DATA

HELPING US BEAT CHOLESTEROL

HEART UK
THE CHOLESTEROL CHARITY

THE ROLE OF RIGOROUS PRIMARY CARE DATA COLLECTION, MANAGEMENT AND ANALYSIS IN SUPPORTING CHOLESTEROL AND CVD PREVENTION AND MANAGEMENT

CONTENTS

FOREWORD

The collection, analysis and use of data have profoundly influenced the provision of healthcare, particularly so for those at risk or suffering from cardiovascular disease (CVD). As a practising cardiologist, and having past experience in clinical audit, I have seen first-hand how data can be used to identify and support people at risk of CVD, and to monitor clinical effectiveness and identify areas for improvement. In turn, the sharing of information derived from such data has delivered tangible improvements in service design, clinical pathways and patient outcomes.

The Five Year Forward View (2014) emphasised, amongst other things, the key importance of prevention in reducing future ill health, and the 'information revolution' which is required for a modern health service. Implementing these widely agreed ambitions will be challenging and requires all of us, healthcare professionals and the public, to see these as priorities and to support efforts being made to make them a reality.

It is true that data relevant to CVD prevention and management has historically been held in a number of places, collected by different software systems and often disconnected from one another. There is much to be gained from greater consistency in data collection, harmonisation of systems and linkage between databases. The efforts of Public Health England in supporting the National Cardiovascular Intelligence Network has been valuable, as is the considerable work being undertaken within NHS England to increase and better coordinate the availability and usefulness of data for clinical and commissioning purposes.

I welcome this report from HEART UK and its emphasis of the importance of data, and the challenges experienced in its collection and dissemination. If we are to be successful in preventing CVD, primary care and CCG commissioners need good data, and as an important risk factor information regarding cholesterol and lipid lowering interventions are key components of this. It will take a concerted effort from all those involved to ensure we take full advantage of the benefits associated with access to better information, but I am optimistic that with the support of organisations such as HEART UK, we will ultimately be successful.

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

EXECUTIVE SUMMARY

The potential of data to help support the integration of services, tackle inequalities, educate patients and deliver efficiencies has been widely recognised by the Government, NHS England (NHSE), Public Health England (PHE) and a range of other organisations operating within the NHS. These benefits include those offered to patients who suffer from cardiovascular disease (CVD) and raised cholesterol.

Key findings

CVD prevention and management programmes and initiatives require data to identify, target and support at risk patients.

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The data landscape for CVD is naturally complex.

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Recent changes to the QOF mean GPs will no longer be rewarded under the incentive scheme for reporting data on cholesterol levels in patients (with the exception of those with diabetes).

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We will not know until the end of 2015 the extent to which data are being reported against retired QOF indicators.

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93% of the GPs surveyed agreed or strongly agreed that consistent cholesterol and CVD data collection and management are important in helping to deliver better patient outcomes.

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There is a wealth of CVD data and information and one of the main challenges is coordinating these various data sources and ensuring the different organisations involved work together.

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Concern exists about variations in the flow and availability of data from NHS Health Checks and the way they are shared with primary care teams in CCGs.

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Findings from HEART UK's FOI audit demonstrated that many CCGs were unsure who holds the main responsibility for cholesterol data collection.

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Despite this, at a local level, there are some examples of positive steps being taken to overcome the issue of fragmented datasets and ensure data are reported back and shared.

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This report was developed by HEART UK following the removal of a number of CVD indicators from the Quality and Outcomes Framework (QOF) after concerns were raised about how data relating to CVD and cholesterol is being collected. The report aims to look at current data collection practices and what barriers exist in utilising data in driving improvements in CVD patient management.

As part of the research undertaken for this report, HEART UK spoke to a series of experts on the importance of rigorous data collection, management and analysis. Freedom of Information (FOI) submissions were sent to CCGs to investigate their data reporting requirements and habits in the absence of QOF, as well as Health Check data management. In addition, HEART UK conducted a survey of GPs to gauge how the QOF changes might impact their practice in relation to cholesterol.

RECOMMENDATIONS

Recommendations of this report:

1

HEART UK encourages researchers to bid for funding to use research databases to perform audits on CVD risk factors and on the NHS Health Checks Programme in order to provide better evidence on prevalence.

2

HEART UK calls for continued support for the National Cardiovascular Intelligence Network to give a more comprehensive picture of outcomes and health inequalities in CVD.

3

Data on CVD risk factors, including cholesterol levels, should be collected in a national patient register in order to drive better CVD prevention and risk management. This should include data on follow up interventions, e.g. if patients have been offered lifestyle advice, cholesterol lowering medication etc. HEART UK calls on the Department of Health to work with NICE to introduce QOF indicators incentivising the use of a CVD risk register.

4

In the absence of QOF incentives, CCGs should provide GPs with clear guidance and advice on the importance of recording and reporting cholesterol levels in at risk patients. GPs should be encouraged to continue to record data against previous QOF codes, despite the removal of financial incentives.

5

CCGs and GP practices should consider measures such as automatic prompts on GP clinical systems to ensure that cholesterol levels in at risk patients are routinely checked as per national clinical guidelines.

6

NHS England, Monitor and other organisations involved in the anticipated review of national incentives should consider developing a new framework to prompt and incentivise GPs to check cholesterol levels and blood pressure in at risk patients, and to record vital data.

7

PHE and the Health & Social Care Information Centre (HSCIC) should work collaboratively to develop a Data Standard to ensure consistent and accurate coding of information.

8

CCGs should encourage members to use NHS Health Check clinical templates or request IT providers to give them clinical templates if they have not got one, to ensure consistent data coding.

9

HEART UK wishes to see detailed, publicly available information on cholesterol by CCG and GP practice, including aggregate known cholesterol levels and data on numbers of patients tested per CCG.

10

Local Authorities need to work in partnership with the NHS (GP practices and CCGs) to develop integrated systems. These need to collect information on clinical follow up as well as Health Check uptake rates and identification of risk factors. The data should be routinely shared with local CCGs.

