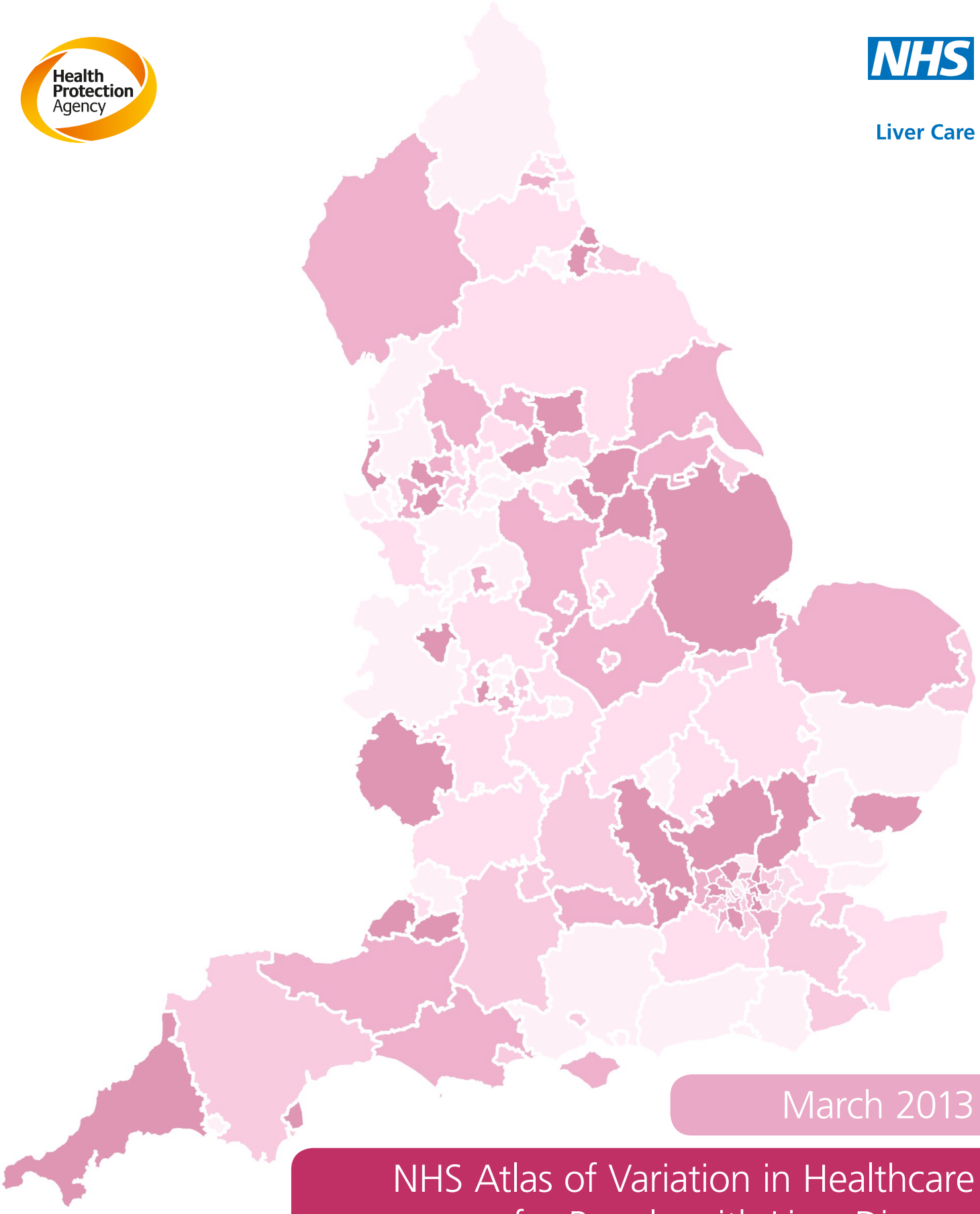
Health Protection Agency

NHS

Liver Care



March 2013

NHS Atlas of Variation in Healthcare for People with Liver Disease

Reducing unwarranted variation to increase value and improve quality

RightCare

www.rightcare.nhs.uk

March 2013

The NHS Atlas of Variation in Healthcare for People with Liver Disease

Reducing unwarranted variation to increase value and improve quality

The Liver Disease Atlas has been prepared in partnership with a wide range of organisations:

NHS Liver Care

NHS Liver Care was created to provide a virtual working environment for national and local healthcare leaders, and professionals involved in the planning and delivery of liver services, to work together to help drive improvements to liver care in England. By providing support to commissioners, providers and primary care teams, it helped to embed safe, evidence-based examples of "what works", leading to better outcomes for patients. From 1 April 2013, NHS Liver Care will become part of NHS Improving Quality.

http://www.liver.nhs.uk/

Health Protection Agency

The **Health Protection Agency** (HPA) is an independent UK organisation set up by the government in 2003 to protect the public from threats to their health from infectious diseases and environmental hazards. It does this by providing support, advice and information to the NHS, local authorities, emergency services, other arms-length bodies, the Department of Health, the devolved administrations and the general public. From 1 April 2013, the HPA will become part of Public Health England (PHE).

http://www.hpa.org.uk/

British Association of Day Surgery – Excellence in short stay surgery

The **British Association of Day Surgery** (BADS) provides insight and information to national organisations, healthcare professionals, patients, relatives and carers of the potential benefits of shorter-stay care in hospital.

http://www.bads.co.uk

BRITISH LIVER TRUST

The **British Liver Trust** is a registered charity pioneering liver health. We tackle the serious and growing public health problem of liver disease which affects over 2 million people in the UK. Our aims are to reach out to as many people as possible by providing up-to-date information and support through our website, helpline and publications, to lobby for the effective services that people with liver disease need and to encourage best possible liver health for all through prevention and early detection.

http://www.britishlivertrust.org.uk/

CHKS – Insight for better healthcare

CHKS, part of Capita plc, is a provider of healthcare intelligence and quality improvement services. In the last 23 years it has worked with 374 healthcare organisations worldwide. With 70% of acute healthcare providers in the UK choosing CHKS to support them on their improvement journey, CHKS has the skills and know-how to boost quality, cost and delivery performance.

http://www.chks.co.uk/

Children's Liver Disease Foundation – fighting childhood liver disease

Children's Liver Disease Foundation (CLDF) is a national charity dedicated to fighting all liver diseases of childhood. We provide a comprehensive information hub for healthcare professionals and the general public, and a tailored support service for young people with liver disease and their families. We are the lead charity supporting medical research into all aspects of children's liver diseases, and the voice for young people, their families and adults diagnosed with liver disease in childhood.

http://www.childliverdisease.org/

DH Department of Health – Commercial Medicines Unit

Department of Health Commercial Medicines Unit (CMU) is part of the Procurement, Investment and Commercial Division. The focus of our work is on strategic supply management and procurement of medicines for use in secondary care. We work in partnership with hospital pharmaceutical procurement colleagues across NHS England, including leading a selective competitive tendering work plan for the implementation of hospital framework contracts. Our objectives are to ensure a stable supply of critical drugs and to maintain, develop and realise the benefits of competition.

http://cmu.dh.gov.uk/

East Midlands Public Health Observatory (EMPHO) is one of nine public health observatories in England, which work together through a single national work programme consisting of national and local elements. We produce information, data and intelligence on people's health and healthcare for practitioners, policy-makers and the wider community. Our expertise lies in turning information and data into meaningful health intelligence to support decision-makers. From 1 April 2013, EMPHO will become part of Public Health England (PHE).

http://www.empho.org.uk

The **Health and Social Care Information Centre** (HSCIC) is the national source of NHS, health and social care information. We collect, process, link, analyse and publish national information for health and social care communities in England. In April 2013, the HSCIC will be established as a new Executive Non-Departmental Public Body (ENDPB). This new organisation will incorporate functions from the existing HSCIC, IT systems delivery functions currently undertaken by NHS Connecting for Health and Strategic Health Authority informatics functions.

http://www.ic.nhs.uk

The Hepatitis C Trust is the only UK-wide charity focused on hepatitis C, supporting the estimated 216,000 people living with the virus. It is led and driven by people with personal experience of hepatitis C. The Trust is committed to increasing prevention, diagnosis and treatment with a view to eradicating the virus in the UK within 15 years. The charity achieves this by raising awareness and funds, driving policy and providing testing, training and support.

http://www.hepctrust.org.uk/

IMS Health is a leading provider of information, services and technology for the healthcare industry. Combining industry expertise and advanced technology they deliver accurate perspectives and in-depth analytics on healthcare dynamics. IMS are committed to innovating to keep pace with an increasingly complex and interdependent global healthcare environment. Utilising analytical, commercial services and consulting capabilities they support decision-makers in life sciences, payers, providers and policy-makers to achieve high-quality, cost-effective healthcare.

http://www.imshealth.com/portal/site/ims

MSD believes the most important thing we make is a difference. We operate in more than 140 countries and through our prescription medicines, vaccines, biologic therapies, and consumer care and animal health products we work with customers to bring innovative healthcare solutions to those who need them the most. We also demonstrate our commitment to increasing access to healthcare through far-reaching policies, programmes and partnerships. MSD is a trade name of Merck & Co, Inc, with headquarters in Whitehouse Station, NJ, USA.

http://www.msd-uk.com/

NHS Blood and Transplant (NHS BT) manages the national voluntary donation system for blood, tissues, organs and stem cells turning these precious donations into products that can be used safely to the benefit of the patient.

http://www.nhsbt.nhs.uk/

NHS Connecting for Health (NHS CFH) is part of the Department of Health Informatics Directorate. Our role is to maintain and develop the NHS national IT infrastructure. This infrastructure includes a number of national services and a range of national applications.

http://www.connectingforhealth.nhs.uk/

NHS Screening Programmes
Infectious Diseases in Pregnancy

NHS Infectious Diseases in Pregnancy Screening Programme (IDPS) in England is responsible for ensuring that all pregnant women are routinely offered screening for hepatitis B, HIV, syphilis and susceptibility to rubella infection. The aims are: to ensure that women with hepatitis B, HIV and syphilis are identified and offered appropriate assessment and management for their health, and strategies are put in place to reduce the risk of mother-to-child transmission; to identify women who are susceptible to rubella, for whom postnatal MMR vaccination could protect future pregnancies.

http://infectiousdiseases.screening.nhs.uk/

NHS South of England

NHS South West became part of **NHS South of England** from 3 October 2011. NHS South of England comprises South Central, South East Coast and South West Strategic Health Authorities (SHAs), which manage the NHS locally, and provide an important link between the Department of Health and the NHS. NHS South of England stretches from Penzance to Margate, serving a population of 13.4 million people. It has a budget of £21.1 billion. Within the region, there are 110 NHS organisations, 1873 GP practices and 34 local authorities.

http://www.southofengland.nhs.uk/

NatCen
Social Research that works for society

National Centre for Social Research (NatCen) is a not-for-profit organisation conducting independent social research covering all areas of social policy. We are dedicated to making an impact on society and advancing the role of social research in the UK. We aim to share our insight and knowledge with the wider research and policy community as our findings have direct, practical application in terms of understanding social behaviour and informing policy.

http://www.natcen.ac.uk/

noo
National Obesity Observatory

The **National Obesity Observatory** (NOO) provides a single point of contact for wide-ranging authoritative information on data, evaluation and evidence related to weight status and its determinants. From 1 April 2013, NOO will become part of Public Health England (PHE).

http://ww.noo.org.uk/

NHS
National Treatment Agency for Substance Misuse

The **National Treatment Agency for Substance Misuse** (NTA) is a National Health Service (NHS) special health authority established to improve the availability, capacity and effectiveness of drug treatment in England. The NTA supports local areas to get drug and alcohol misusers into treatment, helping them to overcome their addiction; to recover from dependency, regain their lives and reintegrate back into society. From 1 April 2013, the NTA will become part of Public Health England (PHE).

http://www.nta.nhs.uk/

NorthWest Public Health Observatory

The **North West Public Health Observatory** (NWPHO), based in the Centre for Public Health at Liverpool John Moores University, has been established for over 10 years and delivers high quality public health intelligence to improve health and wellbeing and reduce inequalities. NWPHO leads nationally on alcohol, drug misuse, violence and dental health intelligence on behalf of the public health observatories in England. From 1 April 2013, the NWPHO will become part of Public Health England (PHE).

http://www.nwph.net/nwpho/

Office for National Statistics

Office for National Statistics (ONS) is the UK's largest independent producer of official statistics and the recognised national statistical institute of the UK. Our main responsibilities as the Executive Office of the UK Statistics Authority include the collection, compilation, analysis and dissemination of economic, social and demographic statistics that serve the public good and meet our legal obligations (domestic and international); the provision of statistical leadership and methodological advice for the benefit of UK official statistics; representing the UK in the international arena; and the development and maintenance of definitions, methodologies, and classifications of statistics.

http://www.ons.gov.uk/ons/index.html

Roche is the world's largest biotech company with truly differentiated medicines in oncology, virology, inflammation, metabolism and CNS. Roche is also the world leader in in-vitro diagnostics, tissue-based cancer diagnostics and a pioneer in diabetes management. Roche's personalised healthcare strategy aims at providing medicines and diagnostic tools that enable tangible improvements in the health, quality of life and survival of patients. Roche in the UK employs nearly 2000 people in pharmaceuticals and diagnostics.

http://www.roche.co.uk

The **South East Public Health Observatory** (SEPHO) aims to improve health and reduce inequalities in the South East region through provision of intelligence to improve decision-making. From 1 April 2013, SEPHO will become part of Public Health England (PHE).

http://www.sepho.org.uk/

The **South West Public Health Observatory** (SWPHO) aims to improve the health of the population in the South West. Through the collection, monitoring and analysis of data, we produce evidence to inform decision-making on health issues at local, regional and national levels. From 1 April 2013, SWPHO will become part of Public Health England (PHE).

http://www.swpho.nhs.uk/

Thames Cancer Registry (TCR) is one of 11 population-based cancer registries in the UK, and collects, processes, analyses and disseminates data on newly diagnosed cancer in residents of London, Surrey, Sussex and Kent. With a population of 12 million, and 2.8 million cancer registration records, TCR is one of the largest cancer registries in Europe. It holds information about cancer incidence, prevalence, survival and mortality spanning five decades and is the national lead registry for lung and upper gastrointestinal cancers. From 1 April 2013, TCR will become part of Public Health England (PHE).

http://www.thames-cancer-reg.org.uk/

Solutions for Public Health (SPH) is a not-for-profit public health organisation within the NHS dedicated to better health and better healthcare for all. SPH works with decision-makers across the public and third sectors to improve health and reduce health inequalities. SPH brings together a unique synthesis of clinical and public health experience, analytical and research skills and business performance to help customers improve the services they offer and commission.

http://www.sph.nhs.uk/

Information regarding innovations and models of good practice has been provided by:

Barts Health NHS Trust was created on 1 April 2012 following the approved merger of Barts and The London NHS Trust, Newham University Hospital NHS Trust and Whipps Cross University Hospital NHS Trust. We aim to provide locally accessible, excellent quality and sustainable services that are focused on clinical excellence and provide a high-quality health service that ensures patient experience is at the forefront of everything we do.

http://www.bartshealth.nhs.uk/

Brownlow Health specialises in general medical and student healthcare. Our primary care team aims to provide not only the highest quality patient care, ensuring equality of access in a friendly, approachable, non-judgemental setting, but also a happy, supportive working environment based on teamwork and a commitment to develop our staff and services. In addition to appointments, we provide a walk-in service, telephone consultations, email advice, and long-term conditions clinics for people with asthma, diabetes, hypertension and heart disease.

http://www.brownlowgroupppractice.org/

Bolton NHS Foundation Trust is an integrated care organisation. We provide patient care in the community at health centres and clinics as well as services such as district and school nursing. We also provide services at the Royal Bolton Hospital. We aim to meet the health needs of our population, improve the safety and quality of care, improve patient experience, and make our services more efficient.

http://www.boltonft.nhs.uk/

King's College Hospital NHS Foundation Trust (KCH) is one of London's largest and busiest teaching hospitals, with a strong profile of local services primarily serving the boroughs of Lambeth, Southwark and Lewisham. Our specialist services are available to patients across a wider catchment area, providing nationally and internationally recognised work in liver disease and transplantation, neurosciences, haemato-oncology and foetal medicine.

http://www.kch.nhs.uk/

Liverpool Primary Care Trust (PCT) ceases to exist as an organisation on 31 March 2013, as part of the changes in the NHS brought about by the Health and Social Care Act 2012. Prior to this, Liverpool PCT was responsible for planning NHS care for the population of Liverpool. Many of the PCT's responsibilities will be taken over by Liverpool Clinical Commissioning Group (CCG), which is made up of local GPs, nurses and other professionals.

http://www.liverpoolpct.nhs.uk/

NHS North East has an overall vision based around seven ambitious aims: no barriers to health and wellbeing; no avoidable deaths, injury or illness; no avoidable suffering or pain; no helplessness; no unwanted waiting or delays; no waste; no inequality. These aims will guide everyone, including staff, patients and the public in making the best possible decisions about health and healthcare. Each aim is underpinned by a set of principles, outcomes and measures to help ensure real change.

http://www.northeast.nhs.uk/

Nottingham University Hospitals NHS Trust is now one of the biggest and busiest acute Trusts in England, employing 13,000 staff. We provide services for over 2.5 million residents of Nottingham and its surrounding communities. We also provide specialist services to a further 3–4 million people from neighbouring counties each year. We have achieved a national and international reputation for many of our specialist services, including stroke, renal, neurosciences, cancer services and trauma.

http://www.nuh.nhs.uk/

Plymouth Hospitals NHS Trust provides comprehensive hospital and specialist healthcare to people in the South West peninsula. We offer a full range of general hospital services and specialist services. We want to provide healthcare services that patients and their families can trust and depend on, and to be a major university teaching hospital and healthcare provider, recognised as one of the best in the country. We will lead with excellence and care with compassion.

http://www.plymouthhospitals.nhs.uk/

The Royal Liverpool and Broadgreen University Hospitals NHS Trust is one of the largest and busiest hospital trusts in the North of England. We provide general hospital services and emergency care to the local community, and nationally and internationally recognised services such as ophthalmology, hepatobilliary, surgery, gastroenterology and pathology to people across the North West, including our regional centre of excellence for nephrology, renal transplantation, cancer surgery, vascular surgery, nuclear medicine, haematology, lithotripsy, tropical and infectious diseases, dermatology and dental services.

http://www.rlbuht.nhs.uk/

Salford Royal NHS Foundation Trust
University Teaching Trust
safe • clean • personal

Salford Royal NHS Foundation Trust is an integrated provider of hospital, community and primary care services, including the University Teaching Hospital, and has the highest consistent rating for service quality. It employs 6000 staff and provides local services to the City of Salford and specialist services to Greater Manchester and beyond. Specialist care is offered to people from all over the UK for brain, neuroscience, kidney, bone, intestine or skin conditions.

http://www.srft.nhs.uk/

University Hospital Southampton NHS Foundation Trust

University Hospital Southampton NHS Foundation Trust provides services to about 1.3 million people living in Southampton and south Hampshire, and specialist services such as neurosciences, cardiac services and children's intensive care to more than 3 million people in central southern England and the Channel Islands. The Trust is also a major centre for teaching and research in association with the University of Southampton and partners including the Medical Research Council and Wellcome Trust.

http://www.uhs.nhs.uk/

University Hospitals Birmingham NHS Foundation Trust

University Hospitals Birmingham NHS Foundation Trust (UHB) is the leading university teaching hospital in the West Midlands, and one of the most consistently high-performing Trusts in the NHS, rated as "excellent" for financial management and for quality of clinical and non-clinical services by the Healthcare Commission. We employ 7200 staff and provide adult services to more than 500,000 patients every year. We are a regional centre for cancer, trauma, burns and plastics, and have the largest solid organ transplantation programme in Europe.

http://www.uhb.nhs.uk/

Right Care continues to pay homage to the inspirational publication, *The Dartmouth Atlas of Health Care*, and the vision and commitment of Professor John Wennberg who first charted this territory.

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Foreword

We wholeheartedly welcome the *NHS Atlas of Variation in Healthcare for People with Liver Disease*. Liver disease is a growing problem in England, and sadly far too many people will already know someone who has died from end-stage liver disease or liver cancer. Deaths have increased by a quarter in less than 10 years, and in this country liver disease affects growing numbers of increasingly younger people in contrast to the other major causes of death which are affecting fewer people at a later age than ever before. All three main causes of liver disease – alcohol-related liver disease, fatty liver disease and viral hepatitis – continue to affect increasing numbers of people despite the fact that all three are preventable.

Sharing and publishing data on the burden of liver disease, the performance of services, expertise, practices and outcomes will help providers to learn from each other and develop a more effective service based on population planning and patient need. It will highlight gaps in prevention initiatives and the provision of health services and will draw attention to localities where improvements are needed. Most importantly, it will empower patients to ask questions about the healthcare they receive and the options available to them, and to help identify ways in which to improve services.

We hear first-hand through our helplines and in forums and networks how variations in liver services affect patients across England: there is variation in when and how people are diagnosed, the information they receive on diagnosis, access to treatments, the support they are offered, their experiences with doctors and nurses, in hospitals and during end-of-life care. For instance, in an All-Party Parliamentary Hepatology Group audit of hepatitis C services in hospitals in England in 2010, it was found that different hospitals had very different policies on who was eligible to receive hepatitis C treatment. These differences in local policies resulted in a fivefold variation in the proportion of new hepatitis C patients being offered treatment in hospital, a range of 20–100%. It is likely that there is an even greater degree of variation in the proportion of patients actually reaching the service for treatment, with a high proportion unlikely to be referred to secondary care.

Another issue of concern is the potential inequity of access in consideration for and referral to liver transplantation. Equally important is the need for effective transition services for the transfer of paediatric patients to adult services. In this case, it is important to build on the successful work undertaken to configure services and manage shared care in the paediatric cohort, which has resulted in a significant reduction in mortality. This group of patients presents a challenge because the small numbers mean that their needs may be considered less important when viewed against mainstream adult services. We emphasise this point in order to alert commissioners and providers to the increasing workload in adult services that will be generated by a group of patients who have very different needs from those of the established adult population.

Although we recognise that there will always be some warranted variation in service models, depending on the demographics and prevalence of liver disease in each locality, all patients need to receive the same high quality of care, access to expertise, procedures and treatments, and should be assured of the same outcomes irrespective of where they live in accordance with the NHS Constitution which declares that the NHS should provide a comprehensive service available to all.

Of greatest concern in this Atlas is the revelation that there are virtually no data on the performance of services or on patient outcomes. It is not only challenging for commissioners, but also unacceptable that many hospitals and other service providers are not able to state how or if the liver services they deliver benefitted patients. Data on how many patients received treatment and how many were cured, on all causes of death, including contributory liver disease, and on the demographics and history of each patient should be routinely collected and published. In the absence of such data, how can patients ascertain whether they are receiving a good-quality service and how can commissioners be sure they are obtaining value for money? Choice is at the heart of the NHS, but patients are not able to make informed choices if they do not have this crucial information. It is vital that each patient is as fully informed as possible about the options available

to them, and is encouraged to identify the best possible care pathway for their condition.

We welcome the increase in the amount of information and data available in the public domain on some of the important elements that contribute to a patient's experience of care at their local hospital or clinic, such as car parking, catering, waiting times and facilities. To date, however, the information made available has not been fit for purpose to answer the most important question for a patient with liver disease: will I get a good service and the best possible outcome?

The publication of the *NHS Atlas of Variation for People with Liver Disease* is a good start in providing area-specific comparative disease data to highlight where variation exists and where commissioners and providers need to focus attention to eliminate waste and increase value. We look forward to continuing to work with the National Clinical Director for Gastrointestinal and Liver Disease, the NHS Commissioning Board, Public Health England, clinical commissioning groups, local authorities and the Care Quality Commission to reduce unwarranted variation and improve the quality and outcomes of care. Only then will people with liver disease have the knowledge they need to make truly informed choices.

Catherine Arkley
Chief Executive
Children's Liver Disease Foundation

Charles Gore
Chief Executive
The Hepatitis C Trust

Andrew Langford
Chief Executive
British Liver Trust

February 2013

Reducing unwarranted variation: right care for people with liver disease

Liver disease and population health

In the *Annual Report of the Chief Medical Officer (CMO), Volume 1, 2011*,[1] liver disease was identified as one of three key issues for population health because it is:

> *"the only major cause of mortality and morbidity which is on the increase in England whilst decreasing among our European neighbours."*

Moreover, liver disease can progress unnoticed for many years; obvious signs and symptoms do not become manifest until the disease reaches a relatively late stage. The CMO identified two strands of work that need to be integrated across all aspects of service provision for optimum efficacy:

1. Preventative measures involving a combination of public health policy initiatives, such as action on obesity and harmful alcohol use, and increased awareness among the public of liver health;

2. Improved detection of the early signs of liver disease through appropriate risk assessment strategies in local populations and the use of appropriate tests to identify liver disease that can be reversed or treated.

To reduce presentations at a late stage of disease, service providers need to adopt a pro-active approach. The CMO's recommendation on liver disease is shown in Box I.1. In addition, the Secretary of State has published *Living Well for Longer: A call to action to reduce avoidable premature mortality*, in which he outlines his ambition to cut avoidable deaths from the five major causes including liver disease.[2]

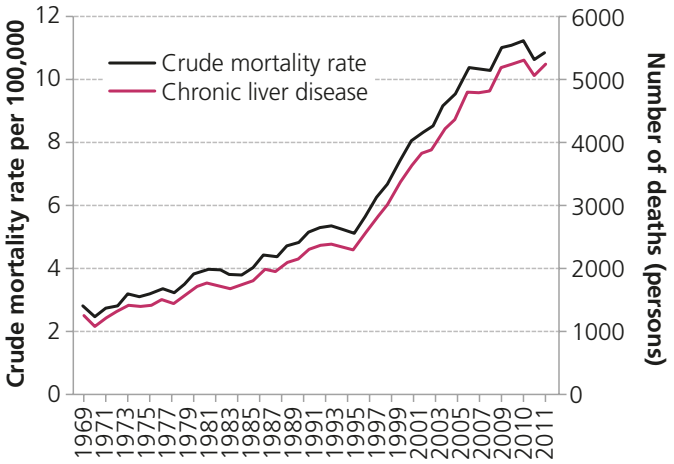
Box I.1: CMO's recommendation on liver disease[1]

Action on preventing, identifying and treating liver disease is a priority and needs to be included in local health and wellbeing strategies.

The burden of liver disease

Mortality from liver disease has been increasing for the past 20 years. During the last few years, it appears to have reached a plateau, although it is not known whether this trend in mortality can be reversed (Figure I.1). When compared with mortality rates in the 1980s, there is an excess of approximately 7 deaths per 100,000 population a year due to liver disease.

FIGURE I.1: MORTALITY FROM CHRONIC LIVER DISEASE 1989–2011



Some of these excess deaths can be ascribed to improved methods of coding and recording data. It is interesting to note that the number of excess deaths is similar to the size of gap between the mortality rate in the UK and mortality rates in Scandinavia, countries renowned for accurate health records (Figure I.2). In recent years, many factors may have contributed not only to the increase in liver disease but also to recorded mortality rates, including increased awareness, and improved diagnosis and coding. The principal causative factors, however, are alcohol-related liver disease and viral hepatitis.

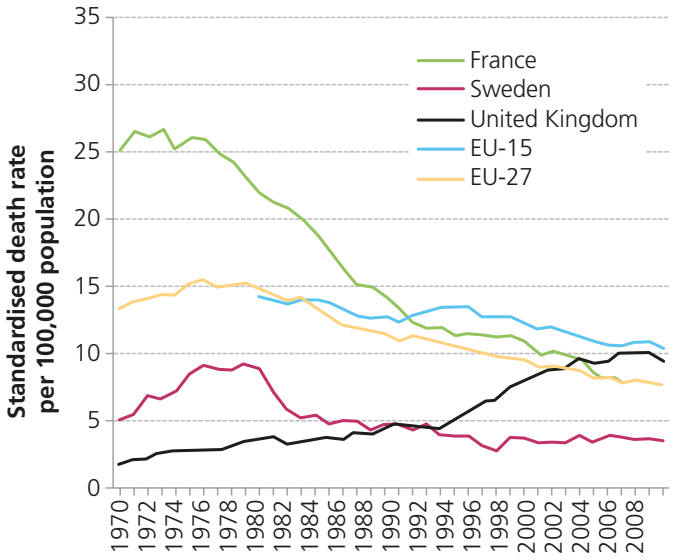
Latterly, there has been an increase in non-alcohol-related fatty liver disease, which is associated with obesity or diabetes. This trend seems to follow that in

1 Davies SC (2012) Annual Report of the Chief Medical Officer. Volume 1, 2011, On the State of the Public's Health. Department of Health, London. http://www.dh.gov.uk/health/2012/11/cmo-annual-report/ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_130401

2 Public Health Policy & Strategy Unit and NHS Commissioning Unit (2013) Living Well for Longer: A call to action to reduce avoidable premature mortality. Department of Health. http://www.dh.gov.uk/health/2013/03/mortality

the USA where non-alcohol-related fatty liver disease is now the leading cause of chronic liver disease, although the contribution it makes to mortality is uncertain.[3] Information on people at risk of so-called 'fatty liver disease', or the more pathological form known as steatohepatitis, can be ascertained only by estimating the number of people who are obese or who have Type 2 diabetes mellitus. In these sub-groups, 65% and 90% of people, respectively, will have excess fat in their livers, causing abnormal liver tests, and about one in five will have steatohepatitis, which may progress to cirrhosis in some people with the condition. The implications for health services of non-alcohol-related fatty liver disease are concerning. Many chronic health problems are caused or exacerbated by obesity, but the rapid increase in numbers means that a proportion of people will also develop liver disease and the attendant complications. Of particular concern is the number of children at future risk of liver disease,[4] and the possible synergistic effect of alcohol and obesity causing greater rapidity in the progression to cirrhosis.[5]

FIGURE I.2: PREMATURE MORTALITY FROM CHRONIC LIVER DISEASE AND CIRRHOSIS IN PEOPLE AGED UNDER 65 YEARS IN THE UK AND EUROPEAN UNION (EU) COUNTRIES (EU-15, EU-27, AND FRANCE AND SWEDEN)



Deaths and morbidity due to viral hepatitis are mainly due to hepatitis C infection, which is most common among people who inject or who have injected drugs using shared paraphernalia.[6] Chronic hepatitis B does not seem to feature prominently as a cause of death, but is known by clinicians to cause liver disease and contribute to mortality in some localities, predominantly among people who acquired the infection either at birth or in early childhood in countries where there is a higher prevalence than that in the UK. Death due to liver disease can be associated with other co-morbidities, such as renal failure and haemophilia. All chronic liver disease carries an increased risk of primary liver cancer, a cause of death not always ascribed to the original aetiology. Although it is unlikely that liver disease or associated mortality is over-reported, they may be under-reported.

Variation in liver disease and liver services in England

The first group of maps in this Atlas highlight variation in the outcomes of liver disease, some of which will be influenced by variations in the burden of disease. Although there is variation in outcomes across England, when compared with outcomes in other EU countries, all localities need to improve. Liver transplant is undertaken for end-stage liver disease in some people who would otherwise die and therefore this indicator may be considered as a crude approximate surrogate of potential mortality. Commissioners will want to ensure that populations not directly served by one of the six transplant centres in England have access to adequate expertise and consideration as and when required. Scoring systems have been devised for liver disease to help predict survival and activity limitations, but in practice they are often used to guide only the timing of referral for consideration of liver transplant and not the planning of end-of-life care.[7] Approximately three-quarters, or more, of deaths due to liver disease occur in hospital[8] and a high proportion of these patients appear to have multiple unplanned admissions in the two years preceding death, which would suggest that care pathways could be better planned.[7] It is hoped that some of the indicators in this Atlas may help focus attention on this issue.

3 Lazo M, Hernaez R, Bonekamp S, Kamel IR, Brancati FL, Guallar E, Clark JM (2011) Non-alcoholic fatty liver disease and mortality among US adults: prospective cohort study. *British Medical Journal* 343 (Nov 18): d6891. doi:10.1136/bmj.d6891

4 Cheung CRLH, Kelly DA (2011) Non-alcoholic fatty liver disease in children. *British Medical Journal* 343; d4460.

5 Liu B, Balkwill A, Reeves G, Beral V, Million Women Study Collaborators (2010) Body mass index and risk of liver cirrhosis in middle aged UK women: prospective study. *British Medical Journal* Mar 11;340:c912. doi: 10.1136/bmj.c912.

6 Health Protection Agency (2012) Hepatitis C in the UK. 2012 Report. http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317135237219

7 Department of Health (2008) End of Life Care Strategy – promoting high quality care for all adults at the end of life. http://www.dh.gov.uk/health/2011/07/end-of-life-care-strategy/ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

8 Effiong K, Osinowo A, Pring A, Verne J (2012) *Deaths from liver disease. Implications for end of life care in England.* National End of Life Care Intelligence Network. http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease.aspx

Several maps on the causation of liver disease have been included because if outcomes are to be improved the root causes need to be tackled through a network of agencies.

Some of the indicators presented in this Atlas are beyond the boundaries of pure liver disease, such as Maps 31–34 on hepatobiliary conditions. This is because there is a considerable overlap between pathways and processes for both sets of conditions, and some of the hepatobiliary indicators suggest variation in service performance that may not be restricted to hepatobiliary conditions.

Why does variation matter?

In service provision, there is no one-size-fits-all solution:

- Local services for some sub-populations need to address particular challenges;
- Service innovation and adaptation can occur at different rates in different situations.

Despite this, it is important to be mindful of variations not only in service provision but also in outcomes, and understand why they may occur to ensure that standards of care are being met.

There are two ways to do this:

1. by auditing services and outcomes against specified guidance or standards – although there have been some excellent examples of this type of approach few to date are relevant to liver disease;
2. by examining datasets in order to pose questions about services, the process of delivery, clinical practice, performance and outcomes.

Maps of variation in healthcare matter because they support an understanding that different resources or solutions may be required in different localities, but they also serve as a powerful tool for orientation, a comparator and a benchmark to show commissioners, clinicians and providers where they stand among their peers. Maps can help to highlight localities where variation in outcomes may require more detailed investigation or a different solution. There are different types of variation, however, and it is important to focus on unwarranted variation in performance, processes and outcomes.

John Wennberg, who founded the pioneering *Dartmouth Atlas of Health Care*,[9] defined unwarranted variation in healthcare as:

> *"variation that cannot be explained on the basis of illness, medical evidence, or patient preference".*[10]

Indeed, many years earlier Glover had documented a doubling in the number of tonsillectomies performed across England and Wales between 1919 and 1937 and described an almost fourfold variation in the incidence of tonsillectomy among regions. Glover commented that for the number of tonsillectomies performed there was

> *"no correlation between the rate of incidence and any impersonal factor, such as overcrowding, poverty, bad housing, or climate".*[11]

Glover suggested that the utilisation of the procedure was due to "variations of medical opinion on the indications for operation". Likewise, Wennberg concluded that:

> *"much of the variation … is accounted for by the willingness and ability of doctors to offer treatment rather than differences in illness or patient preference".*[12]

In the *NHS Atlas of Variation in Healthcare*, first published in 2010, it was demonstrated that unwarranted variation is ubiquitous in England across a wide range of indicators.[13] In the King's Fund report, *Variations in Health Care – the Good, the Bad and the Inexplicable*, it was concluded that:

> *"the existence of persistent unwarranted variations in health care directly impacts on equity of access to services, the health outcomes of populations and efficient use of resources".*[14]

When evaluating variation in clinical practice, Wennberg suggests categorising healthcare into three groups as shown in Box I.2.

9 Wennberg J et al (1996) *The Dartmouth Atlas of Health Care.* http://www.dartmouthatlas.org/downloads/atlases/96Atlas.pdf

10 Wennberg J (2010) *Tracking Medicine: A Researcher's Quest to Understand Health Care.* Oxford University Press. http://www.dartmouthatlas.org/

11 Allison Glover J (1938) The Incidence of Tonsillectomy in School Children. *Proceedings of the Royal Society of Medicine May 1938*; 1219-1236.

12 Wennberg JE (2011) Time to tackle unwarranted variations in practice. *BMJ* 2011; 342 doi: http://dx.doi.org/10.1136/bmj.d1513 (Published 17 March 2011)

13 Right Care (2010) *The NHS Atlas of Variation in Healthcare: Reducing unwarranted variation to increase value and improve quality, November 2010.* http://www.rightcare.nhs.uk/atlas/

14 Appleby J, Raleigh V (2011) *Variations in Health Care – the Good, the Bad and the Inexplicable.* The King's Fund. http://www.kingsfund.org.uk/publications/healthcare_variation.html

Box I.2: Types of variation[12]

- Effective care, defined as interventions for which the benefits far outweigh the risks; in this case the "right" rate of treatment is 100% of patients defined by evidence-based guidelines to be in need, and in this case unwarranted variation is generally a matter of under-use.
- Preference-sensitive care, defined as when more than one generally accepted treatment option is available, such as elective surgery; here, the "right" rate should depend on informed patient choice, but treatment rates can vary extensively due to differences in professional opinion.
- Supply-sensitive care, which comprises clinical activities such as consultations, diagnostic tests, and hospital admissions, for which the frequency of use relates to the capacity and performance of the local healthcare system; these measures commonly reflect care for people with long-term conditions; as Wennberg notes, high rates of use of supply-sensitive care do not necessarily correlate with better outcomes. In other words, increased spending and greater use of health services does not necessarily result in better outcomes and much of medical practice remains empirical.

Does unwarranted variation matter to patients?

Clearly, premature death is an adverse outcome for patients, and is a prominent feature of liver disease, as are unplanned admissions, many re-admissions, and certain complications. The critical factors in addressing these aspects of liver disease are:

- early recognition and diagnosis of the disease;
- the provision of services designed around patients' needs;
- adherence to best-practice guidelines;
- the integration of local services, overseen by clinical leaders.

As liver disease and its complications often take many years to develop, the fact that there is considerable variation in the indicators presented in this Atlas would suggest that the existing system of healthcare is reactive rather than pro-active, problem-orientated rather than outcome-focussed and task-centred rather than transformational for well-being. Thus, it has been designed from the perspective of providing health services rather than from the perspective of ascertaining patients' needs for healthcare. It is for these reasons that in the *NHS Atlas of Variation in Healthcare, November 2011* it was concluded that:

> *"the need to identify and reduce unwarranted variation must be placed at the centre of commissioning decision-making, and also needs to be a priority for clinicians and patients".*[15]

People in the local population, especially those who are patients or carers, need to be assured that service providers are addressing their needs. Therefore, they will be concerned about the existence of unwarranted variation and its consequences. In recognition, we have asked patient organisations to contribute their views in the Foreword of this Atlas and also in the narrative to the ideal pathway (see page 33–37). By this example, we hope that commissioners, providers and clinicians will also include patients and their carers in their deliberations when addressing unwarranted variation.

