol are identified, it is often left unmanaged:** General practitioners are largely responsible for identifying and managing those at high risk of CVD, including those with high levels of non-HDL cholesterol.⁷⁷ While NICE has recommended the wider use of statins for those at high risk of CVD, only 35% of people aged 40-74 identified as being high-risk are currently appropriately managed⁷⁸
- **There is no standardised pathway for FH:** Patients with FH should have their condition diagnosed and managed by specialist lipid clinics. Cascade screening (family genetic testing) may then be utilised to detect family members with the condition so they can be properly managed.

Despite the available treatment options, with no standardised pathway in place and considerable variation in testing capabilities, the vast majority of people with FH are not identified, leaving them at high risk of premature CVD.⁷⁹ The introduction of the AHSN Network's national lipids optimisation programme is an encouraging step, but has an end date of 2023/24.⁸⁰ There is also no single database connecting primary, secondary and genetic services, with the Placement Administration and Support System (PASS) database underutilised throughout England. This is a major hindrance to the development of efficient and integrated FH testing services⁸¹

- **Incentives are possibly not sufficiently aligned with NHS Long Term Plan ambitions:** In 2014, Quality and Outcomes Framework (QOF) indicators on cholesterol measurement were retired.⁸² As such, it is difficult to track performance in the prevention part of the pathway, before patients develop CVD. The CVDPREVENT audit,⁸³ which collects GP held data on diagnosis and management of six high risk conditions that cause CVD and dementia, including familial cholesterol, is a welcome development. However, the 2021 annual report is clear that the CVDPREVENT audit is limited in its work concerning high cholesterol outcomes due to the absence of QOF⁸⁴

Similarly, the introduction of FH and blood pressure diagnosis in the 2022/23 Primary Care Network Contract DES is encouraging,⁸⁵ however, more may be done to ensure that incentivisation is aligned to national policy ambitions by facilitating action on the whole range of CVD risk factors



England

Regional variation in cholesterol health

NHS Health Checks

NHS Health Checks are a key element of disease prevention, and an important vehicle for delivering NHS Long Term Plan ambitions on CVD prevention. The programme is currently subject to long-term reform following a review by Public Health England which examined the strengths and weaknesses of the current approach, and identified opportunities to improve the effectiveness of England's screening offering, such as utilising mechanisms to improve participation considering the significant variation in uptake and follow-up on the health risks identified.⁸⁸

Over the last four years, uptake of NHS Health Checks by the eligible population (adults aged 40-74) has ranged dramatically from 5.4% in York to 66.1% in Bolton (see *Figure 2*). The average across England is 33.4%, which itself highlights room for improvement nationally. The East Riding of Yorkshire (6.7%) and Kingston upon Hull (17.3%) sit alongside York within the 14 local authority areas with the lowest uptake, suggesting possible challenges in the Yorkshire region. The South West appears to be another regional hotspot of poor uptake, with North Somerset (10.9%), Cornwall (14.1%) and Devon (17.0%) all having relatively low uptake.

Taken together, this may point to accessibility issues in more rural areas. The South West is home to many areas with older populations, and therefore a higher rate of people eligible for NHS Health Checks. Decision-makers may consider a more targeted approach, or delivery outside of traditional healthcare settings, to make the programme more accessible to those with more complex needs.

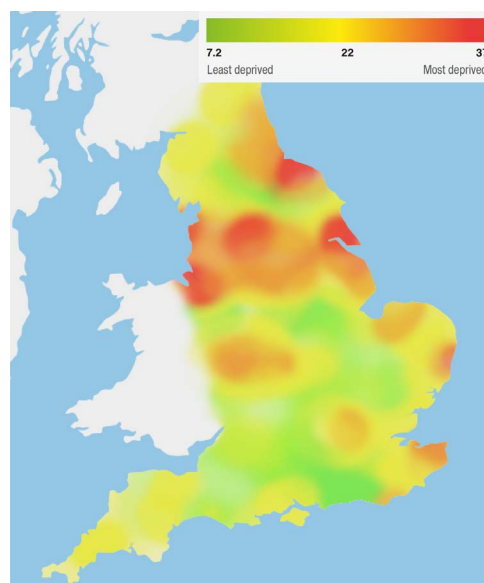


Figure 1: English indices of deprivation, average score by CCG, 2019⁸⁶

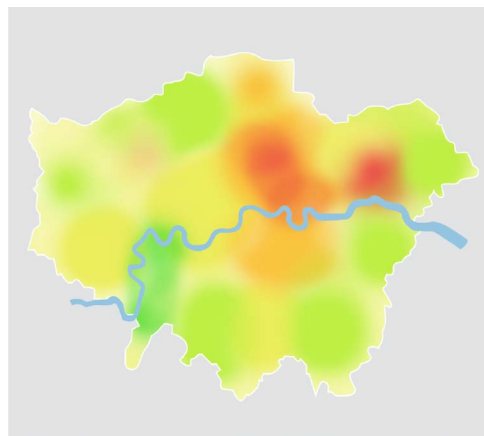
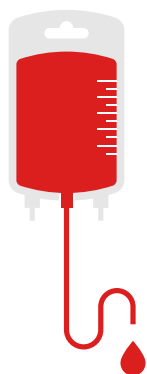


Figure 1a: London



By contrast, several London local authorities achieve higher uptake rates, although we still see variation to an extent. In many cases, high uptake is achieved in some of London's more deprived boroughs, including Newham (65.3%), Tower Hamlets (61.7%), Hackney (57.1%) and Islington (56.9%), which also serve more diverse populations. In Tower Hamlets, NHS Health Checks have been a key element of a wider package of CVD care and targeted outreach, which has incentivised general practice networks to implement the package fully.⁸⁹ This may be a model meriting further exploration as part of ongoing reform of the NHS Health Checks programme, particularly for those deprived communities where patients may benefit from a more targeted outreach.

The association between high deprivation and high uptake is demonstrated elsewhere in England, particularly in the North West (see *Figures 1 and 2*). Alongside Bolton, Rochdale (57.8%) and Lancashire (56.2%) all have relatively high uptake rates, despite being amongst the more deprived areas in England. In some areas however, higher deprivation is associated with lower uptake of health checks, including Kingston upon Hull, Sefton (13.8%), Staffordshire (13.2%) and Nottingham (18.7%).

Prevalence of CHD

1.9 million people are living with CHD in England⁹⁰ – with an average prevalence rate of 3% nationally.⁹¹

Regionally, there is a clear North-South divide in CHD prevalence (see *Figure 3*), with the top ten highest CCGs all in the North of England: NHS Fylde and Wyre CCG (5.0%), NHS North Cumbria CCG (4.8%), NHS East Riding of Yorkshire CCG (4.8%), NHS Northumberland CCG (4.6%), NHS Sunderland (4.6%), NHS County Durham CCG (4.5%), NHS Blackpool CCG (4.5%), NHS South Tyneside CCG (4.4%), NHS St Helens CCG (4.4%) and NHS Barnsley (4.3%).

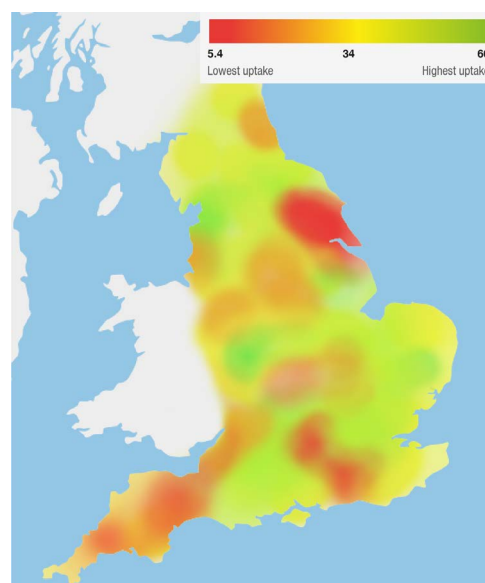


Figure 2: Cumulative percentage of the eligible population receiving an NHS Health Check by local authority, 2016/17 – 2020/21⁸⁷

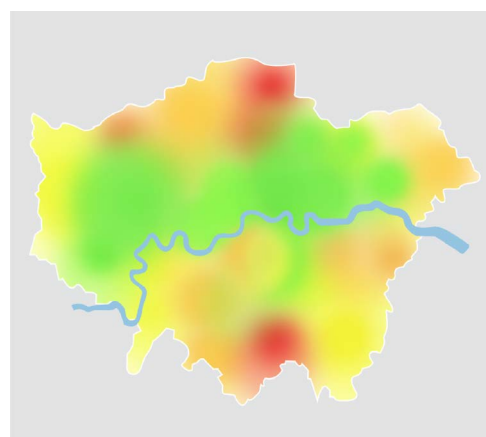


Figure 2a: London

In some cases, there appears to be a clear link with deprivation (see *Figures 1 and 3*) – Blackpool is the second most deprived CCG area in England, with St Helens, South Tyneside, Sunderland, and Barnsley also relatively deprived (although they are outside of the top 20 most deprived). North Cumbria and Northumberland, however, both have lower levels of deprivation comparative to elsewhere in the North, suggesting other factors may be at play such as older population rates. Prevalence is also comparatively high in areas of the South West, including NHS Kernow CCG (4.3%) and NHS Dorset (4.3%) – again areas with lower deprivation rates, but older populations.

In some cases, low uptake of NHS Health Checks does seem to lead to a higher prevalence of CHD – for example in areas such as Cornwall, East Riding of Yorkshire, Sefton, and North Lincolnshire.