1

CVD PREVENTION AND THE ROLE OF DATA

The burden of CVD

Cardiovascular disease (CVD) refers to diseases of the heart or blood vessels. It includes coronary heart disease - the UK's biggest single killer. Despite significant improvements in the management and treatment of CVD over recent years, it remains responsible for over 160,000 deaths per year in the UK[1], and is one of the conditions most strongly associated with health inequalities.[2]

As well as the devastating impact CVD has on patients and their families, it also places major pressure on our health services and wider economy, costing the UK economy around £19 billion a year.[3]

Cholesterol as a risk factor

Raised cholesterol is one of the key risk factors for a number of different cardiovascular diseases, including coronary heart disease. While national guidance recommends that healthy adults should aim for a total cholesterol of 5 mmol/L or less, evidence shows that six out of ten adults in England have cholesterol levels at or above this level.[3]

For a proportion of the population (at least 1 in 500 people), high cholesterol can be as a result of an inherited condition, Familial Hypercholesterolemia (FH)[4]. In these cases, it is crucial that patients are diagnosed early and that family members are also tested. Cholesterol lowering medicines are required for FH patients to make sure that their levels are reduced as much as possible. There is currently a very poor diagnosis rate for FH in the UK, with 80-90% of some 120,000 patients undetected.[5,6]

Thanks to advances in interventions and treatments, raised cholesterol can be relatively easy to manage once diagnosed in both non-inherited and inherited cases. However, it is asymptomatic and too many people are unaware of their cholesterol levels and subsequent risk of CVD. Even when raised cholesterol is identified, its management can vary in different areas of the country. There are a number of prevention and management initiatives in place or in development to try and tackle

these variations, all of which rely on robust data in order to identify and target at risk patients.

Prioritising prevention

Prevention should be at the heart of any strategy to tackle CVD in the UK, and indeed at the heart of the entire NHS strategy.

In his Five Year Forward View for the health service, Simon Stevens, Chief Executive of the NHS, stated:

" The sustainability of the NHS, and the economic prosperity of Britain all now depend on a radical upgrade in prevention and public health."[7]

As mentioned above, raised cholesterol can be controlled and lowered in the majority of cases if managed appropriately, thereby lowering the risk of a major cardiac event. Some patients with elevated cholesterol may require medicines, but for others adopting a healthier lifestyle, increasing their exercise and improving their diet can naturally reduce their cholesterol levels.

There have been a range of initiatives over the past decade aimed at raising awareness of the dangers of poor lifestyle choices and the measures that can be taken to address these. Of these, HEART UK considers the NHS Health Check Programme, first introduced in 2009, to be one of the most exciting and important developments, representing a major step forward in adopting a preventative approach to CVD.

NHS Health Checks, offered to men and women aged 40-74 on a five yearly basis, have the potential to positively impact long term health, preventing heart disease, stroke, diabetes, kidney disease and certain types of dementia. HEART UK firmly believes that the Health Checks can engage the public in health prevention by identifying potential risk factors for CVD and providing individuals with information and support to reduce their risk of CVD through behavioural changes and/or medical treatment where necessary.

" Access to robust data is quite simply one of the most crucial enablers of improvement of care. It provides an understanding of what good looks like, and allows us to make comparisons. However, often data sits with board level staff, but it is essential that this data is fed back to front line clinical teams who can drive real improvements"[8]

Professor Geraldine Strathdee, National Clinical Director for Mental Health, NHS England

Role of data

CVD prevention and management programmes and initiatives require data to identify, target and support at risk patients. Access to and the reporting of quality data across the NHS in general has the potential to significantly improve patient care and outcomes.

This is recognised and promoted by the Government, NHSE, PHE and a range of other organisations operating within the NHS. The Government's 2012 information strategy, The power of information: Putting all of us in control of the health and care information we need, set out the potential for data to drive integration of care, reduce inequalities, improve transparency, empower patients and increase efficiencies within the system.[9]

The strategy states: "Information can bring enormous benefits. It is the lifeblood of good health and wellbeing, and is pivotal to good quality care. It allows us to understand how to improve our own and our family's health, to know what our care and treatment choices are and to assess for ourselves the quality of services and support available. [....] Information also allows professionals to understand the needs of the population they serve, how well different services and treatments work, and the needs and health history of the people they treat."[9]

NHS has advocated this focus on high quality data to drive more informed decision making around patient care and treatment. From a national perspective, this means transparency in performance data can shape commissioning decisions and payment mechanisms, ensuring there are correct incentives in place to improve models of care. For individual patients, it means they can make a choice of where to receive care and treatment based on outcomes.

The most recent national effort to drive forward the information agenda was the launch and attempted rollout of the care.data initiative, the aim of which was to link all GP and hospital records into one central database to provide a nationwide overview of the care received by individuals. However, care.data came under intense public criticism due to a lack of confidence in how the data would be shared and concerns about companies using patient data for commercial gain. NHSE has since announced that the roll out of care.data would be delayed.[10]

The experience of care.data has highlighted the need to better communicate the rigorous safe guards that must be in place to support any data collection as well as address public concern over how data will be used.

In terms of CVD data, there has been considerable improvement over the past decade with numerous audits and registries providing high quality data on individual aspects of CVD. Robust data collection, analysis and feedback are valuable at virtually every level of patient management, for a range of reasons:

— Helping commissioners to make the best decisions possible for local health populations, and to justify and rationalise spending decisions

— Enabling comparisons and benchmarking between providers, which in turn leads to service changes and improved standards. For example, unwarranted variation in outcomes and practice can be spotted early and addressed

— Providing national and local policy makers with evidence to drive policy decisions, including those underpinning public awareness campaigns and service configuration

— Coordinating patient management between public health teams in local authorities and primary and secondary care, ensuring patients are identified and appropriately referred/ managed according to risk

— Providing feedback to public health and clinical teams about their practice and outcomes, thus driving up standards by peer pressure

— Equipping patients with information to make informed choices around the care they receive

— Enabling a wide range of research

— Driving essential third sector analysis, activity and engagement

— Drawing international comparisons

— Ensuring robust regulation
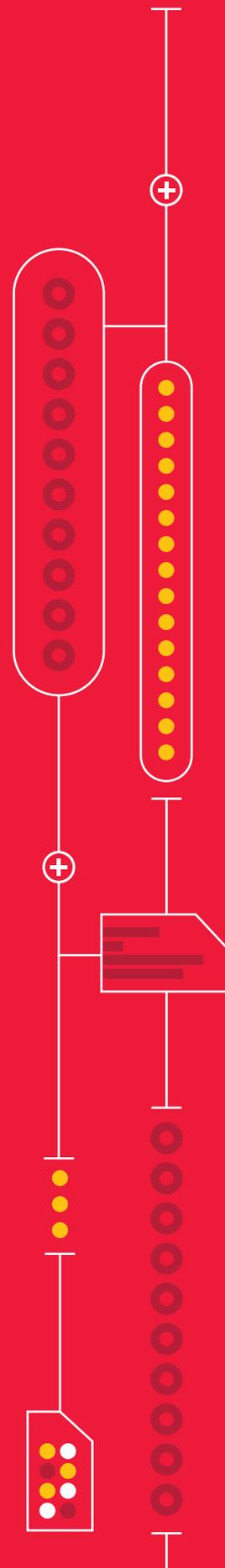
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DIFFERENT CVD DATA SOURCES AND WAYS THEY ARE USED

There are now a wide variety of CVD data sources, tools and initiatives available in the UK for healthcare professionals, commissioners, policy makers and members of the public to use. PHE and the HSCIC both play important roles in collating and analysing data on health protection and health improvement.

