

Familial Hypercholesterolaemia Project Launch Event

FH: A National Overview

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

Hardwick Hall, Co. Durham
18th October 2018



“A National Perspective”

Huon Gray

National Clinical Director (Cardiac), NHS England

Consultant Cardiologist, University Hospital of Southampton

Genetic Testing in Familial Hypercholesterolaemia

Northern England Strategic Clinical Network Event

Hardwick Hall, Co. Durham

12 November 2014

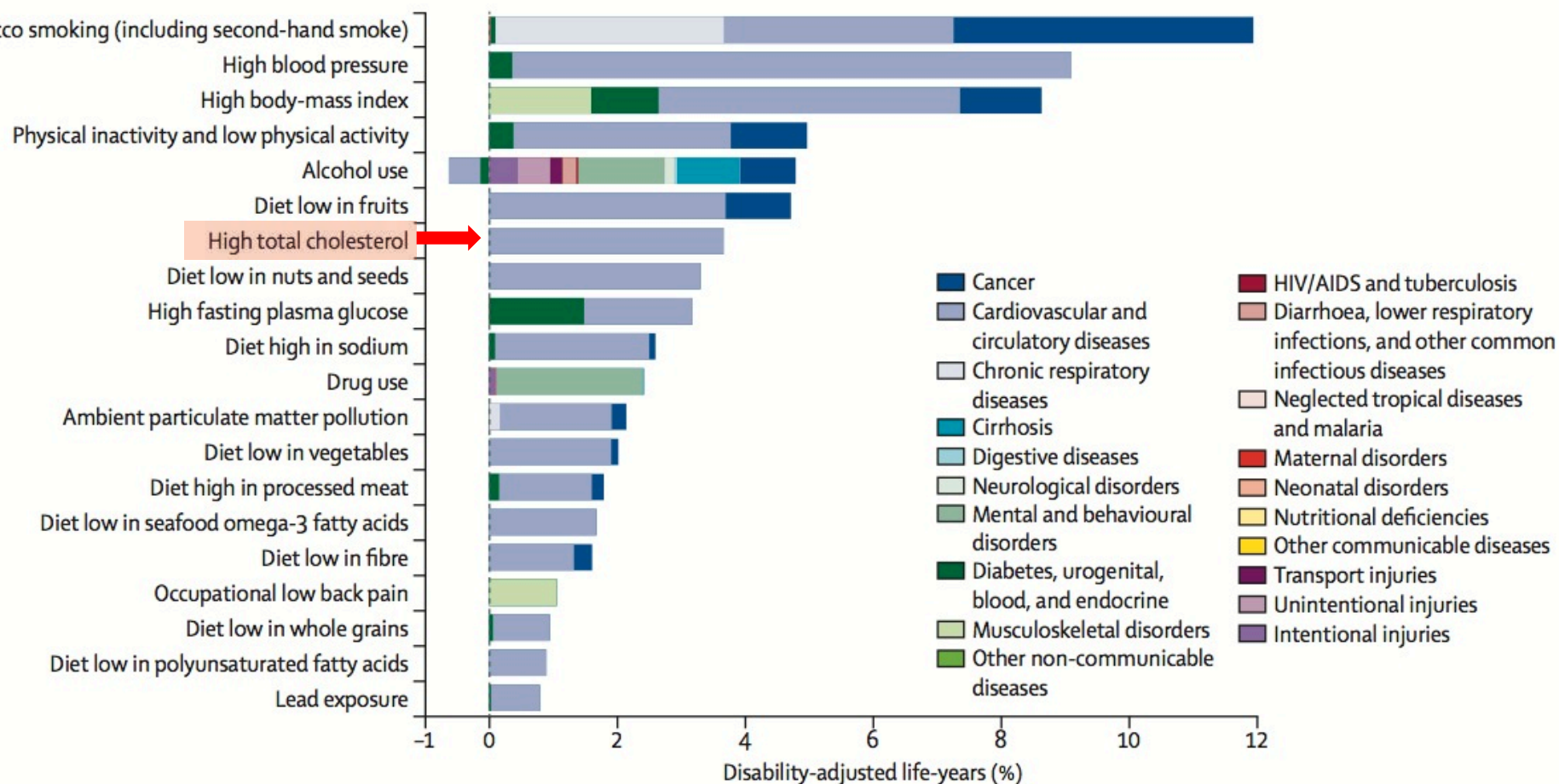


Outline

- Cholesterol is important (particularly FH)
- National recognition
- Progress with cholesterol/FH nationally
- Levers for change
- Conclusions

DALYs Attributable to top 20 (of 67) Risk Factors (UK)

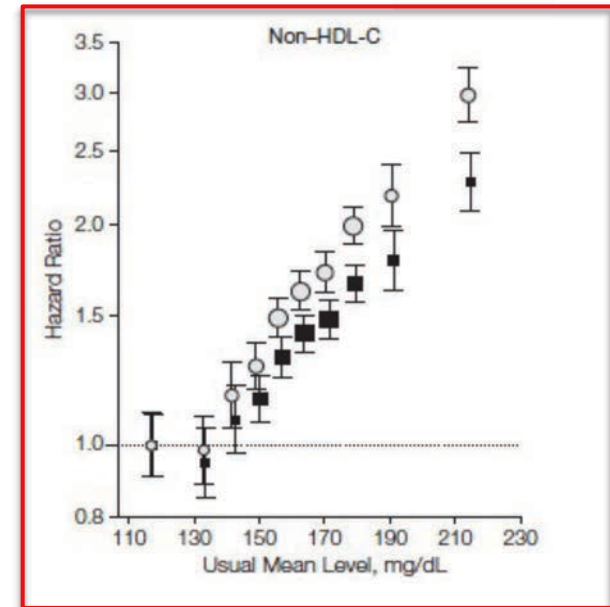
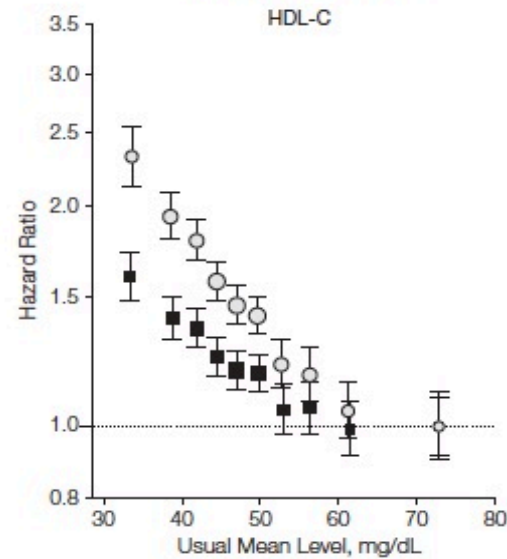
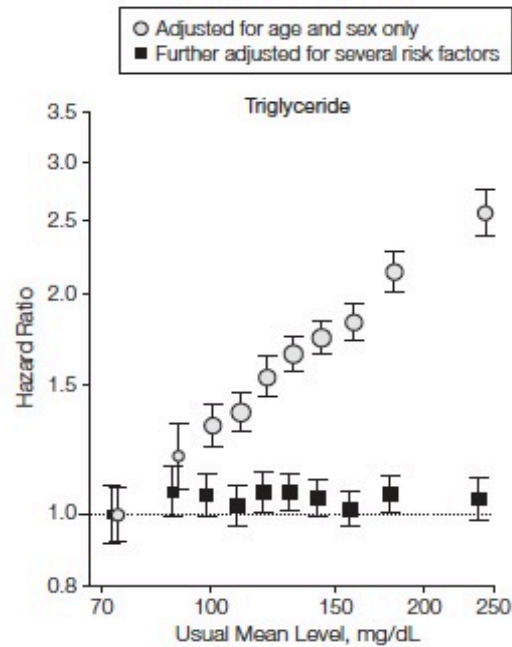
Global Burden of Disease Study. Lancet 2013;381:997-1020