As ICSs take on greater accountability for improving the health and wellbeing of their populations, the North West, North East, and South West appear to be clear hotspots for CHD. Looking to the future, ICSs across the country may wish to prioritise tackling risk factors such as high cholesterol before they lead to illness.

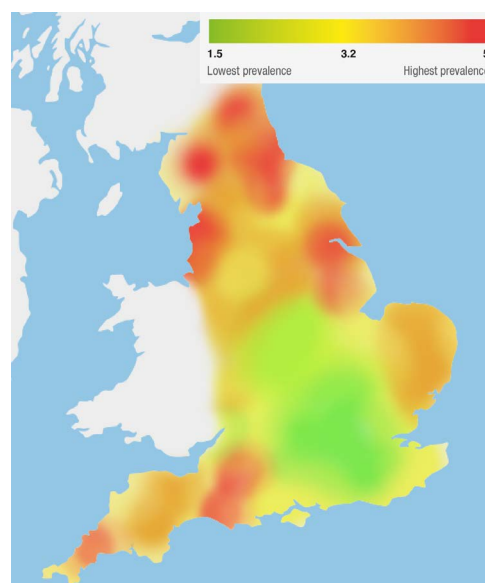


Figure 3: CHD prevalence (%), by CCG, 2019/20²²

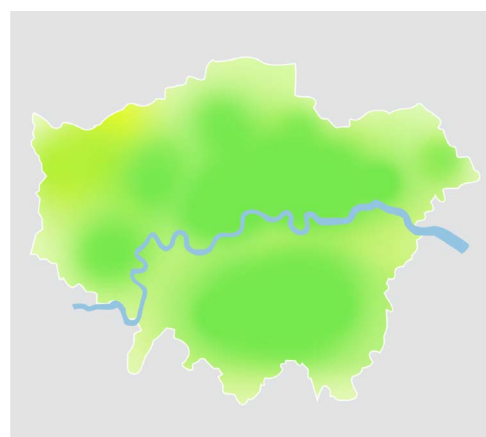


Figure 3a: London

By contrast, the ten CCGs with the lowest prevalence of CHD are all in London – with a prevalence of 2.0% or lower. NHS Hammersmith and Fulham has the lowest prevalence rate in the nation at 1.3%. This lower prevalence may be associated with prioritisation of CVD prevention by the NHS in London – led by the London Cardiovascular Disease Prevention Partnership⁹³ – in addition to the relative success demonstrated in uptake of NHS Health Checks in these areas.

Hospital admissions due to CHD

Although hospital admissions for CHD have been steadily decreasing over the last decade – suggesting improved care pathways in the community, in 2019/20 there were still over 250,000 hospital admissions for CHD in England – 67% of them in men.⁹⁵

As with CHD prevalence, the North of England is disproportionately affected by the burden of CHD hospitalisations, particularly the North West and parts of North East and Yorkshire (see Figure 4). NHS Salford CCG has the highest rate of hospitalisations (797 per 100,000), with NHS Tameside and Glossop CCG (792 per 100,000), NHS Sunderland CCG (732 per 100,000) and NHS Blackburn with Darwen CCG (728 per 100,000) making up the top five. The link between deprivation and hospital admissions merits further exploration to determine the strength of association and care pathways that might be put in place.

Interestingly, NHS Luton CCG (777 per 100,000) and NHS Telford and Wrekin CCG (720 per 100,000) both have high admission rates despite having lower CHD prevalence. This may point to specific challenges in out-of-hospital care pathways to manage CHD. In areas with high admission rates, patients may require further support to manage their conditions, for example, through digital tools. This will both improve their own experience of care, whilst reducing costs to the NHS and supporting policy ambitions of keeping patients out of hospital where possible.

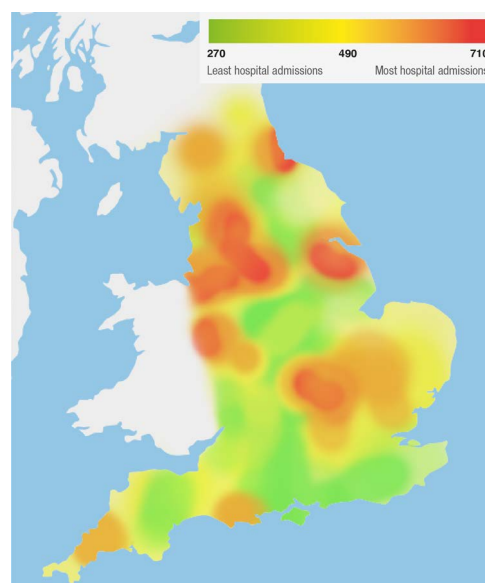


Figure 4: CHD admissions per 100,000 (all ages), by CCG, 2020/21⁹⁴

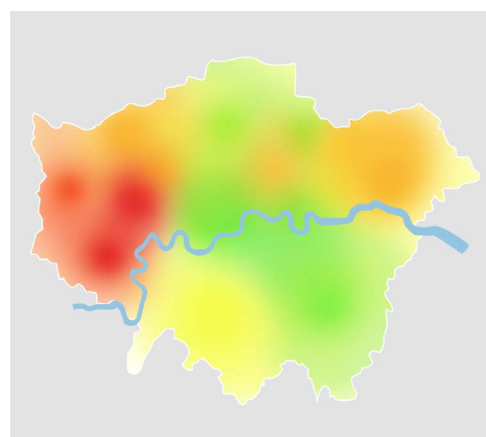


Figure 4a: London

CCGs with lower rates of hospitalisation for CHD are largely concentrated in the Midlands and South, with considerably lower admission rates than the highest areas. This includes more deprived areas such as NHS Stoke on Trent CCG, (325 per 100,000) and NHS Tower Hamlets CCG (349 per 100,000).

Cornwall and Dorset, despite having higher prevalence rates for CHD, have lower rates of hospitalisation and premature death (see below). While the reasons for this are unclear, there may be a correlation with the fact that these areas are less deprived than parts of the North West and West Yorkshire, and patients feel more empowered to take control of managing their CHD at home.

Premature death from CHD

CHD is the single biggest cause of premature death in England, killing around 19,000 people under 75 each year (and around 52,000 people of all ages).⁹⁷ While premature death rates across the country have decreased in the past five decades, the pace of decline has slowed in the last ten years.⁹⁸

Significant variation continues to exist in premature mortality rates, with ICS footprints in the West Midlands, North West and Yorkshire regions disproportionately affected compared to those in the South of England (see *Figure 5*).⁹⁹ NHS Manchester CCG and NHS Blackpool CCG have the highest premature death rates in the country by a significant margin – 75 and 74 per 100,00 respectively.¹⁰⁰ Hotspots elsewhere in the North West include NHS Heywood, Middleton, and Rochdale CCG (63 per 100,00), NHS Blackburn with Darwen CCG (63 per 100,00), while Oldham, Bolton, Knowsley, East Lancashire, Liverpool, Tameside and Glossop, St Helens and Salford all have rates over 50 per 100,000, significantly higher than the England average of 38 per 100,000.¹⁰¹

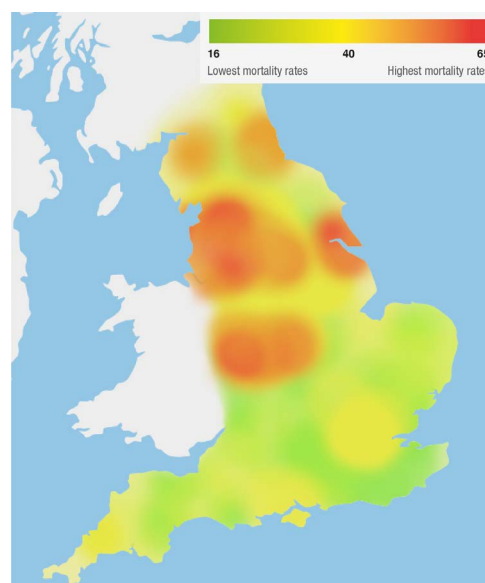


Figure 5: CHD mortality rates per 100,000 (under 75 years), by CCG, 2017-19⁹⁶

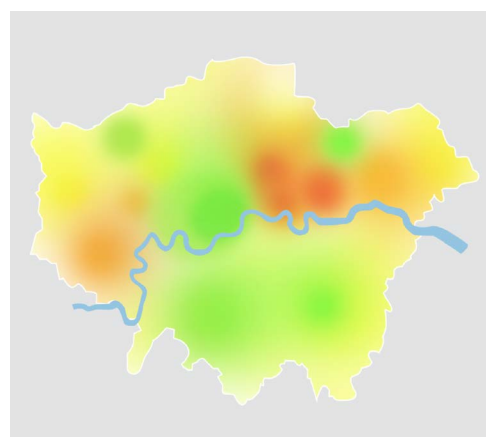


Figure 5a: London

Thinking back to Bolton's high uptake of NHS Health Checks, this may point to the need for enhanced mechanism to follow-up with patients at risk, once they have been identified through the programme.

A region with high deprivation, the North West repeatedly appears to have poorer CHD outcomes, particularly in more deprived areas. ICS boards in the North West, supported by NHS England, may explore taking steps to implement programmes for the primary and secondary prevention of CVD that are specially targeted to more deprived communities, protecting these more vulnerable patients from early death.

Areas of the West Midlands score significantly more poorly on these indicators than for CHD prevalence and hospital admissions. NHS Sandwell and West Birmingham CCG (65 per 100,000), NHS Wolverhampton CCG (64 per 100,000) and NHS Walsall CCG (61 per 100,000) are all amongst the ten CCGs with the highest CHD premature death rates. Although the reasons are unclear, these are again areas with high levels of deprivation and diverse populations,¹⁰² with communities that may require more targeted outreach to facilitate engagement with health services.