Coordination of data collection

The data landscape for CVD is naturally complex, ranging from NHS Health Check data relating to CVD risk factors, primary care data recorded through the QOF, hospital episode statistics and national clinical audits among many others.

In working to bring these sources together, the CVD community can learn from cancer intelligence in the UK. Cancer registration has become a sophisticated model of population-based data collection and analysis, coordinated originally by eight independent regional cancer registries and, since 2013, by the National Cancer Registration Service (NCRS). The National Cancer Intelligence Network (NCIN), run by PHE, manages the analysis and clinical interpretation of these data.

HEART UK campaigned for the introduction of a similar umbrella organisation for CVD and was delighted with the announcement in the 2013 CVD Outcomes Strategy that there would be a new National Cardiovascular Intelligence Network (NCVIN). Like the NCIN, it is a PHE-hosted organisation made up of epidemiologists, analysts, clinicians and patient representatives – including HEART UK as a member of the NCVIN Partnership Board.

The NCVIN brings together disparate data sources into one place, linking them to other routinely available datasets and analysing them, with the aim of providing meaningful and timely CVD intelligence. The network has produced a number of tools, which are continuously updated when fresh evidence becomes available, to guide and inform commissioning decisions. In order to do this, the NCVIN relies of having access to accurate data sets. On the following pages are examples of data collection for CVD and cholesterol.

Quality and Outcomes Framework (QOF)

What is it?

An annual voluntary incentive programme for all GP surgeries in England. Introduced in 2004 as part of the GP contract, the QOF rewards GP practices financially depending on their achievements against specific indicators.

Who produces it?

NICE develops a menu of QOF indicators for inclusion in the scheme year on year. NHSE and the devolved administrations of Northern Ireland, Scotland and Wales use the NICE QOF menu to help decide which indicators are included in the QOF within their countries. This happens through a negotiation process. In England, this is between NHS Employers on behalf of NHSE, and the General Practitioners Committee on behalf of the British Medical Association. The HSCIC works with NICE to develop and test potential new indicators, develop technical specifications and business rules for new indicators, and collate and publish annual datasets of results.

What is it used for?

Incentivising and rewarding GPs for:

— managing some of the most common chronic diseases
— implementing preventative measures
— offering extra services
— providing a high quality service
— complying with the minimum time a GP should spend with each patient at each appointment.

Not only does QOF serve to incentivise and prompt GPs to take action in certain areas, but it provides a valuable dataset detailing practice achievement results against specific indicators. These datasets provide comprehensive information on the pattern of common chronic diseases, including the performance of primary care and variations between practices.

Does it cover cholesterol?

Until 2013/2014, there were six indicators relating to cholesterol. Of these, five were withdrawn in 2014, meaning that the current QOF only rewards GPs for measuring cholesterol levels in patients with diabetes. Of particular concern to HEART UK was the removal of the secondary prevention indicator CHD003: The percentage of patients with coronary heart disease whose last measured total cholesterol (measured in the preceding 12 months) is 5 mmol/l or less.

What were the benefits?

Research in 2010 found that GP practices who better met evidence-based quality targets related to CVD and risk factor management had lower hospital admission and death rates from CHD.[11]
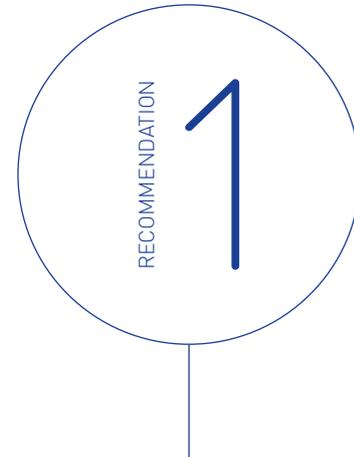
RECOMMENDATION

1

HEART UK encourages researchers to bid for funding to use research databases to perform audits on CVD risk factors and on the NHS Health Checks Programme in order to provide better evidence on prevalence.

Other data sets

As well as QOF, there are other databases available which maximise the way anonymised NHS clinical data can be linked to enable many types of observational research. For example, the Clinical Practice Research Datalink (CPRD) is an interventional research service, jointly funded by the NHS National Institute for Health Research (NIHR) and the Medicines and Healthcare products Regulatory Agency (MHRA). Another such tool is The Health Improvement Network (THIN) database which contains the electronic medical records of 11.1 million patients. THIN is a collaboration between two companies; In Practice Systems (INPS) and IMS Health and is again used for research purposes.

National Diabetes Audit (NDA)

What is it?
The largest annual clinical audit in the world[12], integrating data from both primary and secondary care sources. It measures the effectiveness of diabetes healthcare against NICE Clinical Guidelines and Quality Standards in England and Wales. The NDA collects and analyses data for use by a range of stakeholders to drive changes and improvements in the quality of services and health outcomes for people with diabetes.

Who manages it?
It is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit Programme (NCA) and delivered by the Health and Social Care Information Centre in partnership with Diabetes UK and the NCVIN. The NDA receives expert input from clinicians and people with diabetes across England and Wales.

What is it used for?
Assessing local practice against the National Service Framework for diabetes and NICE guidelines, and driving service improvement. It provides comparisons between different NHS organisations, identifying and sharing best practice, and highlighting gaps or shortfalls in commissioning services. Through participation in the audit, local services are able to benchmark their performance and identify where they are performing well, and improve the quality of treatment and care they provide.