How should we orientate our direction of travel against a map showing variation?

As yet, there is no national specification for services related to liver disease. Our "compass" to help chart where we appear on the maps, therefore, should be the ideal service and optimal outcomes to which we all aspire. Although it is not always obvious what the ideal model should be, our guiding principles are:

- the NHS Constitution (see Box I.3);
- relevant guidance from the National Institute of Health and Clinical Excellence (NICE)[16] and/or from specialist societies when available;
- the quality standards developed for services related to liver disease.

15 Right Care (2011) *The NHS Atlas of Variation in Healthcare: Reducing unwarranted variation to increase value and improve quality*, November 2011. http://www.rightcare.nhs.uk/atlas/

16 As of 1 April 2013, the National Institute for Health and Clinical Excellence will be known as the National institute for Health and Care Excellence; it will retain the acronym NICE.

Box I.3: Extracts from the NHS Constitution[17]

The NHS belongs to the people.

It is there to improve our health and well-being, supporting us to keep mentally and physically well, to get better when we are ill and, when we cannot fully recover, to stay as well as we can to the end of our lives. It works at the limits of science – bringing the highest levels of human knowledge and skill to save lives and improve health. It touches our lives at times of basic human need, when care and compassion are what matter most.

Seven key principles guide the NHS in all it does:

1. The NHS provides a comprehensive service, available to all
2. Access to NHS services is based on clinical need
3. The NHS aspires to the highest standards of excellence and professionalism
4. NHS services must reflect the needs and preferences of patients, their families and their carers
5. The NHS works across organisational boundaries and in partnership with other organisations in the interest of patients, local communities and the wider population
6. The NHS is committed to providing best value for taxpayers' money and the most effective, fair and sustainable use of finite resources
7. The NHS is accountable to the public, communities and patients that it serves

Some consideration of "value for money" is also essential; quality and innovation are important contributors to this concept.

Healthcare knowledge is often described as "asymmetrical", with the flow being mainly from clinician to patient. It is important, however, to listen carefully to the "patient voice" – customer care is a key component of healthcare and affects the nature of outcomes.

We have sought the views of patient groups about what they consider to be the components of a "good" liver service; these have been collated and are presented in the section following this Introduction, entitled "A patient's view of the ideal pathway" (page 33).

The Constitution states that:

- the NHS will serve people irrespective of gender, race, disability, age, sexual orientation, religion or belief;
- the NHS has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life-expectancy are not keeping pace with those in the rest of the population.

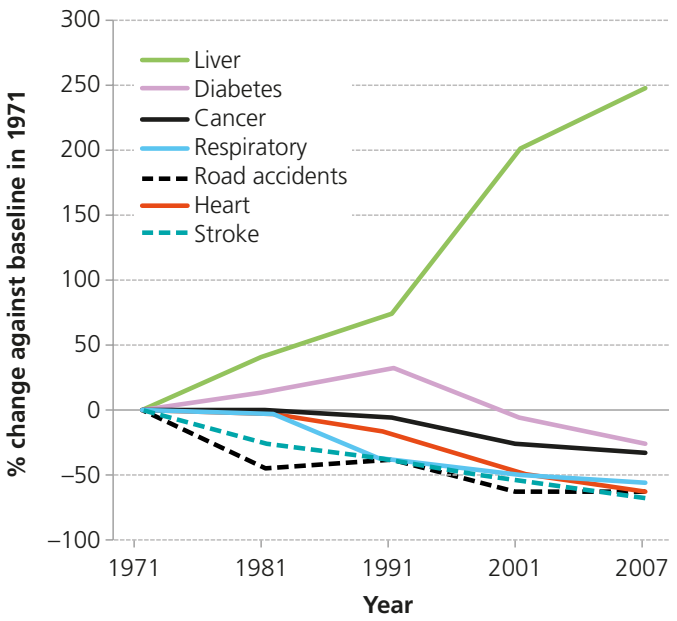
This section of the Constitution is particularly relevant to some of the subgroups in the population who are at risk of liver disease.

Data and information on variation in liver diseases and liver services

The Atlases of Variation in Healthcare are not prepared on a blank canvas and do not simply reflect differences in what NHS service providers deliver or do. The burden of disease that presents to the NHS has its origin in society and to an extent in peoples' behaviours and lifestyle choices, which may vary among different communities or settings. This is the case for liver disease, as it is for cardiovascular and respiratory disease. During the last 20 years, however, attitudes about cardiovascular or respiratory disease have changed, such that both the diseases and the causes of those diseases have been tackled, and the benefits can be seen in declining levels of mortality. By comparison, this is not the case for liver disease, especially as mortality has been increasing (see Figure I.3); thus, we are only at the beginning of this process. We need to acknowledge not only the problem but also the extent of the problem before progress can be made in reversing the trend. Essential to this process of recognition and acknowledgement is developing a better understanding, based on data, of the causes of variation, and whether they are warranted or unwarranted.

17 Department of Health (2012) The NHS Constitution for England. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132961

FIGURE I.3: TREND IN MORTALITY FROM LIVER DISEASE IN RELATION TO TRENDS IN MORTALITY FROM OTHER CAUSES, ENGLAND, 1971–2007



In preparing this Liver Disease Atlas, it became clear there was a dearth of routinely collected detailed information about liver disease (see Box I.4 for a list of items for which data are limited); finding information about liver services was also challenging.

Box I.4: Aspects of liver disease for which data are limited

- The numbers of people with established and/or different stages of cirrhosis
- The number of people experiencing complications that require expensive resource or intervention
- The numbers of people receiving various levels of interventions for alcohol-related problems and the associated outcomes
- The numbers of people tested and treated, or not treated, for hepatitis B or hepatitis C, and the outcomes of treatment
- The outcomes of interventions for people with fatty liver disease
- Activity data for treatment of patients in primary care and ambulatory care settings (e.g. outpatient clinics)

Information about alcohol-related issues is a particular problem because alcohol-related disease is often regarded as 'someone else's responsibility'. Although alcohol is the most important cause of liver disease, it also contributes to injuries due to trauma and violence, to cardiovascular disease and to other diseases.

The data that are available tend to be focussed towards the severe and late end of the spectrum of liver disease.[18] 'Upstream' data on the number of people at risk or identified with early disease are lacking. In the absence of such data, it may be difficult to plan and deliver services and to understand the outcomes of care. In the Liver Disease Atlas, however, we have taken a first step in exploring some of the related datasets, with the aim of providing useful information and thereby helping patient groups, clinicians, providers and commissioners pose questions about services for people with liver disease.

Some of the indicators in the Liver Disease Atlas have appeared in other NHS Atlases or in previous publications; however, the set of indicators in this Atlas have been collated to present a snapshot of services relevant to liver disease. Some indicators relating to pancreatobiliary conditions have been included because those patients frequently present with abnormal liver tests. As some of the services are shared, these indicators can highlight how services or teams are performing on specific elements of a pathway that should be integrated, i.e. they can act as 'warning signals' on a map of local services.

As the progression of liver disease is silent until the disease is at an advanced stage, most people who have or are at risk of liver disease are not aware that they have liver damage. It is usually identified by a series of blood tests or imaging tests. It has been estimated that up to 10–20% of the population of England are potentially at some risk of developing a degree of liver damage during their lifetime and, at any one time, between 600,000 and 700,000 individuals may have a significant degree of liver damage (Table I.1).

18 Beynon C, Hungerford D et al (2012) Burden of Liver Disease and Inequalities in the North West of England. http://www.nwph.net/nwpho/Publications/Burden%20of%20Liver%20Disease%20in%20the%20North%20West%20of%20England.pdf

Table I.1: Groups in the population at risk or affected by differing degrees of liver damage

Population subgroup in relation to liver diseases	Numbers at risk/affected (population of England: 56,000,000)	Basis of estimate [Data source: 2011 Census (England & Wales) unless otherwise stated]
At risk of liver disease	Up to 12,000,000	>20% of population is obese
At risk of alcohol-related liver damage	2,000,000	2,000,000 drink at harmful levels (>50 units/week for men; >35 units/week for women)[19]
With significant liver disease at least	600,000	Estimated from end-stage figures and natural history
With chronic viral hepatitis B and C at least	400,000	Estimated from data from HPA and surveys (at least 50% of hepatitis B and C is undetected)
With cirrhosis	30,000–60,000	Estimated from sources and natural history (up to 50% of cirrhosis is undetected)
Have liver disease as a direct cause of death	Up to 12,000 per annum	Liver disease is contributory in up to 36,000 deaths per annum[8]
Have primary liver cancer	~3000 per annum	Primary liver cancer only[20]
Adults undergoing liver transplant	~ 600 per annum	England & Wales

It is not known, however, how many of these individuals are aware that they have or are known by others to have liver damage. The available datasets are biased towards the severe end of the spectrum, i.e.:

- people admitted to an inpatient hospital bed, as recorded in hospital episode statistics (HES);
- people who die from liver disease, as recorded by death certification;
- people identified through cancer registries or laboratory reporting mechanisms.

The vast majority of people with liver disease are not recorded within these datasets. As it can take up to 20 years for liver disease to progress to a stage where people would first appear in these records, it is only possible to estimate the burden of liver disease when using these datasets. To gain a more complete picture, some of the assumptions can be triangulated with data from other sources and from surrogate sampling. For instance, in a laboratory survey in Leeds and Bradford covering a population of 1.3 million people extrapolated over one year, it was found that 10% of liver blood tests ordered in primary care were abnormal.[21] It is also possible to investigate community and hospital prescribing of drugs used predominantly for patients with liver disease (see Maps 12–14).

The importance of improving outcomes for people with liver disease

The NHS reforms[22,23] have highlighted the need to concentrate on outcomes, principal among which is:

> *To reduce premature mortality due to liver disease in people below 75 years*

This reduction in mortality is required from:

- an NHS-amenable perspective;[24]
- a public health avoidable mortality perspective.[25]

In a recent report on liver disease mortality, it was found that liver disease accounted for 12% of mortality in men aged 40–49 years.[8] For women under 75 years in the North West of England, liver disease is the principal cause of years of life lost,[26] a composite measure of the number of people dying and their age at death (see Map 2).

19 National Audit Office (2008) Department of Health - Reducing Alcohol Harm: health services in England for alcohol misuse. http://www.nao.org.uk/publications/0708/reducing_alcohol_harm.aspx

20 National Cancer Intelligence Network. http://www.ncin.org.uk/publications/data_briefings/liver_and_gall_bladder.aspx

21 Jones R, personal communication.

22 Department of Health (2010) Healthy lives, healthy people: our strategy for public health in England. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121941
Department of Health (2011) Healthy lives, healthy people: update and way forward. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128120

23 Department of Health (2010) Equity and excellence: Liberating the NHS. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

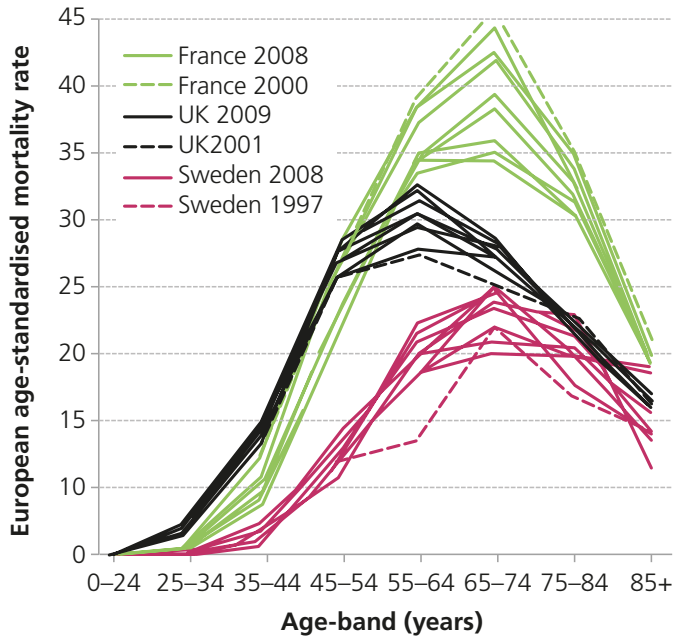
24 Department of Health (2011) NHS Outcomes Framework 2012/13. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131700

25 Department of Health (2012) Healthy lives, healthy people: Improving outcomes and supporting transparency. Part 1: A public health outcomes framework for England, 2013-2016. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_132559.pdf

26 Analysis conducted in 2010 by Tom Kennel, North West Public Health Observatory.

The findings in these reports underline that people with liver disease in the UK die at a younger age than people dying from the other main causes of mortality, such as cardiovascular disease, stroke, cancer or respiratory disease. Furthermore, people with liver disease in the UK appear to die at a younger age than their counterparts in other European Union (EU) countries (see Figure I.4). As alcohol is the main cause of death from liver disease in all countries, the reasons for this discrepancy are unclear but the recent trend in the UK of drinking large volumes of alcohol at a younger age could be a contributing factor.

FIGURE I.4: MORTALITY FROM CHRONIC LIVER DISEASE AND CIRRHOSIS BY AGE-BAND, 1997–2009 (SOURCE: WORLD HEALTH ORGANIZATION EUROPEAN DETAILED MORTALITY DATABASE)[27]



While developing a strategy to tackle the rising burden of liver disease, detailed consideration has been given to the relatively young age at death from liver disease, not only in relation to other conditions but also in relation to peers in other EU countries. It was concluded that much more needs to be done at an earlier stage of liver disease to reduce premature mortality. Indeed, the opportunities for intervention and the effect of intervention probably diminish with the progression of liver disease, whereas the relative costs of the interventions that can be applied increase (Figure I.5). Thus, early intervention:

- reduces costs;
- reduces the need for complex interventions;
- improves outcomes.

Expenditure on hepato-pancreato-biliary problems in NHS England

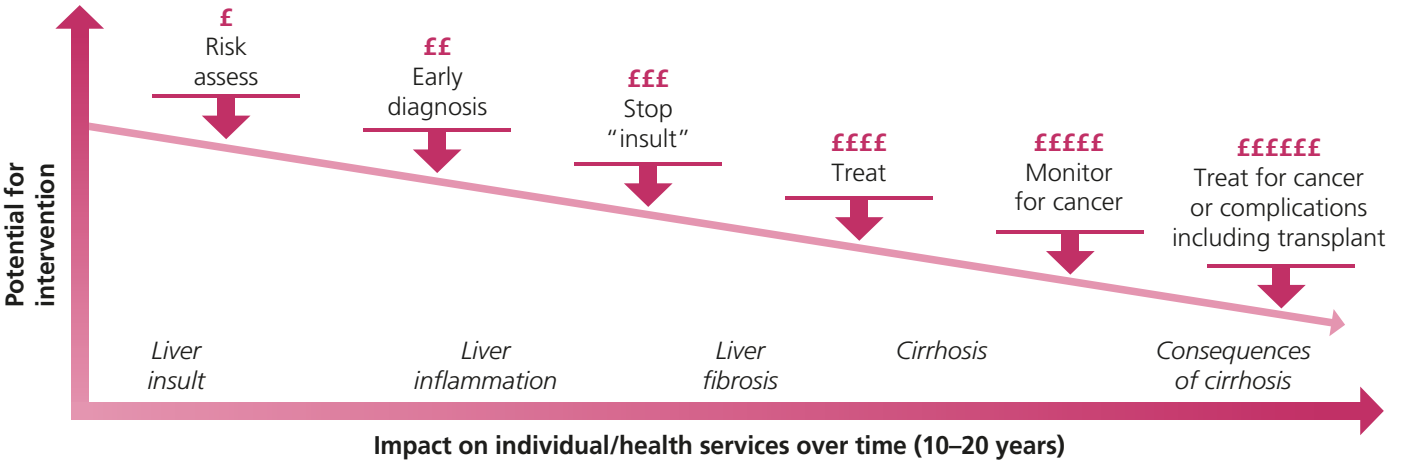
Programme budgeting and data on expenditure

Programme budgets are a retrospective appraisal of expenditure by health problem, based on the World Health Organization (WHO) International Classification of Disease (ICD). Healthcare organisations are required to split their expenditure by programmes of care based on medical condition.

Collecting expenditure data at commissioner level allows healthcare commissioners:

- to assess activity in healthcare programmes and the respective outcomes, leading to efficiency – value for money;
- to re-adjust the pattern of spending to obtain a better fit with the needs of the local population, leading to increased effectiveness – better outcomes;
- to reduce health inequalities, leading to a fairer share of resources and a reduction in inequity of health outcomes.

FIGURE I.5: THE POTENTIAL FOR, AND COST OF, INTERVENTION IN RELATION TO THE COURSE OF LIVER DISEASE



27 http://data.euro.who.int/dmdb/

Commissioner-level programme budgeting data are published annually in the form of a benchmarking tool[28] that enables commissioners to identify:

- how they spend their allocation over 23 disease categories and the respective subcategories;
- how expenditure at the level of disease category is split across 12 care settings (2010/11 data only);
- how their expenditure distribution pattern compares with other commissioners nationally and locally or who have populations with similar characteristics.

Other resources are also available, including the CCG Spend and Outcome Factsheets and Tool (SPOT).[29]

Degree of variation in expenditure on diseases of the hepato-pancreato-biliary system

Expenditure on liver disease and hepato-pancreato-biliary (HPB) disorders is reported annually in programme budgets. As programme budgets are based on health problems, it is possible to link expenditure with activity and outcomes, especially for inpatients. There is ongoing work to refine further the precision and relationship to activity for other aspects of expenditure including outpatient activity, community care and pharmacy activity.

The purpose of collecting data at this level is to obtain a greater appreciation of "where the money is going" and a global view of "what we are getting for the money we invest in the NHS". Comparative data are presented in this Atlas to empower commissioners, clinicians and providers to ask appropriate questions about local services and expenditure, and relate expenditure on services to disease activity and outcomes in their locality. Such a review may need to explore whether coding can be applied more consistently, but the principal purpose is to consider whether any of the variation observed is unwarranted.

For PCTs in England in 2010/11, the rate of expenditure on HPB problems ranged from £2042 to £23,327 per 1000 population (11-fold variation; see Map I.1, page 24). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is £7606–£18,794 per 1000 population, and the variation is 2.5-fold. Given that 51% of this expenditure is due to non-elective inpatient activity, and a further 27% is due to elective hospital activity (plus an additional 5% on outpatients and an additional 7% on specialist commissioning), an understanding of how these data relate to service activity and patient outcomes should be possible at a local level through a more detailed exploration of the datasets. Currently, payment by results (PbR) tariff spend accounts for about 65% of overall expenditure therefore local clinical commissioning groups (CCGs) are pivotal in the drive to optimise effective spending to achieve desirable outcomes.

At present, programme budgets cannot be linked directly to outcomes. Indeed, the interpretation of modelling on this topic poses difficulties, for example, mortality rates are available for liver disease whereas expenditure encompasses HPB disorders. Nonetheless, it is worthwhile for commissioners to reflect on the relationship between budget and relevant factors such as service provision, prevalence of disease and patient outcomes.

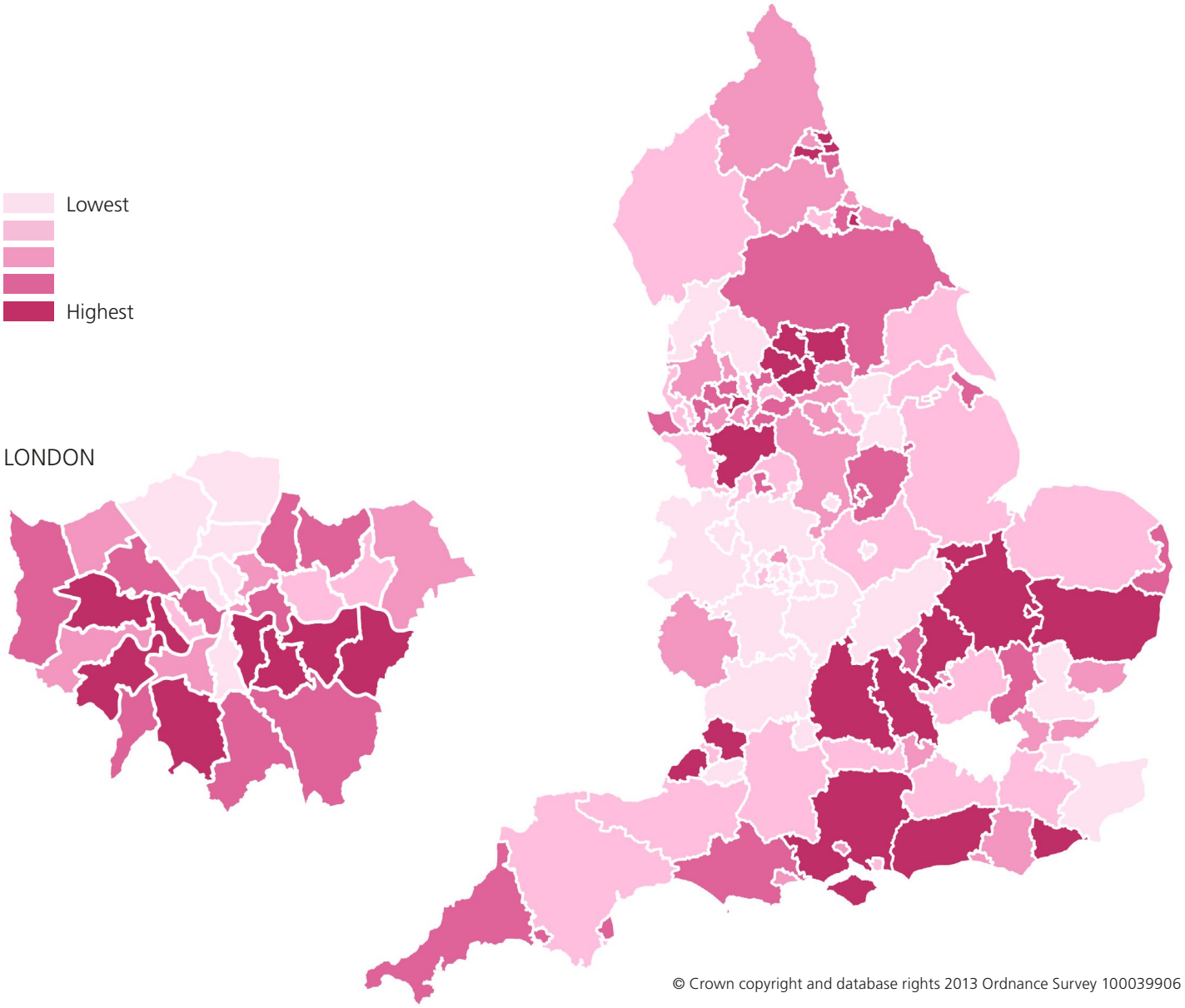
Various measures of liver disease, such as prevalence, admission rate, and mortality rate, can be used as a proxy for the burden of disease on the population. Moreover, the degree of correlation among these measures is strong. Two of the indicators in this Atlas that can be used as a proxy for the burden of liver disease – chronic liver disease mortality and admissions to hospital for alcohol-specific conditions in men – have been plotted in relation to the rate of expenditure on HPB problems by PCT (see Figures I.6 and I.7, respectively). Although there is only a weak, or a slight negative, correlation, respectively, there could be many reasons why expenditure appears to be higher or lower in relation to a higher or lower burden of disease. The principal reason for presenting programme budgeting data is to prompt questions at a local level so that commissioners, clinicians and providers can gain a greater understanding of:

- The level of expenditure on HPB disorders;
- Reasons for the expenditure;
- The ways in which expenditure is used;
- The potential for variation;
- If variation is apparent, the reasons(s) for the variation observed;

28 Department of Health – Programme budgeting PCT benchmarking tool – 2011. http://www.dh.gov.uk/health/2011/12/programme-budgeting-pct-benchmarking-tool-2011/

29 Department of Health. NHS Manual for Accounts Programme Budgeting 2011-12 – Programme Budgeting Guidance 2011–12. http://www.info.doh.gov.uk/doh/finman.nsf/4db79df91d978b6c00256728004f9d6b/07e5bbc99bedcc2880257a1b0039b860?OpenDocument
CCG Spend and Outcome Factsheets and Tool (SPOT). http://www.yhpho.org.uk/resource/view.aspx?RID=49488

MAP I.1: RATE OF EXPENDITURE ON HEPATO-PANCREATO-BILIARY PROBLEMS PER 1000 POPULATION BY PCT 2010/11 (POPULATION WEIGHTED BY AGE AND NEED)



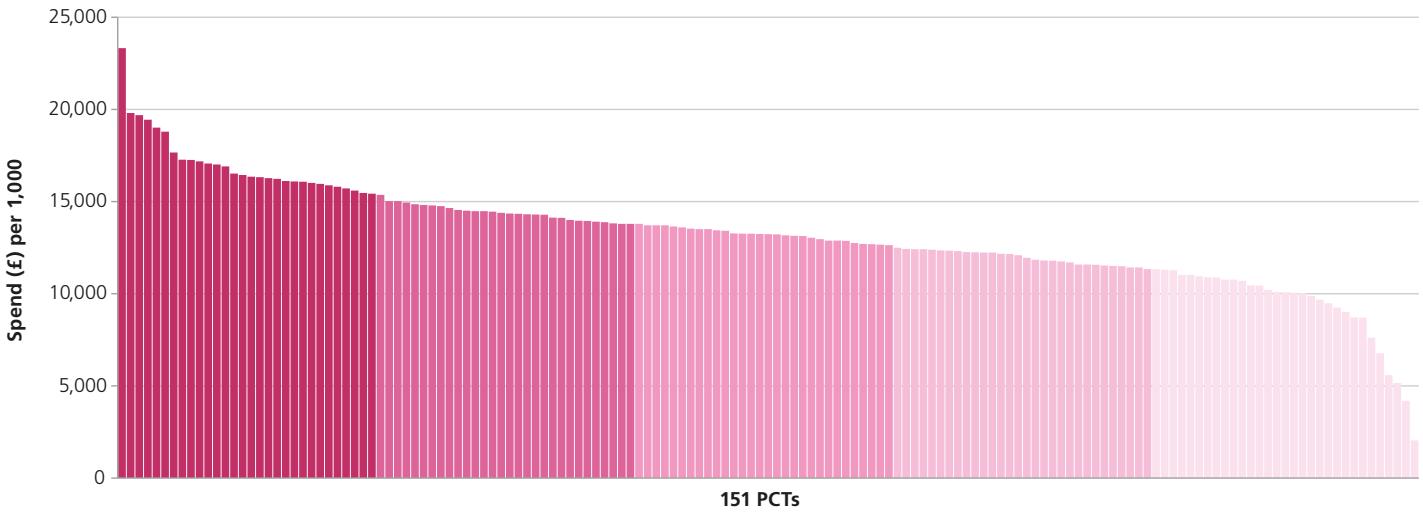


FIGURE I.6: CHRONIC LIVER DISEASE MORTALITY IN PEOPLE AGED UNDER 75 YEARS PER 100,000 POPULATION 2008–2010 IN RELATION TO EXPENDITURE ON HEPATO-PANCREATO-BILIARY PROBLEMS PER 1000 POPULATION 2010/11

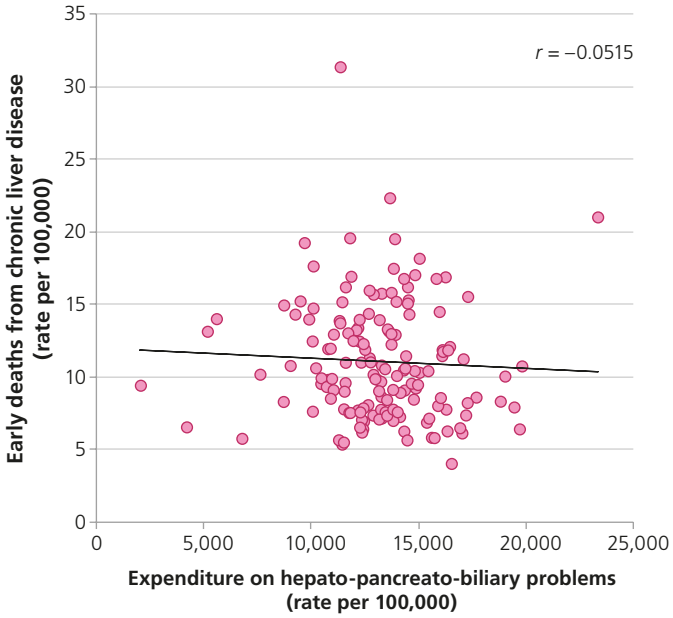
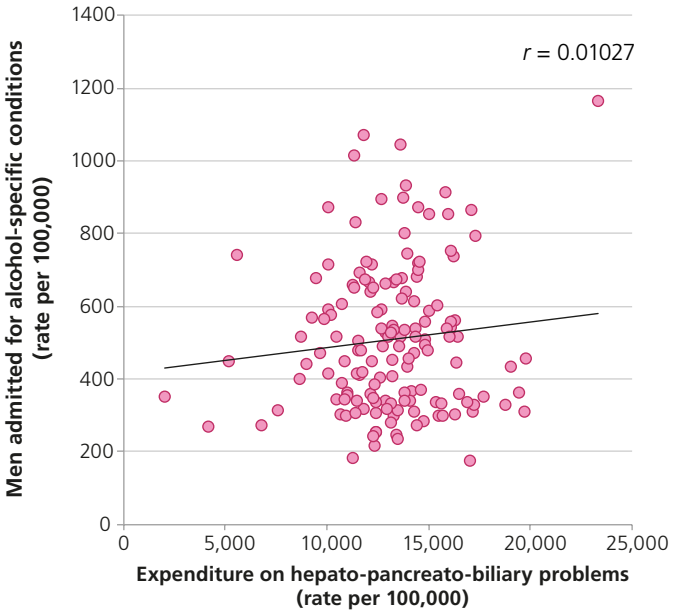


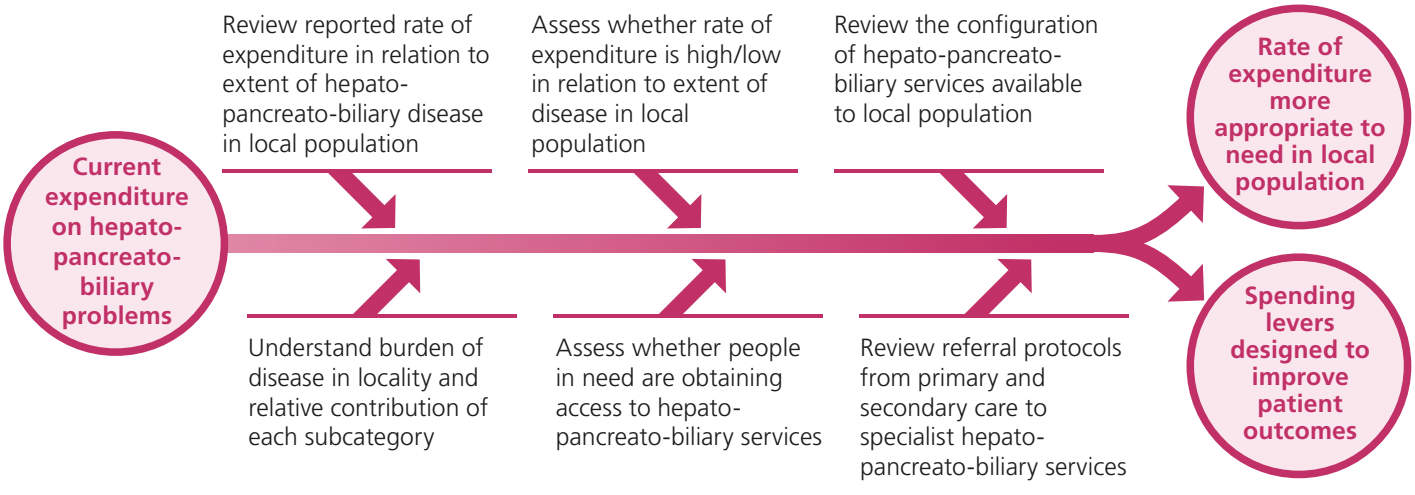
FIGURE I.7: ADMISSIONS TO HOSPITAL WITH ALCOHOL-SPECIFIC CONDITIONS IN MEN OF ALL AGES PER 100,000 POPULATION 2010/11 IN RELATION TO EXPENDITURE ON HEPATO-PANCREATO-BILIARY PROBLEMS PER 1000 POPULATION 2010/11



- Whether any of the variation observed is unwarranted;
- The potential reasons for unwarranted variation.

The options for action when investigating the level of expenditure on hepato-pancreato-biliary problems are shown in Figure I.8. One reason for variation in expenditure could be the level of deprivation in a local population. There is a moderately strong correlation (r=0.6753) between liver disease, and some of its causes, and the Index of Multiple Deprivation (IMD) 2010 (Figure I.9). The nature of this association is poorly understood, but the excessive consumption of equivalent amounts of alcohol appears to have a disproportionately harmful impact on people from deprived communities when compared with its effect on less-deprived people.[30] This disproportionate effect could be due to the presence of co-morbidities or to other factors such as the quality of nutrition. Although deprivation has been identified as a potential contributor to the variation in liver disease, it cannot account for the degree of variation observed in some of the indicators presented in this Atlas.

FIGURE I.8: OPTIONS FOR ACTION WHEN INVESTIGATING EXPENDITURE ON HEPATO-PANCREATO-BILIARY PROBLEMS



30 Erskine S, Maheswaran M, Pearson T, Gleeson D (2010) Socioeconomic deprivation, urban-rural location and alcohol-related mortality in England and Wales. *BMC Public Health* 10; 99-106. doi:10.1186/1471-2458-10-99 http://www.biomedcentral.com/1471-2458/10/99

FIGURE I.9: RATE OF YEARS OF LIFE LOST IN PEOPLE AGED UNDER 75 YEARS DUE TO MORTALITY FROM CHRONIC LIVER DISEASE INCLUDING CIRRHOSIS PER 100,000 POPULATION BY PCT 2008–2010 IN RELATION TO THE INDEX OF MULTIPLE DEPRIVATION (IMD) 2010 (1 = THE LEAST DEPRIVED; 100 = THE MOST DEPRIVED)

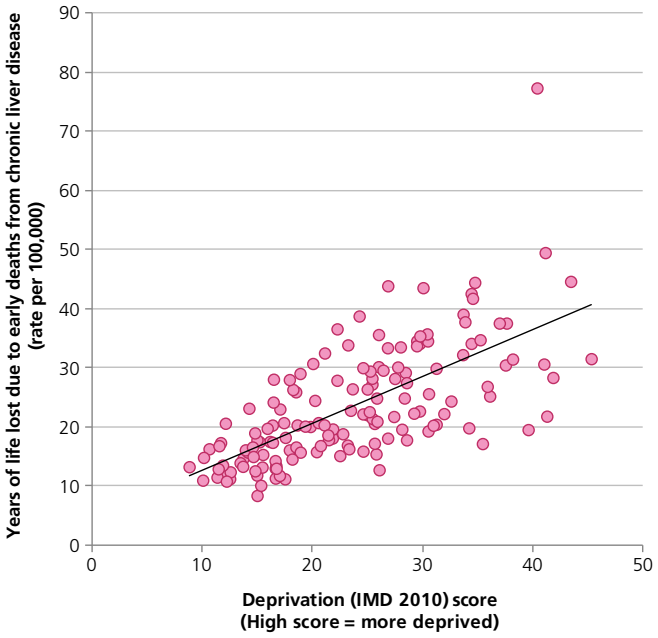
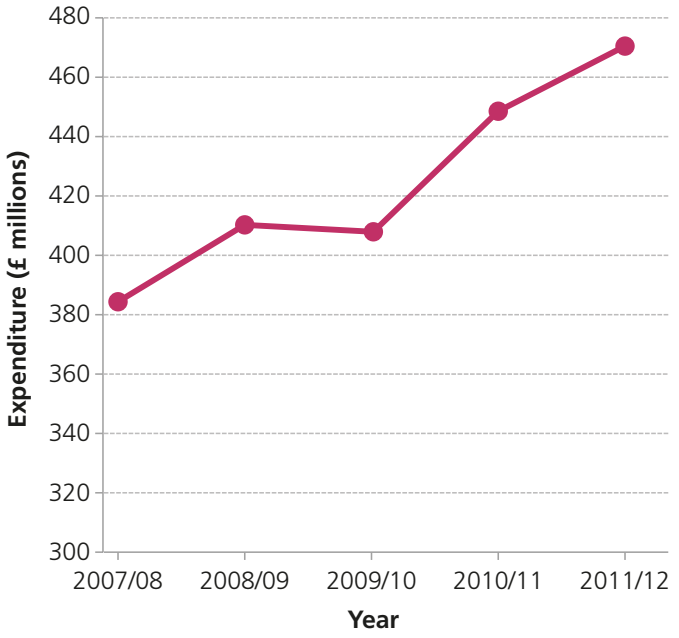


FIGURE I.10: HEPATO-PANCREATO-BILIARY INPATIENT PAYMENT BY RESULTS (PbR) TARIFF 2007/08–2011/12



Given the link with some of the socio-economic determinants of health, it is not possible for the NHS to address the issues surrounding liver disease by acting in isolation. In the Chief Medical Officer's recent report,[1] attention was drawn to the wider social context relating to liver disease, and which the Government has sought to address in the *Call to action on obesity*[31] and in its Alcohol Strategy.[32]

Although liver disease is only one aspect of HPB disorders, the volume of cases is growing, as is the impact of liver disease on population health (see Table I.1). From the indicators presented in this Atlas, it is vital that local commissioners, clinicians and providers take action not only to reduce unwarranted variation, but also to contain the escalating costs of service provision for HPB disorders (see Figure I.10) in the quest to derive increased value and improved patient outcomes from NHS resources.

Organisation of liver services in NHS England

Until relatively recently, there was very little information on the organisation of liver services in England. In the absence of such information, it is difficult for commissioners to assess whether there is adequate provision in their locality or region.

- Other than the six liver transplant centres in England, and some centralisation of liver and related surgical services in a defined number of hospitals,[33,34] there is no formal categorisation of liver services provided by the NHS.