259 diseases and injuries and for 67 risk factors

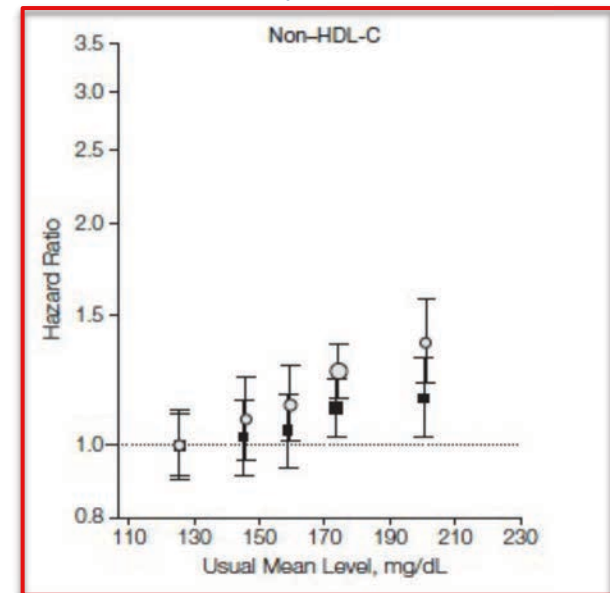
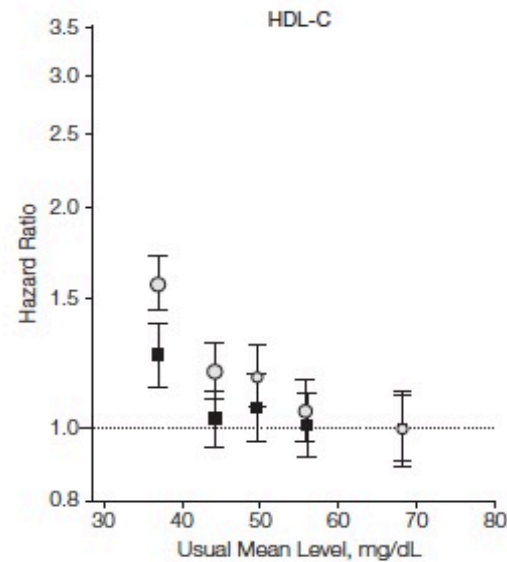
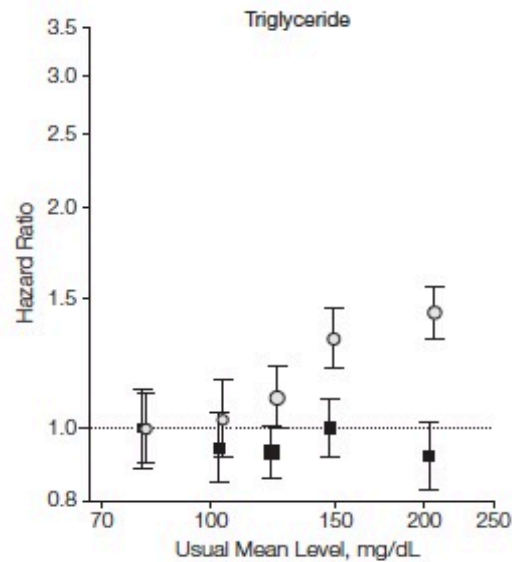
Figure 7: Burden of disease attributable to 20 leading risk factors for both sexes in 2010, expressed as a percentage of UK disability-adjusted life-years
The negative percentage for alcohol is the protective effect of mild alcohol use on ischaemic heart disease and diabetes.

Coronary Heart Disease (68 Studies, n=302,430)



JAMA. 2009;302(18):1993-2000

Ischaemic Stroke (32 Studies, n=173,312)



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Launched 29th September 2016 (World Heart Day)

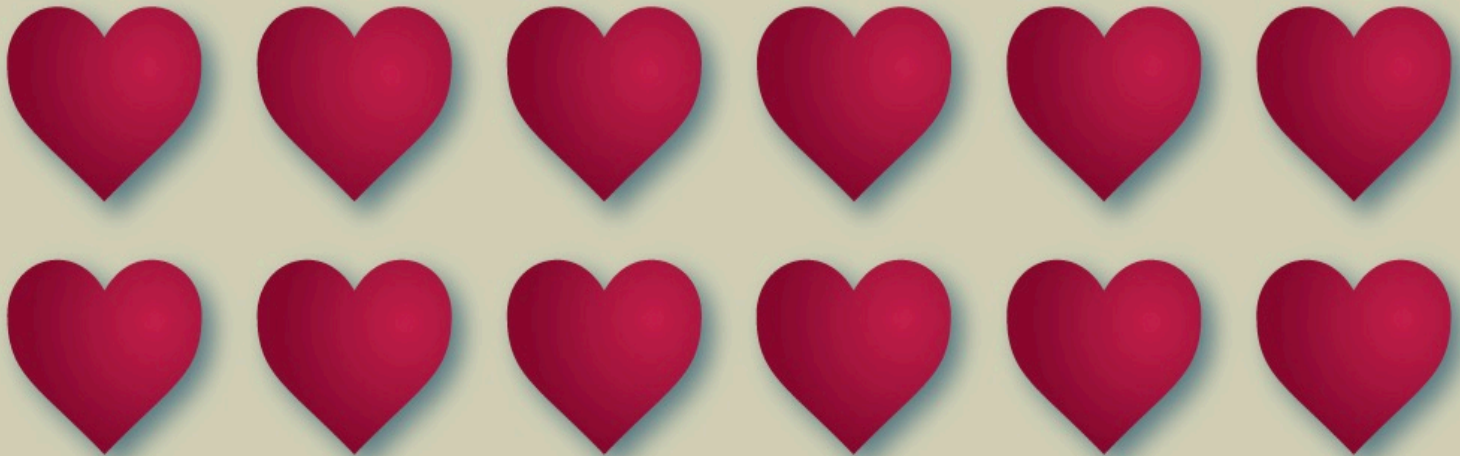
<https://www.gov.uk/government/publications/cardiovascular-disease-getting-serious-about-prevention>