We see a similar picture in London. NHS Newham CCG (53 per 100,000), NHS Tower Hamlets CCG (50 per 100,000) and NHS City and Hackney CCG (49 per 100,000), for example, despite performing well in previous indicators, have high rates of premature mortality. The reasons behind this disparity in performance are not clear but may be linked to these areas being among the more deprived in London.

The areas with the lowest premature death rates are also amongst those with the lowest levels of deprivation nationally, including CCGs in Surrey, Buckinghamshire, Oxfordshire, and Hampshire.

Case study: Improving patient outcomes in Bradford¹⁰³

The Bradford's Healthy Hearts programme brings together all Bradford GP practices, and the wider NHS, with the aim of addressing the higher-than-average rate of CVD prevalence and mortality in Bradford, one of the most deprived cities in England. Workstreams include optimising statin therapy, in addition to addressing atrial fibrillation and improving care of those with hypertension (other risk factors for CVD). Examining GP records, 6,000 patients had their treatment switched within three months in line with NICE guidelines, resulting in significant improvements in cholesterol levels.



The burden of FH

With a prevalence rate of between 1 in 250 to 1 in 500, familial hypercholesterolaemia (FH) is a relatively common inherited condition in the UK.¹⁰⁴ All ICS footprints are estimated to be home to at least 460 people living with FH (see Figure 6).¹⁰⁵

Some CCGs, such as NHS Oldham and NHS South Tyneside, have a significantly higher prevalence of FH compared to the national average of 0.18% (1.77% and 1.25%, respectively).¹⁰⁶ While the reasons for this are not fully explained, the discrepancy may be due in part to differing approaches to diagnosis (see Figure 6 and accompanying case study) around the country, resulting in varying proportions of people with FH being identified. While some areas, such as NHS South Tyneside, have established early cascade testing programmes to identify people at an earlier age, these are not yet commonplace.¹⁰⁷ The AHSN network is currently leading a child-parent pilot screening programme across seven regions which could be rolled-out nationally if proved successful.^{108,109}

Detection is most common in the 60-79 age group, with falling rates in the over 80s – when individuals are at a higher risk of heart disease and death.^{110,111} As a result of varying diagnosis rates around the country, people living with undiagnosed FH in some areas will be placed at greater risk of preventable CVD. However, the journey towards integrated care does present a timely opportunity to adopt system-wide approaches for the detection and management of people with FH.

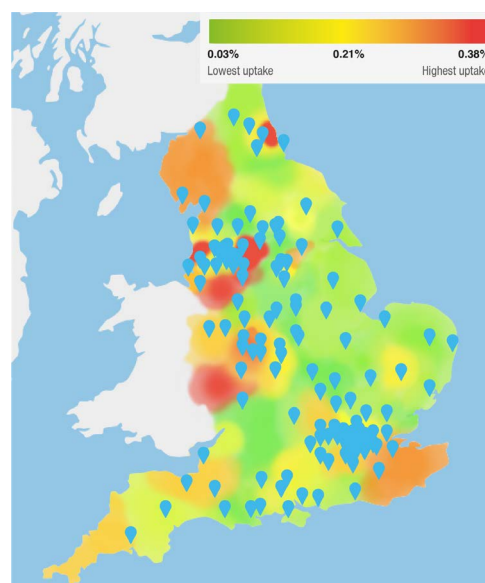


Figure 6: prevalence of GP recorded possible, probable or confirmed FH, by CCG¹¹³

 Location of lipid clinic

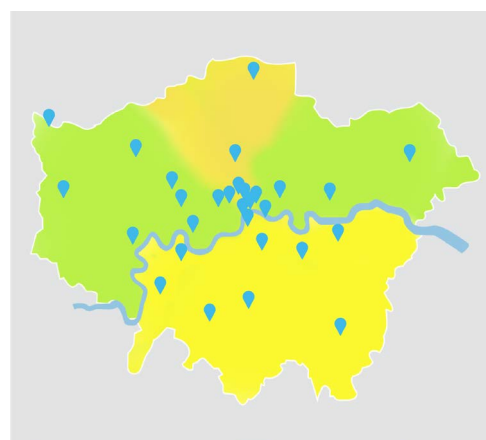


Figure 6a: London

According to national guidelines, patients with FH should be referred to specialist lipid clinics for diagnosis, counselling, and cascade testing, with primary care also taking a leading role in case finding.¹¹² Unsurprisingly, lipid clinics are much more sparsely located in rural areas, seen for example in the South West and North West of England (see *Figure 6*). Here, the longer distances to travel may inhibit the achievement of ambitions on FH.

To support the delivery of NHS Long Term Plan commitments on FH, ICS leaders could explore how the role of primary care can be expanded in the detection and management of FH, with streamlined pathways into more specialist services. Remote or virtual services may be able to support better case-finding and management of FH patients, building on learnings from the pandemic on delivery of remote services.

Case study: improving FH detection in North East England¹¹⁴

North East and Cumbria AHSN introduced a pilot project seeking to improve FH diagnosis rates, including through improved GP system searches to improve identification of patients who may have FH, cascade testing, strengthened collaboration between primary and secondary care, and improved education and awareness-raising. From the 24 FH positive patients identified, 244 family members were identified for cascade screening, of whom around 80 are expected to be FH positive. Through appropriate management, these patients can now have their risk of CVD significantly reduced.



Uptake of treatment

High cholesterol can be effectively managed through healthy lifestyle choices, and where appropriate, lipid lowering therapies may be offered according to clinical guidelines.¹¹⁵ Lipid lowering therapies, such as statins, can be used as an effective form of secondary prevention in those who have already been diagnosed with CVD and are at further risk of harm.¹¹⁶ Increasing treatment is a core commitment of the NHS Long Term Plan to prevent more cases of heart disease and stroke.¹¹⁷

Encouragingly, the CVDPREVENT audit reveals a high proportion of those with CVD have been prescribed a lipid lowering therapy. On average, 92.9% of patients in England received treatment in line with clinical guidance, with notable equity between deprivation quintiles.¹¹⁸ However, there remains notable differences in treatment uptake between gender and ethnic groups.

Of those diagnosed with CVD, women are on average less likely to be offered a lipid lowering therapy than men (90.8% compared to 94.2%). In some CCGs, the gap between genders is as high as 6%.¹¹⁹ Similarly, while patients of Asian heritage are prescribed treatment to levels above the national average, treatment falls considerably in those of African and Caribbean heritage (95% compared to 87.3%, respectively), with a significant 7.7% gap in treatment between the ethnic groups.¹²⁰

The difference between treatment uptake between genders and among different ethnic groups is difficult to explain based upon the existing data presented in CVDPREVENT. These patients have already been identified as being at increased risk following a diagnosis of CVD, and the inequalities in access to treatment using this measure cannot be explained by missing diagnosis or late presentation in these groups. The data are, however, supportive and consistent with additional studies which have found unexplained differences in statin prescriptions between ethnic groups,¹²² while concerns have been raised more broadly about a gender bias in how health services approach and treat CVD in women.^{123,124}

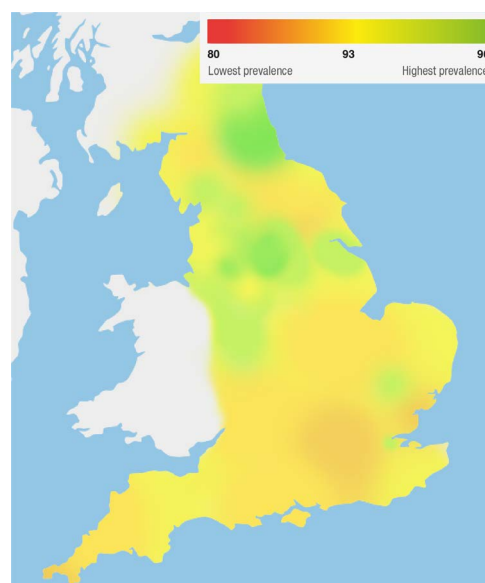


Figure 7: percentage of patients aged 18 and over with GP recorded CVD, with a previous prescription for lipid lowering therapy¹²¹

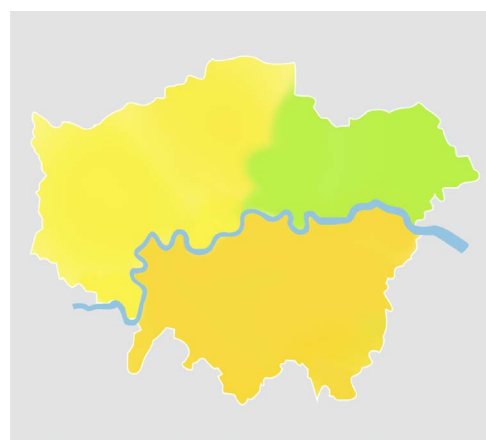


Figure 7a: London



Improving the cholesterol pathway in England: key recommendations

1

NHS England should consider working in partnership with the Office for Health Improvement and Disparities to develop a national framework for CVD prevention, which encourages the adoption of best practice models for reducing the association between high deprivation and poorer outcomes. In developing this framework, policymakers should consider a national target for average cholesterol levels to 'level up' England's cholesterol health, and examine re-introducing national incentives for local health services to measure cholesterol

2

In developing the forthcoming White Paper on Health Disparities, the Department of Health and Social Care should consider prioritising CVD prevention as a matter of urgency, given the strong association between CVD and inequalities. The White Paper could set out action to reduce inequalities in access to preventative measures for all groups, including women, deprived communities, and people from ethnic minority backgrounds, particularly those of African and Caribbean heritage