On a national level, wide participation in the audit also provides an overview of the quality of care being provided in England and Wales and serves to inform diabetes policy and guidelines, including NICE guidance, clinical pathways and indicators within the Clinical Commissioning Group Outcomes Indicator Set (CCGOIS). Finally, patient groups and healthcare professionals use the data to raise awareness amongst national and local decision-makers, patients and the general public.

What data sources are used?
Data are extracted from routinely recorded GP practice and specialist electronic patient records and held by the HSCIC. Supplementary information relating to specific complications and procedures is sourced and linked within the HSCIC. Currently this is predominantly from the Hospital Episodes database and Patient Episode Database for Wales (PEDW) and the Medical Research Information Service (MRIS) - Mortality data. HSCIC in partnership with NCVIN provide analysis.

Does it cover cholesterol?
Yes, it publishes the percentage of diabetes patients by type in England and Wales meeting the treatment target for cholesterol levels.

Communicating data

These types of datasets inform clinical decision-making, commissioning strategies, national and local policy making and patient choice. However, these datasets are only meaningful if the data can be extracted and effectively communicated. The NCVIN strives to bring the different datasets together and provide additional analysis and recommendations/toolkits off the back of the raw data. A notable example of this includes:

Commissioning for Value packs

What are they?
Evidence packs for local commissioners showing them what they need to change to drive improvements in outcomes, quality and efficiency. They pull together key data on CVD prevention, prevalence, primary care, secondary care and social care to show local performance and highlight variations.

Who produces them?
Commissioning for Value is a collaboration between NHS Right Care, NHSE and PHE. For CVD, the NCVIN publishes Commissioning for Value (CfV) focus packs for each CCG.

What are they used for?
Identifying priority programmes which offer the best opportunities to improve healthcare for specific local populations. NHS Right Care can then, if required, begin to work directly with CCGs to develop improvement plans. The NCVIN can also provide additional practice level slide sets to allow CCGs to better understand practice variation in their area.

What datasets are used to create them?
Specific indicators are set in order to draw conclusions and trends. These are based on a range of sources, including for example:

— Quality and Outcomes Framework (QOF)
— Health Survey for England
— Population estimates, Office for National Statistics (ONS)
— Hospital Episode Statistics (HES)

Do they cover cholesterol?
When first produced, HEART UK was pleased to see information in the packs on primary care cholesterol management and how that particular CCG compared to benchmark. This analysis was based on data collected through cholesterol indicators in the 2013/14 QOF.

RECOMMENDATION

2

HEART UK calls for continued support for the National Cardiovascular Intelligence Network to give a more comprehensive picture of outcomes and health inequalities in CVD.

"We have received great feedback from the Commissioning for Value packs and understand they are being widely used by local commissioners. They are developed by pulling together a range of different data, including QOF datasets which have proved to be a rich source of primary care information across different CVD risk factors. Following the removal of a number of CVD-relevant indicators from the QOF, we launched a work programme to identify other ways of extracting primary care data and ensuring vital information is not lost."[13]

Lorraine Oldridge, Associate Director, National Cardiovascular and Health Intelligence Network. www.ncvin.org.uk

Through 2014 and 2015, the NCVIN has also run a series of well-attended master classes in collaboration with Strategic Clinical Networks (SCNs) for health professionals to increase their understanding of CVD data and information, and develop skills and knowledge to improve investigative work, planning and quality performance monitoring.

Sally Crick, Network Manager at the NCVIN and Information Specialist from PHE explains the benefits of the CVD data masterclass programme:

" The NCVIN Masterclass Programme aims to provide practical support with report interpretation, increase understanding of the data intelligence available across the cardiovascular family of diseases and ensure that this translates into quality improvement.

The masterclasses allow delegates to explore data, tools and information in a number of short, self-selected practical sessions run by experts in their field. The emphasis is on active learning and discussion in small groups to increase understanding of CVD intelligence and thinking about how it can be applied in everyday planning and practice. The session also offers an opportunity to investigate local data and identify where there is variation from the picture for England and/or relevant comparators.

Delegates can learn about information available from our cardiovascular network partners including the National Diabetes Audit, the National Institute of Cardiovascular Outcomes Research (NICOR), the Sentinel Stroke National Audit Programme (SSNAP), The UK Renal Registry, Commissioning for Value and the NHS Health Check and blood pressure programme. Tools including the Cardiovascular disease profiles, CVD intelligence pack, prevalence models and Cardiovascular outcomes vs expenditure tool are also highlighted.

The masterclasses are being delivered around England in partnership with NHS England's Strategic Clinical Networks. Details of forthcoming masterclasses are available here: www.ncvin.org.uk."[14]

Cause for concern

Despite the number of datasets and tools currently available in the UK, HEART UK is concerned about future of CVD data.

The completeness of these datasets is currently under threat with the retirement of a number of cholesterol QOF indicators. Furthermore, there continue to be variations in the flow and availability of data.

The following chapters look at these issues in more detail and include a series of recommendations to help address there concerns.

3

INCENTIVES FOR PRIMARY CARE CHOLESTEROL MANAGEMENT

De-prioritising cholesterol through the QOF

As set out in the previous chapter, recent changes to the QOF mean GPs will no longer be rewarded under the incentive scheme for reporting data on cholesterol levels in patients (with the exception of those with diabetes). This is because five out of a previous six cholesterol indicators have been removed from the QOF.

Removed cholesterol indicators in 2014:

— **CHD003:** The percentage of patients with coronary heart disease whose last measured total cholesterol (measured in the preceding 12 months) is 5 mmol/l or less

— **PAD003:** The percentage of patients with peripheral arterial disease in whom the last measured total cholesterol (measured in the preceding 12 months) is 5 mmol/l or less

— **STIA004:** The percentage of patients with stroke or TIA who have a record of total cholesterol in the preceding 12 months

— **STIA005:** The percentage of patients with a stroke shown to be non-haemorrhagic or a history of TIA whose last measured total cholesterol (measured in the preceding 12 months) is 5 mmol/l or less

— **MH004:** The percentage of patients aged 40 or over with schizophrenia, bipolar affective disorder or other psychoses who have a record of total cholesterol in the preceding 12 months.

Remaining cholesterol indicator for 2014/15

— **DM004:** The percentage of patients with diabetes, on the register, whose last measured total cholesterol (measured within the preceding 12 months) is 5 mmol/l or less

Jules Payne, Chief Executive of HEART UK, explains the charity's reaction to the removal of cholesterol indicators from the QOF:

" HEART UK understands that QOF is overly bureaucratic and in need of reform. However, we are concerned that the one remaining cholesterol indicator only covers patients with diabetes. This is an important group, but QOF has lost five indicators covering people with stroke, CHD, peripheral arterial disease and mental health problems, where cholesterol may be a significant risk factor without concurrent diabetes.