Public Health
England

Protecting and improving the nation's health

Action on cardiovascular disease: getting serious about prevention



September 2016



Public Health
England

CVD: Getting Serious about Prevention

7 million

people in the UK affected
by cardiovascular disease

27%

of all deaths caused by
cardiovascular disease

1 in 4

premature deaths
caused by
cardiovascular
disease

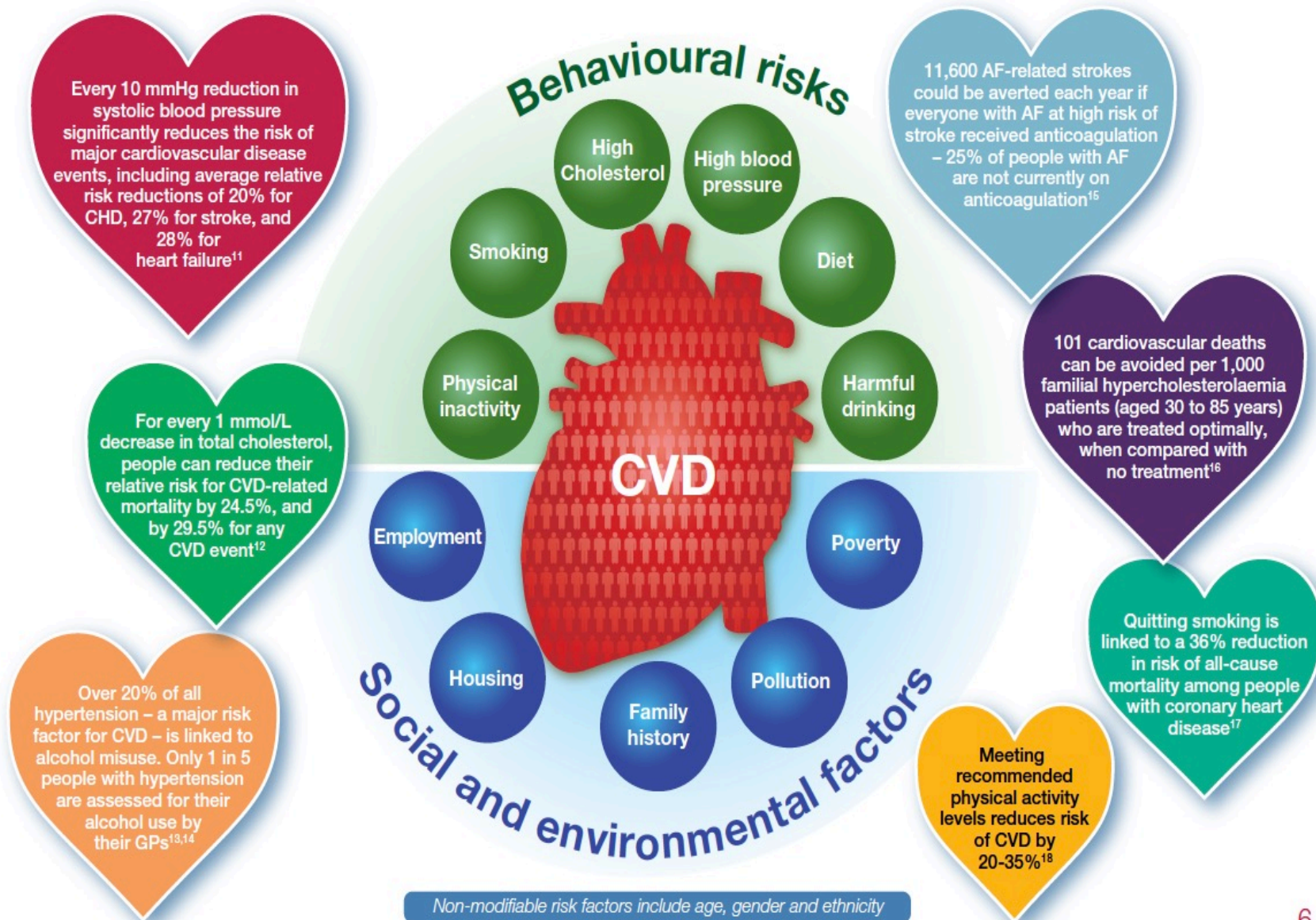
cardiovascular disease
costs the NHS

£6.8 billion

a year



The key risk factors for cardiovascular disease



The key risk factors for cardiovascular disease

For every 1 mmol/l decrease in total cholesterol, people can reduce their relative risk for CVD-related mortality by 24.5%, and by 29.5% for any CVD event.



Figure 1.4 Age-standardised death rate per 100,000 from cardiovascular disease (CVD), by gender, aged under 75, United Kingdom 1969 to 2015



bhf.org.uk/statistics

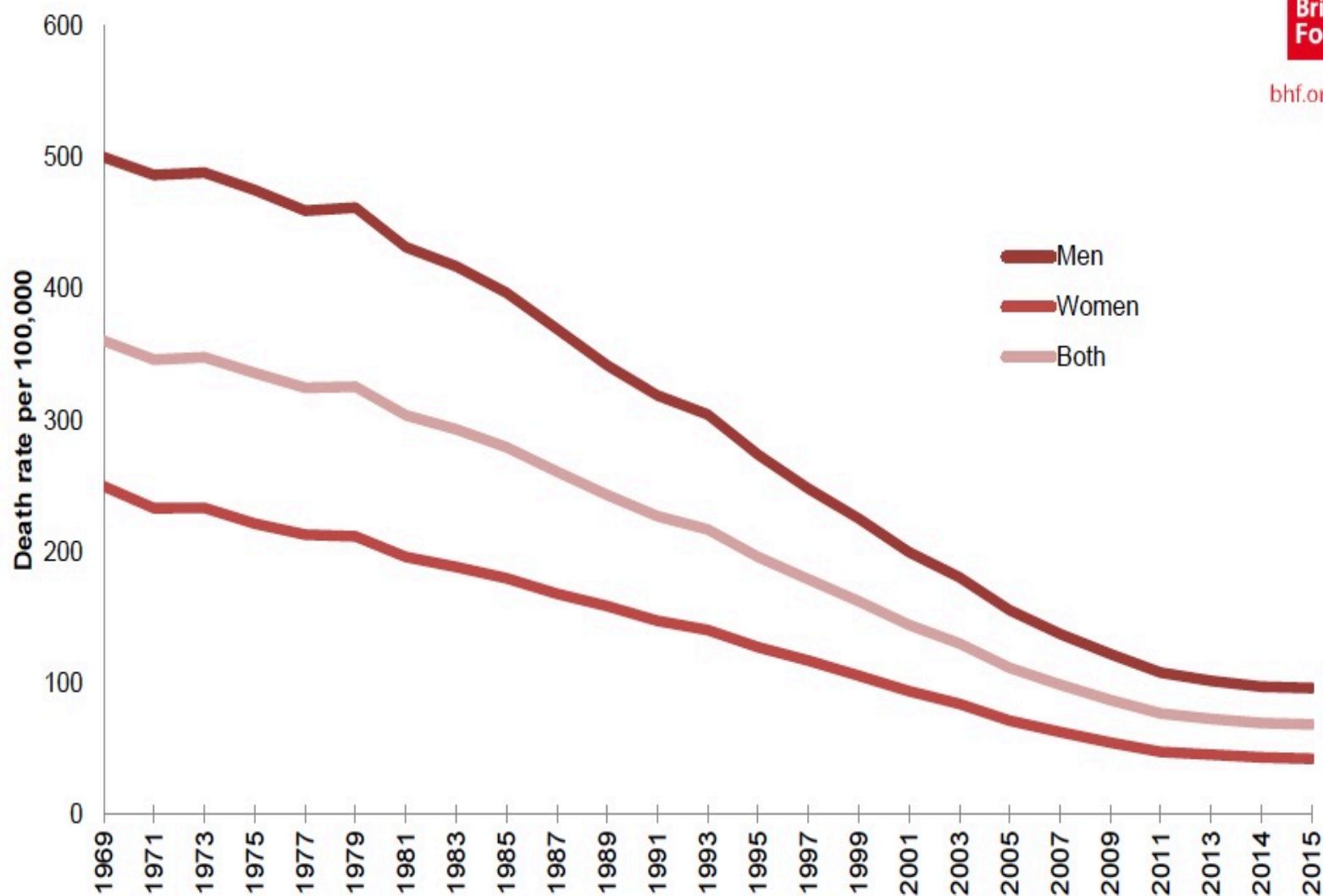
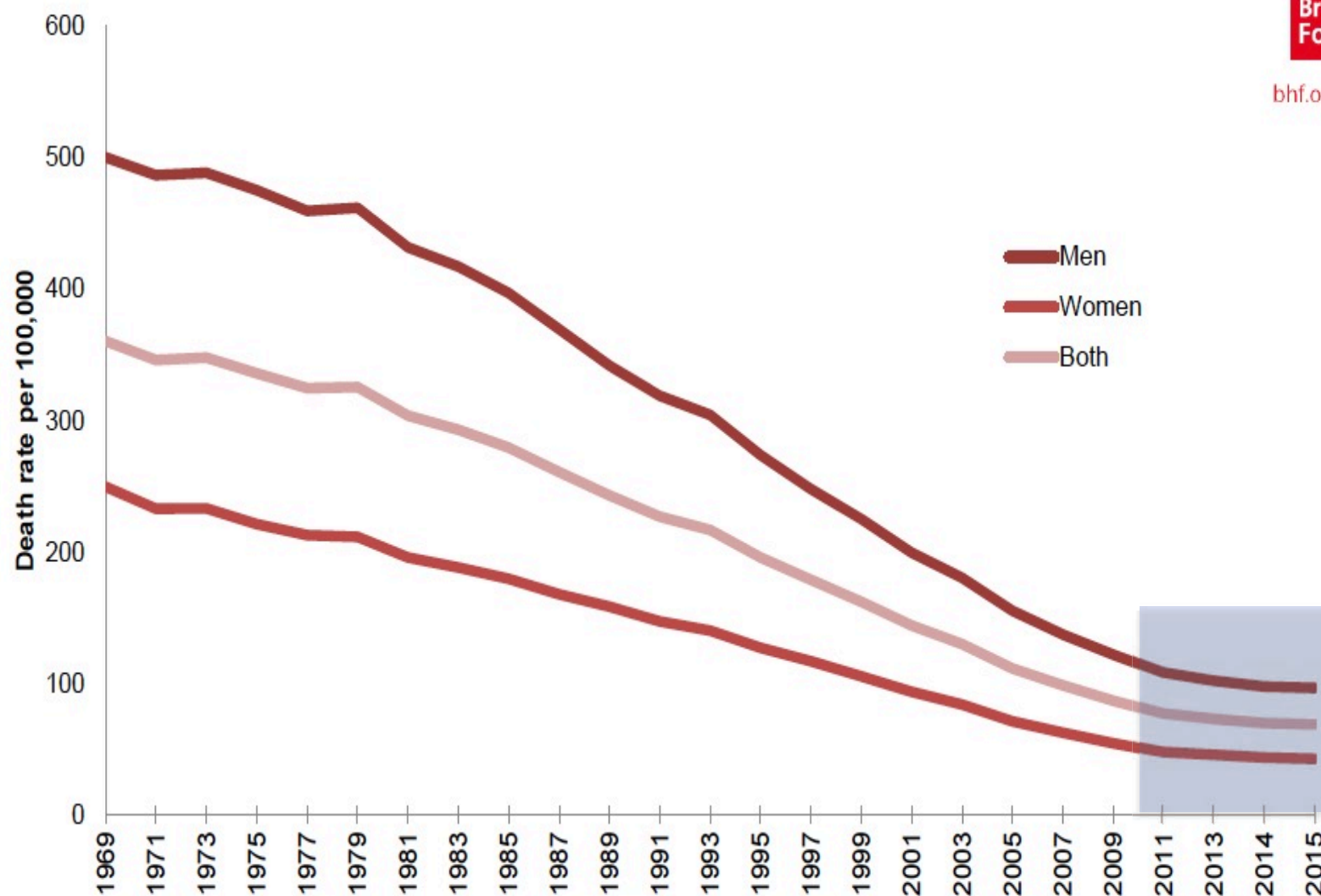