- There is a lack of clarity about which professionals should be responsible for providing liver services, as highlighted in a report prepared by the British Association for the Study of the Liver (BASL) and the British Society of Gastroenterology (BSG) (Liver Section).[35] The professional societies acknowledge that the majority of liver services (Hepatology) are provided by gastroenterologists, but have also indicated that

31 Department of Health (2011) Healthy lives, healthy people: A call to action on obesity in England. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_130401

32 Home Office (2012) The Government's Alcohol Strategy. http://www.homeoffice.gov.uk/publications/alcohol-drugs/alcohol/alcohol-strategy?view=Binary

33 A Census of Medical Workforce & Infrastructure for Liver Disease Strategy: Summary of Findings (Final 2011). http://www.liver.nhs.uk/document.php?o=40

34 Liver Disease Patient Landscape and Care Provision. June 2011. http://www.liver.nhs.uk/publications/

35 British Association for the Study of the Liver (BASL) and the British Society of Gastroenterology (BSG) (Liver Section) (2009) A Time to Act: Improving Liver Health and Outcomes in Liver Disease. The National Plan for Liver Services U.K. 2009. http://www.bsg.org.uk/attachments/1004_National%20Liver%20Plan%202009.pdf

they and the British Liver Trust, which represents patients, would prefer to see more of the specialist services provided by hepatologists. There is no register of personnel with a particular interest in liver disease. Moreover, other specialists, such as infectious disease physicians, may also provide some services relevant to liver disease, i.e. treatment of viral hepatitis.[36]

Accordingly, information about acute Trust adult liver services was collected through a Census of Medical Workforce conducted by the Department of Health in 2010 (before the current reconfiguration of NHS organisations).[33] As part of the Census, regional leads were asked to collect information about all Trusts in each region in terms of their liver services, as well as gathering information about the specialists – consultant gastroenterologists and hepatologists – who provide diagnostic and treatment services for people with liver disease. On the basis of responses received, supplemented by an analysis of datasets covering activity in liver disease:

- adult liver services were categorised using the scheme shown in Box I.5;
- adult liver service networks across the country were visualised to show the different configurations that exist (see Figures I.11 and I.12 for two of the networks; for networks in all regions, see http://www.liver.nhs.uk/resources/regional_referral_maps/).

Despite the current reconfiguration of NHS organisations, the results of the Census still have validity because most liver services developed within the previous SHA boundaries; these, and the training Deaneries, appear to have been the main determinants of referral patterns. The situation, however, is complicated by two types of supra-regional referral arrangements:

- The number and location of liver transplant centres (n=6), which evolved for historical reasons rather than as planned service configurations;
- Hepatobiliary cancer services, reconfigured as a result of implementing the strategy 'Improving outcomes: a strategy for cancer'.[37]

The validity of the categorisation in Box I.5 is supported by an analysis of volume of activity (using HES data) for each category of liver service (see Figure I.13).

Box I.5: Classification of adult liver services

- Liver transplant centre: provides liver transplant services and (usually) a full complement of liver and hepatobiliary services
- Tertiary liver centre: has three or more hepatologists,[38] with two or more other units referring in for two or more liver services (a liver referral centre)
- Gastroenterology unit with hepatology: a gastroenterology unit which has at least one consultant spending more than 50% of their clinical time in liver services (not a major liver referral centre)
- Gastroenterology unit: a gastroenterology unit that does not have any hepatologists or gastroenterologists who spend more than 50% of their time in liver services

The North West liver service network shown in Figure I.11 does not have a liver transplant centre within its boundary. To access transplant services, patients travel to Newcastle, Leeds and Birmingham. This is in the context of the North West having greater need for liver services than most, if not all, other parts of England.

The East of England liver service network shown in Figure I.12 is centred on Cambridge/Addenbrookes Hospital, where the liver transplant centre is located. Some hospitals also refer patients into London for transplant at the Royal Free liver transplant centre. In general, the East of England has lower levels of liver disease and risk factors associated with liver disease when compared with the North of England, however, the current levels of liver disease are higher than levels seen in previous decades and higher than those presently seen in certain other European countries.

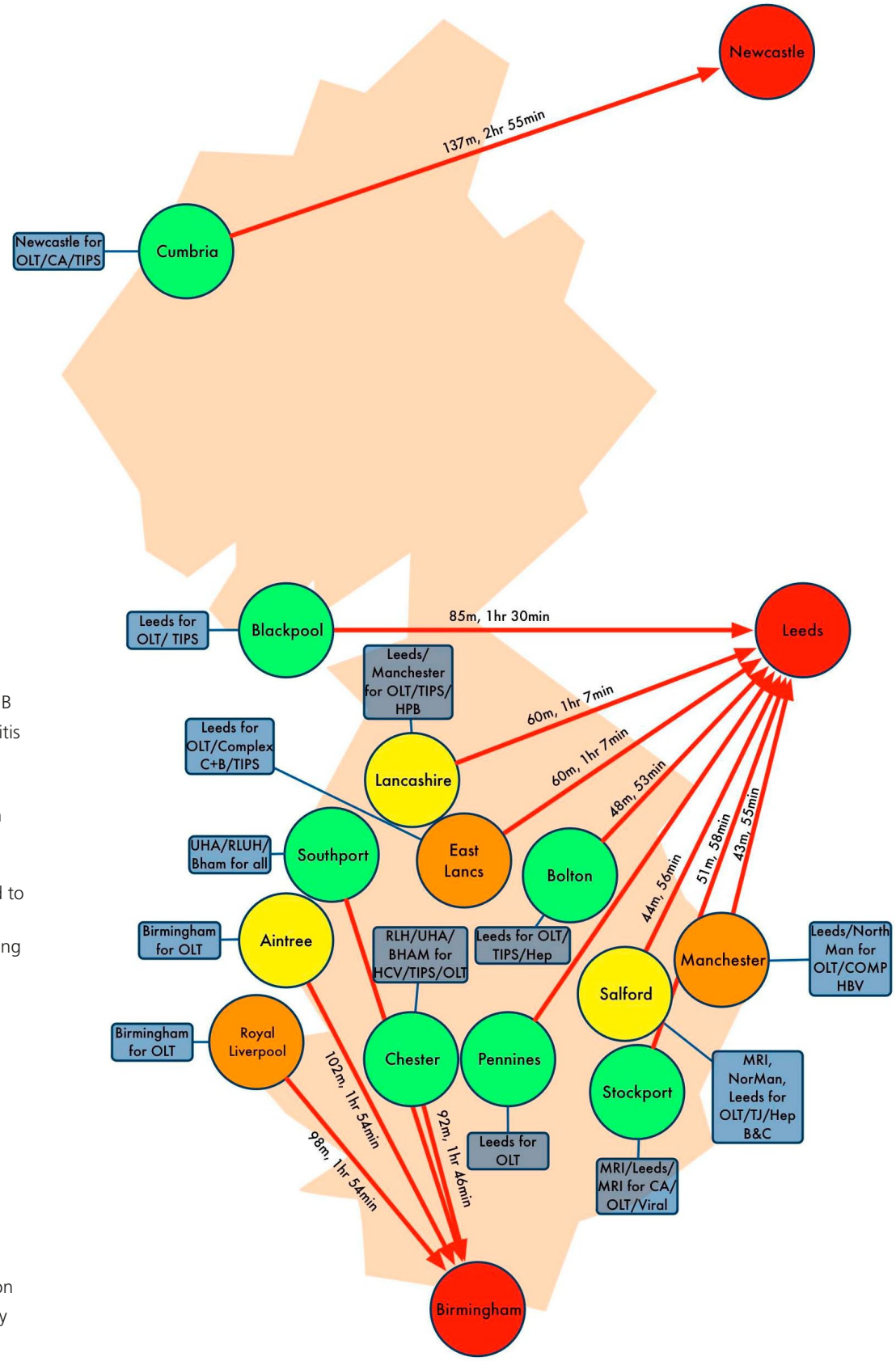
Liver transplant centres and the corresponding referral patterns can have a major impact on the quality of adult liver services and level of expertise available in

36 Parkes J, Roderick P, Bennett-Lloyd B, Rosenberg W (2006) Variation in Hepatitis C services may lead to inequity of health-care provision: a survey of the organisation and delivery of services in the United Kingdom. *BMC Public Health* 6:3. doi:10.1186/1471-2458-6-3. http://www.biomedcentral.com/1471-2458/6/3

37 Department of Health (2011) Improving outcomes: a strategy for cancer. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123371

38 A hepatologist has been self-defined as a clinician who spends more than 50% of their clinical time treating liver patients. Hepatology is a medical liver specialty and excludes surgery.

FIGURE I.11: THE NORTH WEST LIVER SERVICE NETWORK



Key to abbreviations (Figures I.11 & I.12)

COMPHBV = complex hepatitis B

Complex C & B: complex hepatitis C & B

HCV: hepatitis C virus

Hep = hepatitis; also used as an abbreviation for Hepatology

HPB: hepato-pancreato-biliary (usually but not exclusively used to refer to surgery)

MRI: magnetic resonance imaging

OLT: orthotopic liver transplant

TIPS: transvenous intrahepatic portasystemic shunt

TJ: transjugular, usually in the context of a liver biopsy (TJLBx) or TIPS

TJB: transjugular biospy

Locations:

Bham: Birmingham

NorMan: North Manchester

RFH: Royal Free Hospital, London

RLUH: Royal Liverpool University Hospital

UHA: University Hospital Aintree

Liver transplant centre

Tertiary liver centre

Gastroenterology with hepatology

Gastroenterology unit

Referrals

Referral type

FIGURE I.12: THE EAST OF ENGLAND LIVER SERVICE NETWORK

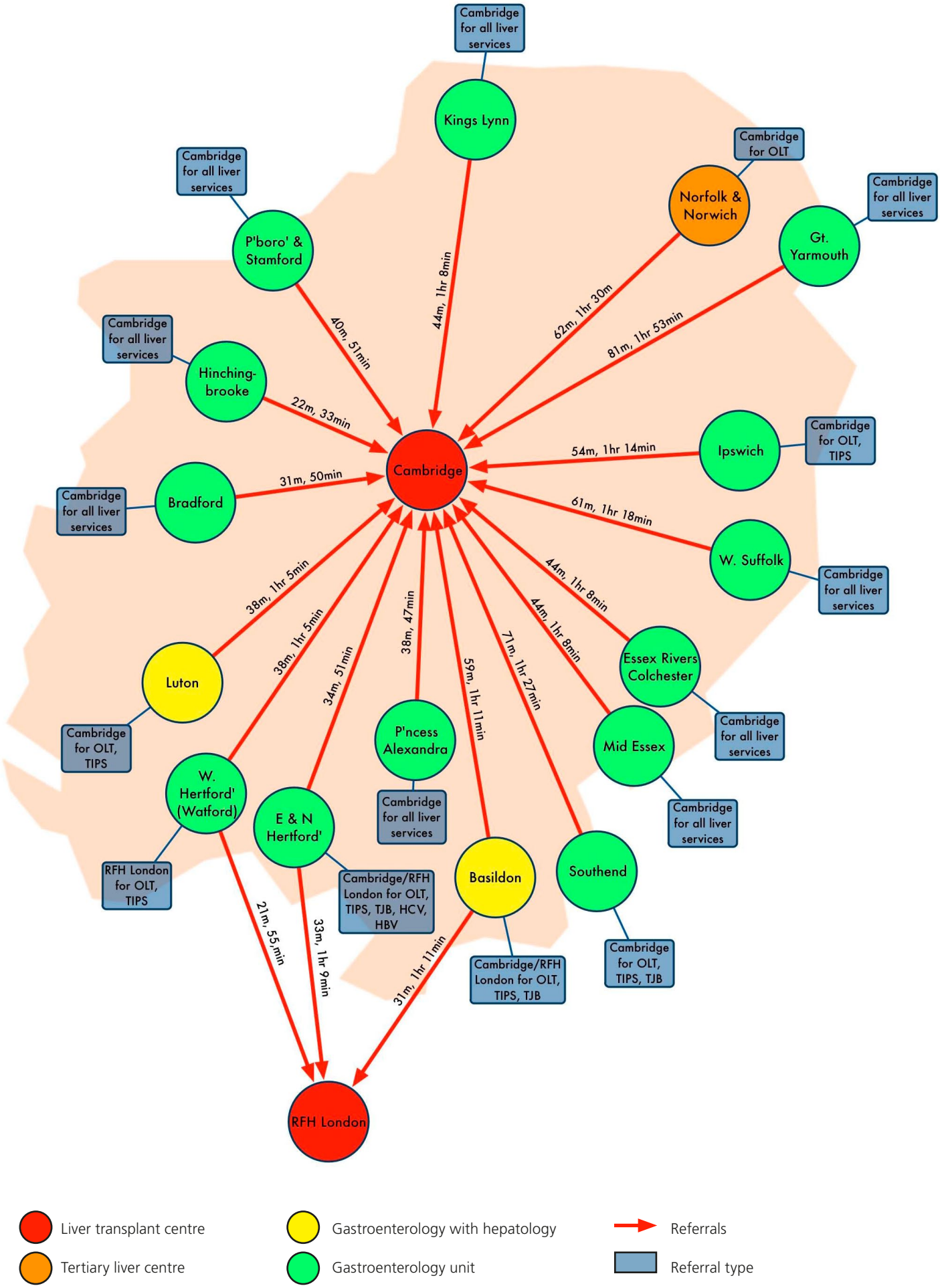
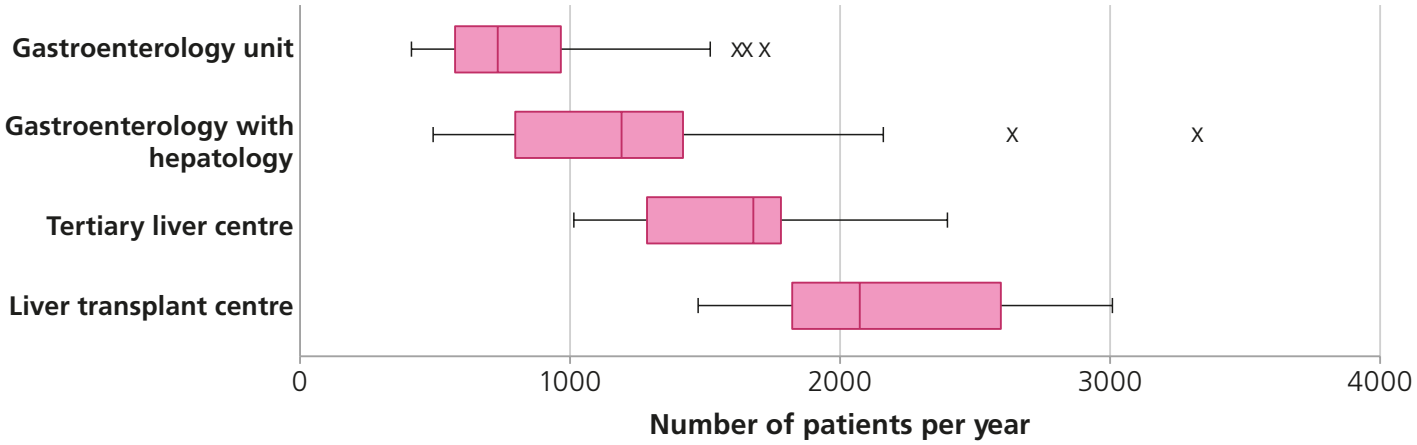
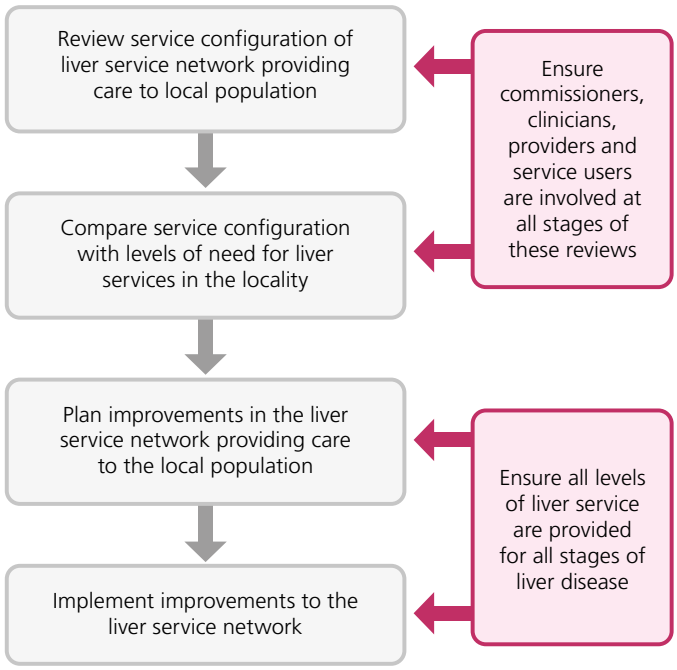


FIGURE I.13: NUMBER OF PATIENTS PER UNIT PER YEAR BY TYPE OF ADULT LIVER SERVICE[34]



the referring hospitals, especially as they play a central role in the training of hepatologists. Commissioners need to ensure that the local population has access to appropriate expertise including transplant assessment. The options for action are shown in Figure I.14.

FIGURE I.14: OPTIONS FOR ACTION TO ENSURE ACCESS TO EXPERTISE IN ADULT LIVER SERVICES



In Map I.2, this newly developed classification of liver services has been superimposed onto the map of mortality from liver disease (see also Map 3) to highlight those localities in which:

- liver services may require further development;
- there is the expertise to help commissioners gain a better understanding of how to improve quality and increase value for people with liver disease, including through reducing unwarranted variation.

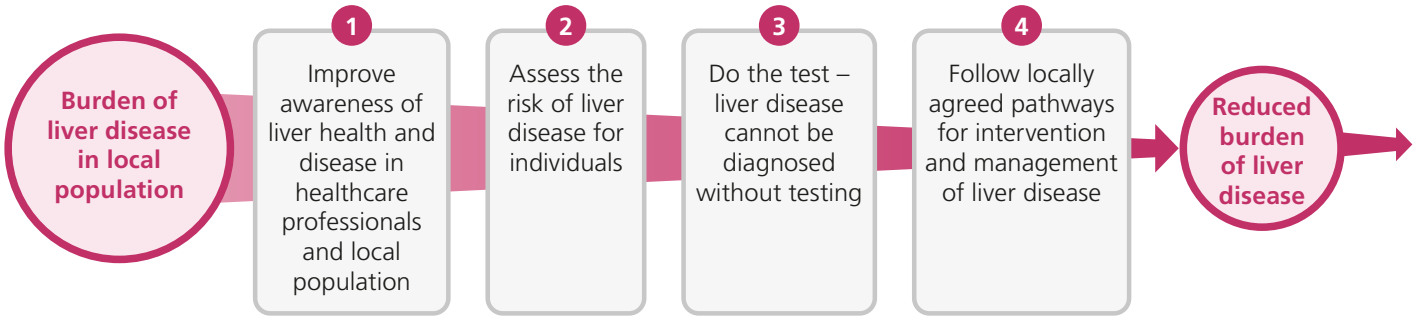
One caveat to emphasise when considering this information is that there are no robust datasets on community or ambulatory activity (primary care activity or secondary care outpatient activity) for people with liver disease. This needs to be taken into consideration when planning services. The expertise in tertiary liver or transplant centres is likely to be needed when planning improvement or development in community or ambulatory services.

Reducing premature mortality and the increasing burden of liver disease

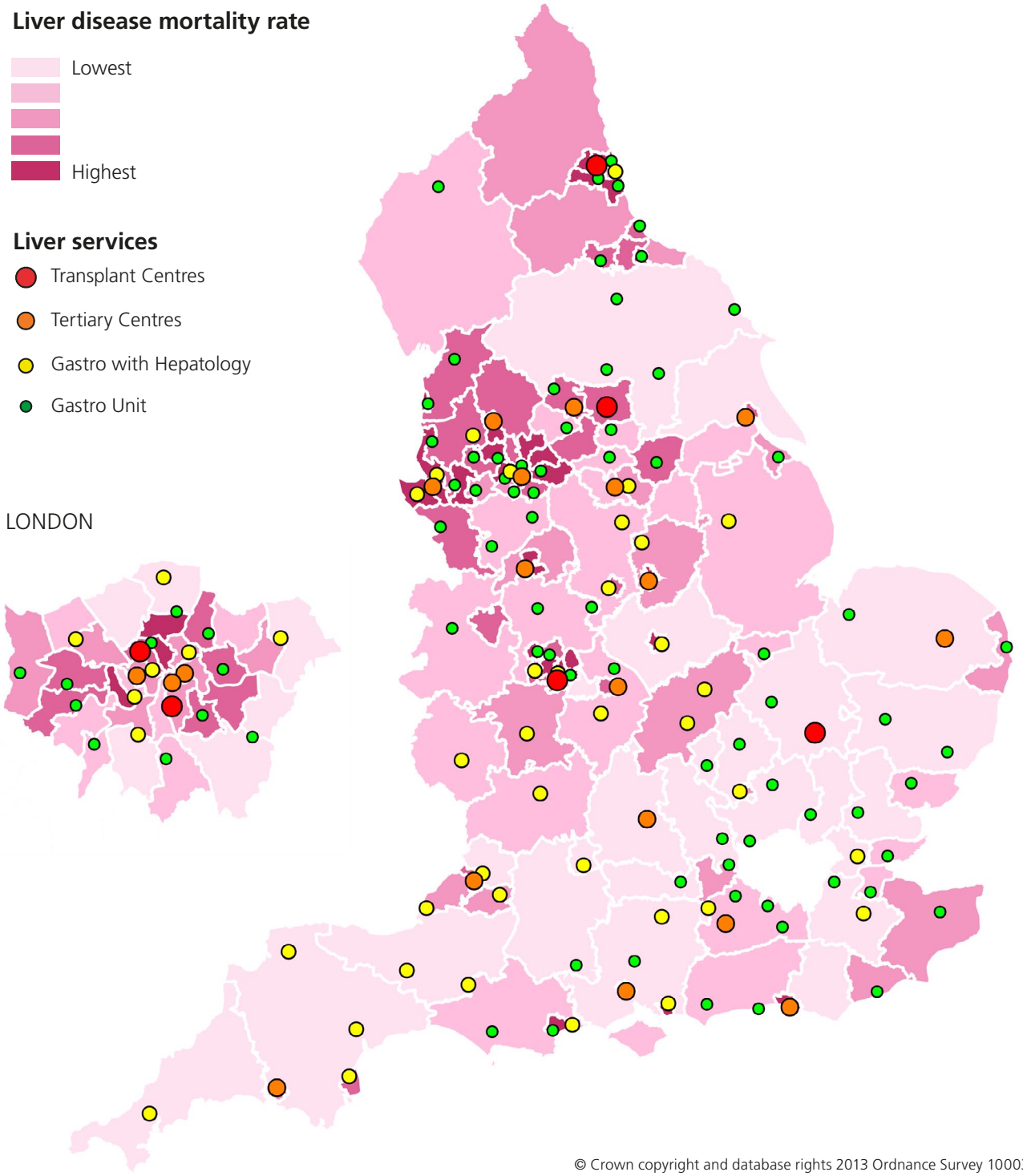
To address premature mortality from liver disease and the increasing burden of liver disease in people who often are not aware that they have it, there are four basic steps that need to be undertaken (see Figure I.15).

Above all, we hope that patients, clinicians, service providers, commissioners, public health agencies and others will use the maps in this Atlas to ask questions and set up a dialogue in their localities about reducing the burden of liver disease. If the dialogue leads to a focus on data, information and outcomes, a better understanding of the reasons for variation may be achieved. Once this understanding has been gained, all stakeholders will be in a better position to discover what more needs to be done to address unwarranted variation in the care of people with liver disease and to improve outcomes.

FIGURE I.15: BASIC STEPS IN REDUCING THE BURDEN OF LIVER DISEASE



MAP I.2: LIVER SERVICES AT ACUTE TRUSTS IN ENGLAND SHOWN IN RELATION TO CHRONIC LIVER DISEASE MORTALITY IN MEN PER 100,000 POPULATION BY PCT 2006–2008



A patient's view of the ideal pathway

Introduction

In this section, we have tried to capture a patient's view of good-quality care for people with liver disease. The ideal pathway is one to which all commissioners, service providers and clinicians need to aspire. There are many examples of good practice, some of which are described in pages 123–127. Even in centres developing innovations and implementing good practice, the work is driven by committed individuals in the face of many barriers. Commissioners in particular need to find ways to promote the local creativity and enterprise that many clinicians possess in order to improve the service for patients with liver disease.

Narrative	Care-planning considerations/implications
Awareness	
I want to be more informed about my liver: what it does, how important it is and how I can keep it healthy. I want to understand how my lifestyle may affect my liver. People know about their hearts and the importance of cholesterol and blood pressure but are not aware that their liver keeps them alive. Most people now know someone, or know someone who knows someone else, who has died from liver disease, usually due to alcohol. I want to be made aware in a non-patronising, non-judgemental way. I don't want to be preached to. I want to gain this information in a variety of ways (not just a leaflet) so I can access it within my own time-frame and when I am ready to hear the messages. I like to find information online so I can do this anonymously and thereby gain information about my options. I am not aware that babies get liver disease. I need to be told, preferably in antenatal classes, what I should do if my baby has prolonged jaundice, and about the risks of maternal transmission of hepatitis B. I want my children to receive information in an age-appropriate way about the impact of their behaviour on their future health – they think it won't happen to them.	› When providing information, the tone and style of delivery are critical; always consider the audience, and the different media available in which to explain about the transmission or development of a liver condition. › Information needs to be made available in a range of formats including online, with access to translation services to facilitate patient choice. › Consider settings in which information can be delivered in conjunction with other health management pathways, such as antenatal classes, drug and alcohol interventions, or other learning opportunities, such as school Personal, Social and Health Education (PSHE) sessions. › Patients need signposting to online information considered to be reliable and balanced.
Risk	
I know too much alcohol is dangerous, but I'm not sure how much is too much or what the dangers are. I am not aware that being overweight or obese causes liver disease and I have no idea what other risk factors there are. I am not aware of how my behaviour may increase my risk of getting liver disease. I may have taken risks many years earlier, but do not relate these to my health now. I am not aware that I could have acquired a virus from my mother at birth which affects me only now as an adult. I am not aware that liver disease develops slowly. I am not aware of how it will affect my children or how I can influence this. I want to be informed about risk in a sensitive and encouraging way which gives me hope that I can turn things around if need be. I want someone who is knowledgeable and able to explain my personal risks and their implications. I need people to respect me, my life and my decisions.	› Information is a key element in empowering patients to take responsibility for their liver and their liver condition (if appropriate). › Knowledge about liver disease is only one aspect of information-sharing. It is also important to help the patient apply the knowledge about liver disease to their specific circumstances and identify the implications for them. › Patients need access to appropriately trained and skilled professionals, who are knowledgeable about the subject and can help patients to identify their personal risk factors and the implications of those risk factors.

Narrative	Care-planning considerations/implications
Early identification	
I am not considered to be at risk of liver disease because I do not 'fit the profile'. It is possible that healthcare workers collude with me to deny real risk. Some healthcare workers do not know the "risk profiles" or have incomplete knowledge to be able to identify which people are at risk or to support my efforts to get tested despite me thinking I may be at risk. I don't want people to be judgemental about me or my lifestyle because I want to be tested. I want people to say if they don't know, not try to fob me off or give me incorrect or uncorroborated information. If I do not get a test, I will never be identified. Tests (blood tests) have to be made easier – either a finger-prick first-screen test, or making available a blood-testing facility not dependent on me seeing a professional who may or may not know about liver disease. I need to know what tests should be done so that I can check whether the tests that have been requested are the right ones. I also need to know what the results mean so I can be sure whether the interpretation of my test results is right. I need information to explain what happens during testing and what will happen next if I have liver disease. Will I have a fight on my hands to get treatment? I am really scared about what all this means and need to know what support is available in the event that I do have a liver disease. I want to be listened to. I am concerned that some professionals may fob me off before I am diagnosed and I would prefer to rely on qualifications or kitemarks so that I know who to see. Once I have been identified as having early liver disease, I want information, lots of it, from specialists who know what they are talking about and who can tell me what I need to do and answer the questions that are important to me. Being given the news that I have liver disease is a shattering experience. I need someone to help me get a sense of it all. I'm overwhelmed by all the emotions I'm experiencing. Are there charities/patient groups that can help me and my family? I want the help and support that I need, not the help that others think I need. I want to be able to go back and speak to someone who can explain the meaning of the diagnosis once I've had a chance to take it all in. There's a lot to take in at one go.	› Professionals at all points in the pathway at which patients could access testing services must have appropriate knowledge and training to be able to identify people at risk and encourage them to go forward for testing and to ensure that people coming forward for testing are tested. › It is essential to develop and implement testing and follow-up protocols. › Professionals in primary care, and at other points in the pathway where patients access testing services, must be able to understand the needs of people coming forward for testing and the impact testing will have in order to support patients effectively; it is also important for healthcare professionals to understand the limits to patients' knowledge. › Professionals involved in testing services need to be able to signpost the people being tested to information and support services, including national and local charities/patient groups, to provide accurate and clear information and services to a defined local standard and to ensure fully informed patient choice takes place. › A liver service needs to include a multidisciplinary team which provides social and psychological support; it is important to recognise that most patients will be significantly disturbed by a diagnosis of a liver disease/condition and will need support to help them come to terms with it. › Team support needs to be led by the needs of the patient and their specific circumstances, and should include the provision of information to carers and relatives. › Teams need to provide named contacts to encourage a dialogue between the patient and the healthcare providers to ensure that patients are able to ask further questions or express concerns and have them addressed.

Narrative	Care-planning considerations/implications
Monitoring progression	
Whatever my risk factor is, it is likely that my liver disease may progress – what do I need to look for, how will I know when it gets very bad, and what should I do if it gets bad? I need to know how my liver disease is going to be managed and monitored so I can make informed decisions about what I am and am not prepared to do or have done. I need access to information so I can be sure that what is being proposed is the best thing for me and is up to date. How can I gauge the expertise of the team caring for me? I need to know that I will have access to the right specialists at each stage in the pathway if and when needed and irrespective of where I live. I don't want to be caught up in red tape. I want to know that I have choice and equity of access to services. I don't want to be patronised or stigmatised. As a child with liver disease, I want reassurance that my life and education will be interrupted as little as possible and I expect the team to support me in achieving this through sensible timing of appointments and consideration of treatment timing. I want to know what will happen with my liver disease as I grow up. Where will I be seen? Will the doctors know about my liver condition because they're used to treating adults? As an adult with liver disease, I need to make sure that I can maintain my job and support myself and my family while attending to my health needs. I need a regular blood test but would rather not have to make multiple trips to a remote centre of excellence to get this. If I receive sufficient information to begin with, I can be equipped to monitor my own liver disease if I am given access to readily available blood tests and results. I have been taught what to look out for in the results backed up by IT and information. I know I can contact my healthcare worker by email or telephone if I need to. I want to take responsibility for my liver and my health but I can do that only if the team is prepared to listen to me and share information. I recognise that monitoring my liver condition is complicated and means reviewing blood test results together with other tests such as liver biopsy. I need help to talk to my family about my liver condition and its implications. I find talking to them difficult and tiring. I need help in deciding who else I should tell and how to go about it.	› Appropriate information must be made accessible to support disease monitoring and management. › Data on experience and outcomes at the unit providing liver services, and other organisations involved in service provision, need to be made available and offered to patients. › Patients should be encouraged and supported to take responsibility for their liver condition and make informed decisions about treatment options. › Protocols for shared care must be developed and networks of service providers identified. › Programmes of transfer to adult services need to be developed and delivered, with joint ownership between adult and paediatric teams. › Patient needs are central in the development of treatment and monitoring care plans. › Patients need access to specialist nursing services and other allied professionals, such as social workers, psychologists, and dieticians. › Patients need access to relevant tests, for which clear protocols for follow-up and action have been established.

Narrative	Care-planning considerations/implications
Advanced disease	
I know what treatments I am on, what their side-effects are and how to monitor these (also by blood tests, as above). I see my healthcare expert as regularly as I need to and they often call me. I have automated recall for tests to support early detection of complications or cancer so that these conditions can be treated if found. I want to be sure that I have access to specialist nurses so I can speak to someone if I'm worried or concerned. I want to make sure my family are fully informed. I work in partnership with the professionals, particularly those who deal with things on a day-to-day basis. Good communication is pivotal, as is respect for my knowledge and expertise about my condition and treatment. I don't want to argue about the medicines that the hospital thinks I need. I want to avoid admission to hospital if at all possible. The team caring for me need to arrange a review within a couple of days so that I do not have to attend my GP or A&E with my liver problem if things are going wrong. If I need a transplant, I want to understand how the waiting list works, how people are prioritised and what this means for me. I want to be sure I will have an equal chance of receiving a donor organ irrespective of where I am being treated. I want my family to receive help in understanding what is happening to me and the plans for further treatment. I want to be made aware of the financial support and other help that me and my family are entitled to.	› It is essential to develop care protocols for patients with advanced disease. › Communication and shared-care protocols with primary care teams are critical in the care of patients with advanced disease. › Teams at all levels of service provision need to have knowledge about the management of advanced liver disease. › There needs to be acknowledgement of the concept of the expert patient by teams at all levels of service provision. › It is important to provide information that will signpost family and friends to support and further information. › Access to social work support also needs to be provided. › Data on transplantation, waiting times and outcomes need to be made available to patients.
Complications or cancer	
I want to be informed about complications, what I need to look out for and what to do if I notice anything. When complications are discovered, I need to be contacted promptly and fully informed about my condition, how it will be treated, its prognosis, and how to get regular treatment. I want my family to be informed about the help and care I need. I don't want them to be over-burdened – they need to be supported in their care of me.	› Care teams need to have knowledge about the management of advanced liver disease and its complications. › It is important to provide information that will signpost family and friends to support and further information. › Access to social work support needs to be provided.
End-of-life care	
I am now an expert on my condition because I have been involved in my own care for many years and have a good longstanding relationship with a team of healthcare experts whom I trust. They have told me that they may be able to predict when I have only a couple more years to live. I want to make informed decisions but I also realise that some things are just unpredictable and can't be foreseen. I may have been considered for a liver transplant, but if not I need to understand why I have not been considered or why I have been taken off the transplant list. I have agreed with my healthcare team how I would like any further complications to be managed. I want to maintain my quality of life as much as possible and remain out of hospital. I know that I can gain access to my healthcare team within 24 hours if need be so I know I will never need to attend A&E for an unplanned admission. I want my wishes to be respected and my family supported in the decisions I make. I want any pain to be managed.	› Develop end-of-life care protocols and implement them effectively. › Patients need access to expert teams such as those involved in pain management. › It is important to provide patients with signposting to other agencies, charities, voluntary bodies and other services.

Narrative	Care-planning considerations/implications
Carers and relatives	
We have been aware that our relative has a liver condition which may progress. We have been involved, or invited to be involved, in the care and support of our relative. We feel that we have sufficient information and knowledge to do this, and we have also been supported whenever we needed to contact relevant health professionals. We have a good understanding of consent and confidentiality issues. At times, it has taken a lot of effort to get the information we need, sometimes by reason of confidentiality or because no-one has had the time to help us get the necessary information. We've had to find things out by ourselves. The internet has been great but there's a lot of information out there and some of it can conflict with what we have been told by the healthcare team.	› There needs to be recognition of the role of family and carers in the management, care and support of a patient with a chronic, possibly terminal, condition. › Relatives and carers need access to appropriate information and signposting to relevant services, other agencies, charities, groups and voluntary bodies including social work support and bereavement counselling. › It is important to develop and implement protocols for referral and access to respite care and other tertiary support including specialist palliative care.

Map and chart presentation

Selection of indicators

In devising the Liver Disease Atlas, we have worked closely with many partner organisations, including the Health Protection Agency.

Most of the datasets available contain information relating to the more severe end of the spectrum of liver disease and its final stages. Despite the patchy availability of data, in the Liver Disease Atlas, we are also concerned with prevention, such as vaccination against hepatitis B in newborn babies, and the major risk factors for liver disease, e.g. alcohol intake, and obesity.

Indicators relating to cholecystectomy and endoscopic retrograde cholangiopancreatography (ERCP) are also included in this Atlas because patients undergoing these interventions often use the same services or facilities as patients with liver disease and often have abnormal liver function tests.

In the Liver Disease Atlas, indicators are constructed using populations from primary care trusts (PCTs), PCTs responsible for providing health services to one or more prisons, local authorities (LAs), drug action team (DAT) areas, strategic health authorities (SHAs), or regions.

Owing to NHS reorganisation at the time of writing, PCTs are currently in transition to clinical commissioning groups (CCGs); in some localities, CCGs will have a different geography than the previous PCT, and SHA boundaries have also changed during the preparation of this Atlas.

Despite these structural changes, the indicators presented in the Liver Disease Atlas will provide the new organisations with sufficient comparative data to help them consider the questions they need to ask about liver services for their local populations.

Order of appearance

Indicators in the Liver Disease Atlas are grouped into sections to highlight similar areas of need or of service provision, for instance, there is a group of indicators relating to hepatitis C, a major risk factor for liver disease, and another group of indicators relating to transplantation.

Data sources

Data for most of the indicators in the Liver Disease Atlas have been extracted by colleagues in the Department of Health, the Health Protection Agency (HPA), North West Public Health Observatory, Health and Social Care Information Centre (IC), National Treatment Agency (NTA) for Substance Misuse (including the National Drug Evidence Centre, University of Manchester, and the National Drug Treatment Monitoring System), The Centre for Drug Misuse Research, University of Glasgow, National Obesity Observatory (NOO), British Association of Day Surgery (BADS), CHKS Ltd, Office for National Statistics (ONS), and Solutions for Public Health (SPH) from a variety of sources including:

- Hospital Episode Statistics (HES);
- The Office for National Statistics mid-year population estimates;
- The Office for National Statistics mortality records;
- NHS Comparators;
- IC indicators portal;
- ePACT, NHS Business Services Authority;
- NHS IDPS Screening Programme;
- Prison Health Performance and Quality Indicators, NHS South West;
- Health Survey for England;
- Connecting for Health;
- Roche;
- MSD;
- PharmEx, Commercial Medicines Unit (CMU), Department of Health;
- IMS SCM data, IMS Health.

A metadata document with methodology, data extraction coding schemes and data sources for every indicator is available from the website at: http://www.rightcare.nhs.uk/atlas/

Classification

Data for each of the indicators are displayed as both a column chart and map to show variation in terms of magnitude and geographical location within England. London is shown as a page inset on all PCT, upper-tier local authority and DAT area maps to keep detail that otherwise might be lost.

The charts and maps for all indicators are colour classified into thematic displays, which group the indicator values into categories and allow the reader to view and compare them on the column chart and map without having to refer to individual values. Data are displayed on the maps as geographical areas.

A simple method of classification using equal counts of geographical areas was used to display all indicators, regardless of distribution of data within indicators. Five equal counts of areas or 'quintiles' were classified for all indicator data where possible. However, as most of the indicators include a total number of areas that are not divisible by five (e.g. 151 PCTs), in most cases the classifications do not include exactly the same number of areas. The method used to create the classification was to rank order the areas from highest to lowest values, then divide the ranks into five equal categories. However, in some cases, indicators included tied ranks (i.e. where some area values were exactly the same) and no areas were split into different categories where the rank was equal; this meant that an equal split was not possible in these cases. For the few indicators where there were many tied ranks of equal data, the split between categories was adjusted to ensure a 'best fit' of equal numbers, without splitting areas or centres with the same values.

The disadvantage with equal counts of data is that it does not take into account the distribution of the data, and categories can be created with very different ranges of variation between the highest and lowest values. This should be taken into consideration when comparing areas in different categories within indicators.