The revised QOF places no importance on cholesterol, which is at odds with best clinical practice.

As a charity we have worked tirelessly to raise awareness amongst policy makers, clinicians, commissioners and the public of the importance of cholesterol as a major risk factor of CVD. Cholesterol is asymptomatic and, in our view, too often the forgotten risk factor which is swept under the carpet.

Raised cholesterol is relatively easy to control and lower if properly managed. Public health and primary care teams therefore play an essential role in driving CVD prevention by helping to identify at risk patients and support them to manage their cholesterol levels accordingly.

HEART UK feels the removal of primary care incentives for cholesterol management sends out the worrying message that cholesterol is simply not a priority and that the public do not need to be concerned about their cholesterol levels."

RECOMMENDATION

3

Data on CVD risk factors, including cholesterol levels, should be collected in a national patient register in order to drive better CVD prevention and risk management. This should include data on follow up interventions, e.g. if patients have been offered lifestyle advice, cholesterol lowering medication etc. HEART UK calls on the Department of Health to work with NICE to introduce QOF indicators incentivising the use of a CVD risk register.

HEART UK is not the only patient group to express concern around the removal of indicators.

"The Stroke Association is concerned at the removal of stroke related QOF indicators, particularly those around atrial fibrillation and high blood pressure."[15]

Jon Barrick, Chief Executive of the Stroke Association

" Public Health England report that in ten years, 7,000 years of life could be saved and £120m not spent on related health and social care if we achieve an improvement in the diagnosis of high blood pressure. The proportion of English adults aware of their high blood pressure remains at least 10% behind detection levels in the US and 15% behind those in Canada, suggesting a further improvement is possible.

Blood Pressure UK is concerned that the weakening of blood pressure and important public health indicators undermines the importance of preventing, detecting and managing high blood pressure. Regular checks, consistent data collection and lifestyle advice on how to lower your blood pressure naturally – thus avoiding the progression to hypertension and costly medication - are elements we have worked so hard to promote over recent years. It gives the wrong message to public health and primary care teams, not to mention to the public."[16]

Katharine Jenner, Chief Executive of Blood Pressure UK

In the previous chapter, we provided examples of the data sources used to develop commissioning plans and toolkits. Organisations and individuals working in CVD relied on QOF data to provide a picture of how cholesterol was being managed in primary care at both a national and local level, enabling benchmarking between regions and practices. HEART UK believes that we need to take data capture one step further by routinely recording information on CVD risk factors in a national register. In the potential absence of robust QOF datasets for cholesterol and other CVD risk factors, the need for this is even greater.

The primary route for bringing in such a register would be to incentivise it through the QOF. Alternatively, it could be added within the GP contract as part of a fixed sum of money or separately as a Direct Enhanced Service (DES).

Katherine Thompson, NHS Health Check National Programme Manager, PHE shares HEART UK's views on the need for a national risk register:

" Currently, the number of people at risk of CVD is not recorded through primary care. The routine collection of this data through a national register would provide an extremely valuable source of information on prevalence."[17]

Assessment of potential impact of withdrawal of cholesterol indicators from QOF

HEART UK, along with other organisations and individuals, have put in a number of requests to NHSE and the Department of Health for clarity on how cholesterol management would be prompted and incentivised at primary care level, and how cholesterol data would be captured following the removal of QOF indicators – in particular relating to the coronary heart disease indicator, CHD003. We were repeatedly assured that "GPs will still input data if clinically appropriate for those patients where they would have for CHD003 and other CHD indicators"[18] and "The removal of these indicators does not mean that GPs should stop monitoring patients' cholesterol."[19]

Whilst no formal measure has currently been made public, NHSE are in the process of developing the specifications and reporting protocols that will be required to capture the information provided by the retired indicators. As these indicators are no longer part of the main QOF, they are required to create a new extraction programme which will not publish their captured data against the retired indicators until the end of 2015.

However, the QOF results from 2013/14, the year when the removal of cholesterol indicators was announced but before it came into force, show a decrease in achievement of those indicators compared with the previous year. The HSCIC analysis report stated: "Achievement for this group of indicators has also decreased. This is likely due to indicator changes in the last year."[21] For the group of CHD indicators, there was an overall achievement rate of 93.12 per cent of GP practices in 2013/14, which represented a 5.2 per cent drop in achievement compared

with the previous year, when 98.22 per cent of practices met the target.[21] This drop in achievement after the changes were announced but before they were even implemented does not bode well for cholesterol management now the incentives have been removed.
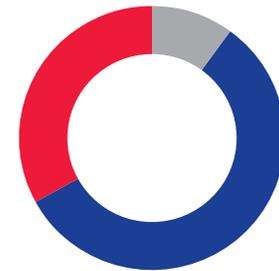
As we will not know until the end of 2015 the extent to which data are still being reported against the now retired QOF indicators, HEART UK conducted a survey of GPs to gauge how the QOF changes might impact their practice in relation to cholesterol.

Our survey found clear consensus within the GP community that consistent cholesterol and CVD data collection and management are important in helping to deliver better patient outcomes. Of the 211 GPs asked about this viewpoint, 93 per cent agreed or strongly agreed with it.

In relation to how changes to the QOF are affecting GP practice, we asked GPs to what extent they are continuing to check cholesterol levels for patients in those groups for which QOF indicators have been retired - peripheral arterial disease, CHD, stroke, transient ischaemic attack, schizophrenia, bipolar affective disorder and other psychoses. Fifty seven per cent of responses (121 GPs) said they always do this, while the remainder do it fairly often or only sometimes.

As the chart on the right shows, there is variation in the importance and prioritisation different GPs place on checking cholesterol. HEART UK is concerned that, without measurable targets such as those within the QOF, cholesterol management and data collection have become more selective.

Proportion of GP's continuing to check cholesterol levels

● 57% Always
● 33% Fairly often
● 10% Sometimes

In the absence of QOF incentives, CCGs should provide GPs with clear guidance and advice on the importance of recording and reporting cholesterol levels in at risk patients. GPs should be encouraged to continue to record data against previous QOF codes, despite the removal of financial incentives.