Figure 1.4 Age-standardised death rate per 100,000 from cardiovascular disease (CVD), by gender, aged under 75, United Kingdom 1969 to 2015



bhf.org.uk/statistics



FH Key Facts

- Heterozygous FH is **common** (1:250 in UK)
 - >150k adults and 50k children under 18 in England have FH

“There are about 35,000 children and young people with diabetes in the UK” (96% Type 1).

Diabetes Facts & Stats. Diabetes UK (2014)

FH Key Facts

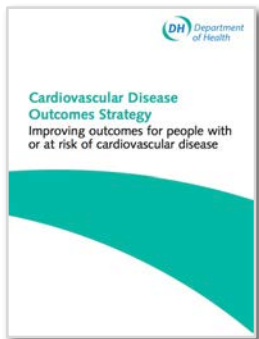
- Heterozygous FH is **common** (1:250 in UK)
 - >150k adults and 50k children under 18 in England have FH
- It **runs in families** as autosomal dominant
 - 50% of offspring affected
- It is **serious**
 - 50% of men have MI by age 50, and 30% of women by age 60
- It is **under diagnosed** (especially in those under 35 yrs)
 - Only \approx 6% of all cases known
 - <50% of the population have access to an FH service
 - Cascade testing is effective
- **Treatment** is safe, effective & (mostly) cheap

Identification and management of familial hypercholesterolaemia

Issued: August 2008

NICE clinical guideline 71

guidance.nice.org.uk/cg71



CVDOS (2013): Recommended Actions (10)

Jeremy Hunt
Secretary of State
for Health

David Nicholson
Chief Executive
NHS Commissioning Board

Duncan Selbie
Chief Executive
Public Health England

Action 4: The NHS CB will work with interested parties to develop new tools to support case finding in primary care. NHS IQ and the Strategic Clinical Networks will provide support to GP practices that have low detection rates for CVD.

Action 5: The NHS CB will take the lead, working with the Chief Coroner as appropriate, to improve the processes for identifying inherited cardiac conditions. The National Clinical Director for Heart Disease will work with all relevant stakeholders to develop and spread good practice in relation to FH and sudden cardiac death.

Action 6: The NHS CB will work with stakeholders to identify how to incentivise and support primary care consistently to provide good management of people with or at risk of CVD. This will include Department of Health (DH) asking NICE to review the relevant QOF indicators and promotion of primary care liaison with local authorities, the third sector and PHE to ensure optimal provision of prevention services, including secondary prevention.

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Progress with FH

- FH Steering Group
- Meetings
 - Meetings with Bruce Keogh (NHSE) & Duncan Selbie (PHE)
 - NHSE Senior Management Team 9th (April 2014)
 - Kings Fund FH Meeting for Commissioners (24th November 2014)
 - FH Session at BCS Annual Conference (Manchester, June 2015)
 - PHE/NHSE FH Conference (5th November 2015)
 - **Academy of Med Sciences** Stratified Medicine Roundtable (17th March 2016)
 - **NHSE Board** (25th May 2016)
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 - **Deputy CMO** Roundtable Meeting on Cholesterol (14th Nov 2016)
 - NHSE FH Roundtable meeting (10th March 2017)
 - **NHSE Medical Directorate** MAG (20th June 2017)
 - Various AHSN and Clinical Networks meetings
- PASS Software / National Data collection
- **7 New Genomic Laboratory Hubs [Oct 2018] & the 100k Genome Project**

Principles for the NHS Genomic Medicine Service 2018/19 to 2020/12

1. **To ensure comprehensive and equitable access to genomic medicine as part of routine clinical care for the population of England**
2. To improve the quality, value and sustainability of care by providing -
 - prompt and precise diagnosis
 - personalisation of interventions
 - a step change in prevention**
 - active participation of patients.
3. To support learning, research & development through new collaborative partnerships between the NHS and with academia and UK life science sector and international collaborators;
 - new diagnostics, treatments & devices, better patient access to clinical trials.
4. To build the political, ethical and moral trust in genomic medicine
 - ensuring security of patient data & materials,
 - appropriateness of care, upholding the values of the NHS Constitution

Category	Subcategory	Disease
Cardiovascular disorders	Arteriopathies	Familial cerebral small vessel disease
		Familial hypercholesterolaemia
	Connective tissues disorders and Aortopathies	Familial Thoracic Aortic Aneurysm Disease
	Cardiac arrhythmia	Brugada syndrome
		Long QT syndrome
		Catecholaminergic Polymorphic Ventricular Tachycardia
		Unexplained sudden death in the young
	Cardiomyopathy	Arrhythmogenic Right Ventricular Cardiomyopathy
		Left Ventricular Noncompaction Cardiomyopathy
		Dilated Cardiomyopathy
		Dilated Cardiomyopathy and conduction defects
		Hypertrophic Cardiomyopathy
	Congenital heart disease	Fallots tetralogy
		Hypoplastic Left Heart Syndrome
		Pulmonary atresia
		Transposition of the great vessels
		Left Ventricular Outflow Tract obstruction disorders
		Isomerism and laterality disorders
	Lymphatic disorders	Meige disease
		Milroy disease
		Lymphoedema distichiasis

Additional findings offered in the 100,000 Genomes Project

Bowel cancer predisposition:

MLH1 (adult only)

MSH2 (adult only)

MSH6 (adult only)

APC (adult and child)

MUTYH (adult only)

Breast and ovarian cancer predisposition:

BRCA1 (adult only)

BRCA2 (adult only)

Other cancer predisposition:

VHL (adult and child)

MEN1 (adult and child)

RET (adult and child)

Familial hypercholesterolaemia:

LDLR (adult and child)

APOB (adult and child)

PCSK9 (adult and child)

Autosomal recessive carrier status:

CFTR (Cystic fibrosis)

Requirements:

- Reliably detected by genome sequencing
- Curated list of high confidence, high penetrance variants
- Treatable or preventable condition

Other conditions will be added once clinically appropriate and technically feasible

Developing pharmacogenomics panel to identify key areas of patient-drug interaction