3

NHS England should consider working in partnership with OHID, ICSs, and NHS Genomic Medicine Service Alliances to ensure consistent implementation of AHSN-led programmes for the detection and management of FH and cascade testing of family members,¹²⁵ underpinned by a national database

4

The NHS should consider steps to swiftly evaluate and implement digital tools that can support case-finding, detection, and management of people with cholesterol, particularly those that can support ambitions of empowering patients to take greater control of their health

5

As ICSs become statutory bodies, ICS leaders should consider mechanisms for improving the management of high cholesterol, in line with NHS England's CVD prevention ambitions. ICSs could explore:

- a. Appointing 'cholesterol champions' within each locality
- b. Incentivising primary care, including community pharmacy, to drive system action on the detection and management of CVD risk factors, including high cholesterol

6

In developing their Health and Wellbeing Strategies, ICS boards may consider steps to understand the association between deprivation and CVD in their footprints, and develop targeted strategies to address gender and ethnic inequalities

7

ICS leaders may consider exploring how integrated care and virtual care models can be developed to improve the FH pathway

8

Following the publication of the CVDPREVENT audit,¹²⁶ which has highlighted opportunities for improvement in CVD prevention and management, NHS England should consider ensuring that local systems are incentivised to measure a broader range of outcomes – including in cholesterol management – that can further enhance our understanding of existing gaps and opportunities for improvement within the clinical pathway

9

In reforming the NHS Health Checks programme, the Office for Health Improvement and Disparities should consider opportunities to reduce inequalities in access to heart health checks, such as utilising opportunities to carry out health checks digitally and in community settings to improve detection in underrepresented groups

The burden of high cholesterol in Scotland

Nationwide challenges in the cholesterol pathway in Scotland

Over the past decade, the Scottish Government has published a series of strategies and action plans on CVD, culminating in the 2021 Heart Disease Action Plan.¹²⁷ There have, however, been no dedicated policies on raised, or uncontrolled, cholesterol,¹²⁸ despite challenges across the pathway:

- **Data collection on cholesterol is limited:** Cholesterol measurement has not been included in the Scottish Health Survey since 2011, with data unavailable at the health board or local authority levels.¹²⁹ This will hinder efforts both to detect and protect people with high cholesterol, and to identify areas for improvement
- **Many patients with high cholesterol are left untreated:** 51% of adults with a higher than 20% risk of developing CVD within 10 years (around 206,200 people) are not treated with statins.¹³⁰ In the past decade, prescriptions for lipid-lowering medicines have remained relatively stagnant, at 4,826,000 in 2009/10 and 5,173,000 in 2019/20¹³¹
- **Commitments on FH are not being met:** Since 2009, there has been little progress reported nationally on the implementation of cascade testing. While some cascade testing pilots are in place at the local level,^{132,133} wider uptake is slow and patchy, although the reprioritisation of FH in the 2021 Heart Disease Action Plan is an encouraging indicator of future action
- **There is a clear social gradient in cholesterol-related outcomes:** CVD risk factors such as smoking, physical inactivity and obesity, which increase the risk of high cholesterol, are more common in deprived areas of Scotland.⁷⁴ As a result, people living in more deprived communities are experiencing significantly poorer cholesterol-related healthcare outcomes. In the 2018 Scottish Health Survey, reported prevalence of CVD was much higher in the most deprived areas, as shown in Figure 7.¹³⁴ People living in the local authority with the highest level of average deprivation – West Dunbartonshire – are 1.6 times more likely to die prematurely from CVD compared with people in East Renfrewshire, which has the lowest average deprivation in Scotland⁷⁴

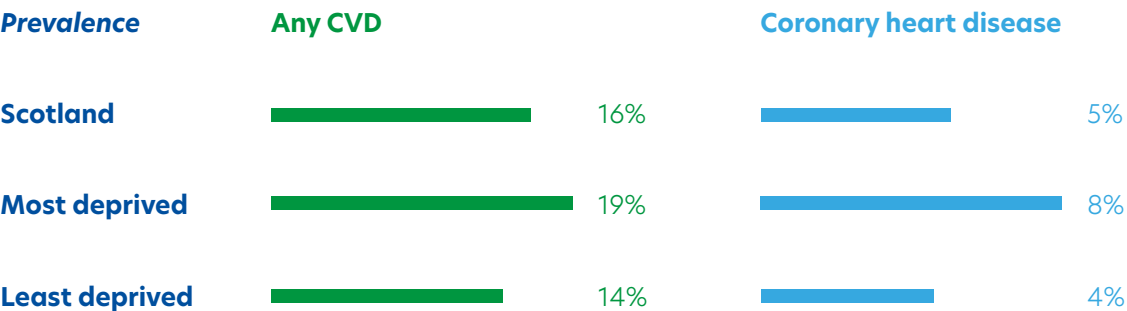


Figure 7: 2018 Scottish Health Survey⁷⁷



Scotland

Regional variation in cholesterol health

Like England, Scotland has previously had a programme in place for identification of health risk factors, the Keep Well Check for those aged 40-64.¹³⁵ However, in 2013 the decision was taken to reduce – and then cease – central funding and support for this service, meaning NHS health boards are now responsible for commissioning such services locally.¹³⁶ As such, data on the availability and effectiveness of health check programmes are not accessible.

Prevalence of CHD

CHD is the most common form of CVD in Scotland, affecting around 260,000 people, 150,000 of whom are men.¹³⁷ At the health board level, there is some evidence that prevalence rates are associated with levels of deprivation. Prevalence per 100 people is highest in NHS Western Isles (5.6 per 100), NHS Ayrshire and Arran (5.0 per 100) and NHS Dumfries and Galloway (4.9 per 100). While NHS Western Isles is amongst the least deprived,¹³⁸ it does have the greatest proportion of lone pensioner households in Scotland – which often leads to loneliness, a risk to health equivalent to smoking.¹³⁹ NHS Ayrshire and Arran meanwhile contains several pockets of high deprivation (see *Figure 8*).

Although health boards cover large geographic areas, meaning that there will be pockets of higher and lower deprivation within each boundary, this is nevertheless telling of the need for health boards responsible for more deprived communities to explore more targeted mechanisms to identify and protect people with risk factors for developing CHD, such as high cholesterol.

In these three health boards, prevalence rates are almost twice as high as those with the three lowest prevalence rates (see *Figure 9*): NHS Lothian (3.1 per 100), NHS Shetland (3.5 per 100) and NHS Grampian (3.6 per 100). These NHS health boards are also associated with the lowest levels of deprivation.

NHS Greater Glasgow and Clyde, despite being an area with high deprivation, has a relatively low rate of CHD prevalence (3.8 per 100), but much higher rates of hospital admissions and mortality for CHD. The reasons for this disparity are unclear, but it could suggest that patients with more complex needs are not seeking healthcare until they become severely ill, and present as an emergency.

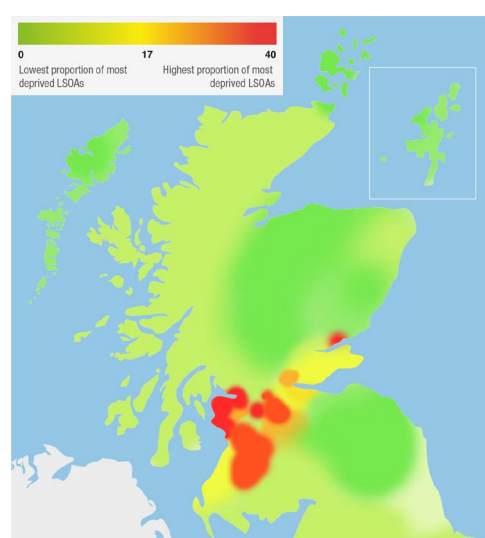


Figure 8: Local share of 20% most deprived lower layer super output areas (LSOAs), by local authority¹⁴⁰

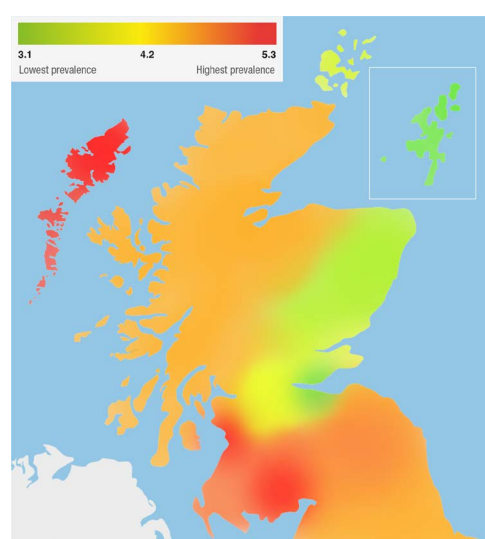


Figure 9: CHD rate per 100,000 people, 2018/19, by NHS health board¹⁴¹

Case study: supporting long-term condition management in Scotland¹⁴²

Scale-up BP in Scotland is part of the technology-enabled care programme funded by the Scottish Government. People with suspected high blood pressure are given a validated blood pressure monitor and are prompted regularly to check their blood pressure at home and then asked to report back the readings through a text message system. The system informs them immediately if their blood pressure is on target or to contact a doctor or nurse if it is worryingly high. This model can support with diagnosis and longer-term self-management.