The classification is shaded from light mulberry (lowest value) to dark mulberry (highest value) on both the column charts and maps. The ranges and their shading do not indicate whether a high or low value represents either good or poor performance.

The charts have been originally produced in Microsoft Excel 2007 and the maps originally created using MapInfo Professional 11.0.

Standardisation

Standardisation allows like to be compared with like, by making sure that differences in the number of events (e.g. deaths or infections) observed in two or more populations are not due to differences in the age and sex profile between the different populations. (For example, suppose population A has a higher death rate than population B. However, if population A also has a higher proportion of older people, then we would expect there to be more deaths and it would be misleading to infer that people are dying at a faster rate in population A than in population B.) The two main methods of standardisation are:

- directly standardised rates;
- indirectly standardised rates.

Directly standardised rates adjust for differences in age and sex distribution. The observed rates (e.g. of disease) for each age-band in the study area (e.g. the PCT) is applied to a standard population structure (in this case, the European Standard population) to obtain a weighted average rate. Direct standardisation has been used for the indicators in Maps 1–4, 9–11, 31, 33 and 35–36.

Confidence intervals

Some of the indicators (Maps 1–6, 9–11, 20, 28–31, 33 and 35–36) have error terms associated with them to give an indication of the level of uncertainty of the calculation, referred to as confidence intervals. Statistical uncertainties usually arise because the indicators are based on a random sample of finite size from a population of interest. Confidence intervals are used to assess what would happen if we were to repeat the same study, over and over, using different samples each time. The precise statistical definition of a 95% confidence interval states that, on repeated sampling, 95 times out of 100 the true population value would be within the calculated confidence interval range and for 5 times out of 100 the true value would be either higher or lower than the range. Where these confidence intervals have been calculated for indicators in the Liver Disease Atlas, they are displayed on the columns of the relevant charts as a vertical line intersecting the top of each column. The smaller the confidence interval, the more stable the indicator; a larger number of events leads to a smaller interval.

For indicators where the confidence intervals are very wide (as displayed on the chart), caution is needed when interpreting the data because the limits indicate

that much of the variation within the indicator may not be statistically significant. For instance, Maps 2, 3, 28 and 29 show very wide confidence limits.

Credible intervals

Credible intervals provide a level of uncertainty for the value of an indicator, but they are based on a different set of statistical assumptions to those governing confidence intervals. The precise statistical definition of a credible interval states that, given the known data, there is a 95% probability that the value is within the interval. This interval assumes that the data are fixed (i.e. the indicator values are real, not a sample) and that the parameter (true population value) is uncertain. Credible intervals are referred to in the commentary for Map 19.

Association with deprivation

The association between the indicator in Map 29 and the level of deprivation (Indices of Multiple Deprivation [IMD] 2010) was assessed using Pearson's Product Moment correlation coefficient, which gives a score between 0 and +/–1.

- A correlation coefficient of 0 indicates that there is no association between the level of deprivation and the indicator at PCT level;
- A correlation coefficient of +1 indicates that the PCT with the highest level of deprivation has the highest score on the indicator, the PCT with the second highest level of deprivation has the second highest score on the indicator, etc.
- A correlation coefficient of –1 indicates that the PCT with the highest level of deprivation has the lowest score on the indicator, the PCT with the second highest level of deprivation has the second lowest score on the indicator, etc.

In the Liver Disease Atlas, the strength of correlation has been described according to the terms set out in Table M.1.

A scatterplot showing the association between deprivation and obesity has been produced for Map 29, with obesity plotted on the vertical axis and IMD plotted on the horizontal axis. The values of each upper-tier local authority are represented by dots.

Table M.1: Strength of correlation[1]

Value of correlation coefficient, *r*	Description
0.0–0.2	Weak/slight
0.2–0.4	Mild/modest
0.4–0.6	Moderate
0.6–0.8	Moderately strong
0.8–1.0	Strong

The use of estimated data for local areas

The following indicators of prevalence are not based on actual counts of people in the local area, but have been estimated using various statistical models, based on known prevalence from the published literature, national surveys or local assisted data sources.

- Map 19 uses modelled estimates of hepatitis C prevalence for each DAT area, based on national hepatitis C prevalence data and local data on injecting drug use.
- Map 20 uses two different modelled methods depending upon the availability of data in each local area to create estimates of the number of adults in each DAT area who inject drugs.
- Map 24 uses an HPA model of hepatitis C treatment that estimates the number of adults in each region with chronic hepatitis C who are expected to be diagnosed, referred and accept therapy.
- Map 30 uses a model based on the Health Survey for England and local data to estimate the percentage of adults who are obese in each PCT.

Exclusions

For the indicators in the Liver Disease Atlas mapped to PCT, upper-tier local authority or drug action team (DAT) geography, the calculation of the full range of variation is given in the accompanying commentaries; in addition, the range has then been calculated from which the five highest values and the five lowest values have been excluded.[2] This is because "outliers" could be the result of errors in data management, e.g. some data may not have been returned or events may have been

1 University of Washington. http://faculty.washington.edu/ddbrewer/s231/s231regr.htm

2 The only exception when an indicator has been mapped to PCT level is Map 17; as data from 41 PCTs are missing, after calculation of the full range, the range has then been calculated from which the three highest values and the three lowest values have been excluded.

recorded twice. This exclusion was originally suggested by Professor Sir Mike Richards for Atlas 1.0, and Right Care has continued to use the "Richards heuristic" in Atlas 2.0, the Child Health Atlas, the Kidney Care Atlas, the Respiratory Disease Atlas and the Liver Disease Atlas.

For indicators mapped to the level of "responsible" PCT (n=69), i.e. PCTs in which there is at least one prison for which they commission healthcare, after calculation of the full range, the range has then been calculated from which the two highest values and the two lowest values have been excluded.

For indicators mapped to SHA or region geography, there are no exclusions due to the small number of areas in each geography.

Domains in the NHS Outcomes Framework

Underneath the title for each indicator, the domain or domains in the NHS Outcomes Framework 2012/13 relevant to the indicator have been listed. The five domains are as follows:

- Domain 1 Preventing people from dying prematurely
- Domain 2 Enhancing quality of life for people with long-term conditions
- Domain 3 Helping people to recover from episodes of ill health or following injury
- Domain 4 Ensuring that people have a positive experience of care
- Domain 5 Treating and caring for people in a safe environment and protecting them from avoidable harm

Table S.1: Summary of indicators in the Liver Disease Atlas, showing the range and magnitude of variation before and after exclusions;[1] each indicator has been assigned to one or more of the following categories – activity, cost, equity, outcome, quality (performance as compared with a standard), and safety.

Map no.	Title	Range	Fold difference	Range after exclusions	Fold difference after exclusions	Category of indicator
1	Proportion (%) of admissions attributed to liver disease that are emergency admissions to hospital by PCT 2010/11	23.5–66.2	2.8	26.3–55.4	2.1	Quality
2	Rate of years of life lost in people aged under 75 years due to mortality from chronic liver disease including cirrhosis per 10,000 population by PCT 2008–2010	8.4–77.4	9	11.3–43.6	3.9	Outcome
3	Rate of mortality in people aged under 75 years due to chronic liver disease including cirrhosis per 100,000 population by PCT 2008–2010	4.1–31.4	8	5.8–19.3	3.3	Outcome
4	Rate of people admitted to hospital at least once for cirrhosis per 100,000 population by PCT 2006/07–2010/11	53.7–207.9	3.9	60.7–171.6	2.8	Outcome
5	Rate of liver cancer mortality in people aged under 75 years per 100,000 population by PCT 2006–2010	0.5–5.3	10	0.8–3.6	4.6	Outcome
6	Rate of liver transplants from all donors per million population by PCT 2006/07–2010/11	4.5–28.5	6	6.0–22.5	3.7	Activity and Equity
7	Organ donation rates per million population by SHA 2011/12	13.6–26.4	1.9	Not applicable	Not applicable	Equity
8	Rate of liver transplants from deceased donors per million population by SHA 2011/12	6.7–14.2	2.1	Not applicable	Not applicable	Activity
9	Rate of alcohol-related admissions per 100,000 population by PCT 2011/12	1048.1–3557.3	3.4	1430.6–3060.8	2.1	Activity
10	Rate of alcohol-specific admissions in people aged under 18 years per 100,000 population by PCT 2008/09–2010/11	16.9–138.3	8	25.1–117.9	4.7	Activity
11	Rate of alcohol-specific admissions in men per 100,000 population by PCT 2010/11	176.5–1164.2	7	247.8–915.0	3.7	Activity
12	Annual dose-equivalent of thiamine (100-mg equivalent) per 1000 population by PCT 2011/12	1.1–9.9	9	1.6–7.8	5	Quality, Outcome and Equity
13	Annual dose-equivalent of spironolactone (100-mg equivalent) per 1000 population by PCT 2011/12	0.15–0.70	4.5	0.20–0.62	3.2	Quality, Outcome and Equity
14	Annual dose-equivalent of acamprosate (333-mg equivalent) or disulfiram (200-mg equivalent) per 1000 population by PCT 2011/12	0.13–3.14	25	0.17–2.04	12	Quality, Outcome and Equity

1 For PCTs, upper-tier local authorities and drug action team (DAT) areas, the five highest values and the five lowest values have been excluded, with the exception of Map 17 for which by reason of missing data the three highest values and the three lowest values have been excluded; for "responsible" PCTs, which commission healthcare for one or more prisons, the two highest values and the two lowest values have been excluded; for strategic health authorities (SHAs) and regions, there are no exclusions.

Map no.	Title	Range	Fold difference	Range after exclusions	Fold difference after exclusions	Category of indicator
15	Proportion (%) of women receiving antenatal care who are screened positive for hepatitis B by region	0.15–1.02	7	Not applicable	Not applicable	Quality and Equity
16	Percentage of hepatitis B vaccination coverage in new prison receptions aged 18 years and older by responsible PCT 2011/12	3.7–100	27	12.4–100	8	Equity
17	Percentage of infants immunised for hepatitis B by their first birthday born to mothers with persistent hepatitis B infection by PCT 2011/12	9.1–100%	11	42.3–100	2.4	Quality and Equity
18	Rate of laboratory reports for confirmed hepatitis C per 100,000 population by region 2011	10.4–29.3	2.8	Not applicable	Not applicable	Activity and Quality
19	Estimated prevalence of chronic hepatitis C infection in people aged 15 years or older per 100,000 population by drug action team (DAT) area 2005–2007	194.3–1560.8	8	218.8–1027.5	4.7	Activity
20	Estimated prevalence of opiate and/or crack cocaine injecting in people aged 15–64 years per 1000 population by drug action team (DAT) area 2009/10	0.7–11.5	17	1.0–6.5	6	Activity
21	Number of drug users that left drug treatment successfully who do not then re-present to treatment again within 6 months as a proportion (%) of the total number in treatment by local authority 2010	5.1–33.6	7	6.0–24.0	4	Outcome
22	Percentage of hepatitis C test uptake among people who inject drugs receiving drug treatment by PCT 2011/12	14.8–87.4	6	26.5–74.2	2.8	Quality and Equity
23	Percentage of hepatitis C test uptake among adult new prison receptions by responsible PCT 2011/12	0–27.5	Not applicable	0–24.5	Not applicable	Quality and Equity
24	Estimated proportion (%) of people aged 15 years or older with chronic hepatitis C infection expected to access treatment who received treatment by region 2006–2008	38.9–70.2	1.8	Not applicable	Not applicable	Outcome and Equity
25	Estimated rate of cost (£) to treat people with chronic hepatitis C who did not receive treatment per 1000 population by drug action team (DAT) area 2006–2008	1234–11,773	10	1367–8657	6	Cost
26	Rate of hospital admissions for hepatitis C-related end-stage liver disease per 100,000 population by PCT 2008/09–2010/11	0.4–15.1	39	0.8–9.0	11	Quality
27	Rate of mortality from hepatitis C-related end-stage liver disease per 100,000 population by region 2008–2010	0.3–0.8	3.1	Not applicable	Not applicable	Outcome
28	Percentage of children in school reception year classified as overweight or obese by PCT 2010/11	14.9–28.6	1.9	18.8–27.2	1.4	Outcome
29	Percentage of children in school year 6 classified as overweight or obese by PCT 2010/11	24.6–41.8	1.7	28.8–40.3	1.4	Outcome

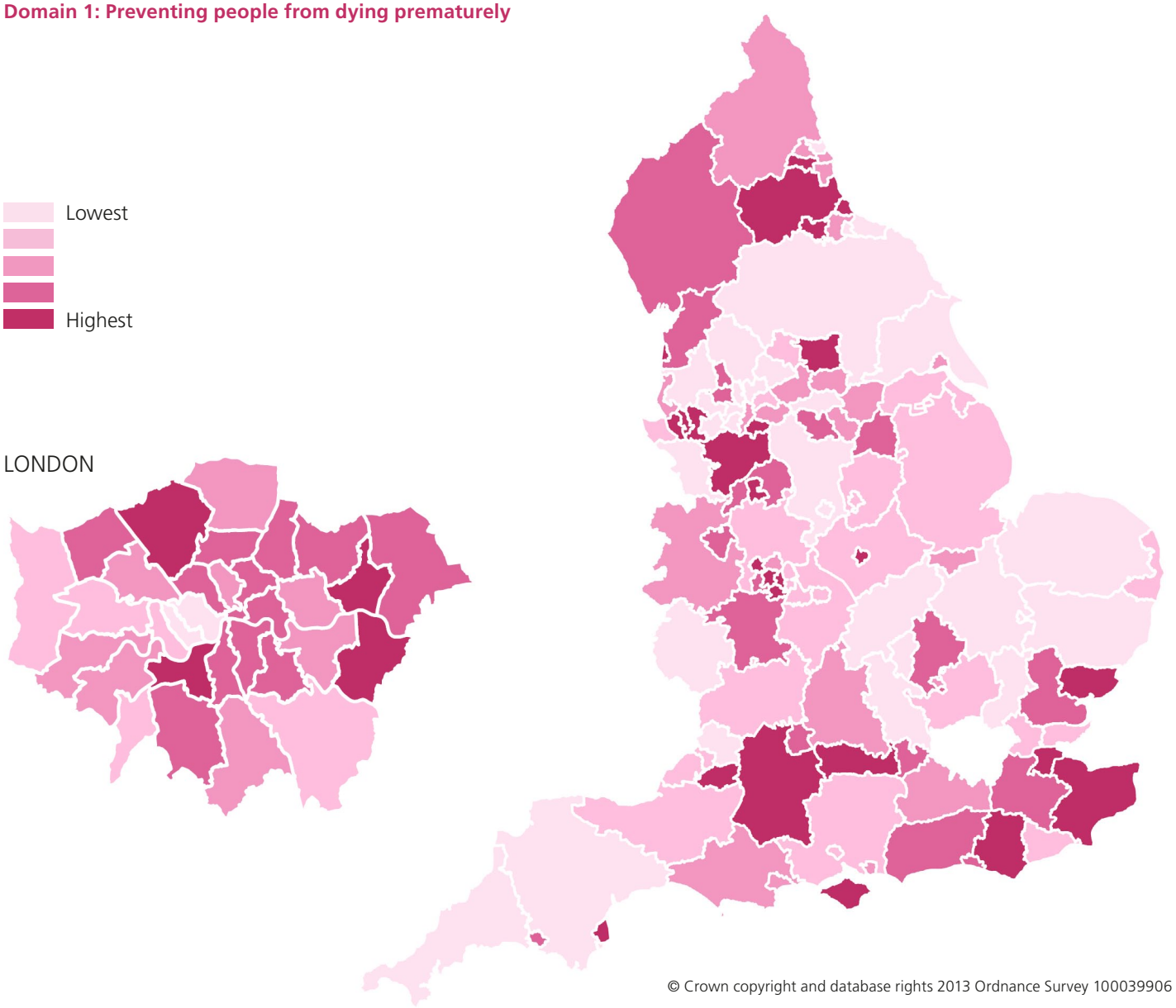
Map no.	Title	Range	Fold difference	Range after exclusions	Fold difference after exclusions	Category of indicator
30	Percentage of estimated adult obesity (body mass index ≥30 kg/m^2) by PCT 2006–2008	14.0–30.7	2.2	15.6–29.0	1.9	Outcome
31	Rate of cholecystectomies per 100,000 population by PCT 2010/11	40.8–198.7	4.9	62.1–151.1	2.4	Activity
32	Percentage of elective adult day-case laparoscopic cholecystectomy per all elective cholecystectomies by PCT 2010/11	0–69.0	Not applicable	6.9–56.7	8	Quality
33	Rate of endoscopic retrograde cholangiopancreatography (ERCP) procedures per 100,000 population by PCT 2010/11	15.8–105.4	7	39.9–86.1	2.2	Activity
34	Percentage of elective endoscopic retrograde cholangiopancreatography (ERCP) procedures performed as day cases by PCT 2010/11	3.2–89.6	28	6.8–86.6	13	Quality
35	Rate of mortality from pancreatic cancer in people aged under 75 years per 100,000 population by PCT 2008–2010	3.7–10.7	2.9	4.3–8.2	1.9	Outcome
36	Rate of admissions to hospital where diagnosis includes paracetamol overdose per 100,000 population by PCT 2010/11	34.6–251.3	7	39.0–186.1	4.8	Outcome
37	Rate of mortality from paracetamol poisoning per 100,000 admissions for paracetamol overdose by SHA 2008–2010	330.9–567.6	1.7	Not applicable	Not applicable	Outcome
38	Estimated annual rate of use for alanine aminotransferase (ALT) tests ordered by GPs per 1000 practice population by PCT 2011	1.9–468.9	252	6.9–388.3	56	Activity

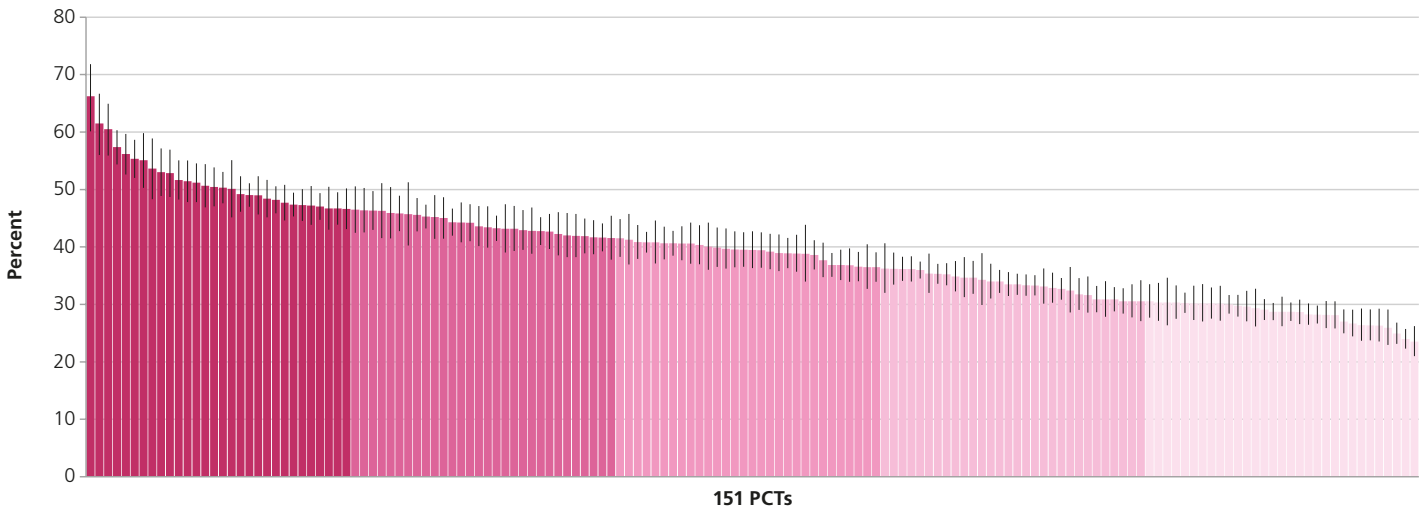
EMERGENCY ADMISSIONS

Map 1: Proportion (%) of admissions attributed to liver disease that are emergency admissions to hospital by PCT

2010/11

Domain 1: Preventing people from dying prematurely





Context

Over the last 10 years, liver disease has become recognised as an increasing cause of morbidity and premature death. Although there are myriad causes, the rapid rise in presentation and death is related to alcohol, obesity and diabetes, hepatitis B and hepatitis C. These are all preventable causes of liver disease, but if prevention strategies are not implemented or are ineffective patients will continue to present to secondary care in increasing numbers.

Magnitude of variation

For PCTs in England, the proportion of admissions attributed to liver disease that are emergency admissions to hospital ranged from 23.5% to 66.2% (2.8-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 26.3–55.4%, and the variation is 2.1-fold (see Table 1.1 for 2009/10 data).

In some localities, people are twice as likely to be admitted to hospital as an emergency attributable to liver disease than they are in others. The reasons for variation are not always clear, but could include differences in:

- the distribution of risk factors for liver disease;
- the prevalence of liver disease in different populations;
- the types and volumes of liver disease;
- the coding of cases.

The degree of variation observed, however, probably includes unwarranted variation due to differences in the organisation and management of care for people with liver disease in local health services.

Options for action

When planning service improvement or development to reduce emergency admissions to hospital attributed to liver disease, commissioners, clinicians and providers need:

- to identify whether there is a problem with liver disease in the local population;
- to consider reconfiguration of services and the development of integrated care pathways for liver disease;
- to improve the organisation and management of care for people with liver disease to reduce unwarranted variation;
- to improve care for patients admitted as an emergency to prevent readmissions;
- to review emergency admissions to assess methods of prevention and better management in primary care;
- to encourage early diagnosis of liver disease with pro-active management in primary and community care;
- to review policies and procedures for discharge planning;
- to encourage GP follow-up after discharge to improve management in primary care and prevent readmission.

Preventative strategies for liver disease are important, but will require coordination for effective implementation. Furthermore, there will be a long lead-in time before any positive health outcomes can be identified. In the meantime, services need to be organised to address the increasing burden of disease. Actions to prevent liver disease are shown in Box 1.1. Commissioners and providers need to address points 1 and 2; clinical networks are an effective way to coordinate responses to points 3–6.

Box 1.1: Actions to prevent liver disease

1. Conveying information to people about the health of their liver and the causes of damage
2. Early identification of liver disease and early intervention in primary care
3. Supporting outreach services: in areas of high prevalence, secondary care needs to play its role in the community to help reduce the burden of admission
4. Effective collaboration among primary and secondary care providers to ensure patients gain access to appropriate expertise and services that can manage their disease
5. Raising awareness of the scale of the problem of liver disease among professional groups
6. Skills development in the identification and management of liver disease for healthcare professionals
7. Using digital and multimedia resources to enable people to become more involved in self-management
8. Liaising with private and third sector organisations in the local community to enlist their support in promoting healthy lifestyles

RESOURCES

- NICE (2010) Alcohol-use disorders – physical complications (CG100). http://guidance.nice.org.uk/CG100
- NICE Pathways. Alcohol-use disorders overview. http://pathways.nice.org.uk/pathways/alcohol-use-disorders
- NICE (2006) Obesity (CG43). http://guidance.nice.org.uk/CG43
- NICE (2012) Hepatitis B and C – ways to promote and offer testing (PH43). http://guidance.nice.org.uk/PH43
- NHS Liver Care. http://www.liver.nhs.uk/
- Liver Matters (newsletter). http://www.livermatters.nhs.uk/

Table 1.1: Proportion (%) of admissions attributed to liver disease that are emergency admissions to hospital by PCT over two time-periods

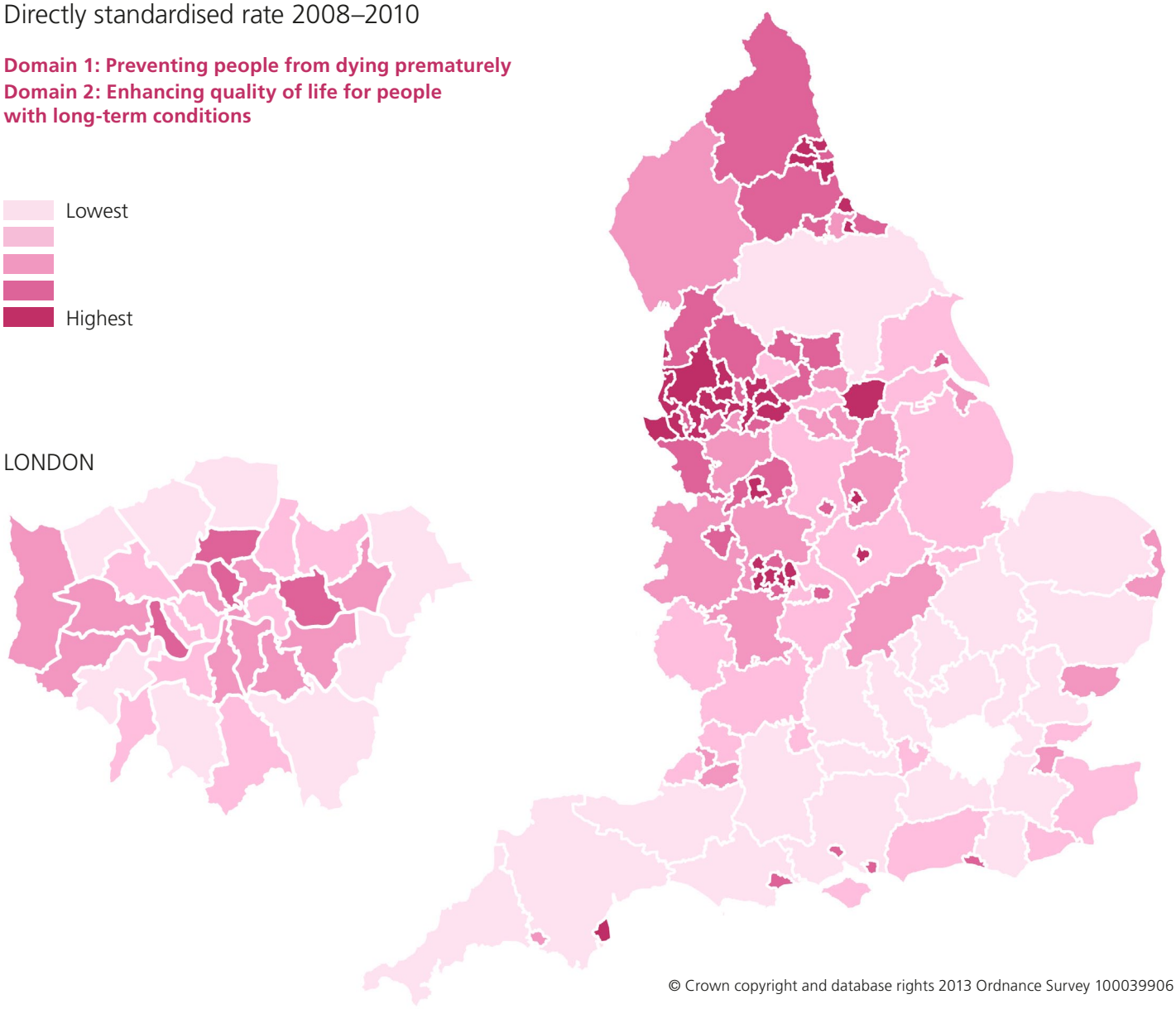
Date of data	Range before exclusions	Fold difference before exclusions	Range after exclusions	Fold difference after exclusions	Notes
2009/10	20.5-62.1%	3	25.7-54.4%	2.1	The 2009/10 data have been revised since publication in Atlas 2.0 (Map 46)
2010/11	23.5–66.2%	2.8	26.3–55.4%	2.1	

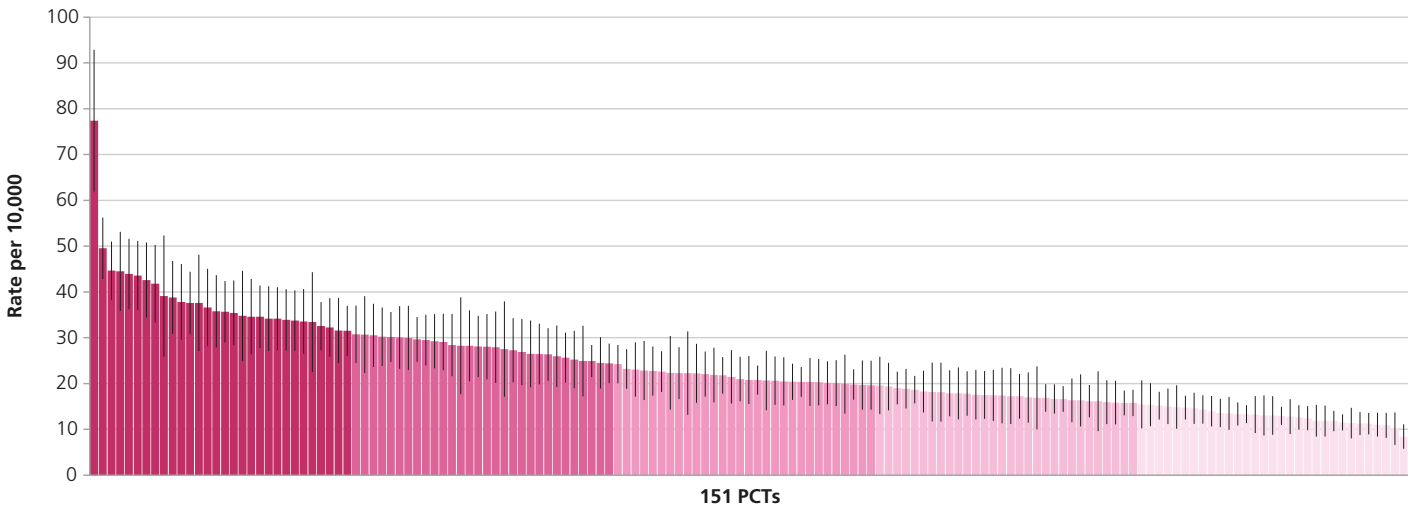
CHRONIC LIVER DISEASE

Map 2: Rate of years of life lost in people aged under 75 years due to mortality from chronic liver disease including cirrhosis per population by PCT

Directly standardised rate 2008–2010

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions





Context

Premature death from chronic liver disease has been rising in recent years, and between 1993 and 2010 the directly age-standardised mortality rate in England increased by 88%.[1] Chronic liver disease is now the fifth largest cause of death, and the leading cause of months of life lost for women under the age of 75 years.[2] The rate of years of life lost (YLL) from chronic liver disease is higher than that for stroke, land transport accidents and colorectal cancer (see Figure 2.1).

Chronic liver disease is largely preventable. The major contributing causes of liver disease are:

- alcohol; with the increasing consumption and the decreasing cost of alcohol, more people are being diagnosed with alcohol-related liver disease;
- hepatitis C, largely due to injecting drug use and shared paraphernalia, and the transfusion of contaminated blood products prior to 1990, which affected large numbers of people. Almost 50% of people with hepatitis C remain undiagnosed; among those known to have hepatitis C, treatment rates are low;
- chronic hepatitis B, which is usually acquired at birth or in early childhood, and occurs predominantly in people who now reside in England but were born in other countries where prevalence is higher; a small proportion of adults who acquire acute hepatitis B through sexual transmission or injecting drug use may also develop liver disease;
- obesity and diabetes, both of which are increasing – England has high rates of obesity and diabetes when compared with many other countries; people with diabetes or who are obese are susceptible to many health problems, but 5–10% will develop cirrhosis of the liver, and a proportion have non-alcoholic fatty liver disease (NAFLD) and non-alcoholic steatohepatitis (NASH), which in certain cases can progress to cirrhosis. As the prevalence of diabetes and of obesity increase, the number of people with cirrhosis will increase.

This compound indicator reflects the fact that on average people with chronic liver disease die at a younger age than people dying from other diseases such as cancer, cardiovascular disease or respiratory disease.

Magnitude of variation

For PCTs in England, the rate of years of life lost in people aged under 75 years due to mortality from chronic liver disease including cirrhosis ranged from 8.4 to 77.4 per 10,000 population (9-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 11.3–43.6 per 10,000 population, and the variation is 3.9-fold.

Potential reasons for the degree of variation observed include differences in:

- the prevalence of diabetes, obesity, hepatitis B and hepatitis C;
- the level of alcohol consumption;
- the level of investment in preventative measures;
- the configuration of services;
- the timing of diagnosis;
- degree of adherence to clinical guidance;
- level of patient compliance with prevention or treatment.

Options for action

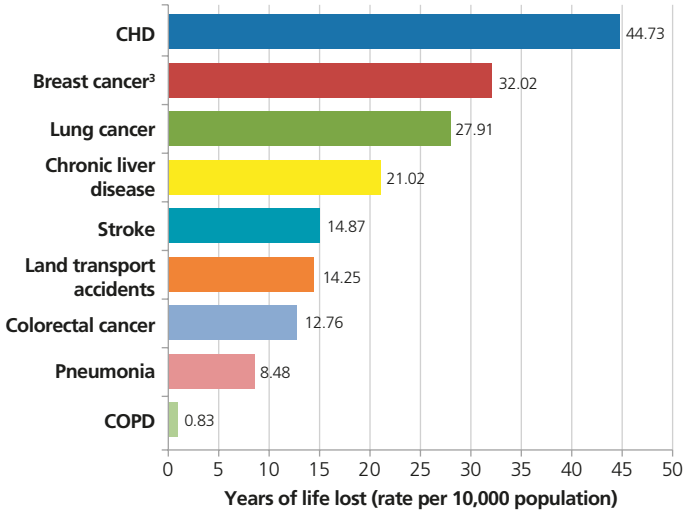
When planning service improvement or development to reduce the years of life lost from chronic liver disease, commissioners, clinicians and providers need:

- to review the rates of years of life lost from chronic liver disease in people aged under 75 years in the local population;
- to assess strategies for preventing and treating chronic liver disease (see Box 1.1);
- to identify and implement improvements in those strategies to deliver reductions in mortality from chronic liver disease;
- to consider reconfiguration of services and the development of integrated care pathways for liver disease;
- to improve self-management through education about prevention and compliance with treatment.

RESOURCES

- Local Alcohol Profiles for England. http://www.lape.org.uk/
- North West Public Health Observatory (2007) Indications of Public Health in the English Regions 8: Alcohol. Association of Public Health Observatories. http://www.apho.org.uk/resource/item.aspx?RID=39304
- NHS Information Centre. Mortality Data and Indicators for Chronic Liver Disease. https://indicators.ic.nhs.uk/webview/
- National Obesity Observatory. http://www.noo.org.uk
- Health Protection Agency. http://www.hpa.org.uk
- NHS Diabetes. http://www.diabetes.nhs.uk
- Diabetes Health Intelligence. http://www.yhpho.org.uk/resource/item.aspx?RID=8467
- National Diabetes Information Service. http://www.diabetes-ndis.org/
- NHS Atlas of Variation in Healthcare for People with Diabetes. http://www.rightcare.nhs.uk/atlas/

Figure 2.1: Rate of years of life lost (directly standardised) in people aged under 75 years for major causes of death per 10,000 population in England 2008–2010 (source: HSCIC)



1 The NHS IC Portal of Indicators. Menu pathway: NHS Information Centre Indicators; Compendium of Population Health Indicators; Illness or Condition; Digestive Diseases & Disorders; Chronic Liver Disease; Mortality from chronic liver disease including cirrhosis: directly standardised rate, all ages, annual trend 1993–2010. https://indicators.ic.nhs.uk/webview/

2 Analysis conducted in 2010 by Tom Kennel, North West Public Health Observatory.

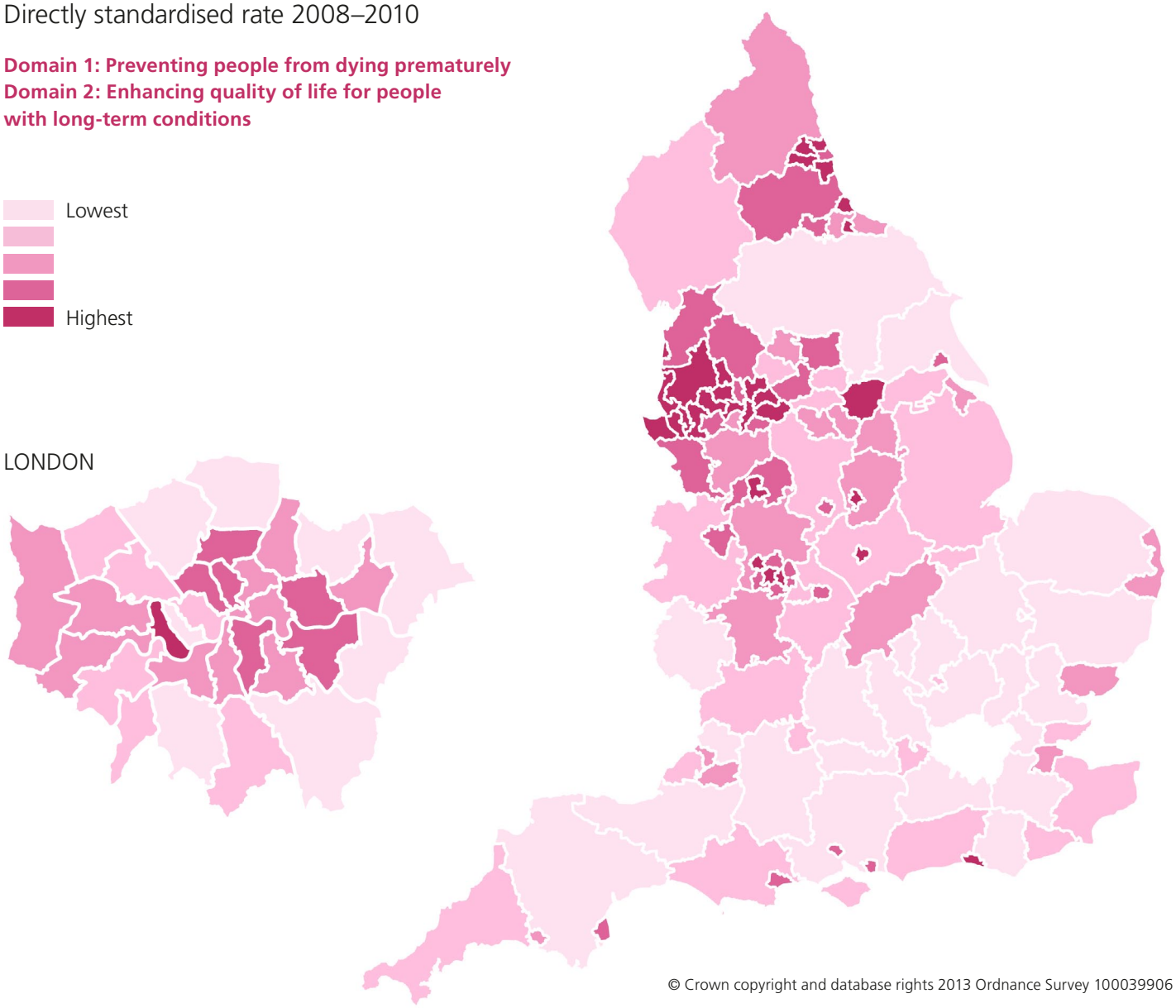
3 Female rate only.