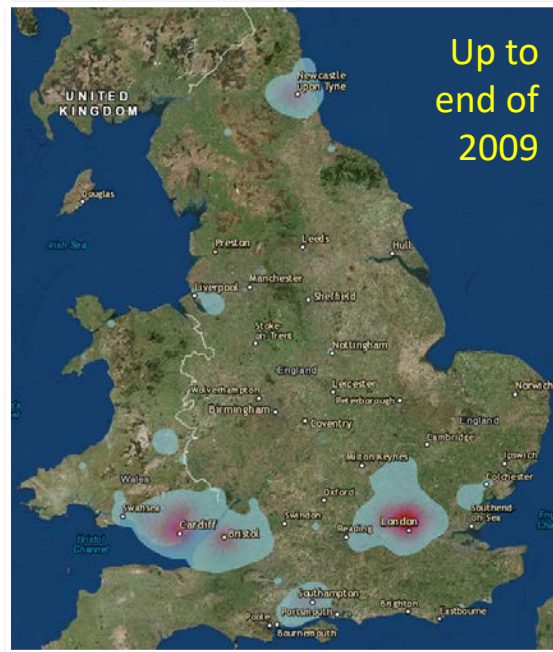
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- **BHF Funding (£1.5m+) – 27 FH Nurses, 12 UK locations, >2,600 new cases diagnosed**

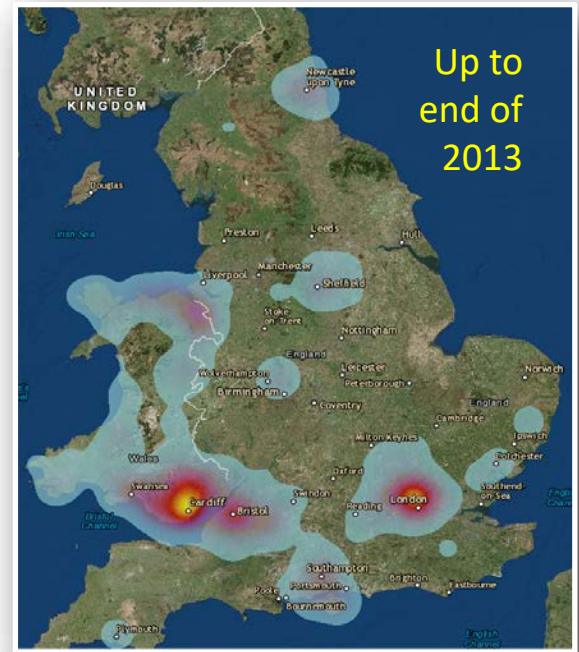
FH Genetic Diagnoses Timeline

**5 fold
Increase
Since
2010
(in this 50%
of UK)**

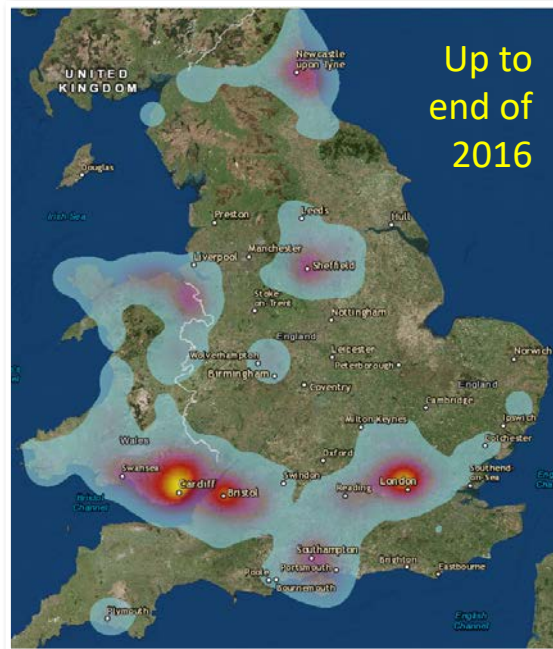
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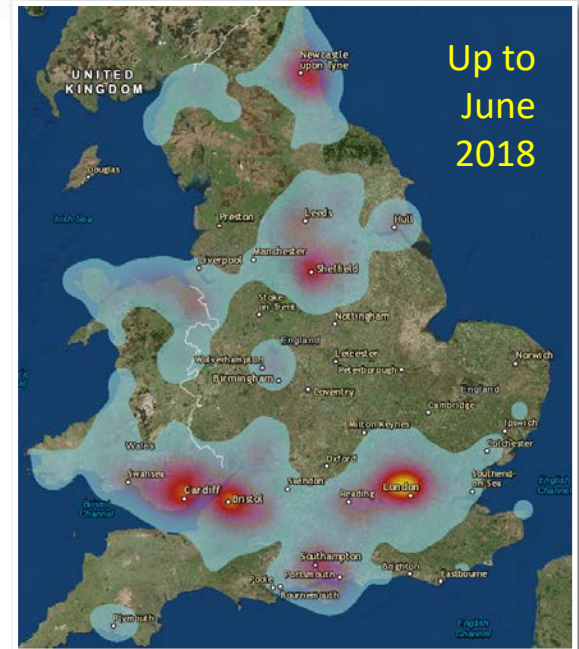
Up to
end of
2009