Hospitalisations due to CHD

Although hospitalisations for CHD in Scotland have declined in the last decade, since 2014/15 admissions have remained at around 24,000 per year. This suggests progress may have plateaued in recent years in supporting CHD patients out of hospital, although the picture may be obscured by the growing and ageing population.¹⁴⁴ Furthermore, hospitalisation rates appear to increase with deprivation: at the national level, the age-standardised discharge rate for the most deprived quintile (1,356 per 100,000) is almost twice as high as that of the least deprived quintile (700 per 100,000).¹⁴⁵

We see a similar picture at the health board level (see Figure 10). In Scotland, health boards with more deprived communities are experiencing much higher rates of hospital discharges due to CHD: the three health boards with the highest discharge rate per 100,000 are NHS Lanarkshire (1,417), NHS Greater Glasgow and Clyde (1,207) and NHS Ayrshire and Arran (1,194). These health board geographies in the West of Scotland also contain local authorities with high levels of deprivation.¹⁴⁶

By contrast, the three health boards with the lowest discharge rate per 100,000, NHS Orkney (563), NHS Shetland (493), and NHS Lothian (427) are also among the least deprived geographies in Scotland. The discharge rate is 187% higher in NHS Lanarkshire than in NHS Shetland.

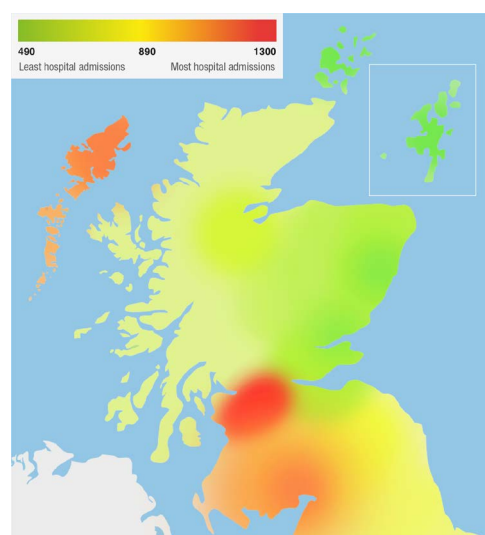


Figure 10: Age-sex standardised discharge rate (per 100,000 people), by health board, 2019¹⁴³

Premature mortality due to CHD

CHD is Scotland's single biggest cause of death, responsible for around 6,600 deaths each year. Although CHD kills more men than women in Scotland, it still kills three times as many women as breast cancer.¹⁴⁸ As with hospital discharges, CHD mortality is about twice as high in Scotland's most deprived quintile (184 per 100,000) than in the least deprived (93 per 100,000).¹⁴⁹ Premature death rates from heart and circulatory disease more broadly are generally higher in Scotland than the rest of the UK, with a particular burden in Scotland's more deprived areas.¹⁵⁰

At the health board level, as with hospital discharges, health boards with greater pockets of deprivation have a bigger burden of premature mortality, including NHS Greater Glasgow and Clyde (61 per 100,000) NHS Ayrshire and Arran (58 per 100,000) and NHS Lanarkshire (53 per 100,000, see *Figures 8 and 11*). NHS Forth Valley also has among the highest premature mortality rates (57 per 100,000), despite having a CHD prevalence more in line with the Scotland average. While the reasons for this are not clear, this may point to poorer outcomes for patients living with CHD in more deprived pockets of this health board geography, such as Clackmannanshire, compared to CHD patients living in less deprived areas.

Again, lower deprivation is associated with better outcomes, with premature mortality rates much lower in NHS Borders (30 per 100,000), NHS Shetland (30 per 100,000) and NHS Orkney (34 per 100,000).

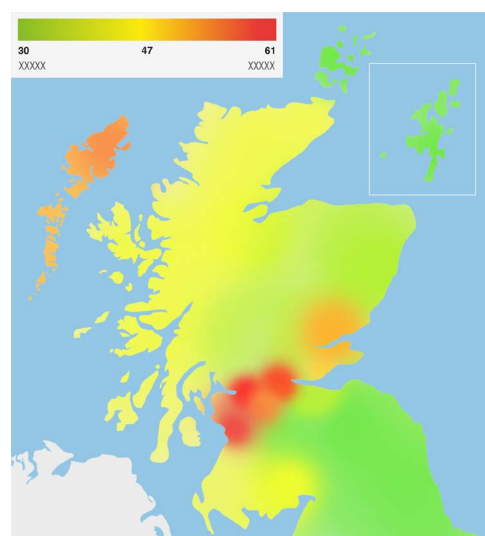


Figure 11: Premature CHD mortality (per 100,000 people), by health board, 2019¹⁴⁷



The burden of FH

Based on health board populations, the estimated number of people with FH per health board ranges from 89 in NHS Orkney to 4,733 in NHS Greater Glasgow and Clyde (see *Figure 12*). The estimated number of people living with FH is highest in urban areas with larger populations: NHS Greater Glasgow and Clyde, NHS Lothian, and NHS Lanarkshire. By contrast, in more remote geographies with smaller populations such as NHS Orkney, NHS Shetland, and NHS Western Isles, the number is much lower.

As is the case in England, national Scottish Intercollegiate Guidelines Network (SIGN) guidance states that patients with a possible diagnosis of FH should be referred to a specialist lipid clinic for investigation and initial management.¹⁵³ Scottish lipid clinics are concentrated in larger urban areas, such as Glasgow and Edinburgh, and only six of the fourteen health boards in Scotland have lipid clinics: NHS Lothian, NHS Forth Valley, NHS Tayside, NHS Greater Glasgow and Clyde, NHS Grampian, and NHS Highland.

While this is to be expected, it is important that people with suspected and confirmed FH living in other, more rural health boards, are able to access specialist lipid services. People in these more remote and rural areas, such as the Western Isles, Shetland, and Orkney, may have to travel significant distances to access a lipid clinic, which may be leading to reduced access to FH diagnosis and treatment.

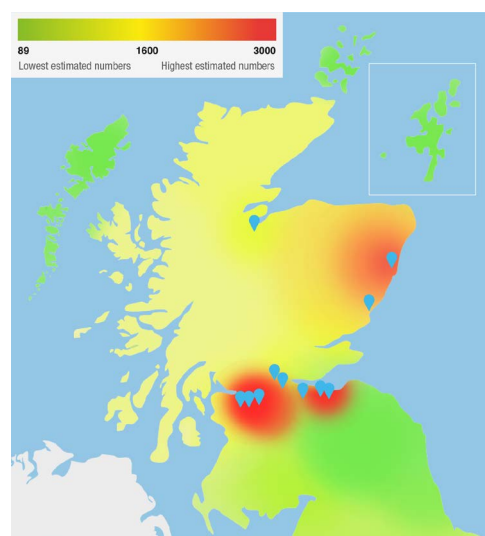
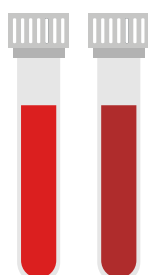


Figure 12: Estimated number of people living with FH, by health board¹⁵¹ and location of lipid clinics¹⁵²

 Location of lipid clinic





Improving the cholesterol pathway in Scotland: key recommendations

- 1** In line with the Scottish National Party's 2021 manifesto commitments to reduce health inequalities and prevent ill health,¹⁵⁴ the Scottish Government should consider exploring how the link between deprivation and increased prevalence of CVD risk factors can be tackled
- 2** The Scottish Government should consider convening a CVD Prevention Taskforce to monitor progress against the 2021 Heart Disease Action Plan,¹⁵⁵ and work with local health boards to facilitate consistent delivery of commitments across Scotland
- 3** The Scottish Health Survey should consider re-introducing routine cholesterol measurement, and the findings should be considered by health services as part of risk stratification efforts
- 4** NHS Scotland should consider steps to swiftly evaluate and implement digital tools that can support case-finding, detection, and management of people with cholesterol, particularly those that can help people with more complex needs look after their health
- 5** Health boards responsible for more deprived populations should consider exploring opportunities for targeted outreach to identify and protect people with risk factors for developing CVD, such as high cholesterol
- 6** To support delivery of the 2021 Heart Disease Action Plan commitments on FH,¹⁵⁶ NHS Scotland should consider undertaking a review of access to lipid services for patients in more rural health boards, and explore how remote or virtual lipid services, or expanded provision in primary care, can be put in place to support better case-finding and management of people living with FH

The burden of high cholesterol in Wales

Nationwide challenges in the cholesterol pathway in Wales

The regular updates by the Welsh Government to its successive national cardiovascular strategies demonstrate the continued policy prioritisation and commitment to tackling CVD at the national level. However, challenges remain, with CVD causing more than a quarter (27%) of all deaths each year.¹⁵⁷ Gaps in the approach to high cholesterol contribute to these challenges:

- **Data collection on cholesterol is limited:** Cholesterol measurement is omitted from the annual National Survey for Wales, despite the collection of statistics on other risk factors such as physical inactivity and high blood pressure.¹⁵⁸ As such, it is difficult to quantify the prevalence of high cholesterol in Wales and identify hotspots where preventative interventions could make a real difference to reducing the burden of CVD
- **Cholesterol management improvements are difficult to verify:** Each year the Welsh Government reports on progress of the National Heart Strategy, for example, announcing improvements in heart disease mortality thanks to cardiac rehabilitation programmes.¹⁵⁹ However, the data sitting behind the reports are not published, meaning there is a lack of transparency about the progress of health improvement initiatives^{160,161}
- **Tracking performance across Wales is challenging:** The lack of publicly available cholesterol management statistics presents challenges in analysing cholesterol-related health outcomes across the nation. Furthermore, the seven Local Health Boards (LHBs) produce information to varying degrees, and local heart disease delivery plans omit quantifiable data on cholesterol – meaning variations and inequalities across the health service are undetected
- **Significant health inequalities exist in CVD outcomes:** Populations in more deprived areas are more likely to engage in behaviours that create CVD risk, with high cholesterol being a key risk factor.¹⁶² This is translating into varying mortality rates between affluent and deprived areas. For instance, people living in Blaenau Gwent (the most deprived local authority) are 50% more likely to die early from CVD than those living in Monmouthshire/Sir Fynwy (the least deprived local authority).¹⁶³ Furthermore, unconscious biases and systematic health inequalities are resulting in poorer CVD outcomes for women, with women less likely to receive timely diagnosis, optimal treatment, and accessible services than men¹⁶⁴
- **Despite significant improvements, FH remains underdiagnosed:** The *All Wales Familial Hypercholesterolaemia Service* was launched in September 2010 and aims to deliver an equitable opportunity for people in Wales to access specialist FH services, including support, counselling, genetic testing, and cascade family testing. While this is a hugely positive step forward, setting Wales apart from England and Scotland, it has reported challenges in the identification of patients with FH from primary care¹⁶⁵



Wales

Regional variation in cholesterol health

In Wales, the 'Add to your Life' programme provides health and wellbeing checks to adults aged over 50.¹⁶⁶ However, data on uptake and effectiveness are not published.