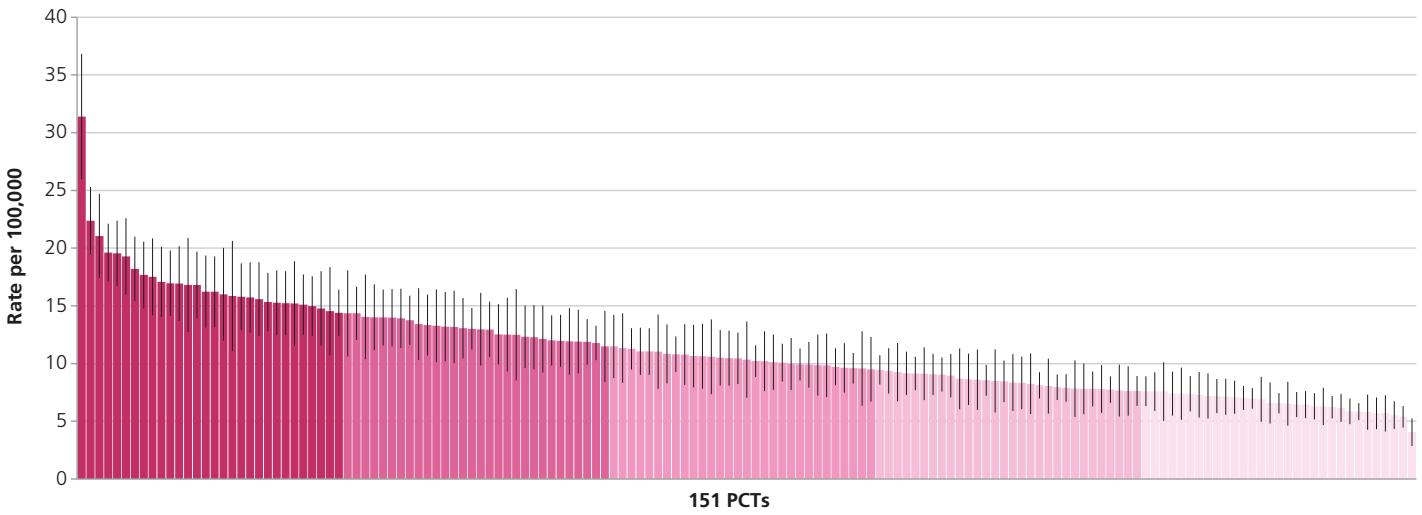
CHRONIC LIVER DISEASE

Map 3: Rate of mortality in people aged under 75 years due to chronic liver disease including cirrhosis per population by PCT

Directly standardised rate 2008–2010

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions





Context

Premature death from chronic liver disease has been rising in recent years, and between 1993 and 2010 the directly age-standardised mortality rate in England increased by 88%.[1] Most people dying from liver disease do so below the age of 75 years, and there is particular concern about increasing rates in younger people aged 35–55 years.[2] Liver disease is responsible for almost 12% of deaths in men aged 40–49 years, and it is now the leading cause of months of life lost for women under the age of 75 years.[3]

Chronic liver disease is largely preventable but many people are not diagnosed until a late stage of the disease when interventions may be limited and costly. The major contributing causes of liver disease are:

- alcohol; with the increasing consumption and decreasing cost of alcohol, more people are being diagnosed with alcohol-related liver disease – peak age for admission and death is 35–55 years, but numbers of admissions and deaths are increasing at all ages;
- hepatitis C, largely due to injecting drug use and shared paraphernalia, and the transfusion of contaminated blood products prior to 1990 that affected large numbers of people. Almost 50% of people with hepatitis C remain undiagnosed; it is an asymptomatic infection until late-stage liver disease ensues;
- chronic hepatitis B, usually acquired at birth or in early childhood, and occurs predominantly in people who now reside in England but were born in other countries where prevalence is higher; a small proportion of adults who acquire acute hepatitis B through sexual transmission or injecting drug use may also develop liver disease;
- obesity and diabetes – both of which are increasing; England has high rates of obesity and diabetes when compared with rates in many other countries with developed economies.

Premature death from chronic liver disease varies substantially across the country. At strategic health authority level, the range in mortality rate is from 6.8 to 15.2 per 100,000 population under 75 years (2.2-fold variation).

Magnitude of variation

For PCTs in England, the rate of mortality in people aged under 75 years due to chronic liver disease including cirrhosis ranged from 4.1 to 31.4 per 100,000 population (8-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 5.8–19.3 per 100,000 population, and the variation is 3.3-fold.

Potential reasons for the degree of variation observed include differences in:

- the prevalence of diabetes, obesity, hepatitis B and hepatitis C;
- the level of alcohol consumption;
- the level of investment in preventative measures;
- the configuration of services;
- the timing of diagnosis;
- degree of adherence to guidance;
- level of patient compliance with prevention or treatment.

Options for action

When planning service improvement or development to reduce the mortality rate from chronic liver disease, commissioners, clinicians and providers need:

- to review the mortality rates from chronic liver disease in people aged under 75 years in the local population;
- to assess strategies for preventing and treating chronic liver disease (see Box 1.1);
- to identify and implement improvements in those strategies to deliver reductions in mortality from chronic liver disease;
- to develop strategies in which the focus is on risk assessment in particular population subgroups and diagnosing liver disease at an earlier stage;
- to review service configuration and care pathway integration, including end-of-life care, to reduce unplanned admissions.

RESOURCES

- Local Alcohol Profiles for England. http://www.lape.org.uk/
- North West Public Health Observatory (2007) Indications of Public Health in the English Regions 8: Alcohol. Association of Public Health Observatories. http://www.apho.org.uk/resource/item.aspx?RID=39304
- NHS Information Centre. Mortality Data and Indicators for Chronic Liver Disease. https://indicators.ic.nhs.uk/webview/

1 The NHS IC Portal of Indicators. Menu pathway: NHS Information Centre Indicators; Compendium of Population Health Indicators; Illness or Condition; Digestive Diseases & Disorders; Chronic Liver Disease; Mortality from chronic liver disease including cirrhosis: directly standardised rate, all ages, annual trend 1993–2010. https://indicators.ic.nhs.uk/webview/

2 North West Public Health Observatory (2007) Indications of Public Health in the English Regions 8: Alcohol. Association of Public Health Observatories. http://www.apho.org.uk/resource/item.aspx?RID=39304

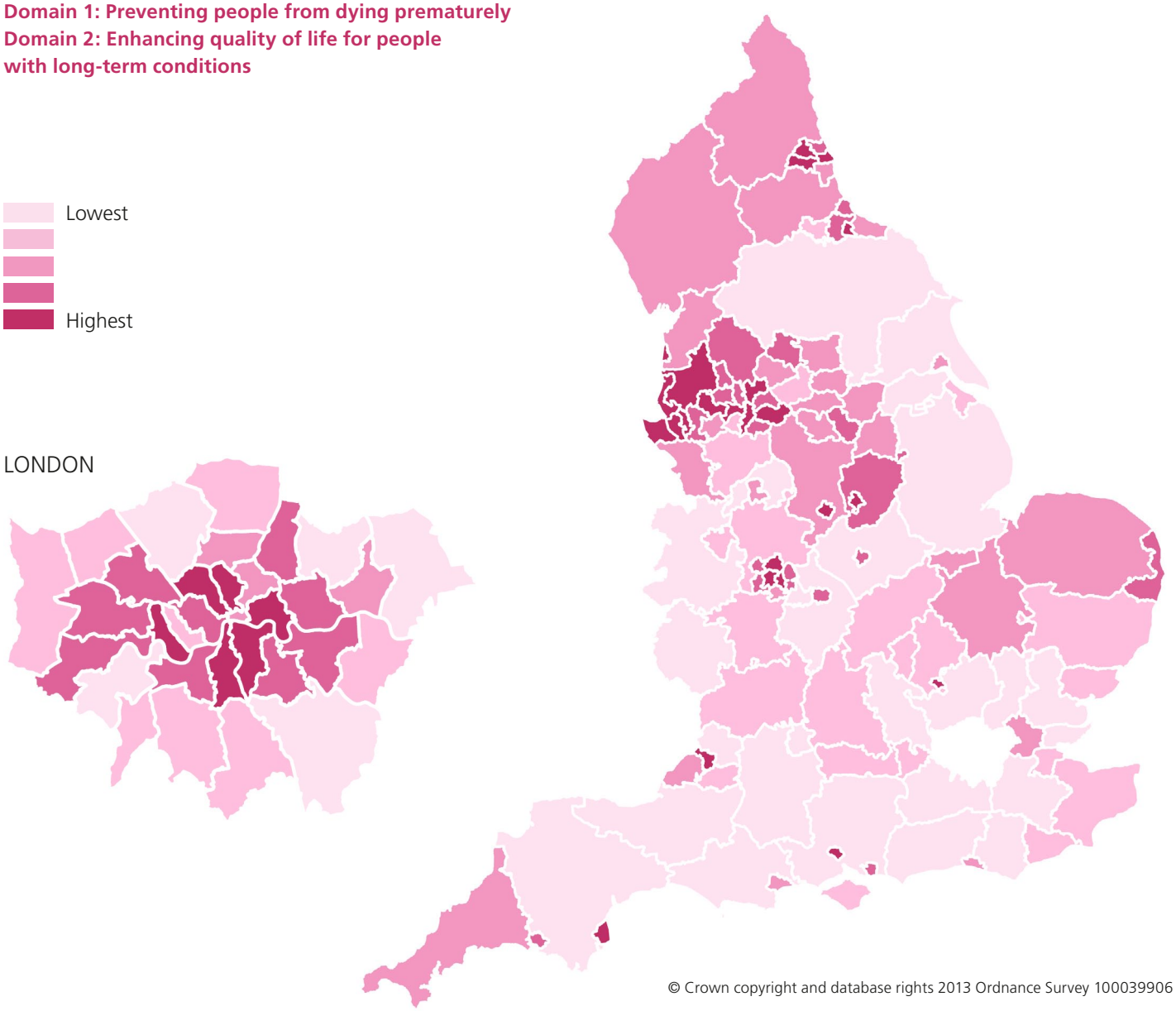
3 Analysis conducted in 2010 by Tom Kennel, North West Public Health Observatory.

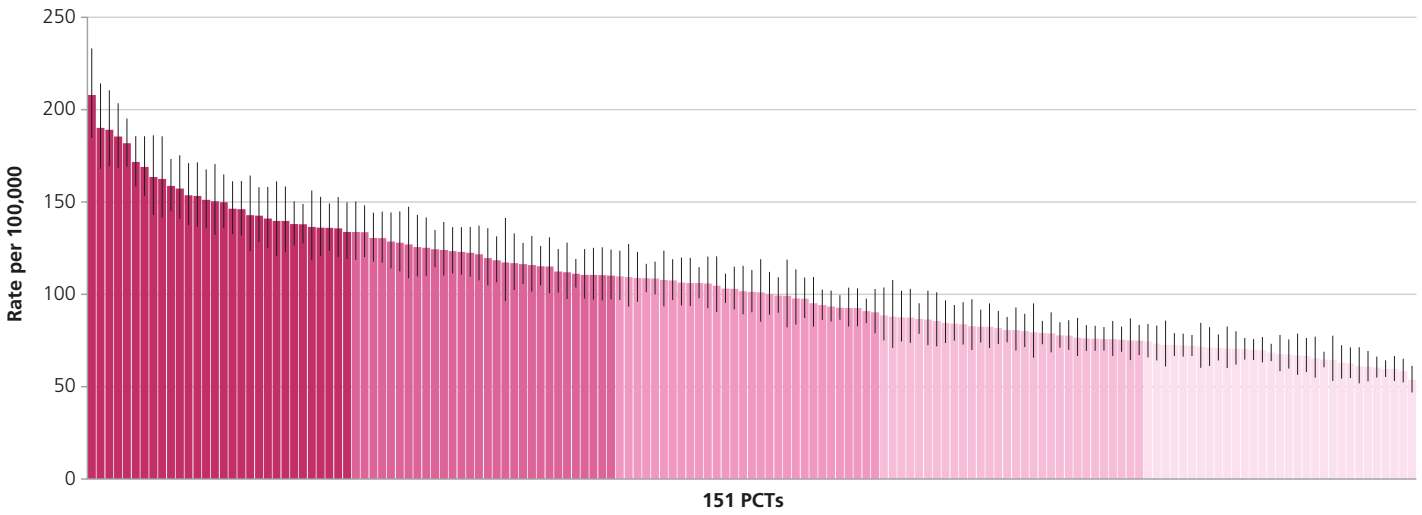
CHRONIC LIVER DISEASE

Map 4: Rate of people admitted to hospital at least once for cirrhosis per population by PCT

Directly standardised rate 2006/07–2010/11

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions





Context

Cirrhosis is a late stage of liver disease, in which scarring of the liver disrupts its normal functioning. It can take 10–20 years for cirrhosis to develop, during which time it can be prevented. Many established cases can be treated to avoid complications, but diagnosis is the key.

Cirrhosis of the liver is an important cause of illness and death. In 2010, it killed more people than were killed in transport accidents and more women than cancer of the cervix. Large rises in death rates from chronic liver disease and cirrhosis have occurred in most age-groups. The rise in deaths from cirrhosis among younger people is of particular concern.

The rising trend in deaths from cirrhosis in the UK is unusual when compared with trends in other countries in the European Union (EU). Most EU countries have declining trends although in general the mortality rates are still higher than the current mortality rate in the UK. In 1970, the mortality rate for liver cirrhosis in the UK was about seven times lower than the EU average. In the period up to 2009, however, the mortality rate for some other countries, e.g. France and Italy, has fallen; among people aged under 65 years, the rate for the UK has now overtaken those in France and Italy (Figure 4.1).

Although there are many different causes of cirrhosis, it is often due to excess alcohol consumption. Another cause that is becoming increasingly important is chronic viral hepatitis, especially hepatitis C. Alcohol consumption will increase the rate of progression of cirrhosis irrespective of the original cause.

This considerable increase in the incidence of chronic liver disease and cirrhosis is reflected in hospital admissions: in 1998/99, there were 7982 admissions for cirrhosis; by 2010/11, this had increased by 159% to 20,697 admissions.

Information about the prevalence or number of people living with cirrhosis is not routinely collected. Variation in prevalent cases has been estimated for this indicator based on individual adults with cirrhosis admitted to hospital, but this probably represents fewer than 10% of the total number of people with cirrhosis in any one year.

Magnitude of variation

For PCTs in England, the rate of people admitted to hospital at least once for cirrhosis ranged from 53.7 to 207.9 per 100,000 population (3.9-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 60.7–171.6 per 100,000 population, and the variation is 2.8-fold.

The reasons for the degree of variation observed are not clear, however, they are likely to reflect higher rates of alcohol consumption.

Options for action

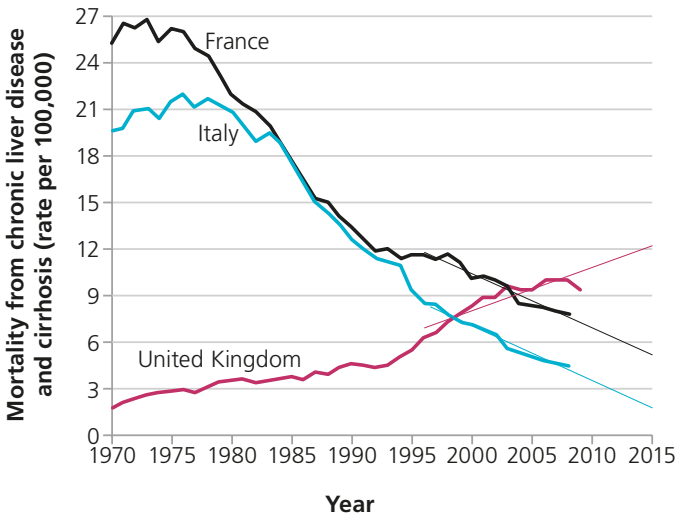
When planning service improvement or development to reduce the prevalence of cirrhosis, commissioners, clinicians and providers need:

- to review hospital admission rates for cirrhosis in the locality;
- to assess the current pathway of care for people presenting with cirrhosis, and identify improvements;
- to focus on the causes of cirrhosis and opportunities for early detection to avoid future admissions and complications;
- to use existing guidelines on liver disease (see "Resources") to reduce or mitigate the consequences of the predictable complications of cirrhosis, such as cancer.

RESOURCES

- Annual Report of the Chief Medical Officer of the Department of Health 2001 (2004) On the State of the Public Health. Department of Health. http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/AnnualReports/Browsable/DH_4094742
- British Society of Gastroenterology. http://www.bsg.org.uk
- European Association for the Study of the Liver. http://www.easl.eu
- American Association for the Study of Liver Diseases. http://www.aasld.org

Figure 4.1: Rate (directly standardised) of mortality from cirrhosis in people aged under 65 years [source: World Health Oganization Health for All Database (HFA-DB), January 2012[1]]



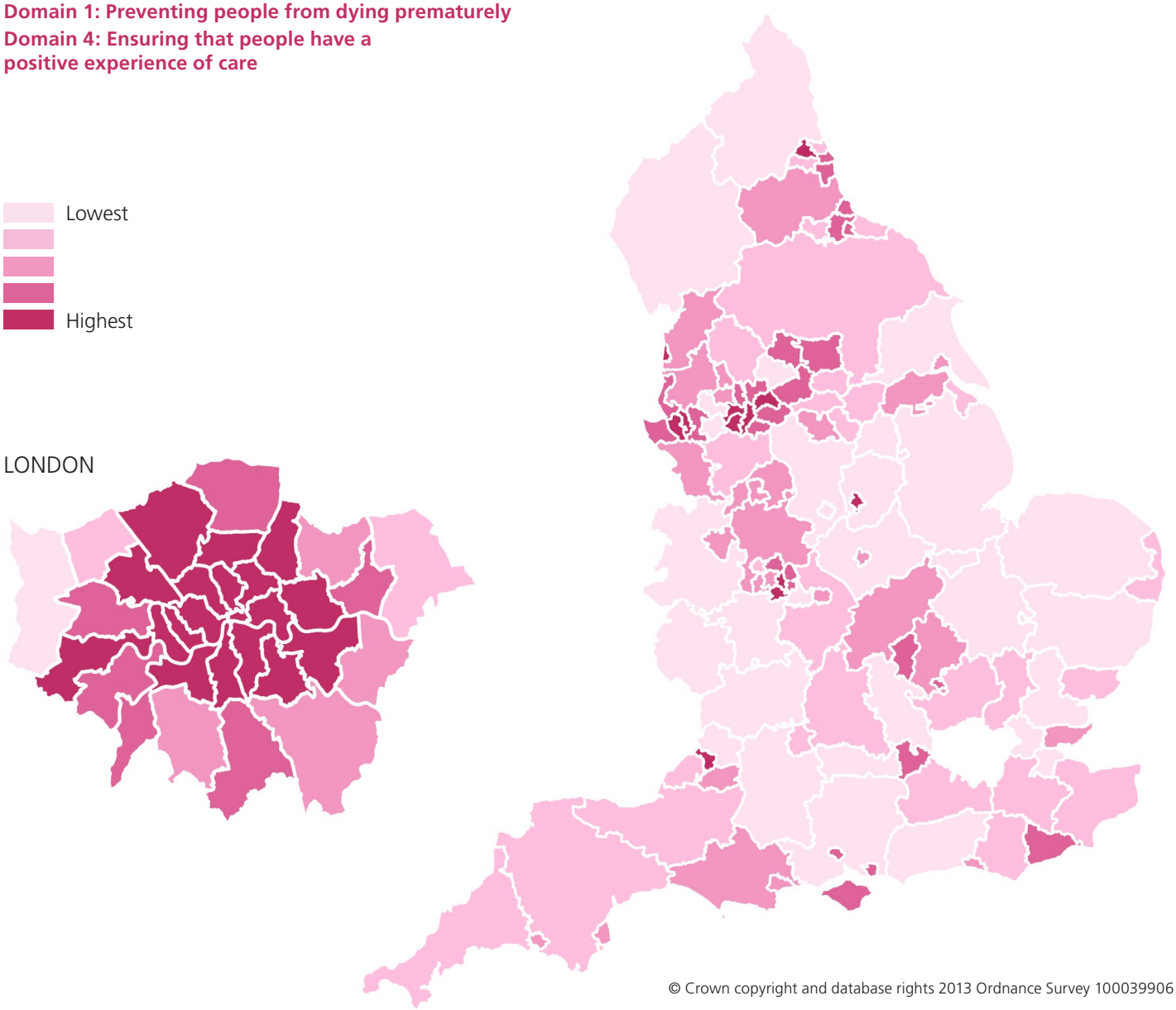
1 January 2012 data http://www.euro.who.int/en/what-we-do/data-and-evidence/update-of-whoeurope-statistical-databases
August 2012 data http://www.euro.who.int/en/what-we-do/data-and-evidence/databases/european-health-for-all-database-hfa-db2

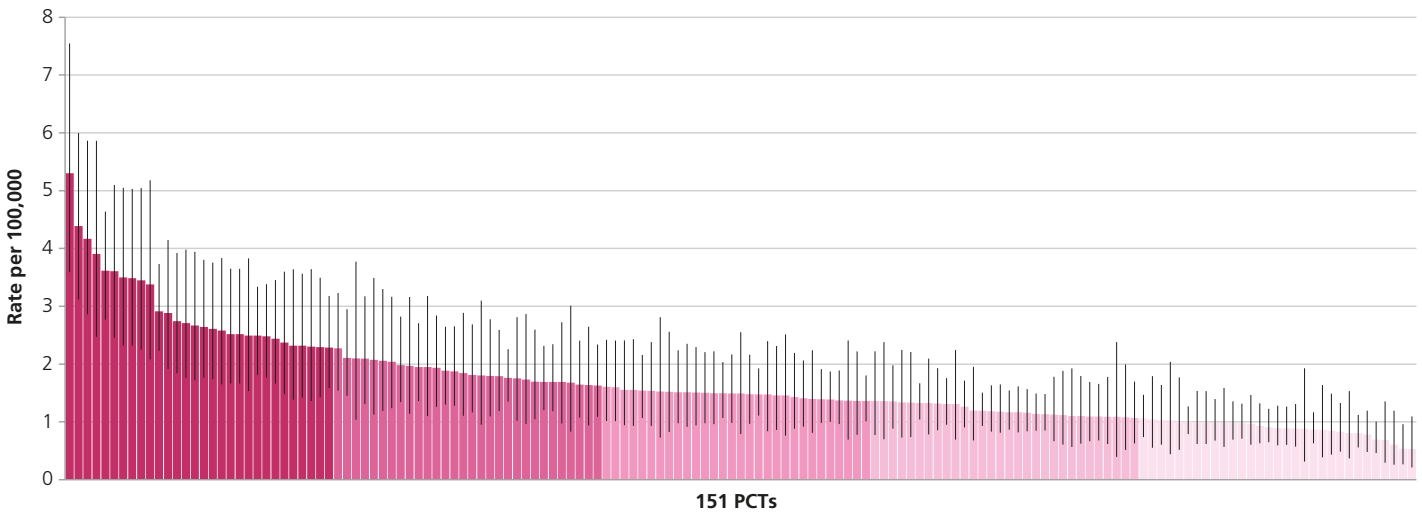
LIVER CANCER

Map 5: Rate of liver cancer mortality in people aged under 75 years per population by PCT

Directly standardised rate 2006–2010

Domain 1: Preventing people from dying prematurely
Domain 4: Ensuring that people have a positive experience of care





Context

The liver controls much of the body's biochemistry, and performs many important functions, including:

- storing nutrients;
- storing and redistribution of fat;
- converting fats to energy when the body needs it;
- producing bile and proteins;
- helping the blood to clot;
- breaking down harmful substances including alcohol;
- helping the immune system to fight infection.

According to Cancer Research UK, around 3900 people every year are diagnosed with primary liver cancer each year in the UK, which accounts for about 1% of all cancers in the UK.[1] Secondary liver cancer, spreading from elsewhere in the body, is far more common than primary liver cancer. Most people in the UK who are diagnosed with tumours in their liver will have secondary rather than primary liver cancer. The most common form of liver cancer is hepatocellular carcinoma.

Primary liver cancer is more prevalent among men than among women. Primary liver cancer is more likely to affect people who are aged over 60 years, and is rare in people under 45 years of age,[2] but is becoming more common at all ages.

The main cause of primary liver cancer (hepatocellular carcinoma) is cirrhosis of the liver, in which the liver is scarred as a result of damage over a long period of time.[2] Other risk factors for liver cancer include:

- chronic hepatitis B and hepatitis C;
- excessive alcohol consumption;
- haemochromatosis, an uncommon genetic condition resulting from an overload of iron in the body – the risk is high if the condition is not treated;
- non-alcoholic fatty liver disease (NAFLD), specifically the advanced form known as non-alcoholic steatohepatitis (NASH), thought to be the cause of many cases of cirrhosis previously ascribed to an unknown cause.[2]

Primary liver cancer arises only in people with cirrhosis and may be seen as an indicator of the failure of an integrated approach to healthcare for people with liver disease. Incidence of primary liver cancer is likely to correlate with and reflect all forms of liver disease; the variation in the incidence of cancer appears to be similar to that in overall mortality from liver disease (see Map 3, pages 50–51).

Liver cancer in adults has a poor prognosis because it tends to be diagnosed late. By the time a person has symptoms and consults a doctor, the disease is frequently at an advanced stage. Only about 1 in 10 people (10%) are diagnosed in the early stages of the disease, and it is only in these early diagnosed cases that surgery would help.[1]

Overall, after diagnosis, around 20% of people live for at least one year and 5% live for at least five years.[1]

Magnitude of variation

For PCTs in England, the rate of liver cancer mortality in people aged under 75 years ranged from 0.5 to 5.3 per 100,000 population (10-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 0.8–3.6 per 100,000 population, and the variation is 4.6-fold.[3]

Potential reasons for the degree of variation observed include differences in:

- the prevalence of hepatitis B and hepatitis C;
- the prevalence of cirrhosis of the liver;
- levels of alcohol consumption;
- the configuration of services;
- the timing of diagnosis;
- degree of adherence to guidance;
- level of patient compliance with prevention or treatment.

Options for action

When planning service improvement or development to reduce the mortality rate for primary liver cancer, commissioners, clinicians and providers need:

- to review the mortality rates and trends for primary liver cancer in the locality;
- to identify whether there are opportunities for improving the early diagnosis of liver cancer;
- to include liver cancer in the assessment of strategies for reducing alcohol consumption and improving outcomes for liver disease;
- to consider developing registries and surveillance programmes at a local level given that the risk groups for primary liver cancer are known;
- to review the clinical management of and configuration of services for primary liver cancer to ensure close collaboration among the different disciplines – hepatology, diagnostic pathology and radiology services, interventional radiology and liver surgery including transplantation.

RESOURCES

- National Cancer Intelligence Network. http://www.ncin.org.uk/publications/data_briefings/liver_and_gall_bladder.aspx
- Cancer Research UK. Liver Cancer Mortality Statistics. http://info.cancerresearchuk.org/cancerstats/types/liver/mortality/uk-liver-cancer-mortality-statistics
- British Liver Trust. Fighting Liver Disease. Liver Cancer. http://79.170.44.126/britishlivertrust.org.uk/wp-content/uploads/2012/12/Liver-Cancer_lores1.pdf

1 Cancer Research UK. The Liver. http://cancerhelp.cancerresearchuk.org/type/liver-cancer/about/the-liver

2 British Liver Trust. Fighting Liver Disease. Liver Cancer. http://79.170.44.126/britishlivertrust.org.uk/wp-content/uploads/2012/12/Liver-Cancer_lores1.pdf

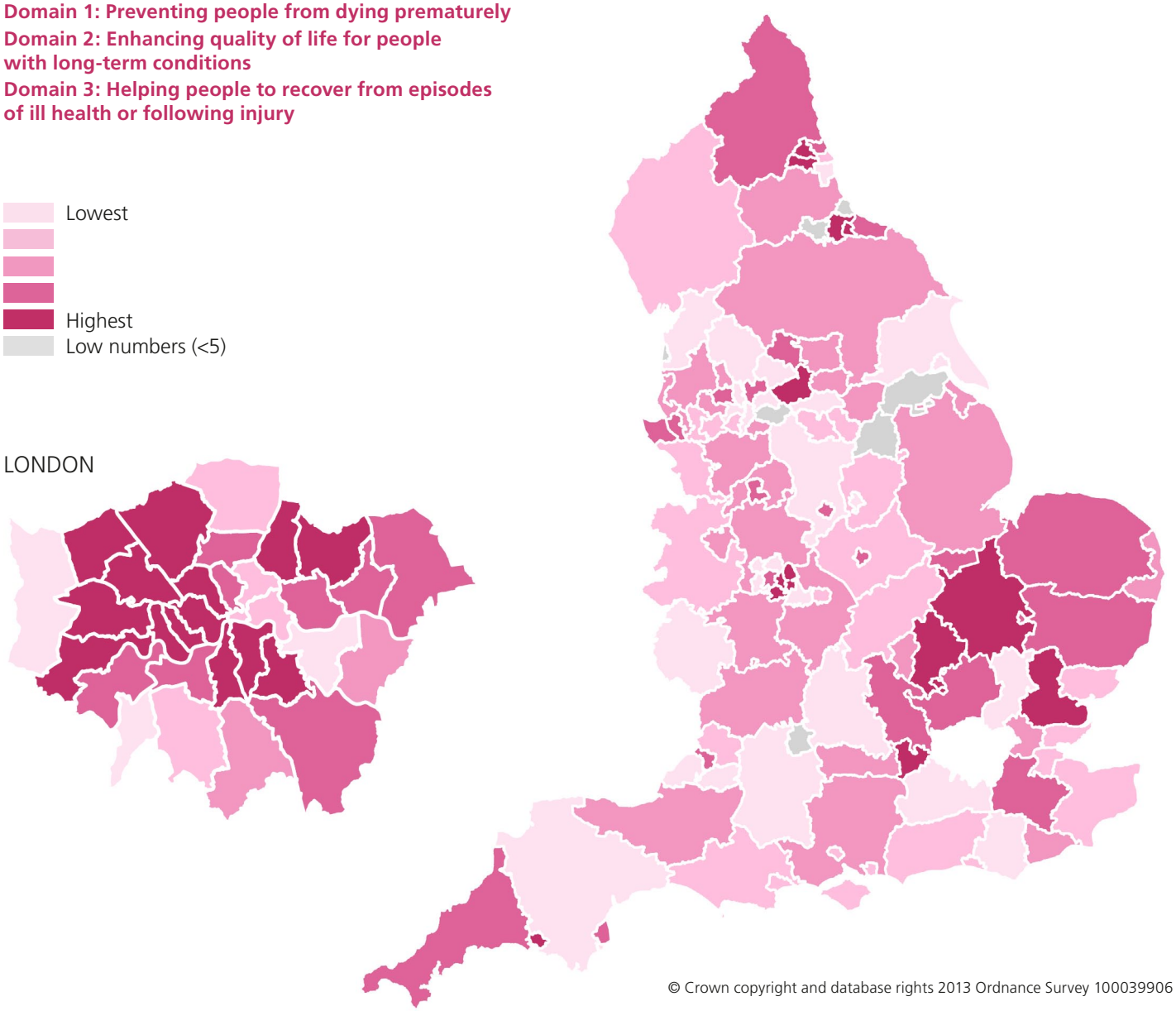
3 The Office for National Statistics (ONS) carried out the original collection and collation of the mortality data but bear no responsibility for their future analysis or interpretation.

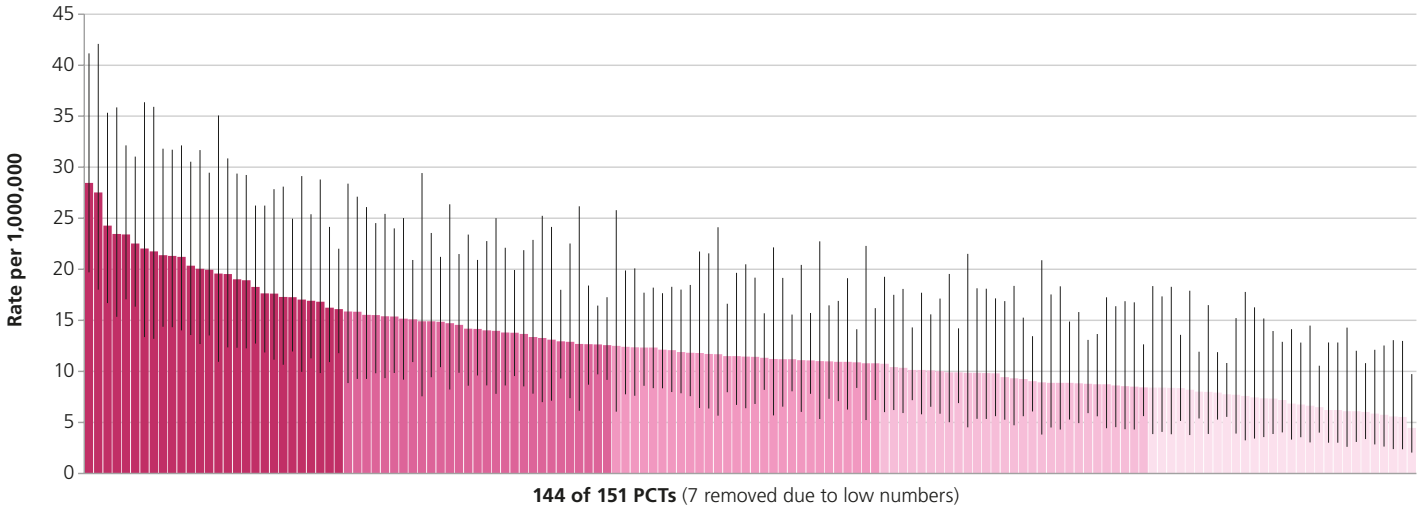
TRANSPLANTATION

Map 6: Rate of liver transplants from all donors per population by PCT

2006/07–2010/11

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions
Domain 3: Helping people to recover from episodes of ill health or following injury





144 of 151 PCTs (7 removed due to low numbers)

Context

Liver transplantation is a recognised therapy for some patients with end-stage chronic liver disease, and some with sudden acute liver failure and coma, however, most people dying from liver failure are not suitable candidates for liver transplantation. The criteria for selection onto a transplant list have been defined, and are reviewed every year, by the Liver Advisory Group at the Organ Donation and Transplantation Directorate at NHS Blood and Transplant (NHSBT).[1] Criteria for referral for consideration of transplantation are different from those for transplantation.

Selection for a transplant list, once referred, is carefully monitored. To ensure that individuals across England have equal access to a transplant centre for prompt assessment of their liver disease, guidelines for referral to a transplant centre are currently being updated by the British Association for the Study of the Liver and the British Society of Gastroenterology, in conjunction with NHSBT. NHSBT are also coordinating an initiative to develop a universal allocation process, identical in all transplant centres.

Approximately 700 liver transplants are performed each year in the UK at six centres in England and one in Scotland. Of all liver transplants, 14% are undertaken as a "super-urgent" procedure for acute liver failure and other causes; the remainder are elective procedures. Survival following liver transplantation is good, and continues to improve: in recent cohorts, survival at one year was 93.2%.

Demand continues to exceed the supply of organs donated: more patients are being registered for a liver transplant than there are organs available for transplantation. At 31 March 2012, there were 553 patients on the active transplant list.[2] In four years (2007/08–2011/12), registrations have doubled and there has been a 25% increase in liver transplants. For people with liver disease on the transplant list, the mortality rate while waiting for a liver transplant is 15%.

Magnitude of variation

For PCTs in England, the rate of liver transplants from all donors ranged from 4.5 to 28.5 per million population (pmp) (6-fold variation)[3] When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 6.0–22.5 pmp, and the variation is 3.7-fold.

In Figure 6.1, the rate of liver transplants (see points) is presented in relation to the mortality rate (directly standardised) from chronic liver disease for people under the age of 75 years (see columns); there appears to be little relationship between mortality rates as an indicator of chronic liver disease prevalence and liver transplantation rates (r=0.0485).

Potential reasons for variation include differences in:

- access to local expertise in liver disease;
- criteria for referral for consideration for liver transplant;
- care pathways for people who may require a liver transplant.

Options for action

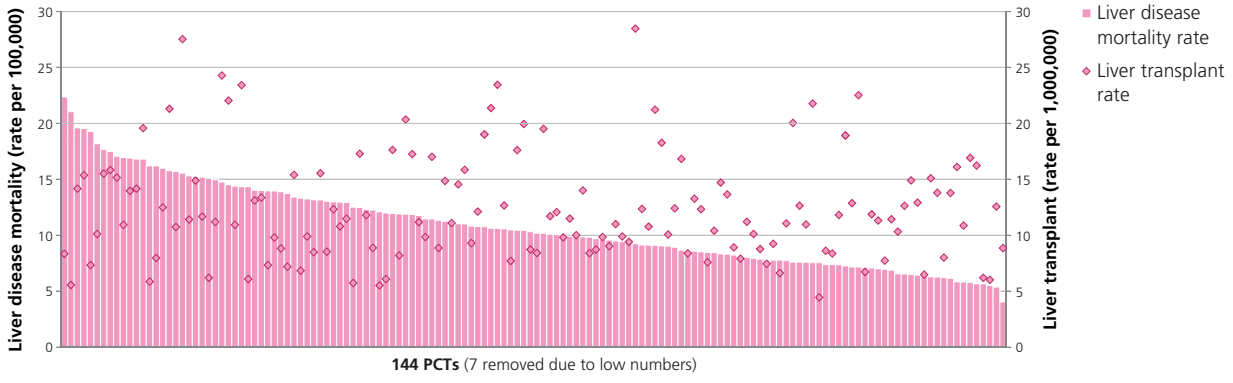
When planning service improvement or development for liver transplantation, commissioners, clinicians and providers could:

- identify whether there are high liver mortality rates but low transplant rates in the locality, and review local services in relation to the adequacy of expertise in gastroenterology and hepatology and of liaison with transplant centres;
- review patient pathways;
- review criteria for selection onto a transplant list to ensure that patients who have the potential to benefit from referral for liver transplantation are considered for the intervention;
- where possible, provide transplant assessment services locally, rather than requiring the patient to travel – this could be achieved via outreach networks from transplant and tertiary centres.