Up to
end of
2013

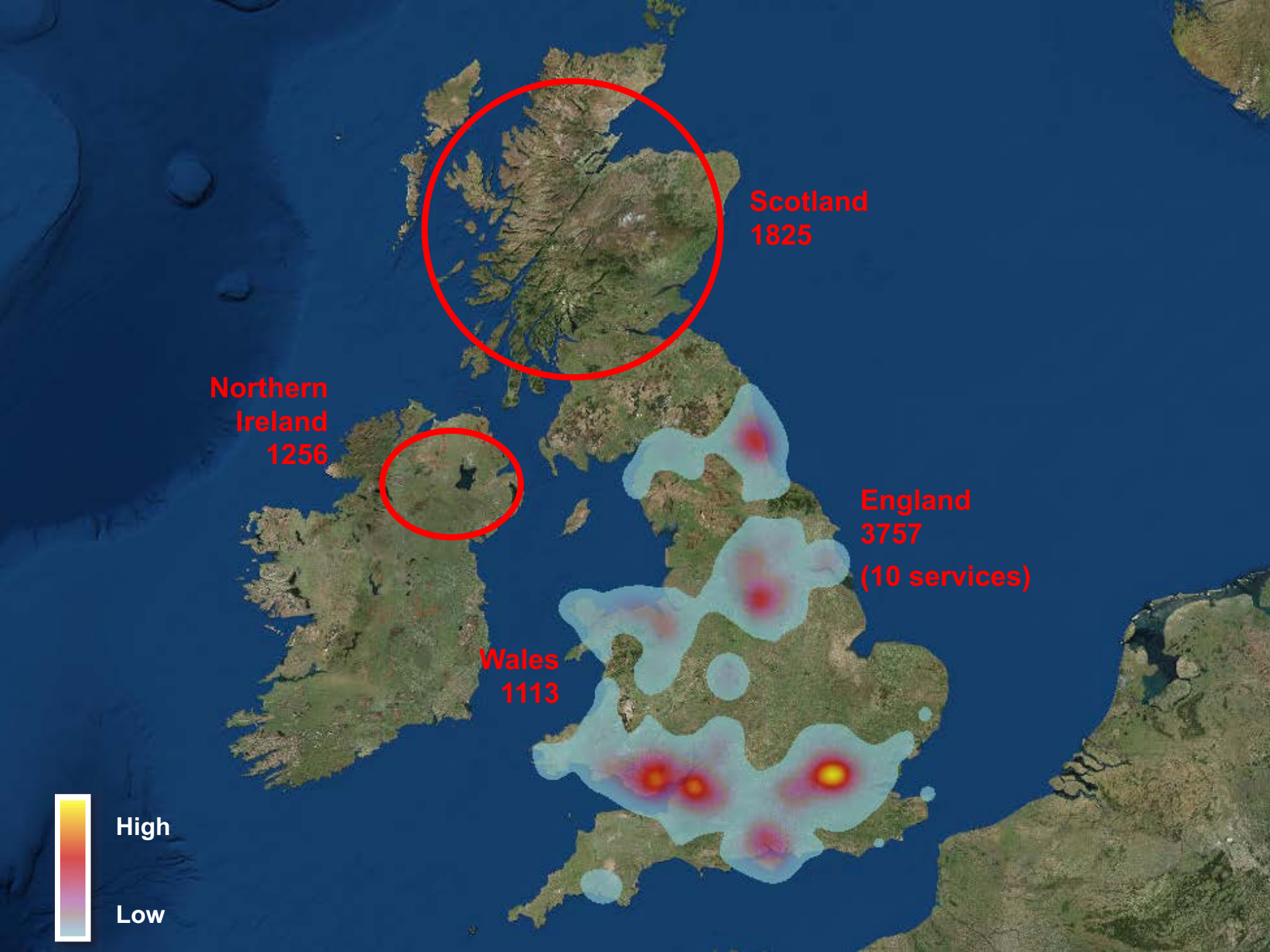


Up to
end of
2016



Up to
June
2018

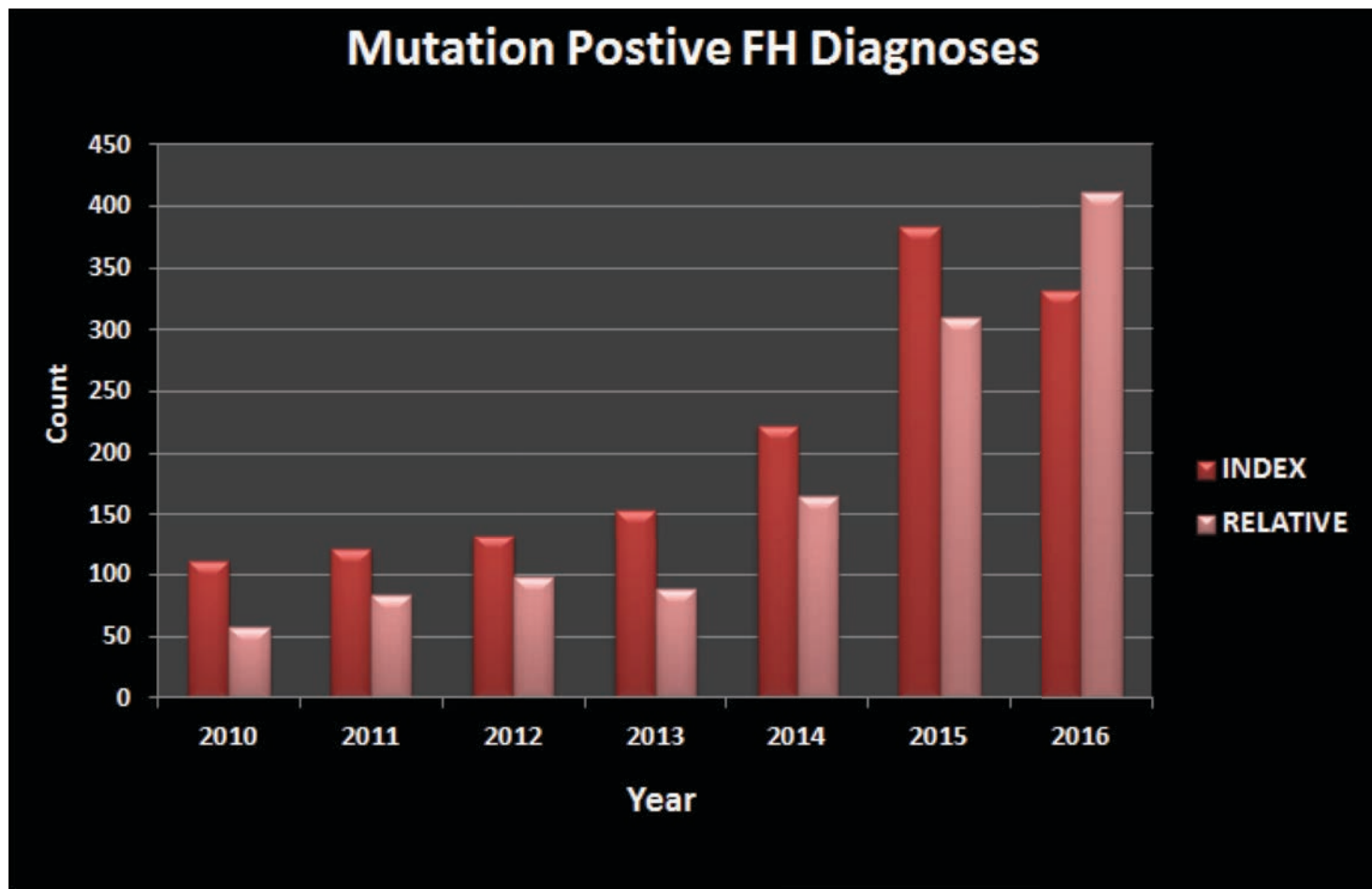
Courtesy: Kate Haralambos



High

Low

FH Genetic Diagnoses by year



Data from Wales and English services who use PASS
Courtesy: Kate Haralambos

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- Genomic Centres & the 100k Genome Project
- BHF Funding (£1.5m+) – 27 FH Nurses, 12 UK locations, >2,600 new cases diagnosed
- **NICE Update [Nov 2017] and Implementation Guide (NHSE/PHE/BHF/HEART-UK) [August 2018]**

National Institute for Health and Care
Excellence

Addendum to Clinical Guideline CG71, Familial hypercholesterolaemia

2nd November, 2017

Recommendations (for heterozygous FH):

- Consider FH if **TC >7.5mmol/l** and/or family history of premature CVD
- Family history = coronary event <60yrs in 1^o relative or index case
- Systematically search 1^o care records for people with **TC >9.0 mmol/l** & refer to specialist
- Specialist to refer for DNA testing, then cascade test 1st, 2nd (& 3rd) degree relatives
- DNA test (and treat where indicated) before aged 10

NB: Total recommendations cover whole of FH pathway in adults & children (diagnosis, treatments & lifestyle etc.) Total = 105.

[Home](#) > [Health and social care](#) > [Public health](#)

Guidance

Familial Hypercholesterolaemia: implementation guide

A guide to support the implementation of NICE Guidance (CG71) Familial Hypercholesterolaemia: identification and management.

Published 13 August 2018

From: [Public Health England](#)

Documents



Familial Hypercholesterolaemia: Implementing a systems approach to detection and management

Ref: PHE publications gateway number: 2018307.

PDF, 1.51MB, 48 pages

This file may not be suitable for users of assistive technology. [Request an accessible format.](#)

Related content

[Public health](#)

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- **Levers for change**
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NHS Health Check is a national risk assessment for people aged 40-74 who do not have an existing vascular disease. The programme **prevents** heart disease, stroke, diabetes and includes an alcohol risk assessment. An

The programme systematically **targets** the top seven causes of preventable mortality, in line with the recommended public health guidance, and the programme is clinically and cost effective.

Top seven causes of preventable mortality: high blood pressure, smoking, cholesterol, obesity, poor diet, physical inactivity and alcohol consumption.

Each year NHS Health Check can on average:

- prevent 1,600 heart attacks and save 650 lives
- prevent 4,000 people from developing diabetes
- detect at least 20,000 cases of diabetes or kidney disease earlier

[Ref 5]

Targets the Top 7 Causes of Preventable Mortality

- High BP
- Smoking
- Cholesterol
- Obesity
- Poor diet
- Physical inactivity
- Alcohol consumption

Five Year Forward View



<http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>



<http://www.england.nhs.uk/wp-content/uploads/2014/12/forward-view-planning.pdf>



<https://www.england.nhs.uk/wp-content/uploads/2015/12/planning-guid-16-17-20-21.pdf>



<https://www.england.nhs.uk/wp-content/uploads/2017/03/next-steps-on-the-nhs-five-year-forward-view.pdf>

Next Steps on 5YFD (2017)