Prevalence of CHD

Across Wales, CHD affects around 117,000 people.¹⁶⁷ At the LHB level, prevalence ranges from 2.7% in Cardiff and Vale University Health Board to 4.1% in both Powys Teaching Health Board and Hywel Dda University Health Board (see Figure 14).

Both Powys and Hywel Dda are home to among the least deprived populations in Wales. However, Powys covers a sparsely populated area with no district general hospital,¹⁷⁰ and has an older population compared to the rest of Wales.¹⁷¹ The rural and elderly nature of the population may be a key driver of CHD prevalence. Hywel Dda is also very sparsely populated.¹⁷² In areas such as these, remote and peripatetic services could be utilised to better identify and support those at higher risk of CHD, including those with high cholesterol.

However, there is some evidence of an association between deprivation and higher CHD prevalence. In the South of Wales, Swansea Bay, Cwm Taf Morgannwg and Aneurin Bevan all have relatively high prevalence rates (3.7-3.8%) and are home to local authorities with higher levels of deprivation.

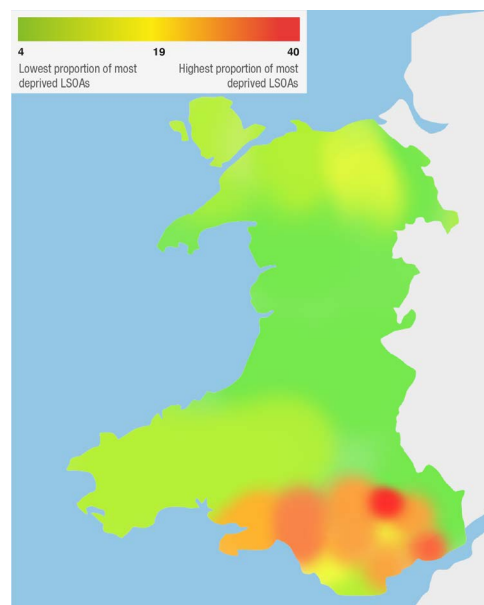


Figure 13: Local share of 20% most deprived lower layer super output areas (LSOAs), by local authority¹⁶⁸

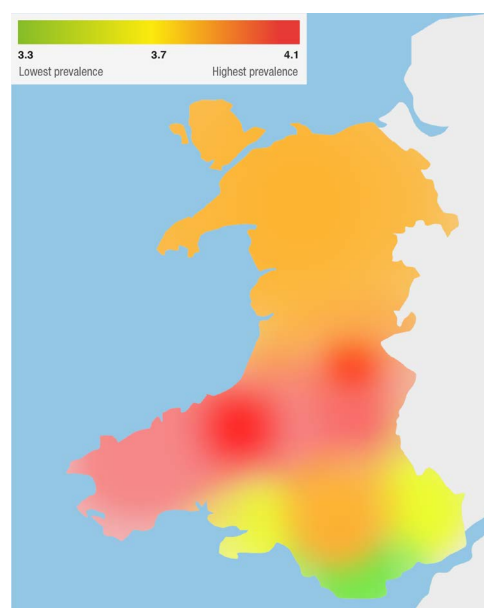


Figure 14: CHD prevalence as % of all patients on disease register, 2018/19, by LHB¹⁶⁹

Hospital admissions due to CHD

As with the rest of the UK, Wales has made significant progress in reducing numbers of hospital admissions for CHD. In more recent years, however, progress appears to have slowed, with 13,663 CHD admissions in 2019/20 compared to a record low of 13,262 in 2017/18.¹⁷³

At the LHB level, hospital admission rates are highest in Powys Teaching Health Board (246 per 100,000), Hywel Dda University Health Board (239 per 100,000) and Cwm Taf Morgannwg University Health Board (227 per 100,000). The correlation between increased prevalence and higher hospital admissions due to CHD is well-defined. However, unlike elsewhere in the UK, the link between deprivation and higher hospital admissions is unclear.

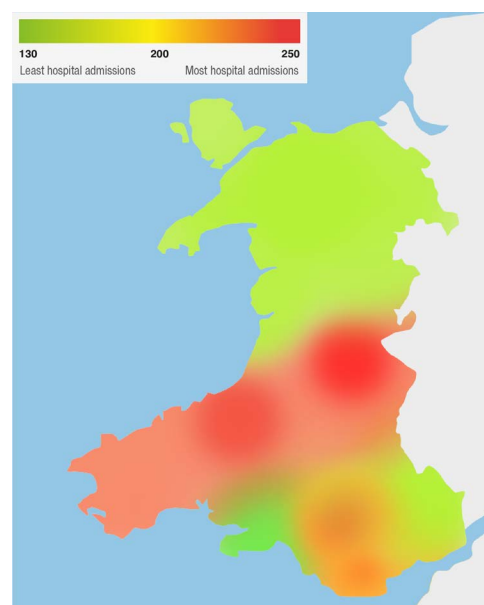


Figure 15: CHD hospital admissions per 100,000, all ages, by LHB, 2019/20¹⁷⁴

Case study: community-based heart failure hub in Swansea¹⁷⁵

During the COVID-19 crisis, Swansea Bay University Hospital Board clinicians stopped routine hospital and community heart failure clinics and designed a temporary community-based heart failure hub. This was distant to acute hospital sites and ensured rapid access for patients with a potential new diagnosis, and support for existing patients at greatest risk of hospital admission. Based on the experience of the community cardiology projects, and the learning from adaptations to models of care throughout the COVID-19 pandemic, core components and principles of community cardiology could be identified and included within All Wales cardiac pathways.

Premature mortality from CHD

CHD is responsible for around 3,600 deaths in Wales every year,¹⁷⁶ and although premature death rates have fallen significantly since the 1960s, in the past ten years they have remained largely stable, suggesting that new strategies may be required to facilitate further improvement.¹⁷⁷

At the LHB level, premature mortality from CHD is the highest in Aneurin Bevan University Health Board (52.6 per 100,000) and Swansea Bay University Health Board (50.3 per 100,000). It is notable that these are also LHBs home to local authority areas with greater pockets of deprivation including Blaenau Gwent, Newport, Neath Port Talbot, and Torfaen (see *Figures 13 and 16*).

By contrast, LHBs with fewer pockets of deprivation, such as Powys Teaching Health Board, Betsi Cadwaladr University Health Board, and Cardiff and Vale University Health Board, have the lowest rates of premature CHD mortality and fall well below the Wales average (39.4, 41.6 and 42.1 per 100,000 respectively). Powys' low premature mortality rate is despite its higher prevalence and admissions rates; however, this may point to its older population becoming ill at a later age and dying over the age of 75.

These data point strongly to a disproportionate premature mortality burden on deprived communities in Wales. However, updates to these data have not been available at the LHB (or local authority) level since 2017. To ensure variation in mortality outcomes can continue to be tracked, and interventions made to support improvement where necessary, the NHS in Wales should consider restarting collection of CVD mortality metrics.

The burden of FH

As Wales' LHBs cover a mix of urban and rural populations, it is unsurprising that estimated numbers of people living with FH varies significantly, from 530 in Powys Teaching Health Board to over 2,000 in Cardiff and Vale University Health Board, Aneurin Bevan University Health Board and Betsi Cadwaladr University Health Board (see Figure 17).

However, lipid clinics are not well distributed across the country: clinics are largely concentrated in the South, and around larger urban areas such as Cardiff, Newport, Swansea, and Bridgend. In LHBs covering larger, more sparsely populated areas, there are much fewer lipid clinics – Powys Teaching Health Board has none. Betsi Cadwaladr University Health Board, despite having the highest numbers of people estimated to be living with FH, has only one lipid clinic in Wrexham – a significant distance for patients living in the west of the LHB's geography.

Whilst this is not unexpected, in order to achieve its ambitions in detection and management of FH, it is important that the All Wales Familial Hypercholesterolaemia Service has the national oversight and resources necessary to deliver equitable access to service across the country. To complement this, the service could work in partnership with LHBs to explore how remote, virtual services, or expanded provision in primary care could be utilised to support better case-finding and management of people with FH in more rural areas.