RECOMMENDATION 4

CCGs and GP practices should consider measures such as automatic prompts on GP clinical systems to ensure that cholesterol levels in at risk patients are routinely checked as per national clinical guidelines.

RECOMMENDATION 5

NHS England, Monitor and other organisations involved in the anticipated review of national incentives should consider developing a new framework to prompt and incentivise GPs to check cholesterol levels and blood pressure in at risk patients, and to record vital data.

RECOMMENDATION 6

Katharine Jenner, Chief Executive of Blood Pressure UK shares HEART UK's concerns about this issue, and likens the survey results to feedback her charity has received from clinicians regarding the withdrawal of blood pressure indicators from the QOF:

" Comments from the clinicians we have spoken to certainly give the impression that data collection may become more haphazard. We know some GPs are very interested in this and good at it, but without prompts and incentives in place, we can't be certain it will remain a priority. This can have a big impact of patient management and outcomes."

Learnings from Canada strongly suggest we need more frequent opportunistic testing not only by general practitioners, but wider staff groups, to have the widest possible reach, and to be able to follow up with those at highest risk. This requires strong leadership and commitment at every level, which is not reflected in QOF."[16]

Despite NHSE assurances that GPs will continue to measure cholesterol levels in at risk patients, only seven per cent of GPs surveyed by HEART UK had received advice, prompts or encouragement from their GP practice, CCG or PHE about continuing to record and report cholesterol data following the withdrawal of indicators.

As well as the GP survey, HEART UK simultaneously conducted a FOI request of all CCGs in England. One of the questions built on this issue of encouraging GPs to keep prioritising cholesterol by asking CCGs for details of any guidance provided to GP practices about continuing to record data.

Of all the 148 CCGs who responded to this FOI question (out of 211 CCGs across England), just four replied saying they had issued specific guidance or taken measures to ensure continued recording and reporting of cholesterol levels in at risk patients. These were Central London, Liverpool, Salford and South Tyneside.

We will have to wait until the data are extracted at the end of 2015 to fully understand whether there has been a drop in cholesterol prioritisation at primary care level, but it would appear that there is a disconnect between the national perception that good clinical practice will prevail and the local responses from GPs and CCGs who seem to be doing little to ensure continued prioritisation.

HEART UK also spoke to Dr Angela Moulson, a GP from Bradford, who talked through the issues around QOF indicator removal and also some of the measures taken in her local area to address the problem:

" I was very worried by the withdrawal of the cholesterol indicators from the QOF, particularly that which covers patients who suffer from severe mental illnesses (SMI). As a result there is a risk that these specific patients will not have CVD risk measured so perpetuating their shocking mortality rates because it removes the prompts and tools to check patients and collect data easily - GPs just want a dead easy template linked to good reports.

QOF is a national system so everything is standardised. With the removal of QOF indicators, data collection regarding cholesterol will be reliant on individual practice systems. As such, data collection across the country will vary on how practices do their own audits."[22]

Case study

Bradford Districts CCG's "Bradford's Healthy Hearts" campaign

Bradford's Healthy Hearts is aimed at reducing the risk of stroke and heart attack for people in risk groups. The campaign brings together all 41 of the CCG's GP practices and the wider NHS with one aim: to reduce the risk of stroke and heart attack. The three-year campaign targets: vascular disease, atrial fibrillation (AF) and heart failure.

The first phase of the campaign's development – which began in October 2014 - aims to improve the care of people with vascular disease. Using QOF data, practices have identified patients who are being prescribed statins and those patients have been given a more effective statin which reduces the risk of stroke or heart attack. Clinicians are also paying particular attention to ensuring optimum cholesterol and blood pressure levels for those at risk, which they are able to do.

To ensure that the campaign has maximum effect, GPs and hospital consultants are working closely together to ensure patients get seamless treatment, whether in hospital or at home. By analysing population QOF data, clinicians are detecting of people with a high risk of developing future heart conditions.

4

BETTER COORDINATION, FLOW AND USABILITY OF DATA

Disconnect and fragmentation

Across the patient care pathway for CVD, from prevention through to management and treatment, there is a wealth of data and information collected at different stages. One of the main challenges to effective data management is coordinating these various data sources and ensuring the different organisations involved work together.

" There are issues around different data systems which cannot 'talk to each other'. The GP extraction system (GPES) has been slow to take off but is progressing. However, the removal of some QOF indicators now risks leaving gaps in the data. We need access to real time data in primary care systems but the concerns about care.data have not helped to progress this – our work is hampered by restrictions to data flow and availability."[23]

John Battersby, Consultant in Public Health, PHE Knowledge and Intelligence Team East

NHS Health Check data flow

An area that needs careful collaboration in the field of public health and prevention is the sharing of information between Local Authorities and CCGs. Since 2013, public health teams and directors of public health have been part of Local Authorities from where they commission public health services, including the NHS Health Checks. While HEART UK is a strong advocate of the NHS Health Checks Programme and the benefits it can bring to patients by detecting CVD risk factors early, there is some concern about variations in the flow and availability of data from the checks and the way they are shared with primary care teams in CCGs. The risk is that this leads to inconsistencies in the way patients are managed following their Health Check.

There are three core data flows around the NHS Health Checks Programme: identification and invitation of eligible population; data transfer back to GP practices; and anonymised data extract from GP practices.

HEART UK understands that the main challenge around information flow is variation in the way data are recorded and the type of information gathered, not only between CCGs and local authorities, but also within them. In terms of primary care data generally, there are three major issues affecting consistency:

Too many read codes: There are numerous different codes against which patient data are recorded. This means practices are not recording information in a standard or consistent way. Too many codes mean there are too many choices and the information is diluted. When extracting the data, it is difficult to get a full picture.

Different IT systems: GP practices commission services from different IT system providers which again cause issues of consistency.

Users inputting data differently: If not using a standard template, Health Check practitioners do not necessarily pick the right codes.

HEART UK welcomes the fact that a proportion of Health Checks are currently delivered away from the GP

practice and in the community, e.g. in pharmacies, gyms, supermarkets, parks etc. This is a positive trend because, in general, offering checks from diverse and innovative locations increases the chance of engaging people from hard-to-reach groups who may be less willing to attend their GP practices for an appointment. However, there can be issues in the way data are reported back to GP practices. Some areas have commissioned sophisticated IT systems which automatically send information to the practices so it is uploaded to patient records, but others use more crude methods, such as faxing the results or sending an email attachment from where it is inputted manually. From there, the data may remain in attachment form rather than being correctly inputted, meaning cholesterol levels/blood pressure results do not always make it onto patient records.