RESOURCES

- Information concerning transplant activity by centre and nationally. http://www.organdonation.nhs.uk/statistics/
- Information concerning the process for allocation of liver donor organs. http://www.organdonation.nhs.uk/about_transplants/organ_allocation/liver/
- Devlin J, O'Grady J (2000) Indications for referral and assessment in adult liver transplantation: a clinical guideline. British Gastroenterological Society Guidelines in Gastroenterology. http://www.bsg.org.uk/clinical-guidelines/liver/indications-for-referral-and-assessment-in-adult-liver-transplantation-a-clinical-guideline.html

Figure 6.1: Liver transplant rate pmp 2006/07–2010/11 (points) in relation to rate of chronic liver disease mortality (directly standardised) per 100,000 population aged under 75 years 2008–2010 (columns)



1 NHS Blood and Transplant. Liver Advisory Group. http://www.organdonation.nhs.uk/about_us/advisory_groups/lag/

2 NHS Blood and Transplant (2012) Organ Donation and Transplantation Activity Report 2011/12. http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2011_12.pdf

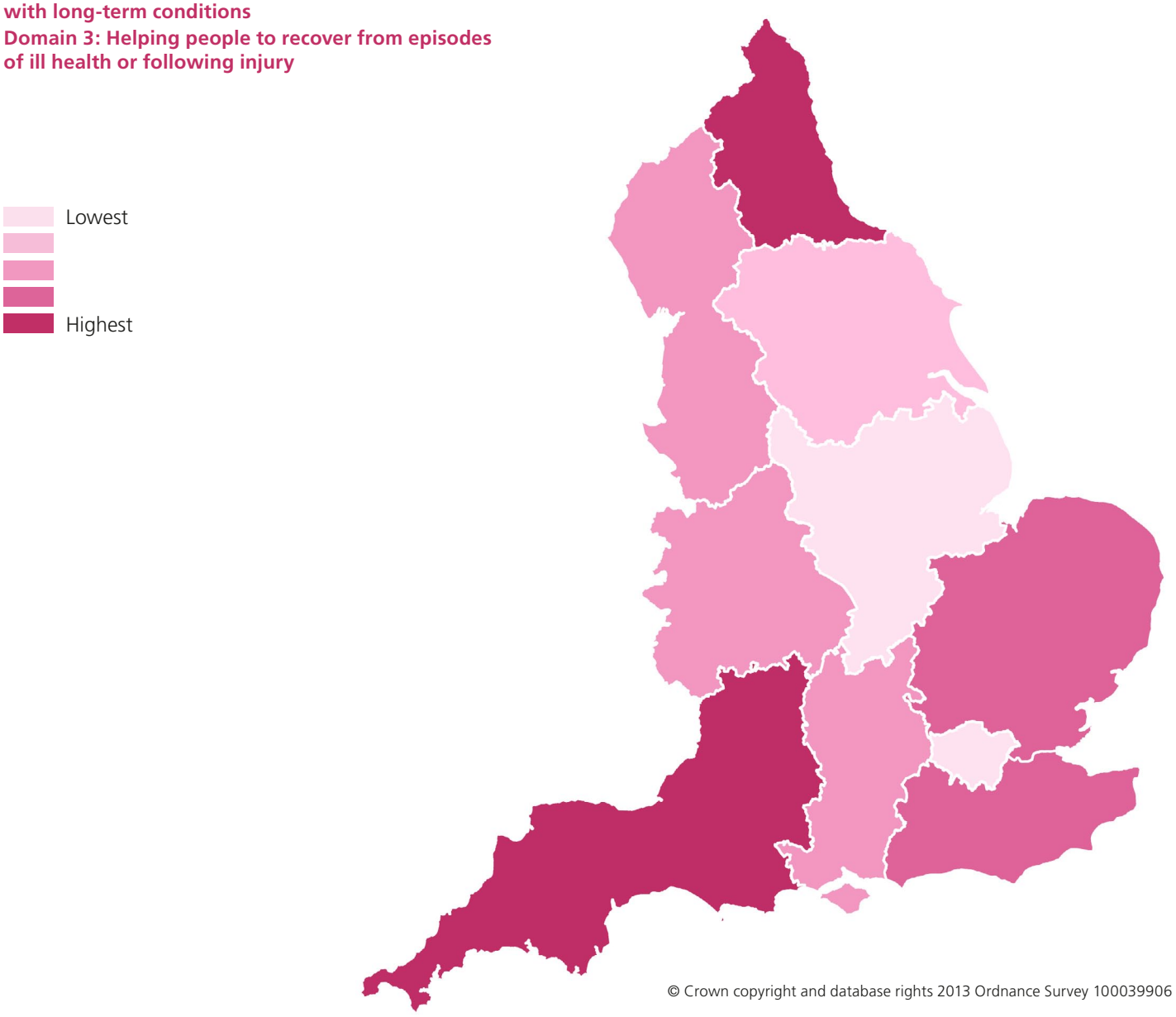
3 Data from seven PCTs have been removed due to low numbers (<5).

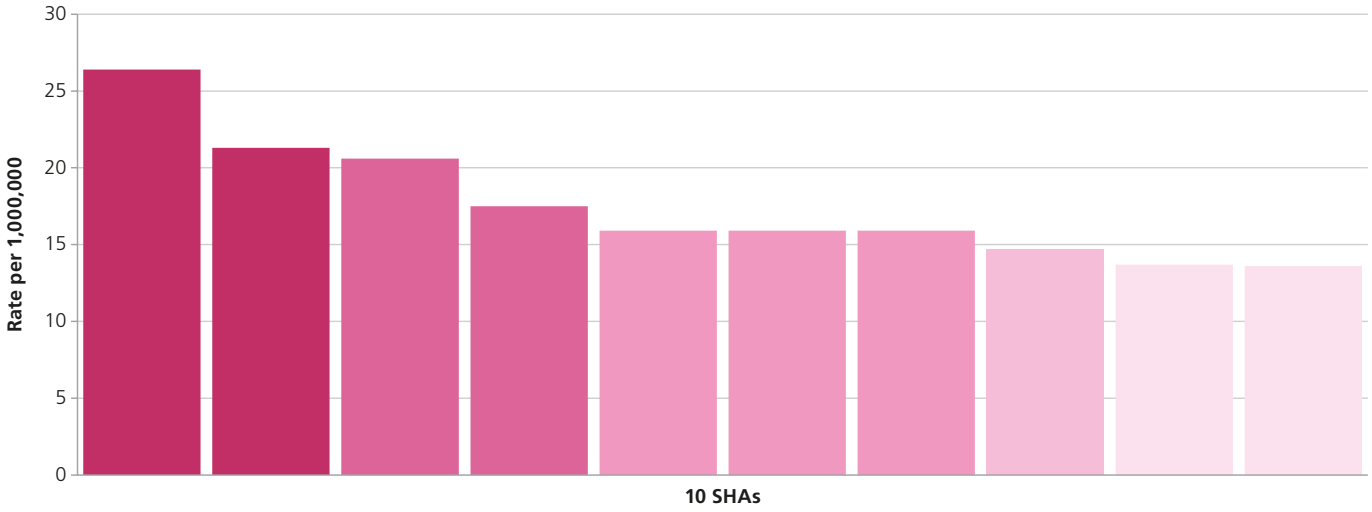
TRANSPLANTATION

Map 7: Organ donation rates per population by SHA

2011/12

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions
Domain 3: Helping people to recover from episodes of ill health or following injury





Context

Organ donation after death saves lives. One donor can help up to nine recipients. The number of people on the NHS Organ Donor Register is increasing,[1] and comprises almost 30% of the UK population.[2] However, families of potential donors can refuse consent.

In the UK, 7636 patients were waiting for a transplant at end March 2012.[1] This does not reflect the true extent of need because many clinicians are reluctant to list more patients than are realistically likely to receive organs,[3] and listing criteria do not encompass all patients who might benefit from transplantation. Need is likely to increase with changing demographics and prevalence of disease:

- an ageing population[3];
- an anticipated increase in the incidence of Type 2 diabetes[3];
- an increase in the number of people receiving renal replacement therapy;
- increases in the rates of cirrhosis and liver cancer;
- an increase in the survival rate of children with congenital heart disease to a stage where replacement is appropriate.

There have also been changes over time in donor characteristics:

- The proportion of deceased donors over the age of 60 years has increased;
- The proportion of deceased donors who are clinically obese has increased;
- The proportion of deceased donors after a trauma death has decreased.[1]

These changes in donor characteristics may affect not only the number of organs suitable for transplantation, but also the quality of organs donated and the subsequent transplant outcome for recipients.

People from ethnic minority groups are under-represented among organ donors: 96% are White, 1% are Asian and 1% are Black (2% are "Other").[1]

In 2011/12, 508 patients died while on the active waiting list for their transplant; a further 819 were removed from the transplant list, mostly as a result of deteriorating health and ineligibility for transplant and many of these patients would have died shortly afterwards.[1]

Part of the remit of NHS Blood and Transplant (NHSBT) is to promote organ donation and the NHS Organ Donor Register (see "Resources"). Actual deceased donor numbers are supplied by NHSBT.

The NHSBT Potential Donor Audit (PDA; see "Resources") measures performance at every stage of the donation pathway. All patients who were suitable potential organ donors can be identified, and if donation did not occur the reasons why are also identified.

In the last five years, there has been a considerable increase in the number of transplants from donations after circulatory deaths.

Magnitude of variation

For strategic health authorities (SHAs) in England, the organ donation rate ranged from 13.6 to 26.4 per million population, a 1.9-fold variation.

If all SHAs achieved an organ donation rate of 26.4 per million population (the highest rate attained in 2011/12), there would be 55% more donors.

Although there has been some work done to understand the different reasons for non-donation, further work is needed, in particular to establish how best to encourage engagement with organ donation after death, especially for people from Black and Asian communities.[2]

Options for action

More needs to be done to promote organ donation, and to make it routine. Commissioners, clinicians and service providers should consider highlighting the need for organ donation among contacts with liver services, which will increase awareness and appreciation for public involvement.

When planning service improvement or development to increase organ donation rates, it is important for every potential donor to be identified and referred to the Donor Co-ordinator network. This network comprises Specialist Nurses for Organ Donation, employed by NHSBT.

RESOURCES

- NHS Blood and Transplant Campaigns supply free leaflets (in English and English/Welsh), leaflet dispensers, posters (A3) and other resources for campaigning. http://www.organdonation.nhs.uk/campaigns/
- Infographics to raise awareness about organ donation. http://www.organdonation.nhs.uk/campaigns/campaign-materials.asp
- NHS Blood and Transplant (NHSBT). http://www.nhsbt.nhs.uk
- NHSBT Potential Donor Audit. http://www.organdonation.nhs.uk/statistics/potential_donor_audit/

1 NHS Blood and Transplant (2012) Organ Donation and Transplantation Activity Report 2011/12. http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2011_12.pdf

2 NHS Blood and Transplant. News Release: NHS Organ Donor Register Hits Record 18 Million. 23rd June 2011. http://www.nhsbt.nhs.uk/news/2011/newsrelease230611.html

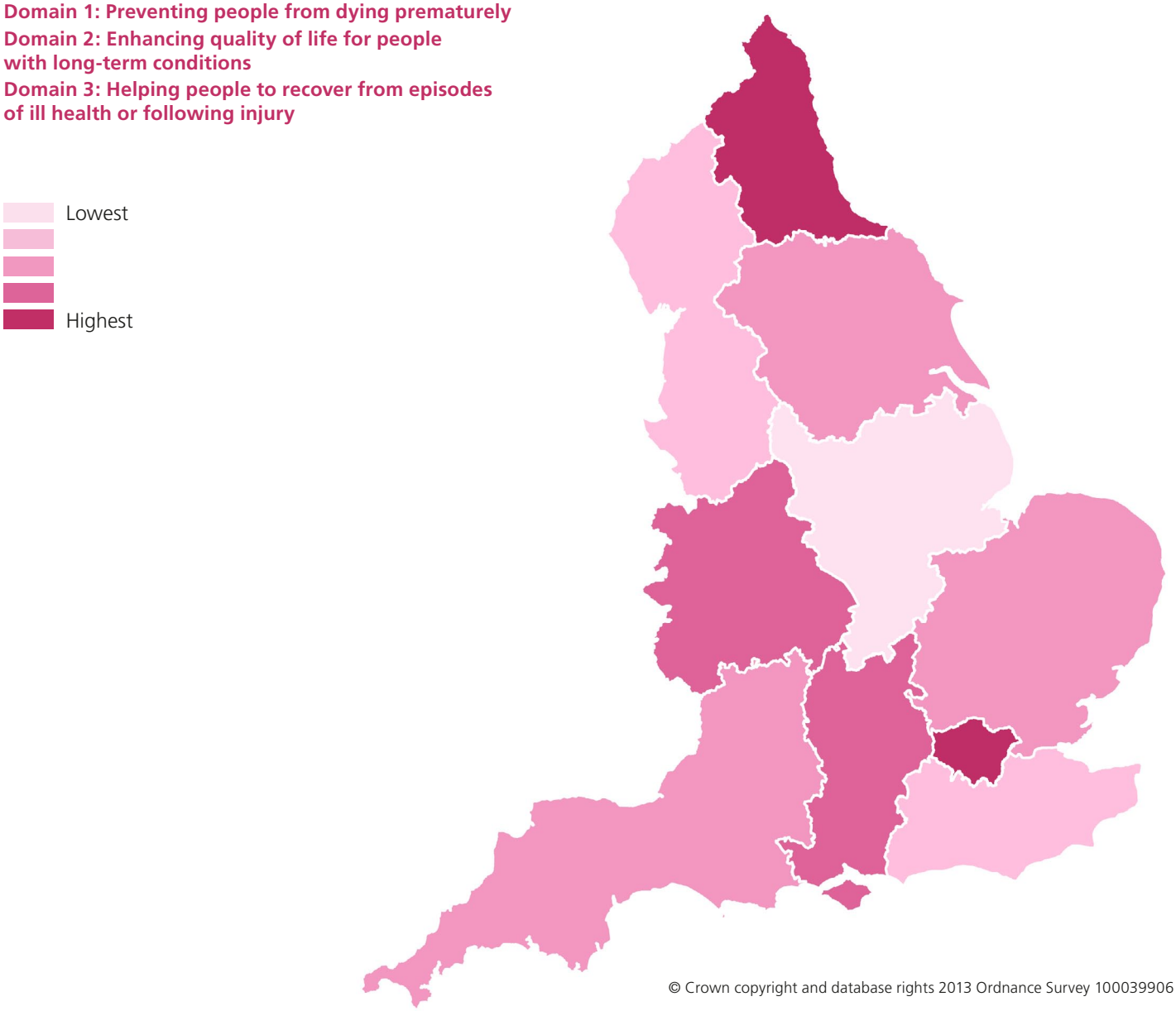
3 Organ Donation Taskforce (2008) Organs for Transplants. A report from the Organ Donation Taskforce. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_082120.pdf

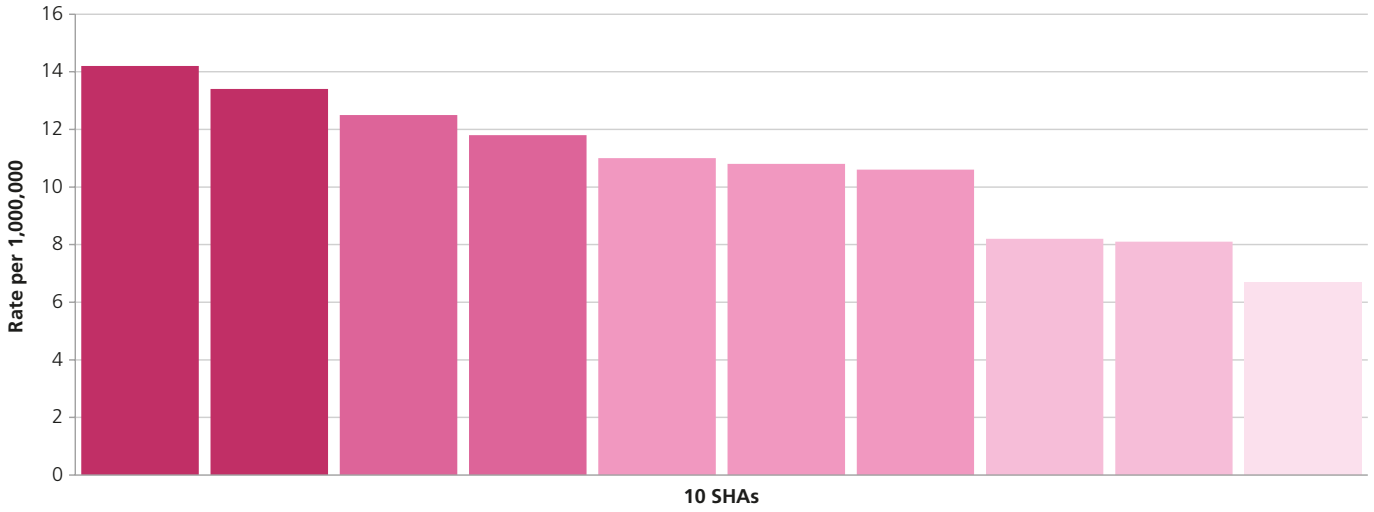
TRANSPLANTATION

Map 8: Rate of liver transplants from deceased donors per population by SHA

2011/12

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions
Domain 3: Helping people to recover from episodes of ill health or following injury





Context

Liver transplantation is a recognised therapy for some patients with end-stage chronic liver disease, and some with sudden acute liver failure and coma, however, most people dying from liver failure are not suitable candidates for liver transplantation. The criteria for selection onto a transplant list have been defined, and are reviewed every year, by the Liver Advisory Group at the Organ Donation and Transplantation Directorate at NHS Blood and Transplant (NHSBT).[1] Criteria for referral for consideration of transplantation are different from those for transplantation.

Approximately 700 liver transplants are performed each year in the UK, in six centres in England and one in Scotland. Of all liver transplants, 14% are undertaken as a "super-urgent" procedure for acute liver failure and other causes; the remainder are elective procedures. Survival following liver transplantation is good, and continues to improve: in recent cohorts, survival at one year was 93.2%.

Demand continues to exceed the supply of organs donated: more patients are being registered for a liver transplant than there are organs available for transplantation. At 31 March 2012, there were 553 patients on the active transplant list.[2] In four years (2007/08–2011/12), registrations have doubled and there has been a 25% increase in liver transplants. For people with liver disease on the transplant list, the mortality rate while waiting for a liver transplant is 15%.

Magnitude of variation

For strategic health authorities (SHAs) in England, the rate of liver transplants from deceased donors ranged from 6.7 to 14.2 per million population (pmp), a 2.1-fold variation (for 2010/11 data, see Table 8.1).

Table 8.1: Rate of liver transplants from deceased donors per million population by SHA over two time-periods

Date of data	Range	Fold difference	Notes
2010/11	7.6–13.2	1.7	Map 47, Atlas 2.0 (2011)
2011/12	6.7–14.2	2.1	

The range and degree of variation observed have increased since 2010/11. Variation in the liver transplant rates among SHAs may indicate:

- differences in the prevalence of liver disease;
- variations in the rate of referral to transplant centres;
- differences among centres in the way organs are allocated to recipients on a transplant list.

Options for action

Selection for a transplant list, once referred, is carefully monitored. To ensure that individuals across England have equal access to a transplant centre for prompt assessment of their liver disease, guidelines for referral to a transplant centre are currently being updated by the British Association for the Study of the Liver and the British Society of Gastroenterology, in conjunction with NHSBT. NHSBT are also coordinating an initiative to develop a universal allocation process, identical in all transplant centres.

RESOURCES

- Information concerning transplant activity by centre and nationally. http://www.organdonation.nhs.uk/statistics/
- Information concerning the process for allocation of liver donor organs. http://www.organdonation.nhs.uk/about_transplants/organ_allocation/liver/

1 NHS Blood and Transplant. Liver Advisory Group. http://www.organdonation.nhs.uk/about_us/advisory_groups/lag/

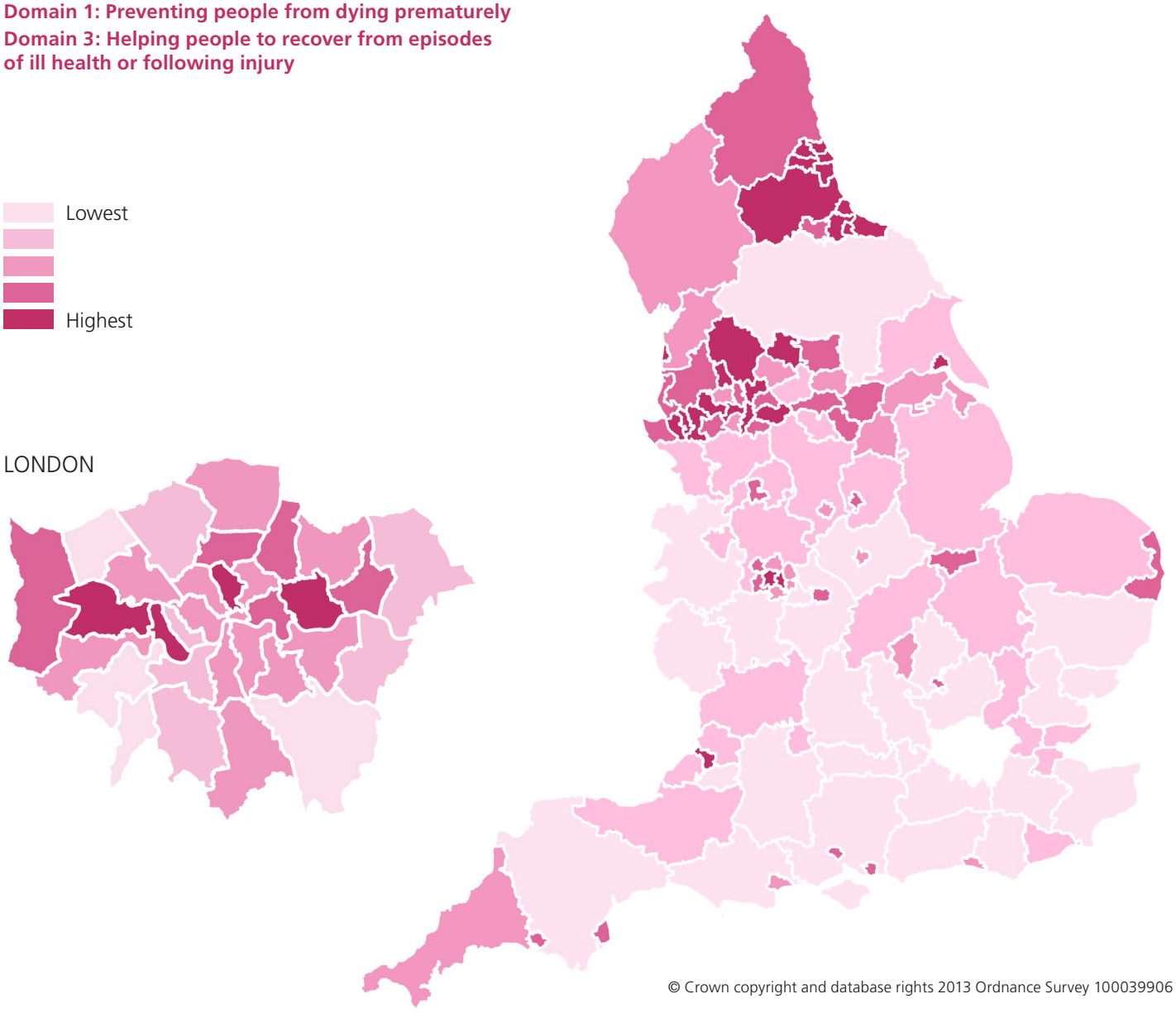
2 NHS Blood and Transplant (2012) Organ Donation and Transplantation Activity Report 2011/12. http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2011_12.pdf

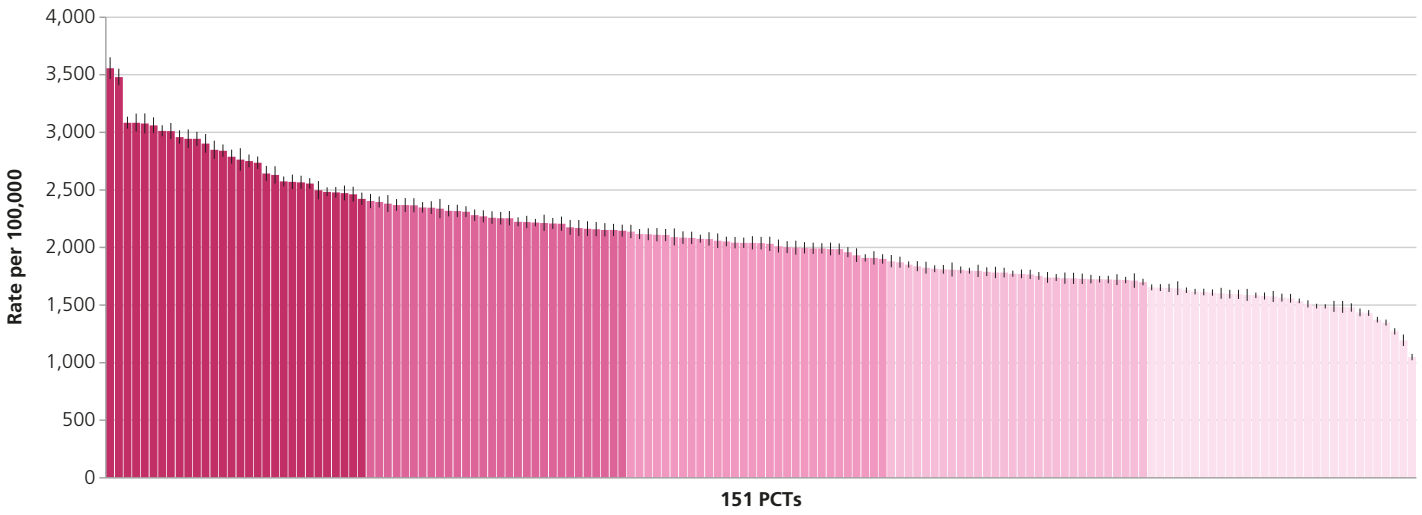
ADMISSIONS FOR ALCOHOL USE

Map 9: Rate of alcohol-related admissions per population by PCT

Directly standardised rate 2011/12

Domain 1: Preventing people from dying prematurely
Domain 3: Helping people to recover from episodes of ill health or following injury





Context

Alcohol misuse costs the country around £21 billion a year.[1] In 2011, the Department of Health estimated the cost to the NHS of alcohol-related harm as £3.5 billion (2009/10 prices; see Table 9.1).

Table 9.1: NHS costs of alcohol-related harm 2009/10[2]

Category of cost	Cost (£ million)
Hospital inpatient & day visits: • Directly attributable to alcohol misuse • Partly attributable to alcohol misuse	 385 1386
Hospital outpatient visits	246
Accident and emergency visits	696
Ambulance services	449
NHS GP consultations	112
Practice nurse consultations	16
Dependency prescribed drugs	8
Specialist treatment services	122
Other healthcare costs	60
Total	**3480**

Department of Health internal analysis shows there has been a 40% increase in alcohol-related admissions based on primary diagnoses over the past 9 years. Mortality rates increased by 16% between 2001 and 2008 to 12.2 per 100,000 population, but in 2011 have decreased slightly to 11.7 per 100,000 population.[3]

Conditions associated with alcohol use include injuries and trauma (alcohol-related violence or road traffic accidents), gastrointestinal, including liver, disease, cancers, stroke, heart and respiratory diseases, and co-existing mental health problems.

Magnitude of variation

For PCTs in England, the rate of alcohol-related admissions ranged from 1048.1 to 3557.3 per 100,000 population (3.4-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 1430.6–3060.8 per 100,000 population, and the variation is 2.1-fold (for 2009/10 and 2010/11 data, see Table 9.2).

Some of the variation is likely to be due to differences in alcohol use, although other factors such as differences in coding for association with alcohol could explain some of the variation.

Options for action

To reduce the rate of alcohol-related admissions, commissioners in collaboration with primary and secondary care providers need:

- To consider implementing the "High Impact Changes" (Box 9.1), especially points 4–6, assessed by the Department of Health as the most effective actions for localities prioritising a reduction in alcohol-related harm;
- To review current patterns of acute service provision and ascertain whether alternatives to hospital admission are available when appropriate;
- To learn from initiatives in other local services, e.g. the Alcohol Liaison Service at the Royal Free Hospital, London (see "Resources");
- To explore opportunities for early detection in the health service;
- To develop a local alcohol treatment pathway (see "Resources").

Box 9.1: High Impact Changes[4]

1. Work in partnership
2. Develop activities to control the impact of alcohol misuse in the community
3. Influence change through advocacy
4. Improve effectiveness and capacity of specialist treatment
5. Appoint an Alcohol Health Worker
6. Identification and brief advice (IBA) – provide more help to encourage people to drink less
7. Amplify national social marketing priorities

RESOURCES

- For NICE Guidance – PH24, CG115 & CG100 – and NICE Pathway, see "Resources", page 65.
- Alcohol Learning Centre. http://www.alcohollearningcentre.org.uk/
- Royal Free Hospital, London, Alcohol Liaison Service. http://www.royalfree.nhs.uk/pip_admin/docs/ALS_1234.pdf
- Department of Health (2009) Local Routes: Guidance for developing alcohol treatment pathways. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110423
- Local Alcohol Profiles for England. http://www.lape.org.uk/

Table 9.2: Rate of alcohol-related admissions per 100,000 population by PCT over three time-periods

Date of data	Range before exclusions	Fold difference before exclusions	Range after exclusions	Fold difference after exclusions	Notes
2009/10	849.5–3114.3	3.7	1196.1–2903.7	2.4	Map 61, Atlas 2.0 (2011)
2010/11	983.3–3275.8	3.3	1357.4–2998.6	2.2	
2011/12	1048.1–3557.3	3.4	1430.6–3060.8	2.1	

1 Health Committee. Written evidence from the Department of Health (GAS 01). Annex B, paragraph 2. http://www.publications.parliament.uk/pa/cm201213/cmselect/cmhealth/132/132we02.htm

2 Department of Health has updated previous published estimates at 2006/07 prices using the same methodology as in The cost of alcohol harm to the NHS in England. An update to the Cabinet Office (2003) study. July 2008. Health Improvement Analytical Team, Department of Health.

3 Data for age-standardised alcohol-related death rates, England, 2001–2011 provided by the Office for National Statistics (ONS).

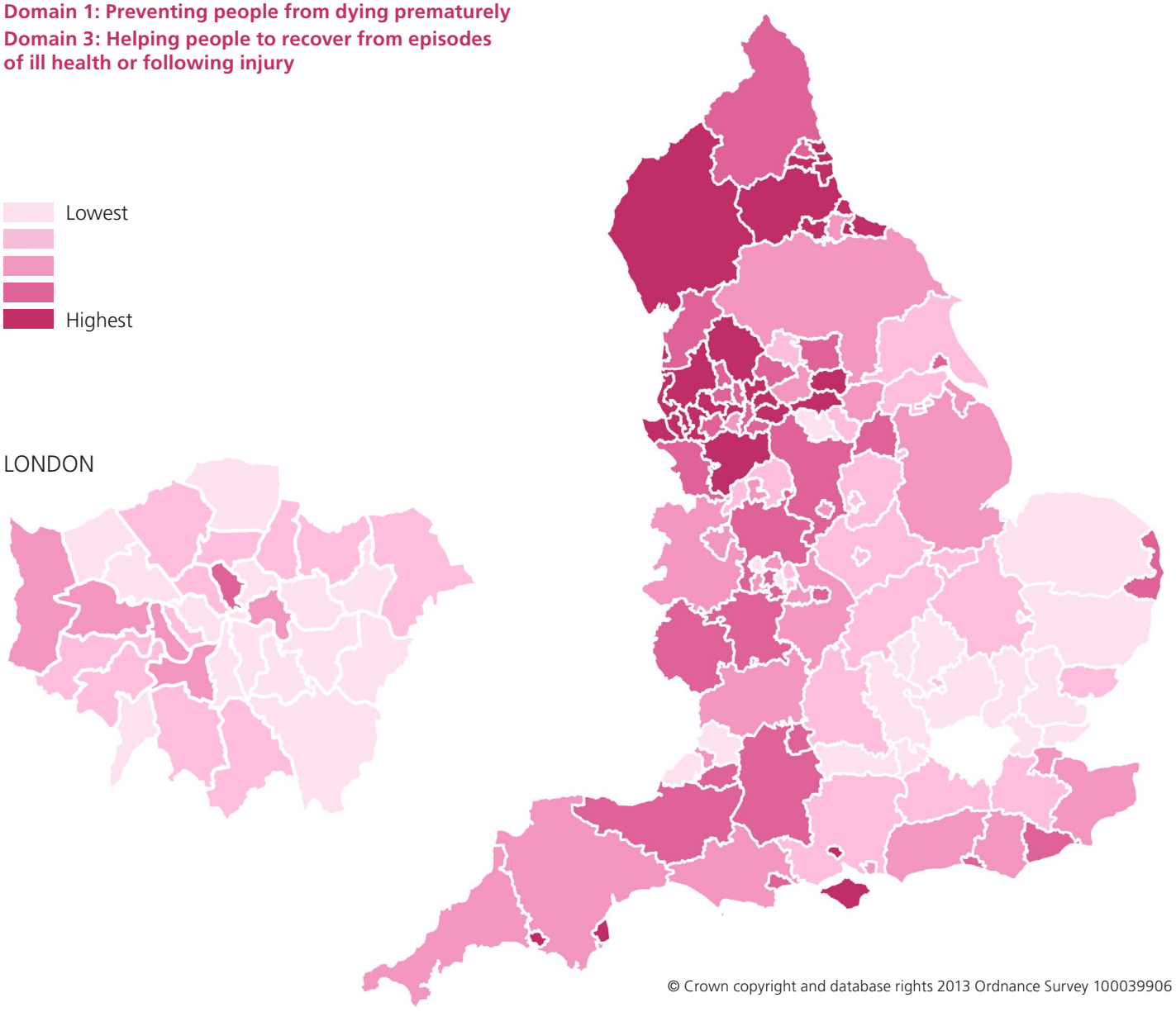
4 Alcohol Learning Centre. High Impact Changes. http://www.alcohollearningcentre.org.uk/Topics/Browse/HIC/

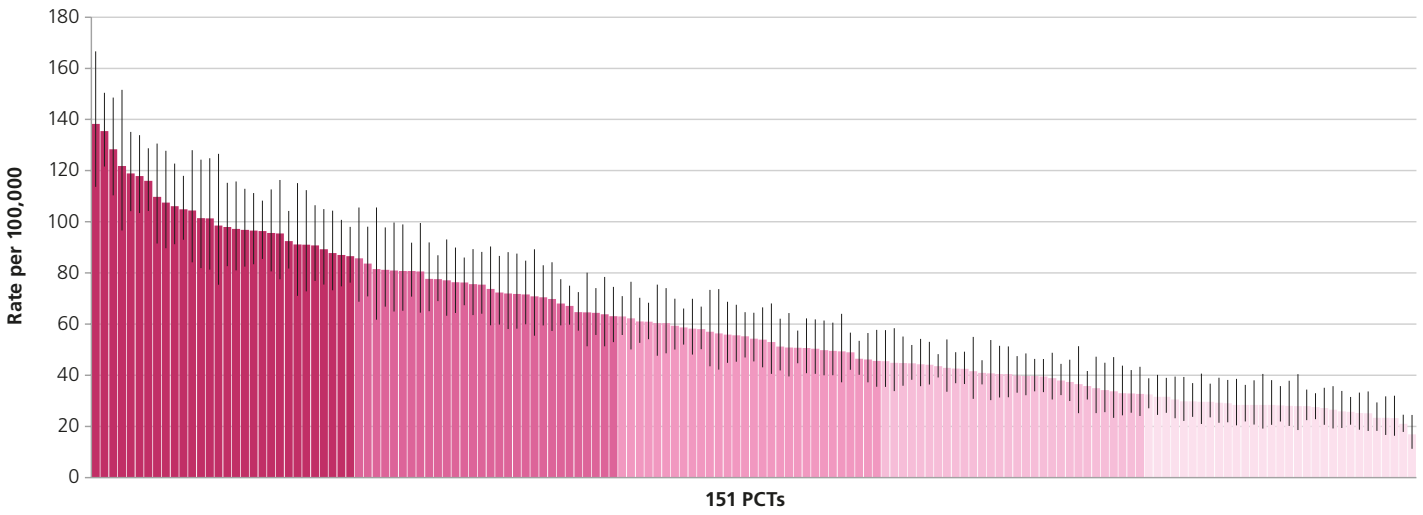
ADMISSIONS FOR ALCOHOL USE

Map 10: Rate of alcohol-specific admissions in people aged under 18 years per population by PCT

Directly standardised rate 2008/09–2010/11

Domain 1: Preventing people from dying prematurely
Domain 3: Helping people to recover from episodes of ill health or following injury





Context

Over the last decade, public concern about the impact of alcohol on health and society has steadily mounted.[1] Particular concern has centred on the level and pattern of drinking among children and young people (see Box 10.1) and the consequences for health, and levels of crime, violence and antisocial behaviour. Professionals from health, education, social care and criminal justice agencies need to identify, assess and appropriately refer young people with alcohol-related problems.[2]

Box 10.1: Patterns of drinking in children and young people

- 11 million units of alcohol are consumed in a week by 11–17-year-olds[3,4]
- By 15 years of age, most children have drunk alcohol: 65% of 15- and 16-year-olds in the UK have drunk alcohol in the last month when compared with the European average of 57%[5]
- 400,000 young people aged 11–15 years were drunk in the previous four weeks[3]
- The majority of 15- and 16-year-olds associate alcohol consumption with positive consequences (75%) and having a lot of fun (68%)[5]
- Starting drinking at an early age is associated with higher trends of alcohol dependence in adulthood and a wide range of other adverse consequences[2]

As an effective approach to tackling this issue, NICE recommends offering brief, one-to-one advice on the harmful effects of alcohol use, how to reduce the risks, and how to find sources of support.[6]

NICE also recommends cognitive behavioural therapy (CBT) as an effective intervention for treating young people's substance misuse.[6] Specialist substance misuse treatment interventions are effective in young people: evidence-based techniques appear to reduce drop-out rates from treatment and benefit aspects of a young person's life beyond their substance misuse.

Magnitude of variation

For PCTs in England, the rate of alcohol-specific admissions in people aged under 18 years ranged from 16.9 to 138.3 per 100,000 population (8-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 25.1–117.9 per 100,000 population, and the variation is 4.7-fold.

Much of the variation observed is likely to be due to differences in the rate of alcohol use. Other reasons for variation include the level of deprivation, which appears to have an adverse impact, the level of obesity, which can worsen the impact of alcohol,[7] demography, and coding for association with alcohol.

Options for action

When planning service improvement or development to reduce hospital admissions due to alcohol-specific conditions in young people, commissioners, clinicians and providers need:

- to follow the framework in the National Treatment Agency for Substance Misuse guidance for an integrated and comprehensive service for young people with substance use problems (see "Resources");
- to provide, as part of the service, psychosocial interventions, such as CBT, as recommended in NICE guidance (CG115; see "Resources");
- to ensure that targeted interventions are directed at vulnerable groups, including young people who began drinking regularly at under 15 years of age.
- to conduct rigorous monitoring and evaluation to enable the impact of interventions to be assessed.