NEXT STEPS ON THE
NHS FIVE YEAR FORWARD VIEW

March 2017

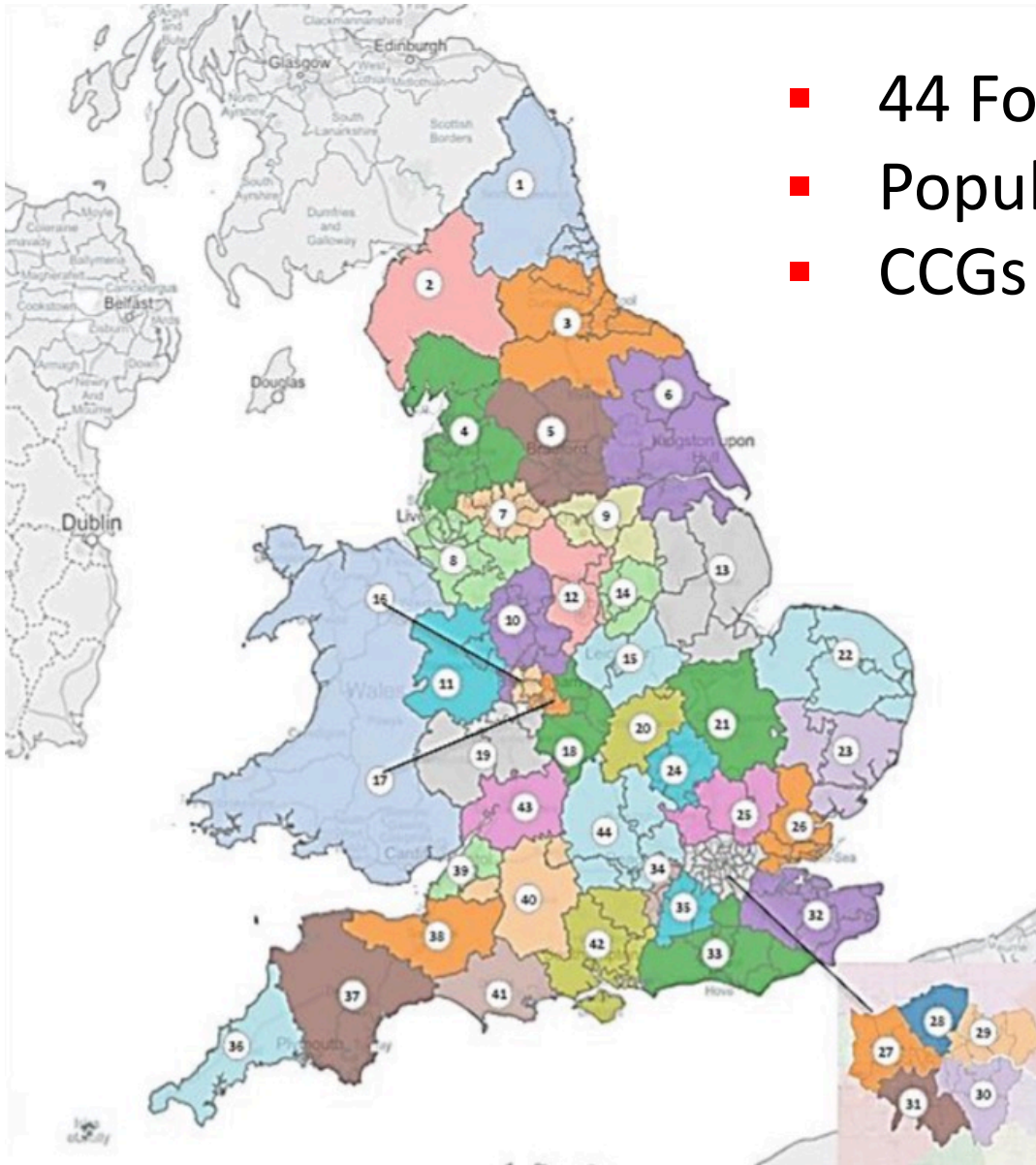
Prevention of CVD

- Primary Care (pharmacists)
- NHS Health Checks
- NHS RightCare

Urgent & Emergency Care

Sustainability & Transformation Partnerships (STPs)

Sustainability & Transformation Partnerships (STPs)



- 44 Footprints
- Populations: 0.3-2.8m
- CCGs per footprint 1-12

What do the 44 STP plans say?

Some common themes in the plans - including important commitments on:

- **Prevention** – including CVD, diabetes, dementia, obesity, smoking, alcohol
- **Improving cancer outcomes** – there are already an estimated 7000+ more people surviving cancer compared to three years ago
- **Better access to mental health services** – 120,000 more patients are getting the help they need compared to three years ago;
- **Modernising the hospital estate**, although not all are close to consultation;
- **Strengthening general practice** using £2.4bn of funding a year by 2020/21;
- **Urgent & Emergency Care:** Joining up A&E with GP, mental health and community health services.

Five Year Forward View

Five Year Forward View
(web version)

New care models –
vanguard sites

Maternity Transformation
Programme

Prime Minister's GP
Access Fund

NHS Shared Planning
Guidance

Sustainability and
Transformation Plans

Support for STP
footprints

Frequently asked
questions – STPs


[Home](#) > [Our work](#) > [Five Year Forward View](#) >

[NHS Shared Planning Guidance](#) > [Sustainability and Transformation Plans](#)

Sustainability and Transformation Plans

In December 2015, the [NHS shared planning guidance 16/17 – 20/21](#) outlined a new approach to help ensure that health and care services are built around the needs of local populations. To do this, every health and care system in England will produce a multi-year Sustainability and Transformation Plan (STP), showing how local services will evolve and become sustainable over the next five years – ultimately delivering the [Five Year Forward View](#) vision of better health, better patient care and improved NHS efficiency.

To deliver plans that are based on the needs of local populations, local [health and care systems came together in January 2016 to form 44 STP 'footprints'](#). The health and care organisations within these geographic footprints are working together to develop STPs which will help drive genuine and sustainable transformation in patient experience and health outcomes of the longer-term.

The footprints should be locally defined, based on natural communities, existing working relationships, patient flows and take account of the scale needed to deliver the services, transformation and public health programmes required, along with how they best fit with other footprints.  [Download the map of STP footprints in England.](#)

search the site



Visit [NHS Choices](#) for patient information.

News and blogs

Watch the live stream of NHS
England's Board meeting

🕒 28 September 2016

Board meeting – 29 September 2016

🕒 27 September 2016

Joining up 'co-production' and
'patient leadership' for a new
relationship with people who use
services – David McNally

🕒 27 September 2016

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experience

Leading Change, Adding
Value

Commissioning
















Involving people in their
own care

Technology, systems and
data

Quick guides – May 2016

These quick guides are designed to help local leaders work together in tackling the big system questions, and build on existing efforts to make progress on some of the most challenging priorities. Each guide starts by setting out what success would look like in 2020, and gives suggestions about how areas could approach implementation.

The guides included in this package distil guidance/information from other publications and do not contain new asks or priorities. They are a description of the top-line objectives we need collectively to achieve by the end of the decade, both nationally and locally.

-  Introduction to the aide memoires
-  Cancer
-  Diabetes
-  Digital
-  Estates
-  Learning disabilities
-  Maternity
-  Mental health
-  New care models
-  Personalisation and choice
-  Prevention
-  Primary care
-  Safety
-  Supporting people to manage their own health, wellbeing and care
-  Urgent and emergency care and 7 day hospital services

Improve detection rates and management of high blood pressure, high cholesterol, atrial fibrillation and raised blood glucose

- Local government commission [NHS Health Checks](#) and CCGs encourage providers to increase offer of Health Checks, testing and risk assessment (being more proactive with deprived groups), particularly via GPs and outreach testing e.g. pharmacy.
- CCGs encourage primary care to: ensure patients receive optimal care and drug treatment where relevant e.g. [hypertension](#) and [AF](#) patients; extend the role of pharmacists in clinical management; and support patient activation and self-care.
- CCGs and local government encourage NHS Health Checks, primary care and NHS Diabetes Prevention Programme providers (where in place) to jointly implement effective referral pathways.

[Home](#) > [NHS RightCare](#) > [Intelligence](#) > [Commissioning for Value products](#) > [NHS RightCare Pathways](#) > Cardiovascular disease prevention pathway

Cardiovascular disease prevention pathway

This pathway has been produced by NHS RightCare. NHS RightCare is a programme committed to reducing unwarranted variation to improve people's health and outcomes and reduce inequalities in health access, experience and outcomes.

It makes sure that the right person has the right care, in the right place, at the right time, making the best use of available resources.

NHS England, Public Health England and clinical commissioning groups (CCGs) have legal duties under the [Health and Social Care Act 2012](#) to reduce health inequalities; and to promote equality under the [Equality Act 2010](#).

The [cardiovascular disease \(CVD\) prevention pathway](#) is the first in a series of optimal value pathways on a number of conditions. These evidence-based pathways are being developed in close collaboration with NHS England's National Clinical Directors, Public Health England, Royal Colleges, NICE and other non-statutory stakeholders including patient groups.