For NHS Health Checks, where there is now a standard set of read codes, the onus needs to be on encouraging practitioners to use them.

RECOMMENDATION 7

PHE and the HSCIC should work collaboratively to develop a Data Standard to ensure consistent and accurate coding of information.

RECOMMENDATION 8

CCGs should encourage members to use NHS Health Check clinical templates or request IT providers to give them clinical templates if they have not got one, to ensure consistent data coding.

HEART UK used its FOI study of all CCGs in England to find out how much CCGs know about their respective populations' cholesterol health. The findings demonstrated that many CCGs were unsure who holds the main responsibility for cholesterol data collection, with most referring us on to different organisations. CCGs were asked if they could identify the number of patients identified as having elevated cholesterol levels, and to provide figures for the latest available twelve month period. Of the 146 CCGs who provided answers to this question, only 20 could provide the figures:

Responses of 146 CCGs	Number	Percentage
CCG does not hold the information	126	86%
Of those not able to provide the information, some:		
— Referred us to NHS England	41	28%
— Referred us to GP practices	11	8%
— Referred us to HSCIC	7	5%
— Referred us to Local authority	5	3%
CCG able to provide the number of patients identified	20	14%

This reinforces HEART UK's second recommendation, that we urgently need a standardised CVD risk register. It would allow primary care practitioners to input data on CVD risk quickly and simply, helping to ensure consistency across the country. CCGs and Local Authorities need to have easy access to data showing patients at risk of CVD to help them plan and commission services.

CCGs were also asked if they could identify the number of patients who were referred for further support/care services following identification of elevated cholesterol levels during the NHS Health Check. The responses were again varied by nature with just 8 out of 166 CCGs which responded able to provide us with the figures:

Responses of 146 CCGs	Number	Percentage
CCG does not hold the information	139	84%
Of those not able to provide the information, some:		
— Referred us to NHS England	33	20%
— Referred us to PHE	3	2%
— Referred us to GP practices	7	4%
— Referred us to HSCIC	2	1%
— Referred us to Local authority	25	15%
CCG does not hold the information currently but will do so later in the year (2015)	2	1%
CCG can access data on referrals but extraction system does not enable them to identify if they came via NHS Health Check	17	10%
CCGs able to provide the number of patients identified	8	5%

These results suggest confusion from CCGs about the way the NHS Health Checks Programme is run. There are also significant differences in the type of data collected and reported back locally.

Katherine Thompson, NHS Health Check National Programme Manager from PHE explains:

" At a local level there is wide variation in the NHS Health Check data returned by providers to local commissioners. All return the data needed for national reporting to PHE – the number of people offered and having a check. Some commissioners also receive much more detailed data that helps them to understand who is accessing local checks and their health status. Where local authorities receive more information, it tends to be categorical aggregated rather than individual level data. This provides a good picture of local activity within the information governance framework that local authorities need to work within.

Some areas do collect information on referrals following a NHS Health Check, for example to weight management services, smoking cessation services etc. and have developed local systems to enable the collection and reporting of this data."[17]

RECOMMENDATION

9

HEART UK wishes to see detailed publicly available information on cholesterol by CCG and GP practice, including aggregate known cholesterol levels and data on numbers of patients tested per CCG.

RECOMMENDATION

10

Local Authorities need to work in partnership with the NHS (GP practices and CCGs) to develop integrated systems. These need to collect information on clinical follow up as well as Health Check uptake rates and identification of risk factors. The data should be routinely shared with local CCGs.

LOOKING AHEAD

As we look ahead to the future, HEART UK is pragmatic and realistic what progress we can hope for in what is a complex and broad agenda. The primary focus should continue to be on helping ensure the right infrastructure is ready and in place, at both a national and local level, to support data collection and sharing. By also driving local responsibility, making sure different data sources link and ensuring there are clear pathways in place there is the potential to drive significant improvement in cholesterol patient management.

Speaking to Jamie Waterall, PHE lead on Health Checks, he summarised:

" Tremendous opportunities exist through the enhanced utilisation of data and digital to improve the quality and outcomes for patients. PHE is committed to exploring and working with partners to ensure that we capitalise on these opportunities and embrace the digital and data revolution."[24]

Local Case study

At a local level, there are some examples of positive steps being taken to overcome the issue of fragmented datasets and ensure data are reported back and shared in a way that ultimately drives clinical improvements.

Teresa Edmans, Programme Manager of the NHS Health Check Programme in Southwark has been involved in shaping and implementation of an integrated data system called Health Check Focus, which has helped Southwark achieve a 66% completion rate during 2014-15 for Health Checks (compared to the 49% national average) in only two and a half year.

" Southwark contracted QMS to develop a clinical and online integrated data system populated with restricted patient data securely exported from local GP practices. It enables our Outreach Nurses carrying out Health Checks in local parks and pharmacies to know if a patient is eligible for a Health Check and for completed Health Check report to be returned to the GP practice to be incorporated into the patients notes. Health Check Focus is also use to carry out a centralised call and recall processes, taking the pressure off practices and providing a consistent approach.

The system is able to produce a wide range of reports which allows us to monitor and analyse uptake and performance as well as case finding. This had meant that we are able to identify where we might need to make changes to the programme, such as reaching those most in need of a check, tailoring the interventions offered to those identified as being as risk or ensuring appropriate follow up is given.

We have since developed the system to interface with the programmes Healthy Lifestyles Hub, were people post Health Check can be directly referred for additional lifestyles support.

Health Check Focus has allowed us to create a system where we are able to feed in data to health and social care services, which is turn helps inform planning for service development and future demand."[25]

GLOSSARY

CCG
Clinical Commissioning Group, 'CCGs are organisations responsible for implementing the commissioning or 'buying' of health and care services to provide local health services in England.'

CVD
Cardio Vascular Disease, 'This refers to conditions that can lead to a heart attack, angina or stroke.'

DES
Direct Enhanced Services, 'These are services that are a) not provided through essential or additional services such as more specialised services undertaken by GPs or b) essential or additional services delivered to a higher specified standard such as extended minor surgery.'

FH
Familial hypercholesterolemia, 'a specific type of inherited high cholesterol that runs in the family.'