Specialist substance misuse services for young people need to be commissioned jointly with agencies such as social services to ensure both health and social care interventions are included.

RESOURCES

- HM Government (2012) The Government's alcohol strategy. http://www.homeoffice.gov.uk/publications/alcohol-drugs/alcohol/alcohol-strategy?view=Binary
- Department of Health (2009) Guidance on the Consumption of Alcohol by Children and Young People. A report by the Chief Medical Officer. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110258
- Britton J, Crompton L (2008) Guidance on commissioning young people's specialist substance misuse treatment services. National Treatment Agency for Substance Misuse. http://www.nta.nhs.uk/uploads/commissioning_yp_final2.pdf
- NICE (2010) Alcohol-use disorders – preventing harmful drinking (PH24). http://guidance.nice.org.uk/PH24
- NICE (2011) Alcohol dependence and harmful alcohol use (CG115). http://www.nice.org.uk/guidance/CG115
- NICE (2010) Alcohol-use disorders – physical complications (CG100). http://guidance.nice.org.uk/CG100
- NICE Pathway. Alcohol-use disorders overview. http://pathways.nice.org.uk/pathways/alcohol-use-disorders
- Department of Health (2009) Local Routes: Guidance for developing alcohol treatment pathways. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110423

1 HM Government (2012) The Government's alcohol strategy. http://www.homeoffice.gov.uk/publications/alcohol-drugs/alcohol/alcohol-strategy?view=Binary

2 Department of Health (2009) Guidance on the Consumption of Alcohol by Children and Young People. A report by the Chief Medical Officer. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110258

3 NHS Information Centre (2012) Smoking, Drinking and Drug Use Among Young People in England 2011. http://www.ic.nhs.uk/pubs/sdd11fullreport

4 Office for National Statistics (2010) General Lifestyle Survey.

5 Hibell B, Guttormsson U, Ahlström S, Balakireva O, Bjarnason T, Kokkevi A, Kraus L (2012) The 2011 ESPAD Report. Substance Use Among Students in 36 European Countries. http://www.espad.org/Uploads/ESPAD_reports/2011/The_2011_ESPAD_Report_FULL_2012_10_29.pdf

6 NICE (2011) Alcohol dependence and harmful alcohol use (CG115). http://www.nice.org.uk/guidance/CG115

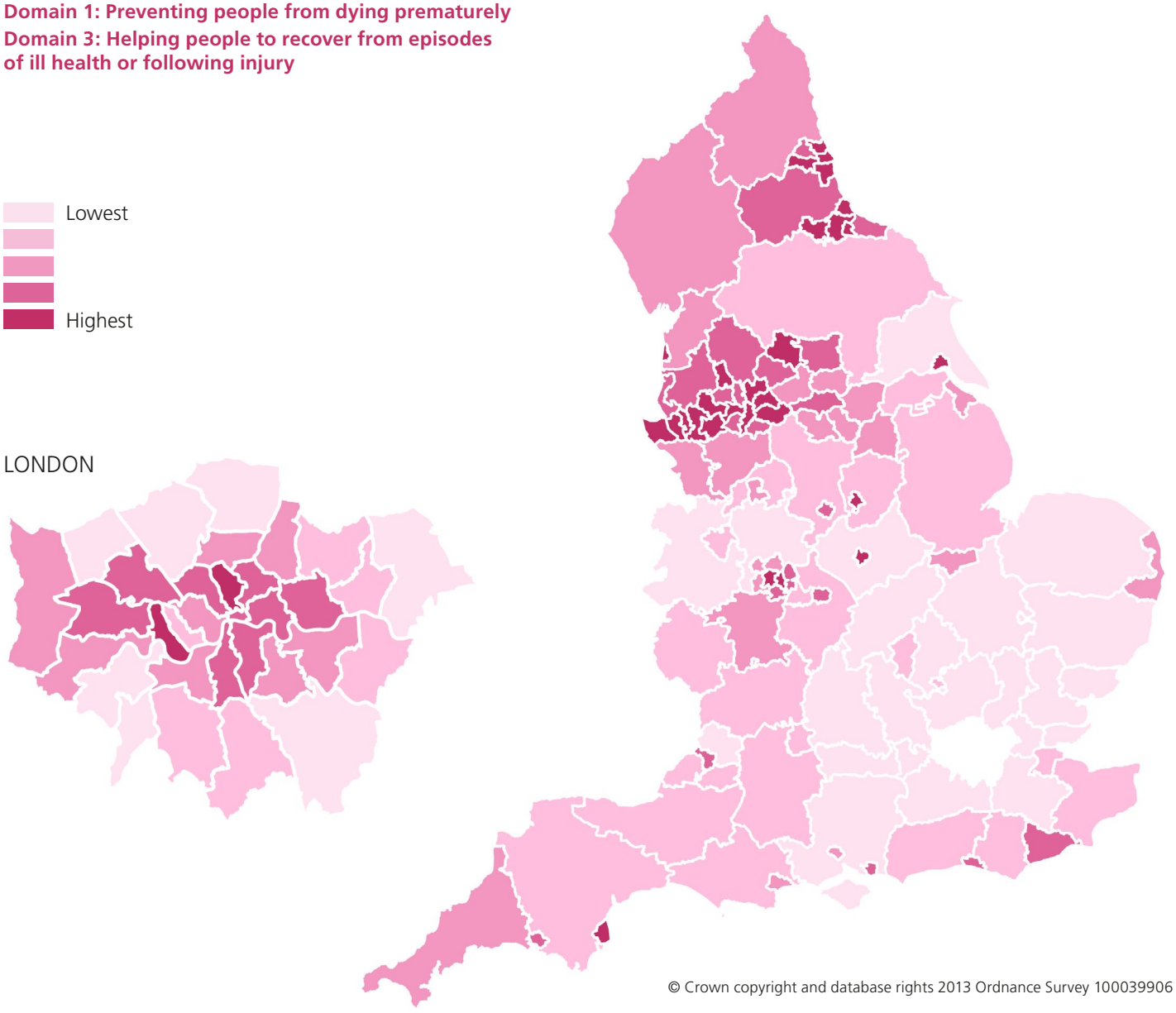
7 Liu B, Balkwill A, Reeves G, Beral V "010) Body mass index and risk of liver cirrhosis in middle aged UK women: prospective study. Bmj.2010;340:c912.(doi):10.1136/bmj.c912

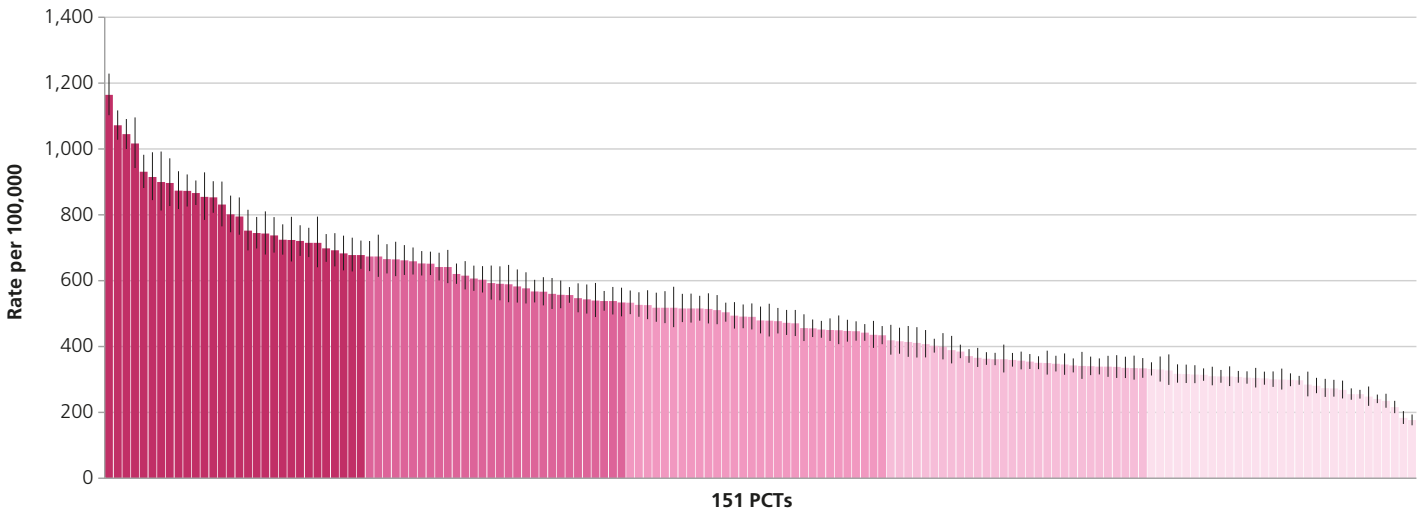
ADMISSIONS FOR ALCOHOL USE

Map 11: Rate of alcohol-specific admissions in men per population by PCT

Directly standardised rate 2010/11

Domain 1: Preventing people from dying prematurely
Domain 3: Helping people to recover from episodes of ill health or following injury





Context

Alcohol misuse costs the country around £21 billion a year.[1] In 2011, the Department of Health estimated the cost to the NHS of alcohol-related harm as £3.5 billion (2009/10 prices;[2] see Table 9.1, page 63).

Department of Health internal analysis shows there has been a 40% increase in alcohol-related admissions based on primary diagnoses over the past 9 years. Mortality rates increased by 16% between 2001 and 2008 to 12.2 per 100,000 population, but in 2011 have decreased slightly to 11.7 per 100,000 population.[3]

All alcohol-related hospital admissions (wholly or partially attributable to alcohol) increased by 4% between 2010/11 and 2011/12. Trends in admission rates are an outcome measure of effective implementation of alcohol strategies.

The focus of this indicator is alcohol-specific admissions, i.e. conditions where alcohol consumption accounts for 100% of the disease, such as alcoholic liver cirrhosis, alcoholic psychosis, alcoholic polyneuropathy, alcoholic cardiomyopathy and alcoholic gastritis.[4]

Magnitude of variation

For PCTs in England, the rate of alcohol-specific admissions in men ranged from 176.5 to 1164.2 per 100,000 population (7-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 247.8–915.0 per 100,000 population of men, and the variation is 3.7-fold.

When rates for men and women are compared (see Figure 11.1, page 122), high rates in men are frequently mirrored by high rates in women.[5]

Much of the variation in alcohol-specific admission rates is likely to be due to differences in the rates of alcohol use across England, although other factors such as differences in demography, the level of deprivation and coding for association with alcohol could explain part of the variation.

Options for action

When planning service improvement or development to reduce the hospital admission rate due to alcohol-specific conditions, commissioners, clinicians and primary and secondary care providers need:

- To consider implementing the "High Impact Changes", especially points 4–6, assessed by the Department of Health as the most effective actions for localities prioritising a reduction in alcohol-related harm (Box 11.1);
- To review current patterns of acute service provision and ascertain whether alternatives to hospital admission are available when appropriate;
- To learn from initiatives in other local services, e.g. the Alcohol Liaison Service at the Royal Free Hospital or the NHS Bolton QIPP exercise;
- To explore opportunities for early detection in the health service;
- To develop a local alcohol treatment pathway;
- To conduct rigorous monitoring and evaluation to enable the impact of interventions to be assessed.

Box 11.1: High Impact Changes[6]

1. Work in partnership
2. Develop activities to control the impact of alcohol misuse in the community
3. Influence change through advocacy
4. Improve effectiveness and capacity of specialist treatment
5. Appoint an Alcohol Health Worker
6. Identification and brief advice (IBA) – provide more help to encourage people to drink less
7. Amplify national social marketing priorities.

RESOURCES

- HM Government (2012) The Government's alcohol strategy. http://www.homeoffice.gov.uk/publications/alcohol-drugs/alcohol/alcohol-strategy?view=Binary
- NICE (2010) Alcohol-use disorders – preventing harmful drinking (PH24). http://guidance.nice.org.uk/PH24
- NICE (2011) Alcohol dependence and harmful alcohol use (CG115). http://www.nice.org.uk/guidance/CG115
- NICE (2010) Alcohol-use disorders – physical complications (CG100). http://guidance.nice.org.uk/CG100
- Alcohol Learning Centre. http://www.alcohollearningcentre.org.uk/
- Royal Free Hospital, London, Alcohol Liaison Service. http://www.royalfree.nhs.uk/pip_admin/docs/ALS_1234.pdf
- NHS Bolton QIPP exercise. arms.evidence.nhs.uk/resources/qipp/29420/attachment
- NICE Pathway. Alcohol-use disorders overview. http://pathways.nice.org.uk/pathways/alcohol-use-disorders
- Department of Health (2009) Local Routes: Guidance for developing alcohol treatment pathways http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110423

1 Health Committee. Written evidence from the Department of Health (GAS 01). Annex B, paragraph 2. http://www.publications.parliament.uk/pa/cm201213/cmselect/cmhealth/132/132we02.htm

2 Department of Health has updated previous published estimates at 2006/07 prices using the same methodology as in The cost of alcohol harm to the NHS in England. An update to the Cabinet Office (2003) study. July 2008. Health Improvement Analytical Team, Department of Health.

3 Data for age-standardised alcohol-related death rates, England, 2001-2011 provided by the Office for National Statistics (ONS).

4 Jones L et al (2008) Alcohol-attributable fractions for England. Alcohol-attributable mortality and hospital admissions. Liverpool JMU & NWPHO. http://www.cph.org.uk/showPublication.aspx?pubid=403

5 Local Alcohol Profiles for England (LAPE). http://www.lape.org.uk/

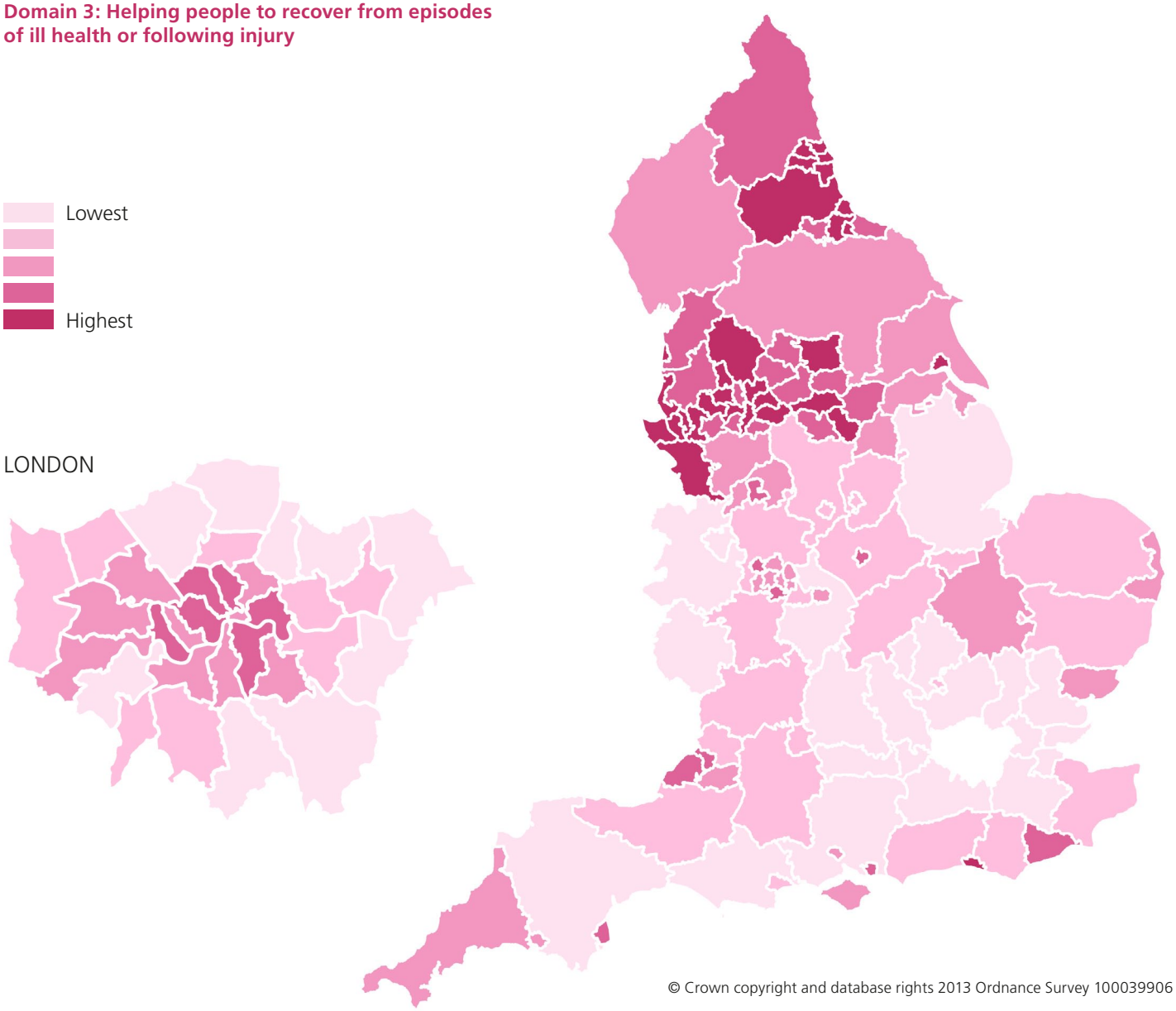
6 Alcohol Learning Centre. High Impact Changes. http://www.alcohollearningcentre.org.uk/Topics/Browse/HIC/

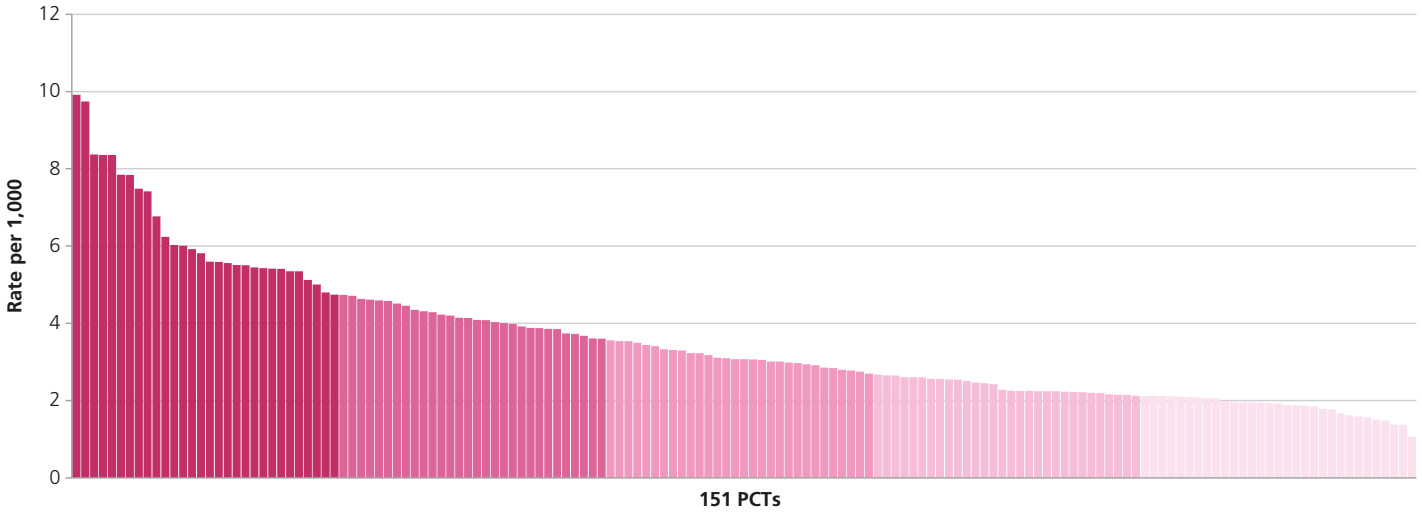
PRESCRIBING

Map 12: Annual dose-equivalent of thiamine (100-mg equivalent) per population by PCT

2011/12

Domain 3: Helping people to recover from episodes of ill health or following injury





Context

In the UK, it is estimated that 24% of adults drink in a hazardous or harmful way. Levels of self-reported hazardous and harmful drinking are lowest in the central and eastern regions of England (21–24% of men and 10–14% of women); they are highest in the North East, North West and Yorkshire and Humber (26–28% of men, 16–18% of women). Drinking in a hazardous or harmful way is commonly encountered among hospital attendees: approximately 20% of patients admitted to hospital for illnesses unrelated to alcohol are drinking at potentially hazardous levels.

The NICE guideline on the diagnosis and clinical management of alcohol-related physical complications (CG100)[2] covers key areas in the investigation and management of the following alcohol-related conditions in adults and young people:

- acute alcohol withdrawal, including seizures and delirium tremens;
- Wernicke's encephalopathy;
- liver disease;
- acute and chronic pancreatitis.

Thiamine is a vital vitamin supplement, together with folic acid, in the treatment of people who are giving up alcohol.

Prescribing data from primary care was obtained from the Health and Social Care Information Centre in order to calculate an annual dose-equivalent of thiamine per population. This indicator is an artificial measure for the purpose of data comparison and it is unlikely to correlate with numbers treated, not least because the denominator is the whole population rather than people who have an alcohol problem. Nonetheless, some degree of correlation might be expected between use of this drug and the burden of alcohol-related disease in a population. In this context, prescribing data cannot be used to infer anything about age-groups, gender, dose or duration of treatment for an individual.

Magnitude of variation

For PCTs in England, the annual dose-equivalent of thiamine (100-mg equivalent) ranged from 1.1 to 9.9 per 1000 population (9-fold variation). When the five PCTs with the highest annual dose-equivalents and the five PCTs with the lowest annual dose-equivalents are excluded, the range is 1.6–7.8 per 1000 population, and the variation is 5-fold.

Reasons for the degree of variation observed could include differences in demography, and dose or duration of treatment.

When interpreting the magnitude of variation, bear in mind:

- these data include only prescribing in primary care;
- the balance of prescribing across primary and secondary care is not known, nor how it differs across the country and if so the degree of variation; however, it is expected that most prescriptions are issued in primary care;
- thiamine is prescribed for some conditions other than those related to alcohol, although this is likely to be minimal;
- the dose-equivalent for this indicator is 100 mg but recommended doses of up to 300 mg are used: the annual dose-equivalent may not consistently represent the number of people prescribed the drug, but should still reflect the overall burden of disease.

There is a strong correlation (r=0.8120) between the annual dose-equivalent of thiamine and hospital admissions for alcohol-specific conditions in men (see Figure 12.1). Although the prescription data are not gender-specific, there is a strong correlation between male and female admissions (see Figure 11.1, page 122), despite the fact that hospital admission rates in men are 2–3 times higher than those in women.

Options for action

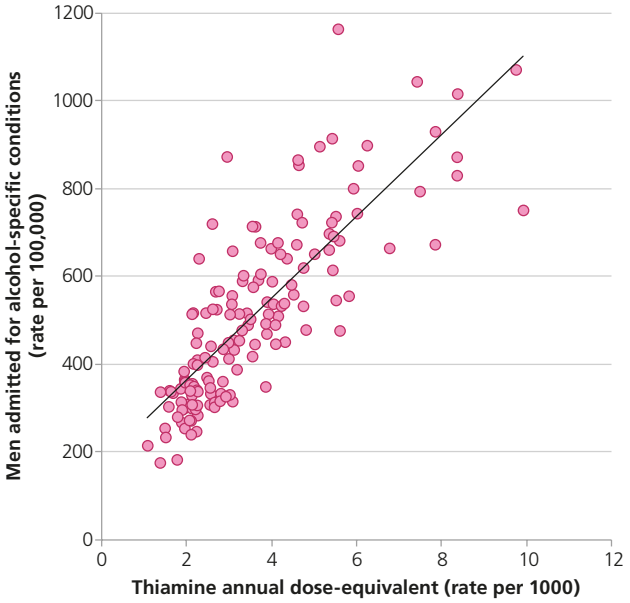
When planning service improvement or development to increase the number of people stopping drinking in a harmful or hazardous way, commissioners, clinicians and providers could consider:

- reviewing the position of the relevant PCT in relation to the prevalence of alcohol problems in the locality;
- assessing whether all the people who would benefit from help with stopping drinking are receiving the help they need;
- reviewing the extent to which NICE guidance (CG100) is being appropriately implemented in the locality – in some localities, CQUINs are used for this;
- using prescribing trends to monitor trends in diagnosis.

RESOURCES

- North West Public Health Observatory (2007) Indications of Public Health in the English Regions 8: Alcohol. Association of Public Health Observatories. http://www.apho.org.uk/resource/item.aspx?RID=39304
- NICE (2010) Alcohol-use disorders – physical complications (CG100). http://guidance.nice.org.uk/CG100
- NICE (2011) Alcohol dependence and harmful alcohol use disorders (CG115). http://guidance.nice.org.uk/CG115

Figure 12.1: Annual dose-equivalent of thiamine (100-mg equivalent) per population 2011/12 in relation to the rate (directly standardised) of alcohol-specific admissions per 1000 population of men by PCT 2010/11



1 North West Public Health Observatory (2007) Indications of Public Health in the English Regions 8: Alcohol. Association of Public Health Observatories. http://www.apho.org.uk/resource/item.aspx?RID=39304

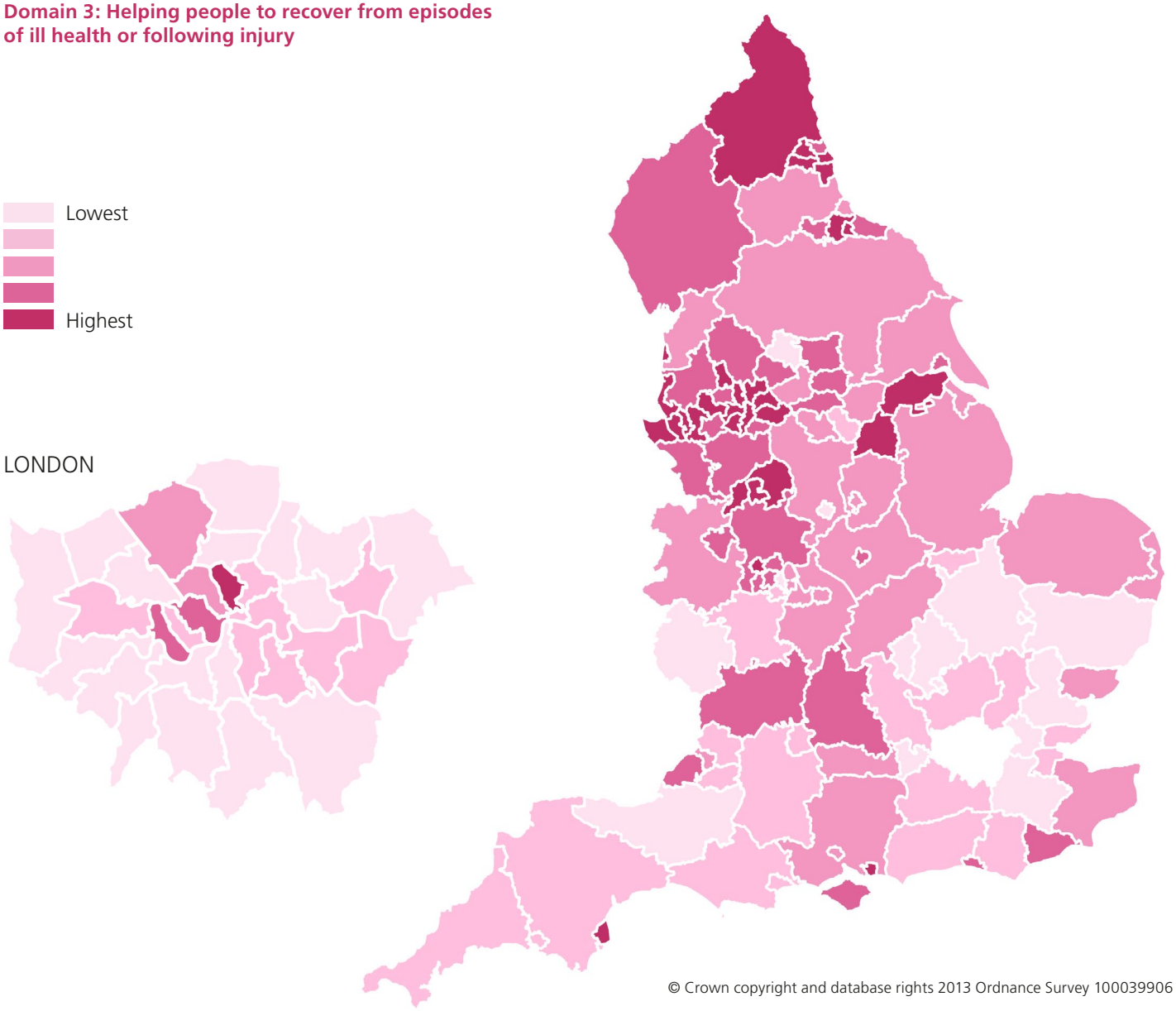
2 NICE (2010) Alcohol-use disorders - physical complications (CG100). http://guidance.nice.org.uk/CG100

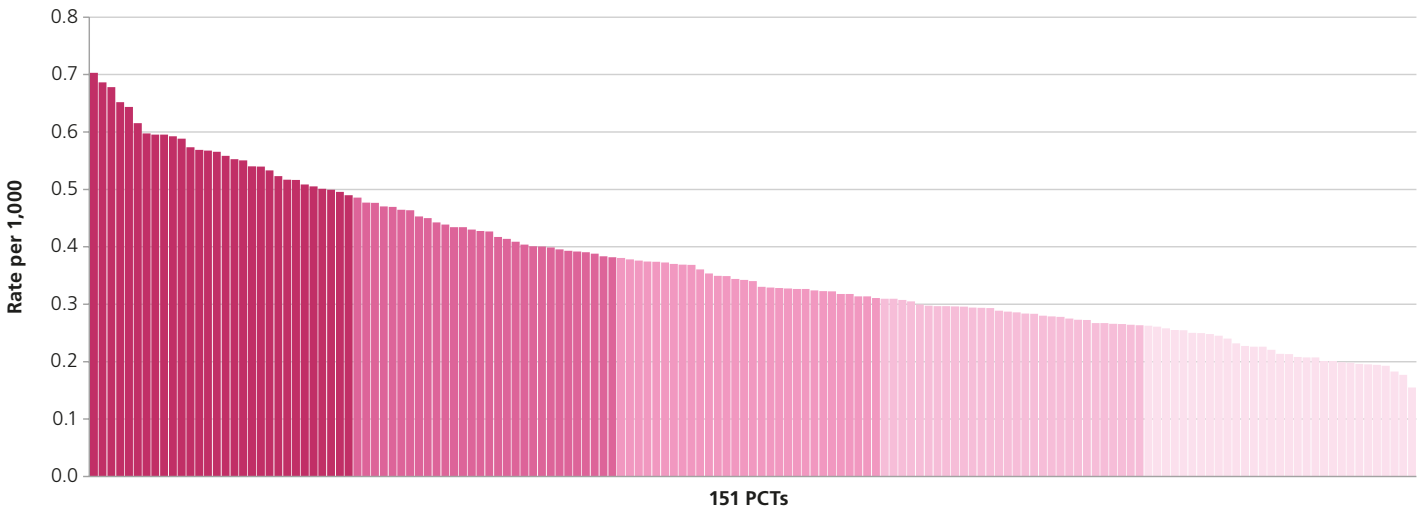
PRESCRIBING

Map 13: Annual dose-equivalent of spironolactone (100-mg equivalent) per population by PCT

2011/12

Domain 3: Helping people to recover from episodes of ill health or following injury





Context

Spironolactone is an aldosterone antagonist most commonly used at doses of 25–50 mg for cardiac failure. In general, it is used at higher doses (≥100 mg) only in advanced liver disease. Spironolactone use therefore may correlate with progression towards death from liver disease.

Primary care prescribing data were obtained from the Health and Social Care Information Centre in order to calculate an annual dose-equivalent of spironolactone (100 mg) per population. The drug is used at doses up to 400 mg on occasion, usually at 100-mg increments but most patients will receive 100–200 mg. The 100-mg dose-equivalent is an artificial measure for the purpose of data comparison. It is unlikely to correlate with numbers treated, not least because the denominator is the whole population rather than people with a liver problem. In this context, prescribing data cannot be used to infer anything about age-groups, gender, dose or duration of treatment for an individual.

There is a moderately strong correlation (r=0.6616) between the annual dose-equivalent of spironolactone and the chronic liver disease mortality rate in people aged under 75 years (see Figure 13.1). This degree of correlation with markers of severe liver disease is not surprising particularly as ascites is one of the parameters in the assessment of severity using the Child–Pugh scoring system,[1] but markers of severity of liver disease at a population level are more difficult to obtain.

Magnitude of variation

For PCTs in England, the annual dose-equivalent of spironolactone (100-mg equivalent) ranged from 0.15 to 0.70 per 1000 population (4.5-fold variation). When the five PCTs with the highest annual dose-equivalents and the five PCTs with the lowest annual dose-equivalents are excluded, the range is 0.20–0.62 per 1000 population, and the variation is 3.2-fold.

When interpreting the magnitude of variation, bear in mind:

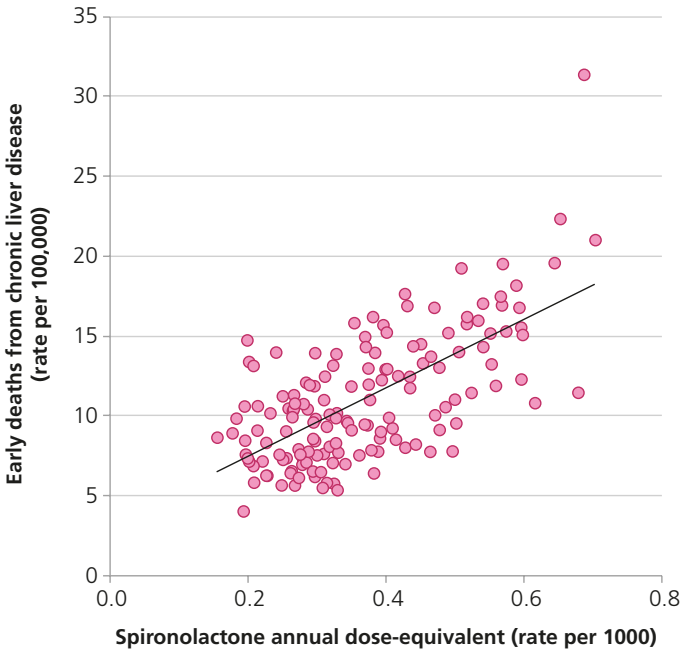
- the data include only primary care prescribing;
- the balance of prescribing across primary and secondary care is not known, nor how it differs across the country;
- spironolactone is prescribed for conditions other than liver disease, e.g. severe heart failure, but to avoid including prescribing for conditions other than liver disease only doses of 100 mg were used to construct the indicator;
- some people receiving spironolactone for advanced liver disease receive much higher doses than 100 mg (up to 400 mg), thus the assessment of annual dose-equivalents may over-state the number of people receiving spironolactone although the most common doses for this indication are 100 or 200 mg.

Options for action

When planning service improvement or development to reduce mortality from liver disease, commissioners, clinicians and providers need:

- to identify whether there is a problem with liver disease and/or its identification and management in the local population;
- to consider reconfiguration of services and the development of integrated care pathways for liver disease across primary and secondary care;
- to avoid unplanned admissions to hospital – the use of the ratio of new to follow-up outpatient consultations alone to address this issue is crude and inappropriate;
- to develop 'end-of-life care' strategies and processes, which may be appropriate for patients on continuous high-dose spironolactone who have a limited life-expectancy;
- to use prescribing indicators at practice or local authority ward level to determine whether interventions to reduce liver disease are appropriate to the needs of the local population.