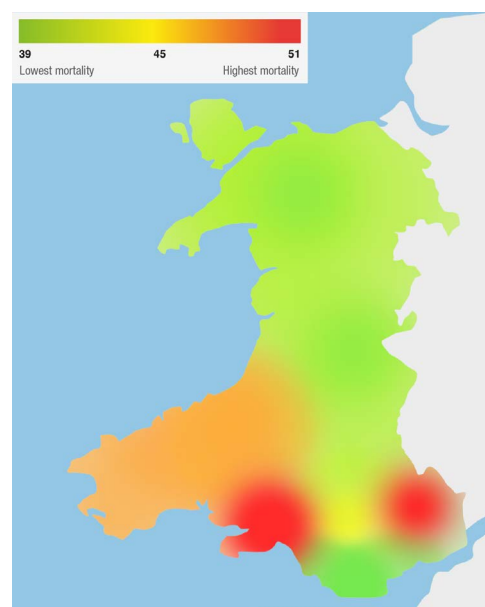


Figure 16: Premature CHD mortality per 100,000, by LHB, 2017¹⁷⁸

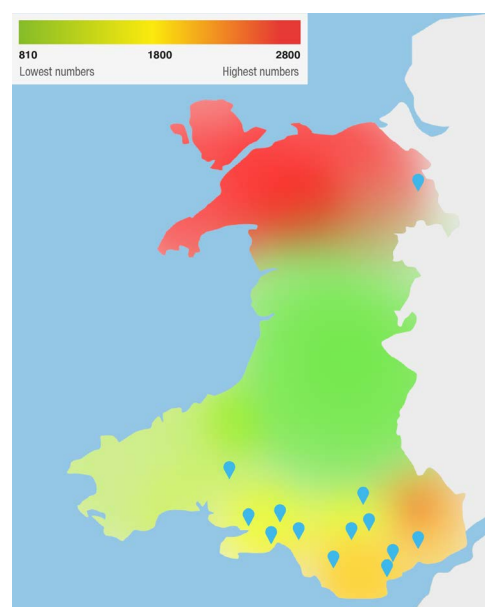


Figure 17: Estimated number of people living with FH, by LHB¹⁷⁹ and location of lipid clinics¹⁸⁰

 Location of lipid clinic

Improving the cholesterol pathway in Wales: key recommendations

- 1** In line with Welsh Labour Party's 2021 manifesto commitments to reduce health inequalities and prevent ill health,¹⁸¹ the Welsh Government should consider exploring how the link between deprivation and increased prevalence of CVD risk factors and premature mortality from CVD can be tackled
- 2** In line with Welsh Labour Party's 2021 manifesto commitments to extend the use of new technologies to engage with patients and carers, the Welsh Government should consider commissioning pilots to boost the use of digital tools in the primary and secondary prevention of CVD – including in cholesterol management – particularly in more deprived communities
- 3** The Welsh Government should consider reviewing the data it is collecting on all aspects of the nation's cardiovascular health to track and support patients at risk of developing CVD. Where data is not currently being collected – for example on cholesterol levels – the Government should consider introducing, and incentivising where appropriate, the collection, analysis and publication of additional metrics
- 4** The All Wales Familial Hypercholesterolaemia Service¹⁸² should consider working in partnership with Local Health Boards (LHBs) to review gaps in FH services in rural areas, and consider the use of peripatetic, virtual, and primary care models to facilitate equitable access across Wales
- 5** LHBs responsible for more deprived communities should consider developing holistic strategies to reduce the association between premature CVD mortality and deprivation, including through primary and secondary prevention initiatives, and remote and community-based support for patients
- 6** LHBs could consider how remote and peripatetic services could be utilised to better identify and support those at higher risk of CVD in remote and rural areas, including those with high cholesterol



The burden of high cholesterol in Northern Ireland

Nationwide challenges in the cholesterol pathway in Northern Ireland

Following the Northern Ireland Executive's declaration of CVD as one of the leading causes of ill health and disability in the nation in 2009,¹⁸³ cardiovascular health and wellbeing appears to have been an increasing public health priority in Northern Ireland in recent years. Despite this, significant challenges remain within the cholesterol pathway:

- **Data collection on cholesterol is limited:** The lack of specificity or breakdown by condition within official CVD statistics, including for hospital admissions and mortality data, makes it challenging to measure the burden of high cholesterol on patients and the healthcare system. Furthermore, the absence of data on efforts to detect people with high cholesterol in primary care hinders the tracking of progress towards early detection commitments
- **Variation in CVD risk and access to treatment:** Causes of high cholesterol are strongly associated with deprivation in Northern Ireland. Alcohol-related hospital admissions, for example, range from 340 per 100,000 in the least deprived cohort to over 1,500 per 100,000 in the most deprived.¹⁸⁴ Coupled with this, inequalities in statin prescriptions are widening, with the gap between the prescription of statins between the most and least deprived increasing by ~2% a year since 2015¹⁸⁵
- **FH remains underdiagnosed:** Genetic services for FH have been created at the national and local levels, leading to improvements in identifying people with FH and testing their family members.^{186,187} However, it has been reported that due to ad hoc screening practices and diagnostic tests showing a poor understanding of polygenic risk, around 70% of cases are still left undiagnosed and untreated, which, although lower than the rest of the UK, leaves many people still at risk of premature CVD¹⁸⁸
- **Impact of the pandemic on access to services:** Like many healthcare services, the NHS in Northern Ireland has experienced considerable pressure during the COVID-19 pandemic. NHS waiting lists are at an all-time high, with 83.9% of patients now waiting longer than five weeks for a first outpatient appointment – well above the 50% target.¹⁸⁹ Additionally, hospitals routinely exceeded their capacity during the pandemic, largely due to an increase in non-COVID patients presenting for care.¹⁹⁰

Regional variation in cholesterol health

In divergence from the rest of the UK, Northern Ireland does not have an NHS-provided health and wellbeing check in place. The gap is filled by the voluntary sector, with 'Well Checks' provided by the Chest, Heart, and Stroke charity.¹⁹¹



Northern Ireland

Prevalence of CHD

Around 74,000 people are living with CHD in Northern Ireland, making it the most common type of CVD in the six counties.¹⁹² At the Health and Social Care Trust (HSCT) level, prevalence ranges from 33.66 per 1,000 people in Southern Health and Social Care Trust to 41.28 per 1,000 people in South Eastern HSCT (see *Figure 18*).

While the prevalence of CHD continues to fall across Northern Ireland, improvements have not been equally experienced by the population. In the ten-year period between 2010 and 2020, Belfast HSCT reduced the prevalence of CHD by 14%, while the reduction has been just 3% in South Eastern HSCT.¹¹⁴ Associations with deprivation are difficult to ascertain at the HSCT level.

Hospital admissions due to heart disease

Significant progress has been made in reducing the numbers of hospital admissions for circulatory diseases in Northern Ireland, with a 16% decline in hospital admissions in the years between 2010/11 and 2019/20.¹⁹⁶

At the HSCT level, the highest admission rate is in Northern HSCT (2094 per 100,000) and Southern HSCT (2093 per 100,000) and lowest in Belfast HSCT (1857 per 100,000, see *Figure 20*). Both Northern and Southern HSCTs are home to local government district areas with higher levels of deprivation, including Newry, Mourne and Down in Southern HSCT and Causeway Coast and Glens in Northern HSCT (see *Figure 19*). While Northern HSCT does also have higher prevalence rates (see *Figure 19*) this is not observed in Southern HSCT, and may point to disproportionately poor outcomes for people living with heart disease in more deprived areas.

As hospital admissions data are not broken down by the type of circulatory disease, it is difficult to assess the unique burden of individual conditions such as CHD on the healthcare system. The statistics currently cover a wide range of disparate conditions, and further information is needed to examine where improvements would be best targeted for the benefit of patients.

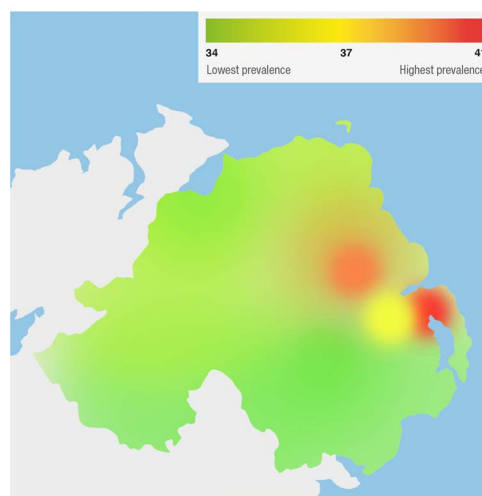


Figure 18: Prevalence of CHD per 1,000, by health board¹⁹³

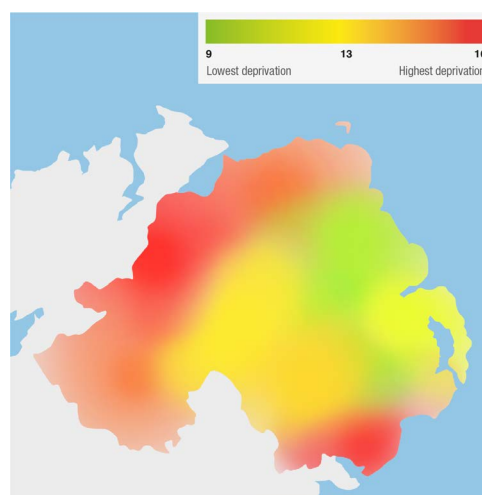


Figure 19: Proportion of the population living in households whose equivalised income is below 60 per cent of the NI median, by local government district (%)¹⁹⁴

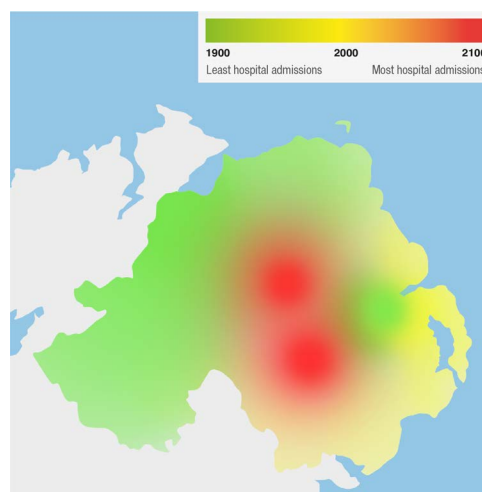


Figure 20: Standardised admissions rate for circulatory admissions, 2016-2018, per 100,000, by HSCT¹⁹⁵

Premature mortality from heart disease

Looking at the national level, CHD is one of the leading causes of death and biggest single cause of premature deaths in Northern Ireland, responsible for around 1,600 deaths each year.¹⁹⁸ Although deaths from heart and circulatory diseases more broadly have fallen significantly in recent decades, they have plateaued in recent years, especially in the case of under 75s, and are now beginning to increase, suggesting progress may be at risk. These diseases still cause a quarter of all deaths in Northern Ireland.¹⁹⁹

In Northern Ireland, between 2014 and 2018, the HSCTs with the lowest under 75 death rates for heart and circulatory diseases were South Eastern HSCT (62.9 per 100,000), and Northern HSCT (68 per 100,000, see Figure 21). These are areas with higher prevalence and admissions rates for circulatory disease, which may point to better access to diagnosis and treatment.