FOI
Freedom of information Requests, 'These are requests to provide information held by any public authorities in the UK.'

HES
Hospital Episode Statistics, 'HES is a data warehouse containing details of all admissions, outpatient appointments and A&E attendances at NHS hospitals in England.'

HQIP
Healthcare Quality Improvement Programme, 'This is a charity which promotes quality in healthcare, and to increase the impact that clinical audit has on healthcare quality in England and Wales.'

HSCIC
Health and Social Care Information Centre, 'This is the national provider of information, data and IT systems for health and social care.'

HWB
Health and Wellbeing Board, 'These are boards formed from key leaders in the health and care system who work together to improve the health and wellbeing of their local population and reduce health inequalities.'

Hypertension
'Abnormally high blood pressure.'

MHRA
Medicines and Healthcare products Regulatory Agency, 'This is the agency responsible for ensuring all medicines and medical devices work and are acceptably safe.'

MRIS
Medical Research Information Service, 'This body collects data from across the health and social care sector and turns it into information for the NHS.'

NCA
National Clinical Audit Programme, 'This is a set of reviews which measure healthcare practice on specific conditions against accepted standards.'

NCIN
National Cancer Intelligence Network, 'This is a UK-wide partnership operated by Public Health England. The NCIN coordinates and develops analysis and intelligence to drive improvements in prevention, standards of cancer care and clinical outcomes for cancer patients.'

NCVIN
National Cardiovascular Intelligence Network, 'This is a body co-ordinated by Public Health England which brings together epidemiologists, analysts, clinicians and patient representatives to strengthen the evidence base for improving cardiac and vascular health.'

NICE
National Institute for Health and Care Excellence, 'This is a public body which produces guidelines, guidance and technology appraisals for all NHS treatments in England and Wales.'

NICOR
National Institute for Cardiovascular Outcomes Research, 'NICOR collects clinical information from UK hospitals into secure registries established by the cardiovascular specialist societies. It helps improve quality of care by checking that the care received by heart disease patients meets good practice standards.'

NHSE
NHS England, 'The National Health Service in England.'

NIHR
NHS National Institute for Health Research, 'This is a body which aims to improve the health and wealth of the nation through research.'

ONS
Office for National Statistics, 'The Office for National Statistics is the UK's largest independent producer of official statistics and is the recognised national statistical institute for the UK.'

PHE
Public Health England, 'This is an agency which protects and improves the nation's health and wellbeing and reduces health inequalities.'

QOF
Quality and Outcome Framework, 'The Quality and Outcomes Framework is the annual reward and incentive programme detailing GP practice achievement results.'

SCN
Strategic Clinical Networks, 'This is a network of commissioners, local government, provider and voluntary organisations which focus on priority service areas to being about improvement in the quality and equity of care and outcomes of their population.'

THIN
The Health Improvement Network, 'This is a medical data collection scheme which collects patient information from GP practices.'

1 Townsend et al (2014). Cardiovascular Disease Statistics, 2014. British Heart Foundation London. Available at: https://www.bhf.org.uk/publications/statistics/cardiovascular-disease-statistics-2014. Last accessed: April 2015.

2 HEART UK (2013). Bridging the gaps: Tackling inequalities in cardiovascular disease. Available at: http://heartuk.org.uk/files/uploads/Bridging_the_Gaps_Tackling_inequalities_in_cardiovascular_disease.pdf Last accessed: April 2015.

3 Townsend et al (2012). Coronary Heart Disease Statistics 2012 edition: British Heart Foundation Health Promotion Research Group and Department of Health, University of Oxford. Available at: https://www.bhf.org.uk/~/media/files/publications/research/2012_chd_statistics_compendium.pdf. Last accessed: April 2015.

4 Nordestgaard BG, et al (2013). Familial Hypercholesterolaemia is underdiagnosed and undertreated in the general population: guidance for clinicians to prevent coronary heart disease. Consensus Statement of the European Atherosclerosis Society. European Heart Journal.

5 National Health Service. Primary Care Service Framework: Familial Hypercholesterolaemia. Available at: https://www.pcc-cic.org.uk/sites/default/files/articles/attachments/primary_care_service_framework_familial_hypercholesterolaemia.pdf Last Accessed: April 2015.

6 HEART UK (2012). Saving lives, saving families: The health, social and economic advantages of detecting and treating familial hypercholesterolaemia (FH).

7 National Health Service (2014). Five Year Forward View. Available at: http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf Last Accessed: April 2015.

8 Strathdee, G. (personal communication, December 2014)

9 Department of Health (2012). The power of information: Putting us all in control of the health and care information we need. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213689/dh_134205.pdf Last Accessed: April 2015.

10 National Health Service England (2014). NHS England acts in response to concerns about information sharing – statement from Tim Kelsey, National Director for Patients and Information. Available at: https://www.england.nhs.uk/2014/02/19/response-info-share/ Accessed: April 2015.

11 Kiran T et al (2010). The association between quality of primary care, deprivation and cardiovascular outcomes: a cross-sectional study using data from the UK Quality and Outcomes Framework; Journal of Epidemiology & Community Health, volume 64, pages 927-934

12 Health & Social Care Information Centre. National Diabetes Audit. Available at: http://www.hscic.gov.uk/nda Accessed: July 2015

13 Oldridge, L. (personal communication, April 2015)

14 Crick, S. (Personal communication, April 2015)

15 Stroke Association (personal communication, May 2015)

16 Jenner, K. (Personal communication, February 2015)

17 Thompson, K. (Personal communication, April 2015)

18 Reynolds, L., NHS England (personal communication, February 2014)

19 Health Minister Dan Poulter gave details of cholesterol data collection following the removal of QOF indicators (HC Deb 2 March 2015 225909WS)

20 Health & Social Care Information Centre (2014). Quality and Outcomes Framework – Prevalence Achievements and Exceptions Report, England, 2013-14. Available at: http://www.hscic.gov.uk/catalogue/PUB15751/qof-1314-report.pdf Last Accessed: April 2015.

21 Health & Social Care Information Centre (2014). Recorded disease prevalence, achievements and exceptions. Quality and Outcomes Framework (QOF) for April 2013 - March 2014, England

22 Moulson, A. (Personal communication, December 2014)

23 Battersby, J. (Personal communication,December 2014)

24 Waterall, J. (personal communication, May 2015)

25 Edmans, T (personal communication, May 2015)

HEART UK
THE CHOLESTEROL CHARITY