The aim is to provide local health economies with:

- a high-level overarching national case for change;
- a best practice pathway for individual conditions; and
- best practice case studies for elements of the pathway demonstrating what to change, how to change and a scale of improvement.

“The CVD prevention pathway is the first in a series of optimal value pathways on a number of conditions. These evidence-based pathways are being developed in close collaboration with NHS England’s National Clinical Directors, Public Health England, Royal Colleges, NICE and other non-statutory stakeholders including patient groups.”

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High value intervention in high cholesterol

The information below relates to the [CVD prevention pathway](#).

- Maintain and improve systematic collection and audit of data on cholesterol levels, high CVD risk and possible familial hypercholesterolaemia (FH) in practices to support detection and management.
- Achieve local clinical consensus and establish an integrated pathway for detection and management of raised cholesterol and CVD risk, which includes FH.
 - Identify and investigate possible undiagnosed hypercholesterolaemia and/or FH.
 - Identify and address suboptimal lipid management.
- Commission local service for FH investigation and cascade testing.
- Work with practices and local authorities to maximise NHS Health Check uptake.
- Build local primary care leadership to address unwarranted variation and drive quality improvement in detection and management.
- Strengthen risk assessment, detection and management through greater use of practice-based and community pharmacists and consider commissioning systematic support specifically for statin adherence from community pharmacy through medicine use reviews (MURs).

Further information

- [NICE pathway on CVD prevention](#)
- [Journal of Public Health: Do health checks improve risk factor detection in primary care? Matched cohort study using electronic health records](#)
- [Case study 1: Improved identification of familial hypercholesterolaemia in primary care](#)
-  [Case study 2: HEART UK – Familial hypercholesterolaemia primary care audit programme](#)
-  [Case study 3: BHF – Cascade testing services for familial hypercholesterolaemia](#)
- [Case study 4: Closing the gap: tools to tackle variation in cardiovascular disease](#)
-  [Return to the CVD prevention pathway.](#)

17th June 2018



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Health

NHS funding: Theresa May unveils £20bn boost

By Nick Triggle
Health correspondent

17 June 2018

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NHS at 70



Mrs May said the extra funding amounted to billions of pounds a year extra for the NHS

The NHS in England is to get an extra £20bn a year by 2023 as a 70th "birthday present", Theresa May says.

It means the £114bn budget will rise by an average of 3.4% annually - but that is still less than the 3.7% average rise the NHS has had since 1948.

18th July 2018

FOR HEALTHCARE LEADERS
HSJ

JAMES ILMAN
Performance watch: An unenviable choice on elective waits

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EXCLUSIVE: STEVENS SETS OUT 10 YEAR PLAN PRIORITIES

Exclusive: Stevens sets out 10 year plan priorities

COMMISSIONING

Exclusive: Stevens sets out 10 year plan priorities

By Dave West | 18 July 2018

7 Comments

NHS England chief executive Simon Stevens has identified five major priorities for the 10 year NHS plan due to be unveiled this autumn.

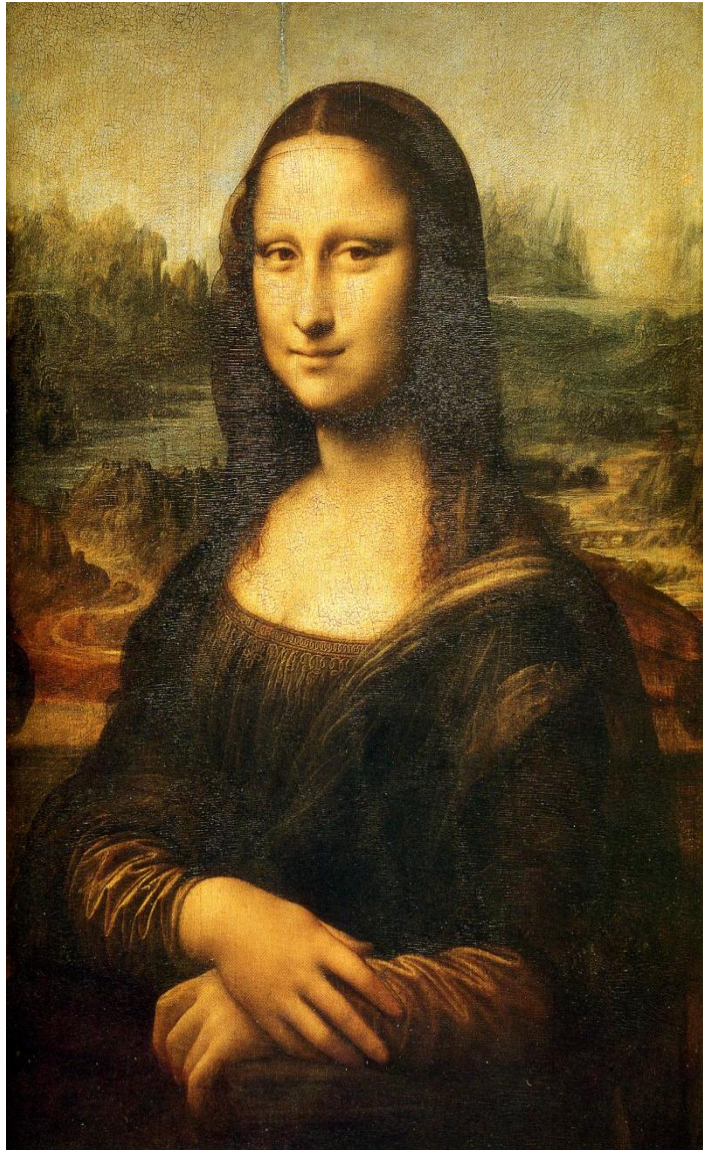


5 Priorities at core of NHS Long Term Plan:

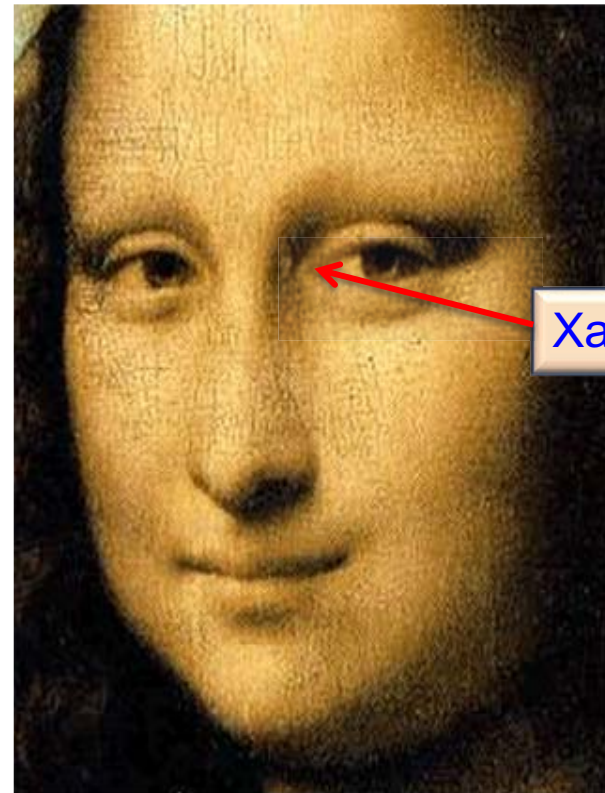
- Mental Health
(especially children)
- Cancer
- **Cardiovascular Disease**
- Children's services
(especially prevention & inequalities)
- Reducing health inequalities

Conclusions

- The importance of cholesterol/FH as a risk factor is now more widely appreciated
 - Focus on prevention, CVD RightCare packs, STPs, Health Checks, AHSNs/Networks etc.
- Relevance of FH to CVD risk and the 'Genomics' (Personalised Medicine) agendas will help drive better access to genetics
- Refreshed NICE Guidance & collaborative Implementation Guide should raise profile of FH
- Challenge is to establish consistent pathways for detection & management of high cholesterol/FH in a devolved system of health & social care



Madonna Lisa Maria di Gherardini
Born Florence 1479
Died 1516 age 37 years



Xanthelasma?