However, in Northern HSCT, which has an elderly population,²⁰⁰ deaths from heart and circulatory diseases may represent a bigger challenge in the over 75s population.

The HSCT with the highest under 75 death rate was Belfast HSCT with 90.3 per 100,000 – significantly higher than other HSCTs and the Northern Ireland average (71.9 per 100,000), even though this area has had lower CVD prevalence and admissions rates. The reasons behind this disparity in outcomes are not clear and may warrant further investigation.

As with admissions data, Northern Ireland Statistics and Research Agency (NISRA) may explore the possibility of breaking down mortality data by form of CVD, to better understand current challenges and opportunities for improvement, and where primary and secondary prevention interventions may be directed, especially for those more deprived populations.

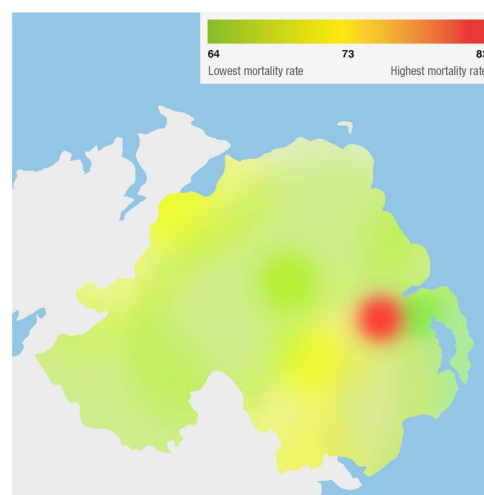


Figure 21: Standardised death rate for circulatory diseases in under 75s, per 100,000, 2014-2018, by HSCT¹⁹⁷

The burden of FH

In Northern Ireland, the number of people estimated to be living with FH per HSCT (calculated by HSCT population) ranges from 1,214 in Western HSCT to 1917 in Northern HSCT (see *Figure 22*). As Northern HSCT covers a large geographical area and is responsible for the largest population of the HSCTs, it is not unexpected that it has a high burden of FH. Western HSCT, meanwhile, has the smallest population of the HSCTs.

In Northern Ireland, lipid clinics appear to be reasonably well distributed (see *Figure 22*), with each HSCT having at least one lipid clinic. Considering their specialist nature, lipid clinics are often located in Northern Ireland's major hospitals such as Belfast City Hospital, the Royal Victoria Hospital (Belfast), Altnagelvin Hospital (Derry), Craigavon Area Hospital, and the Antrim Area Hospital. However, lipid clinics are also accessible in local community hospitals such as Ards Hospital (Newtownards) and Omagh Hospital.

For patients living in more remote areas with further distances to travel to their local lipid clinic, HSCTs should consider how they can build on existing provision for rural populations (for example, remote or peripatetic services and enhanced primary care services) to strengthen case-finding and management of people with FH.

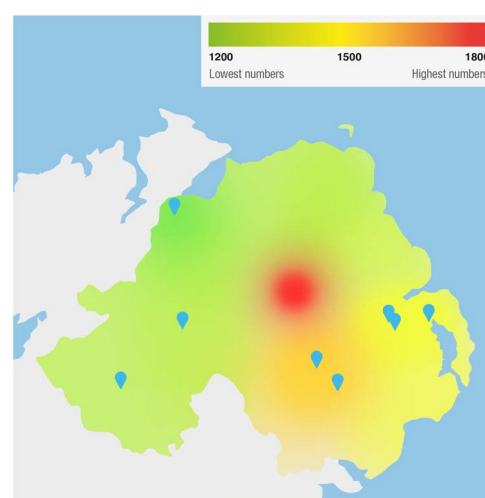


Figure 22: Estimated number of people living with FH by HST,²⁰¹ and location of lipid clinics²⁰²

 Location of lipid clinic





Improving the cholesterol pathway in Northern Ireland: key recommendations

- 1** The Northern Ireland Executive should consider commissioning a new national strategy to improve the prevention, detection, and management of CVD following the expiration of the 2014 Service Framework for Cardiovascular Health and Wellbeing²⁰³
- 2** Ahead of the 2022 Northern Ireland Assembly elections, the governing parties should consider committing to a new public health framework prior to the expiry of the 'Making Life Better' strategy in 2023, with tangible commitments to tackle inequalities in cholesterol health and factors which can increase the risk of poor cardiovascular health
- 3** The Northern Ireland Executive could consider reviewing the data it is collecting on all aspects of the nation's cardiovascular health, to ensure it is able to fully track and support patients at risk of developing CVD. Where data are not currently being collected – for example on cholesterol levels – the government should consider introducing, and incentivising where appropriate, collection, analysis and publication of additional metrics
- 4** Health and Social Care Trusts could consider taking steps to improve targeted primary and secondary prevention of CVD to support individuals living in more deprived communities to better manage their health, through lifestyle and medical interventions where necessary
- 5** Health and Social Care Trusts with more rural and/or older populations may consider how existing community-based outreach (such as satellite clinics in rural areas) can be utilised to make every contact count in encouraging patients to look after their cardiovascular health to support the prevention of CVD
- 6** Health and Social Care Trusts with higher admissions rates for circulatory admissions and responsible for more geographically disperse populations (such as Northern), should consider how remote and peripatetic services can be utilised to enhance detection and management of high cholesterol in the community
- 7** For patients living in more remote areas with further distances to travel to their local lipid clinic, Health and Social Care Trusts should consider how they can build on existing provision for rural populations (for example remote or peripatetic services and enhanced primary care services) to strengthen case-finding and management of people with FH

Conclusions: Raising the bar in cholesterol management across the UK

Every nation of the UK has made significant progress in tackling the burden of CVD since the 1960s. Mortality rates have been dramatically reduced and many people are supported to live well with CVD. But the fact remains that most CVD cases are preventable, and too many people in the UK are still living with and dying from CVD. CVD mortality has a particularly devastating impact on our most deprived communities, with a significant slowdown in progress in reducing overall CVD mortality since 2012.²⁰⁴

Uncontrolled high cholesterol plays a significant role in driving poor and disparate cardiovascular outcomes in the UK. However, evidence shows that high cholesterol can be easily detected and managed successfully through lifestyle and clinical interventions, providing the opportunity for meaningful and swift progress.

To deliver this, health systems across the UK must ensure that care pathways and data architecture enable proactive detection and treatment of high cholesterol, ensuring that all patients are supported to take care of their health.

While efforts to close the cholesterol gap should be taken forward independently by the four nations – and the health systems within them – there are some areas where UK-wide collaboration could further enhance action to tackle inequalities in cardiovascular health:

1

Health systems across the UK should consider sharing learnings on the collection and analysis of data on high cholesterol and other CVD risk factors. NHS England may consider collecting learnings from the development and roll-out of the CVDPREVENT audit in England,²⁰⁵ a model which Scotland, Wales and Northern Ireland could look to introduce and implement

2

The UK four health systems should consider convening a steering group to compare and share learnings on CVD health checks, and make recommendations so that communities across the UK have standardised access to these programmes, the digital and data infrastructure is in place to monitor progress, and the potential for these programmes to be highly cost-effective is maximised²⁰⁶

3

The four UK health systems should consider exploring opportunities to develop a UK-wide model for case-finding and diagnosing people with FH, sitting above national and local models, to support cascade screening beyond borders and provide extra resource in those areas where lipidology and genetic testing capacity is limited

As the pandemic eases and the NHS across the UK continues its recovery, questions will no doubt be asked on where greater resilience could have been built into the nation's health. By putting high cholesterol at the heart of action on health inequalities, reducing its avoidable morbidity and mortality burden, we can make huge gains in levelling up health outcomes between communities.

Further information and contact details

Daiichi Sankyo UK Ltd, working with HEART UK have produced this report and related materials. The project was initiated and funded by Daiichi Sankyo UK Ltd.

About HEART UK

HEART UK is the UK's only cholesterol charity, providing support, information and influencing services for families and health professionals.

About Daiichi Sankyo UK

Daiichi Sankyo UK Limited is a UK affiliate company with corporate origins in Japan. Daiichi Sankyo creates and supplies innovative products to help the NHS to deliver better patient care in the fields of cardiovascular disease and oncology.



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