Figure 13.1: Annual dose-equivalent of spironolactone (100-mg equivalent) per 1000 population 2011/12 in relation to the rate (directly standardised) of mortality in people aged under 75 years due to chronic liver disease including cirrhosis per 100,000 population by PCT 2008–2010



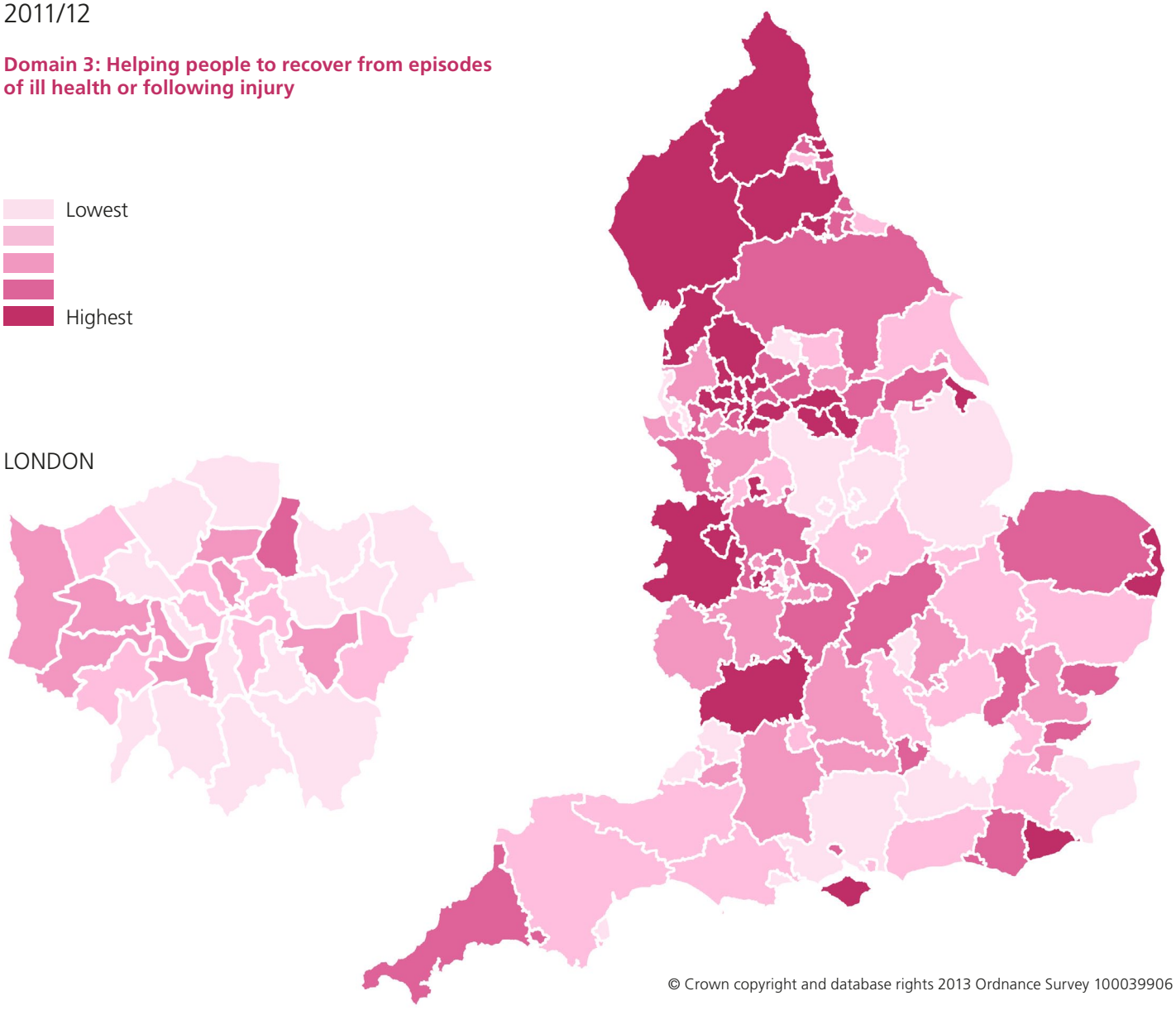
1 http://www.nelm.nhs.uk/en/NeLM-Area/Evidence/Medicines-Q--A/What-is-the-Child-Pugh-score/

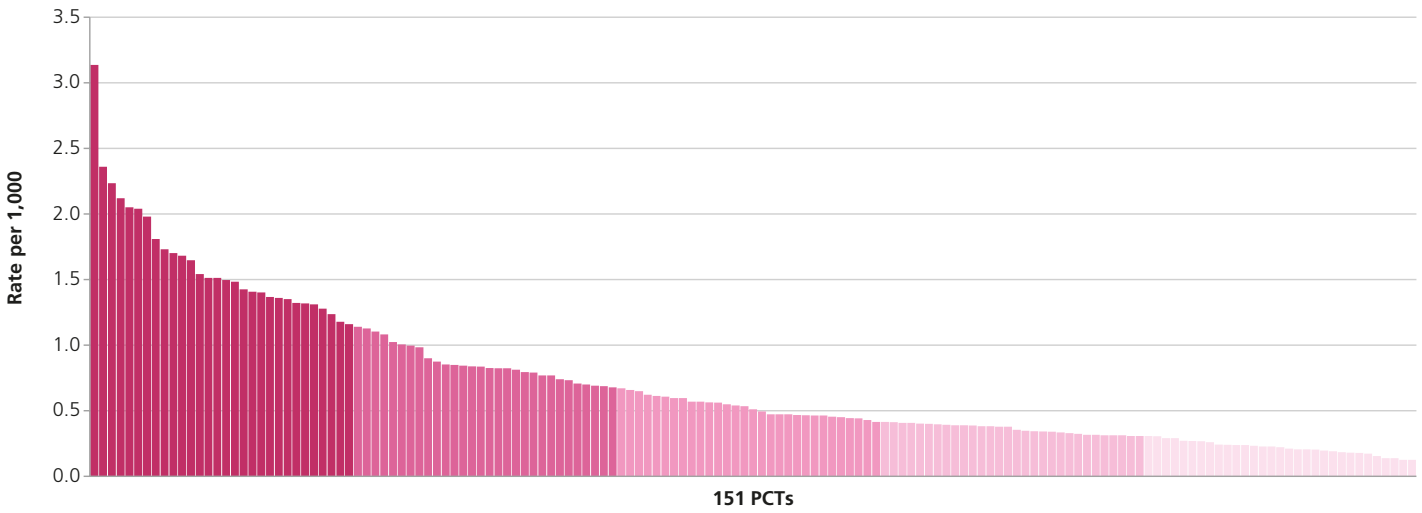
PRESCRIBING

Map 14: Annual dose-equivalent of acamprosate (333-mg equivalent) or disulfiram (200-mg equivalent) per population by PCT

2011/12

Domain 3: Helping people to recover from episodes of ill health or following injury





Context

In England, alcohol dependence affects 4% of people aged between 16 and 64 years (6% of men and 2% of women); over 24% of the population (33% of men and 16% of women) consume alcohol in a way that is potentially or actually harmful to their health or well-being. In England, of the 1 million people aged 16–64 years who are alcohol dependent, only about 6% per year receive treatment:

- there is often a long period between developing alcohol dependence and seeking help;
- there is limited availability of specialist alcohol treatment services in some parts of the country;
- alcohol misuse is under-identified by health and social care professionals.[1]

Diagnosis is made on the basis of the symptoms and consequences of alcohol misuse. Acute withdrawal from alcohol in the absence of medical management can be hazardous in people with severe alcohol dependence: it may lead to seizures, delirium tremens and, in some cases, death.[1]

Current practice across the country differs; access to assisted abstinence and treatment services varies as a consequence. Once alcohol misuse has been effectively treated, many people experience problems in accessing services for co-morbid mental and physical health problems.[1]

There are only limited data on alcohol dependence/addiction services or intervention. This dataset is included to ensure commissioners ask providers to deliver a coordinated service and maintain an appropriate record of efficacy.

NICE recommends considering the use of acamprosate for people with moderate and severe alcohol dependence, and for harmful drinking and mild alcohol dependence.[1] Disulfiram is a commonly used alternative.

Primary care prescribing data from the Health and Social Care Information Centre were used to calculate an annual dose-equivalent of acamprosate or disulfiram per population, an artificial measure for the purpose of data comparison. Although it is unlikely to correlate with numbers of people treated because the denominator is the whole population, not people with an alcohol problem, some relation between use of these drugs and the burden of alcohol dependence in a population might be expected because these drugs are a proxy for addiction treatments. The drugs have been combined because in some localities one is preferred over the other. In this context, prescribing data cannot be used to infer anything about age-groups, gender, dose or duration of treatment for an individual.

Magnitude of variation

For PCTs in England, the annual dose-equivalent of acamprosate (333-mg equivalent) or disulfiram (200-mg equivalent) ranged from 0.13 to 3.14 per 1000 population (25-fold variation). When the five PCTs with the highest annual dose-equivalents and the five PCTs with the lowest annual dose-equivalents are excluded, the range is 0.17–2.04 per 1000 population, and the variation is 12-fold.

Potential reasons for the degree of variation observed include differences in:

- levels of alcohol consumption and addiction;
- presentation and identification in primary care;
- access to alcohol dependence/addiction services.

When interpreting the magnitude of variation, bear in mind:

- the data include only primary care prescribing;
- the balance of prescribing across primary and secondary care is not known nor how it differs across the country;
- other agents were excluded: the BNF favours naltrexone over disulfiram; some services use baclofen;
- other treatment modalities such as cognitive behaviour therapy or other non-medicated therapies were not investigated;
- any variation in the average dose prescribed locally would affect the annual dose-equivalents.

To ascertain the level of coordination between services for liver disease and those for alcohol addiction, the annual dose-equivalent of acamprosate/disulfiram was plotted against that of thiamine (see Figure 14.1). Despite several possible confounding issues, the modest correlation (r=0.3838) suggests coordination could be improved.

Options for action

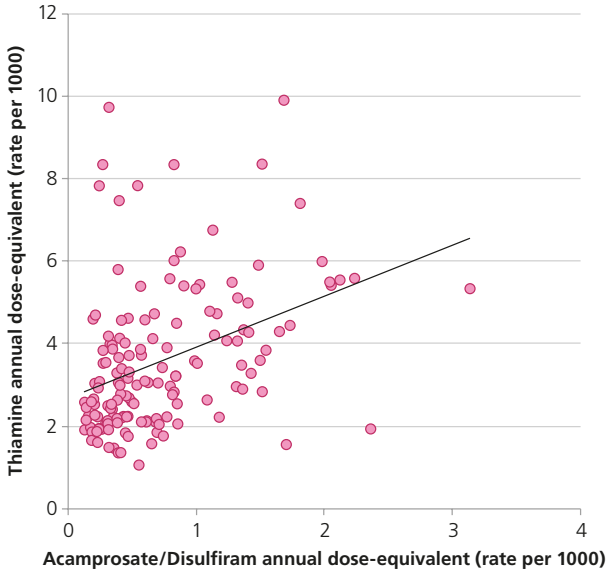
When planning service improvement or development in the provision of alcohol dependence/addiction services, commissioners, clinicians and providers need:

- to review prescribing for acamprosate/disulfiram relative to the prevalence of alcohol problems in the local population;
- to assess whether all those who would benefit from help with stopping drinking are receiving the support they need;
- to review the extent to which NICE guidance (CG115) is implemented in the locality.

RESOURCES

- NICE (2011) Alcohol dependence and harmful alcohol use (CG115). http://guidance.nice.org.uk/CG115

Figure 14.1: Annual dose-equivalent of acamprosate (333-mg equivalent) or disulfiram (200-mg equivalent) per population in relation to annual dose-equivalent of thiamine (100-mg equivalent) per 1000 population by PCT 2011/12



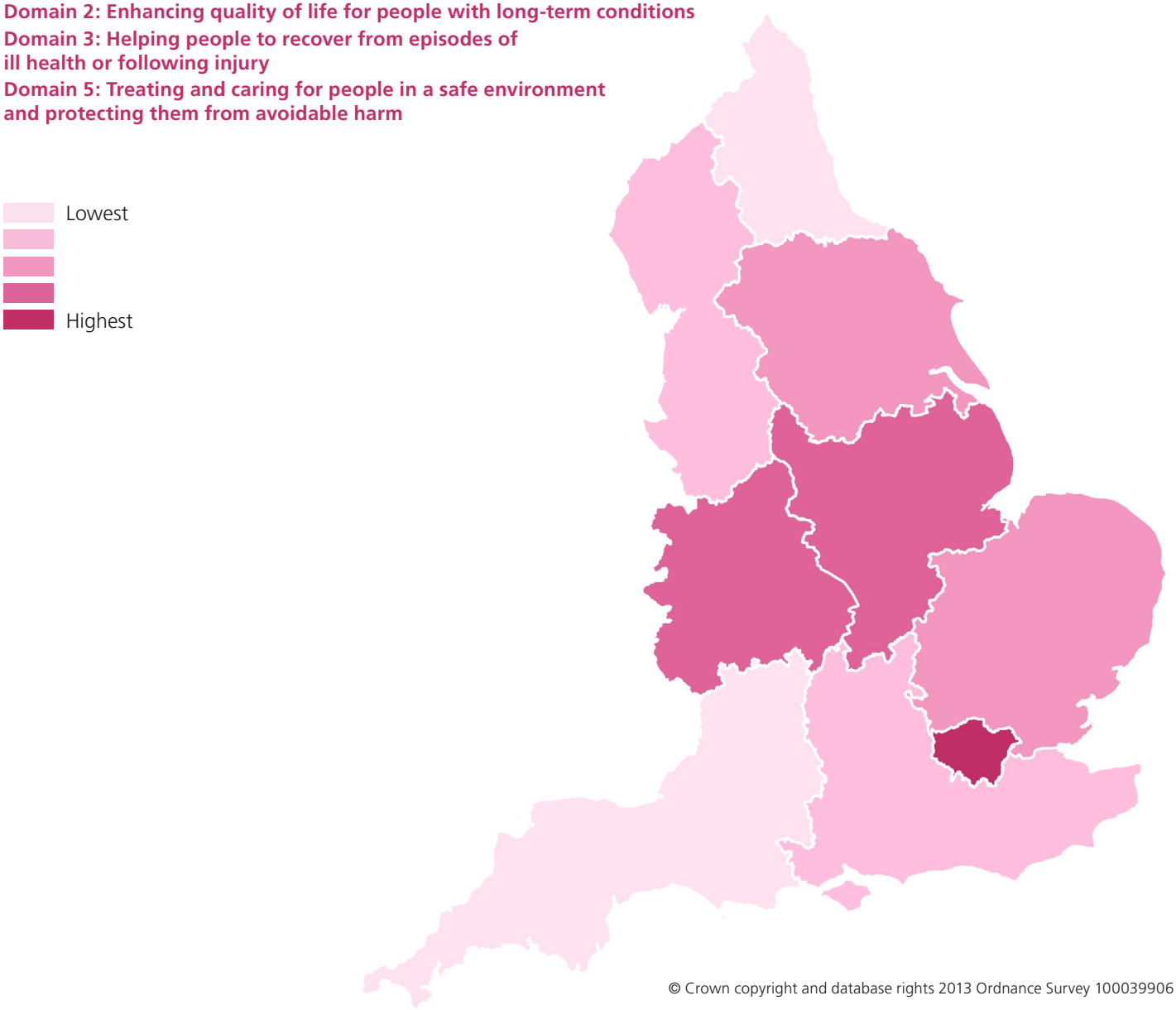
1 NICE (2011) Alcohol dependence and harmful alcohol use (CG115). http://guidance.nice.org.uk/CG115

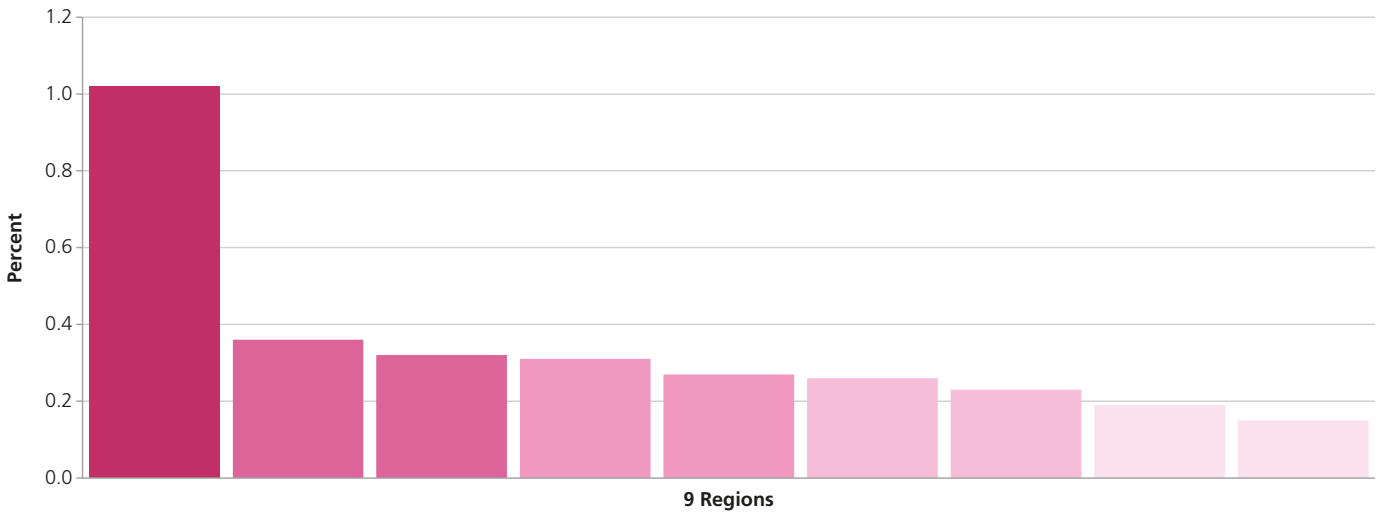
HEPATITIS B

Map 15: Proportion (%) of women receiving antenatal care who are screened positive for hepatitis B by region

2011

Domain 2: Enhancing quality of life for people with long-term conditions
Domain 3: Helping people to recover from episodes of ill health or following injury
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm





Context

The NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme in England is responsible for ensuring that all pregnant women are routinely offered screening for hepatitis B, HIV, syphilis and susceptibility to rubella. The IDPS Programme, if coordinated well at service level, can help to prevent the transmission of infection from mother to child, as well as safeguarding the well-being of women who are identified as positive through screening.[1]

Box 15.1: Findings reported by the Health Protection Agency[2]

- National coverage of antenatal hepatitis B screening increased from 93% in 2005 to 97% in 2011
- In 2011, 0.42% of pregnant women screened for hepatitis B were positive for hepatitis B surface antigen (a marker of current infection); there has been no significant change in hepatitis B-positive rates since 2005
- In 2011, for diagnoses where all information was available, 44% of diagnosed hepatitis B-positive pregnant women were identified through antenatal screening in the current pregnancy; these are women who may not have been diagnosed in the absence of routine screening and whose babies therefore would have been at increased risk of infection through mother-to-child transmission

The data for this indicator are collected from maternity units by regions, with the help of Regional Antenatal Screening Coordinators, and collated into national data by the Health Protection Agency national surveillance centre, Colindale.

Magnitude of variation

For regions in England, the proportion of women receiving antenatal care who are screened positive for hepatitis B ranged from 0.15% to 1.02%, a 7-fold variation.

The denominator used to calculate the uptake and the proportion of women screened positive for hepatitis B is based on booking data, which are derived from different sources:

- laboratory data on the number of tests done;
- the number of women seen for initial booking;
- a combination of these two factors.

Furthermore, some women book in at one hospital and receive all their antenatal care in a different maternity unit. The calculation and interpretation of regional uptake and the proportion of women who are screened positive for hepatitis B take into account differences in the sources of booking data. The variability in the data is likely to be resolved with the implementation of the new national Maternity Services Data Set that will provide more accurate data on the number of women:

- booked;
- tested for infectious diseases;
- found to be infected.

Options for action

When planning for service improvement or development to reduce the prevalence of hepatitis B, commissioners, clinicians and providers could consider:

- reviewing the antenatal offer of screening for hepatitis B in the locality;
- identifying the scope to improve the antenatal screening pathway;
- reviewing the domestic and community circumstances of women who test positive in order to identify any common risk factors, to raise awareness of hepatitis B in communities at increased risk, and to focus efforts on diagnostic testing in those communities.

RESOURCES

- NHS Infectious Diseases in Pregnancy Screening Programme (IDPS) (2011) Annual Report. IDPS Programme. January 2010–March 2011. UK National Screening Committee and NHS Screening Programmes Infectious Diseases. http://infectiousdiseases.screening.nhs.uk/publications
- Health Protection Agency. National Antenatal Infections Screening Monitoring (NAISM). http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1245581538007
- Data Tables for the National Antenatal Infections Screening Monitoring (NAISM) Programme. Surveillance Update: 2011. Programme conducted by: Health Protection Agency. http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317132719355

1 NHS Infectious Diseases in Pregnancy Screening Programme (IDPS) (2011) Annual Report. IDPS Programme. January 2010 – March 2011. UK National Screening Committee and NHS Screening Programmes Infectious Diseases. http://infectiousdiseases.screening.nhs.uk/publications

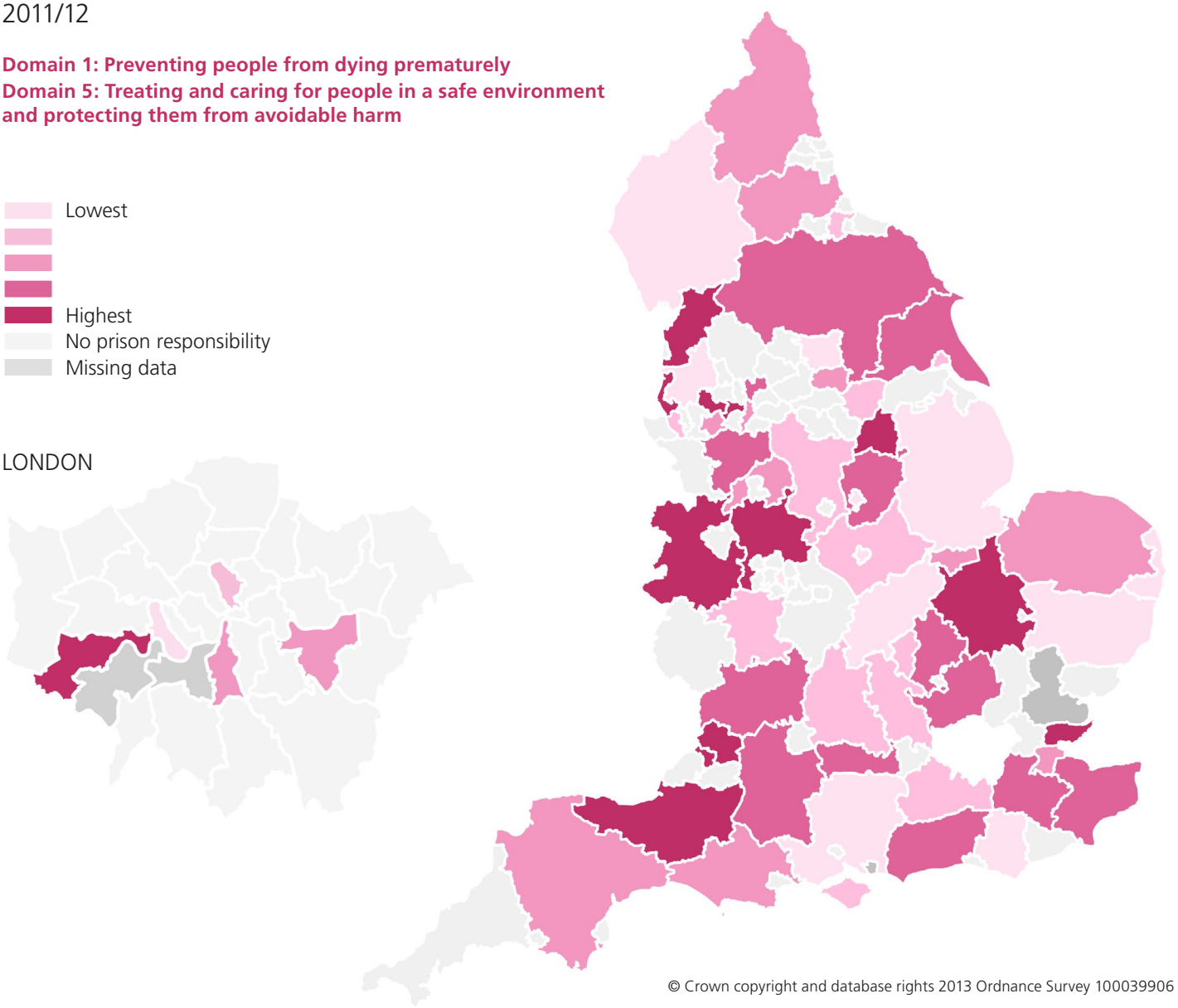
2 Data Tables for the National Antenatal Infections Screening Monitoring (NAISM) Programme. Surveillance Update: 2011. Programme conducted by: Health Protection Agency. http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317132719355

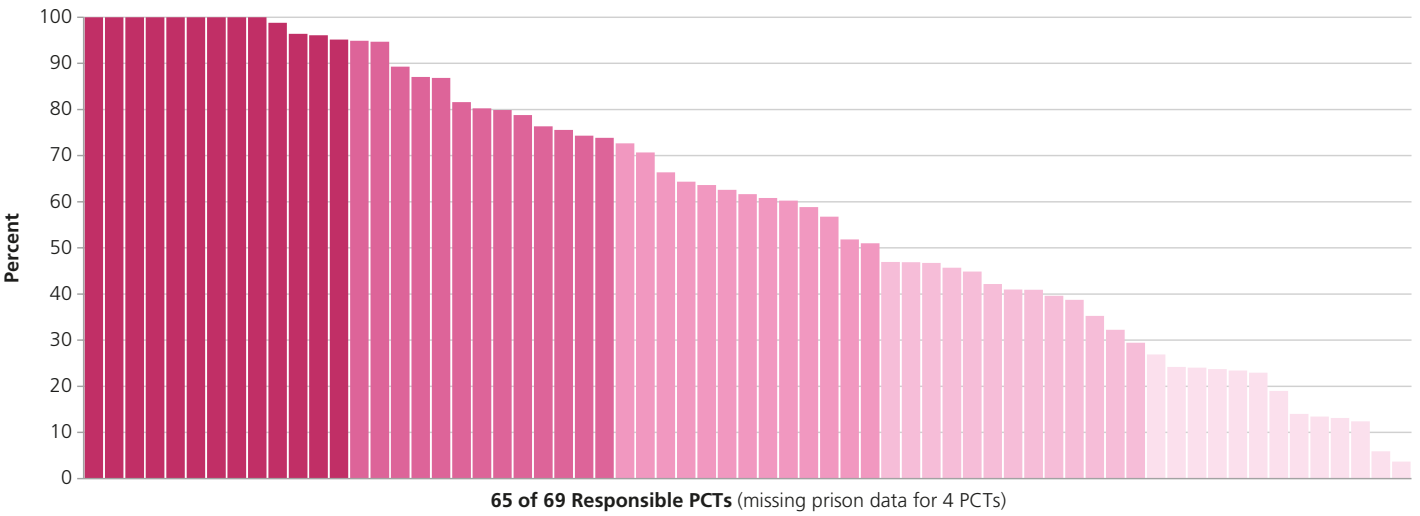
HEPATITIS B

Map 16: Percentage of hepatitis B vaccination coverage in new prison receptions aged 18 years and older by responsible PCT

2011/12

Domain 1: Preventing people from dying prematurely
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm





65 of 69 Responsible PCTs (missing prison data for 4 PCTs)

Context

Hepatitis B can cause an acute illness that lasts several weeks. People can take several months to a year to recover from the symptoms. Hepatitis B can also cause a chronic liver infection that can later develop into cirrhosis of the liver or liver cancer. Symptoms vary from person to person, ranging from a mild illness to one that is severe, overwhelming and can be fatal.[1]

In the UK, most acute cases of hepatitis B infection are contracted through injecting drug use or sexual intercourse. A small proportion of acute cases can progress to liver disease, but hepatitis B acquired at birth or in childhood is the main risk factor for chronic hepatitis B liver disease. Vaccination in high-risk groups forms part of the strategy to prevent transmission of this virus. Groups at risk of acute transmission are:

- men who have sex with men;
- people who inject drugs;
- healthcare and other workers exposed to people with hepatitis B during the course of their work;
- babies born to mothers with chronic infection, who may have acquired it at birth (Map 15, pages 74–75).

Vaccinating high-risk individuals in prison is an effective public health measure to prevent cases of acute hepatitis B among people who inject drugs in the community.[2]

Uptake of hepatitis B vaccination is one of the Department of Health's key performance and quality indicators. This indicator is based on data reported by prisons about the vaccination of new prison receptions. The prison-specific data have been grouped by "responsible" PCT, i.e. PCTs that commission healthcare for one or more prisons, of which there are 69 in England. These data are the best available of successful vaccination of new prison receptions who have not yet been vaccinated and who have not refused vaccination.

Magnitude of variation

For PCTs that commission healthcare for one or more prisons in England, the percentage of hepatitis B vaccination coverage in new prison receptions aged 18 years and older varied from 3.7% to 100% (27-fold variation).[3] When the two responsible PCTs with the highest percentages and the two responsible PCTs with the lowest percentages are excluded, the range is 12.4–100%, and the variation is 8-fold.

Options for action

Vaccination of prisoners at reception is an opportunity to improve the prevention of the spread of hepatitis B. When planning service improvement or development for the vaccination of new prison receptions, commissioners, clinicians and providers who have responsibility for one or more prisons in the locality need:

- to review the rates of vaccination to identify (i) prisons that have low rates of vaccination and discuss how uptake rates can be improved, and (ii) prisons not yet submitting data, discuss the reasons why and agree measures for improving reporting;
- to specify the type of vaccination schedule used – the Health Protection Agency recommends the super-accelerated course,[4] which achieves the objective of protecting the largest number of individuals in the shortest possible time.[1,2]

RESOURCES

- Health Protection Agency. Prison hepatitis B vaccination and hepatitis C testing monitoring. http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/PrisonInfectionPreventionTeam/PrisonHepBVaccAndHepCTestingProgramme/
- Health Protection Agency and Department of Health - Offender Health (2011) Prevention of infection and communicable disease control in prisons and places of detention. A manual for healthcare workers. http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1309970437635
- National AIDS Trust (2011) Tackling Blood-Borne Viruses in Prisons. A framework for best practice in the UK. http://www.nat.org.uk/Media%20library/Files/Policy/2011/NATBlood%20Borne%20VirusesPrisonsMay2011.pdf
- Department of Health. Green Book, Chapter 18: Hepatitis B. http://immunisation.dh.gov.uk/green-book-chapters/chapter-18/
- Humphreys C, Lombard M, Newton A, O'Moore É, Railton C (2013) An audit of the hepatitis C services in a representative sample of English prisons, 2013.

1 Health Protection Agency and Department of Health - Offender Health (2011) Prevention of infection and communicable disease control in prisons and places of detention. A manual for healthcare workers. http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1309970437635

2 Department of Health. Green Book, Chapter 18: Hepatitis B. http://immunisation.dh.gov.uk/green-book-chapters/chapter-18/

3 Eleven of the 137 (8%) prisons did not report rates of vaccination against hepatitis B for 2011/12, thus, data are missing for 4 PCTs and data are partial for 5 PCTs; some prisons reported >100% coverage of vaccinations due to calculation errors, but these have been reported as 100% in the map.

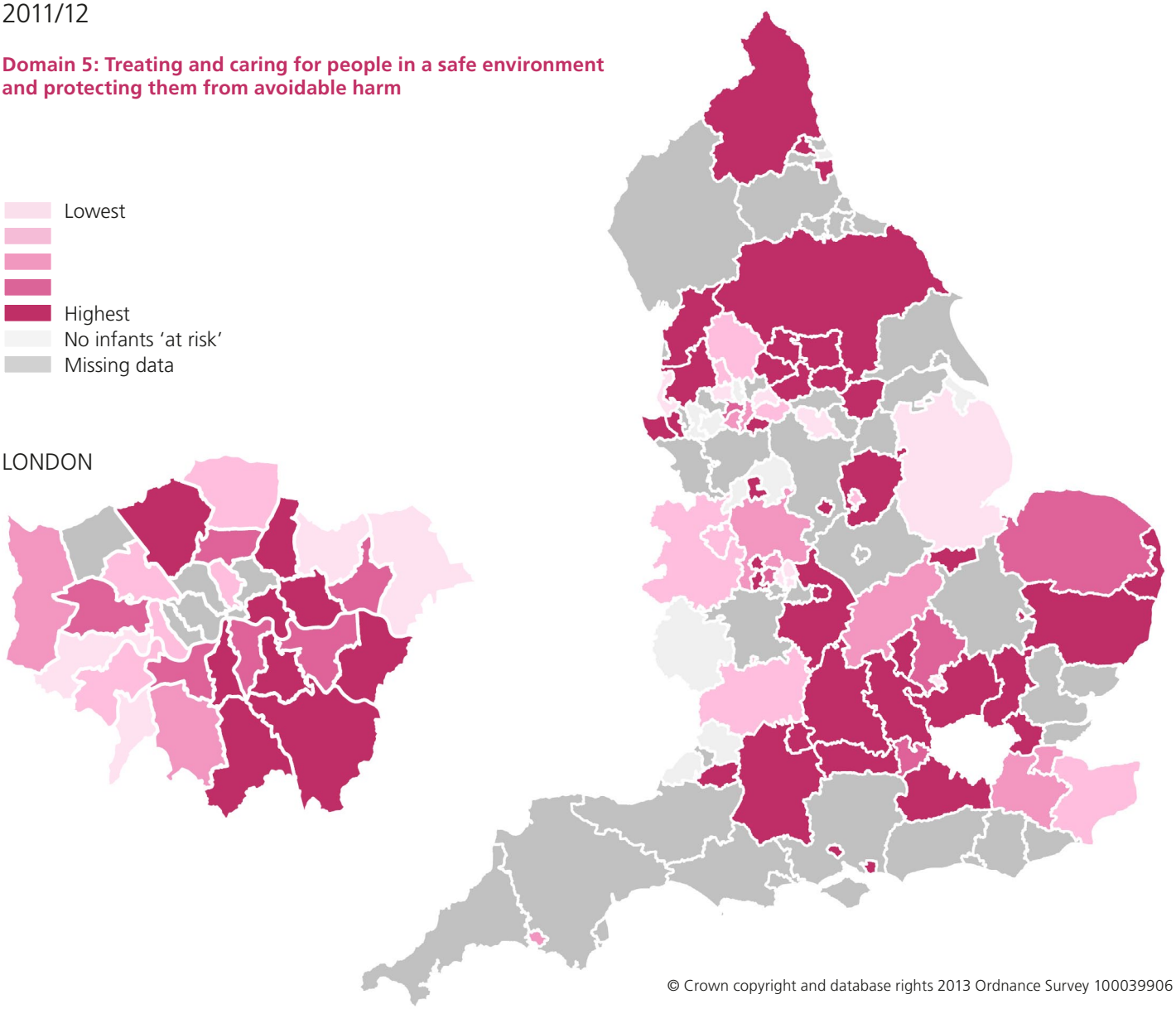
4 Health Protection Agency. Prison hepatitis B vaccination and hepatitis C testing monitoring. http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/PrisonInfectionPreventionTeam/PrisonHepBVaccAndHepCTestingProgramme/

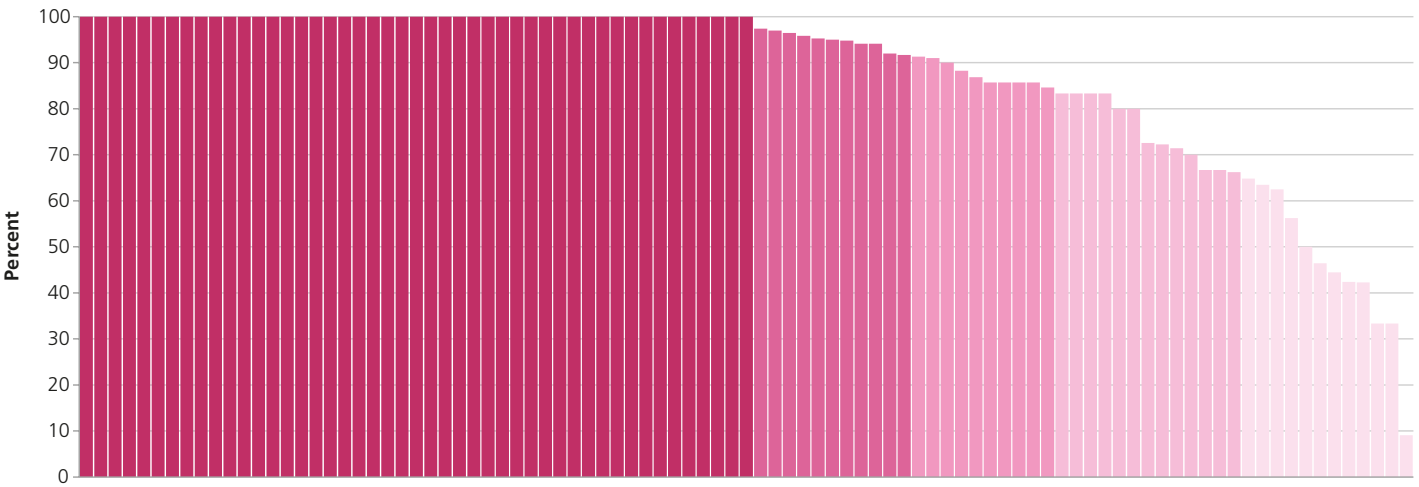
HEPATITIS B

Map 17: Percentage of infants immunised for hepatitis B by their first birthday born to mothers with persistent hepatitis B infection by PCT

2011/12

Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm





93 of 142 PCTs (49 removed due to missing or incomplete data, or small numbers; 9 PCTs had no infants at risk)

Context

The contribution of hepatitis B infection to the burden of liver disease is increasing. When not treated, persistent hepatitis B infection can lead to premature death due to cirrhosis of the liver or liver cancer (hepatocellular carcinoma). Around one-quarter of all liver disease cases in the UK are due to hepatitis infections. Hepatitis B infection transmitted from mother to child during birth accounts for 21% of all new persistently infected cases. Mother-to-child transmission is an important cause of persistent hepatitis B infection, but in most cases it can be prevented.

Since 2000, Department of Health policy has supported the provision of a targeted infant immunisation programme, as outlined in Health Service Circular 1998/127 (see "Resources").

Vaccination coverage is the best indicator of the protection a population has against vaccine-preventable communicable diseases. Vaccination of neonates born to women with persistent hepatitis B infection is:

- highly effective at preventing infection in the infant and therefore of averting the risk of chronic liver disease and cancer;
- cost-saving to the NHS.

Vaccination of newborn infants to pregnant women with hepatitis B should achieve 100% coverage. The UK National Screening Committee and NICE provide guidance on appropriate local arrangements (see "Resources").

PCTs send information to the Health Protection Agency through the COVER programme. Many PCTs are unable to provide valid data on the denominator of children at risk and/or the numerator of children vaccinated with three doses by 12 months of age. PCTs providing zero returns for 2011/12 were asked to confirm that there were no infants born to persistently infected pregnant women in the population. PCTs unable to provide confirmation were coded as missing data.

Magnitude of variation

For PCTs in England, the percentage of infants immunised for hepatitis B by their first birthday born to mothers with persistent hepatitis B infection varied from 9.1% to 100% (11-fold variation).[1] When the three PCTs with the highest percentages and the three PCTs with the lowest percentages are excluded, the range is 42.3–100%, and the variation is 2.4-fold.

Of 114 PCTs with full data, 9 PCTs had no infants at risk, that is, born to women with persistent hepatitis B infection, and 47 PCTs reported 100% coverage for hepatitis B vaccination in infants at one year of age. Eight PCTs reported coverage rates of 50% or less and 12 PCTs with full data were removed from the analysis due to small numbers.

Reasons for the degree of variation observed could be differences in local systems for vaccination, particularly:

- the amount of resource invested;
- the method of measurement;
- access to services.

Another reason for the degree of variation could be differences in access to complete data about infants at risk.

Options for action

When planning service improvement or development for vaccination of the newborn against hepatitis B, commissioners, clinicians and providers need to ensure that local arrangements follow national guidance (see "Resources"). Commissioners also need to monitor valid coverage data quarterly to improve the vaccination rates achieved in 2011/12.

- In localities where reporting is incomplete, as a matter of urgency, commissioners need to review information flows and take action to improve reporting.
- In localities where there are low levels of uptake, commissioners need to review the systems used to coordinate and provide vaccination to newborn infants at risk in order to improve reporting and/or achieve higher rates of coverage.

RESOURCES

- Screening of pregnant women for hepatitis B and immunisation of babies at risk. Health Service Circular 1998/127. 22 July 1998. www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Healthservicecirculars/DH_4004295
- NICE (2009) PH21 Reducing differences in the uptake of immunisations: guidance. http://guidance.nice.org.uk/PH21/Guidance/pdf/English
- Infectious Diseases in Pregnancy Screening Programme (revised & reformatted 2010; updated 2011) Programme Standards. UK National Screening Committee. http://infectiousdiseases.screening.nhs.uk/standards
- Health and Social Care Information Centre, Screening and Immunisation team (2012) NHS Immunisation Statistics England 2011–12. http://www.ic.nhs.uk/searchcatalogue?productid=9990&topics=0%2fPublic+health&sort=Relevance&size=10&page=4#top
- Infectious Diseases in Pregnancy Screening Programme (revised & corrected 2012) Laboratory Handbook, 2nd edition. UK National Screening Committee. http://infectiousdiseases.screening.nhs.uk/standards
- Department of Health (2011) Immunisation Branch. Hepatitis B antenatal screening and newborn immunisation programme: Best practice guidance. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_126195

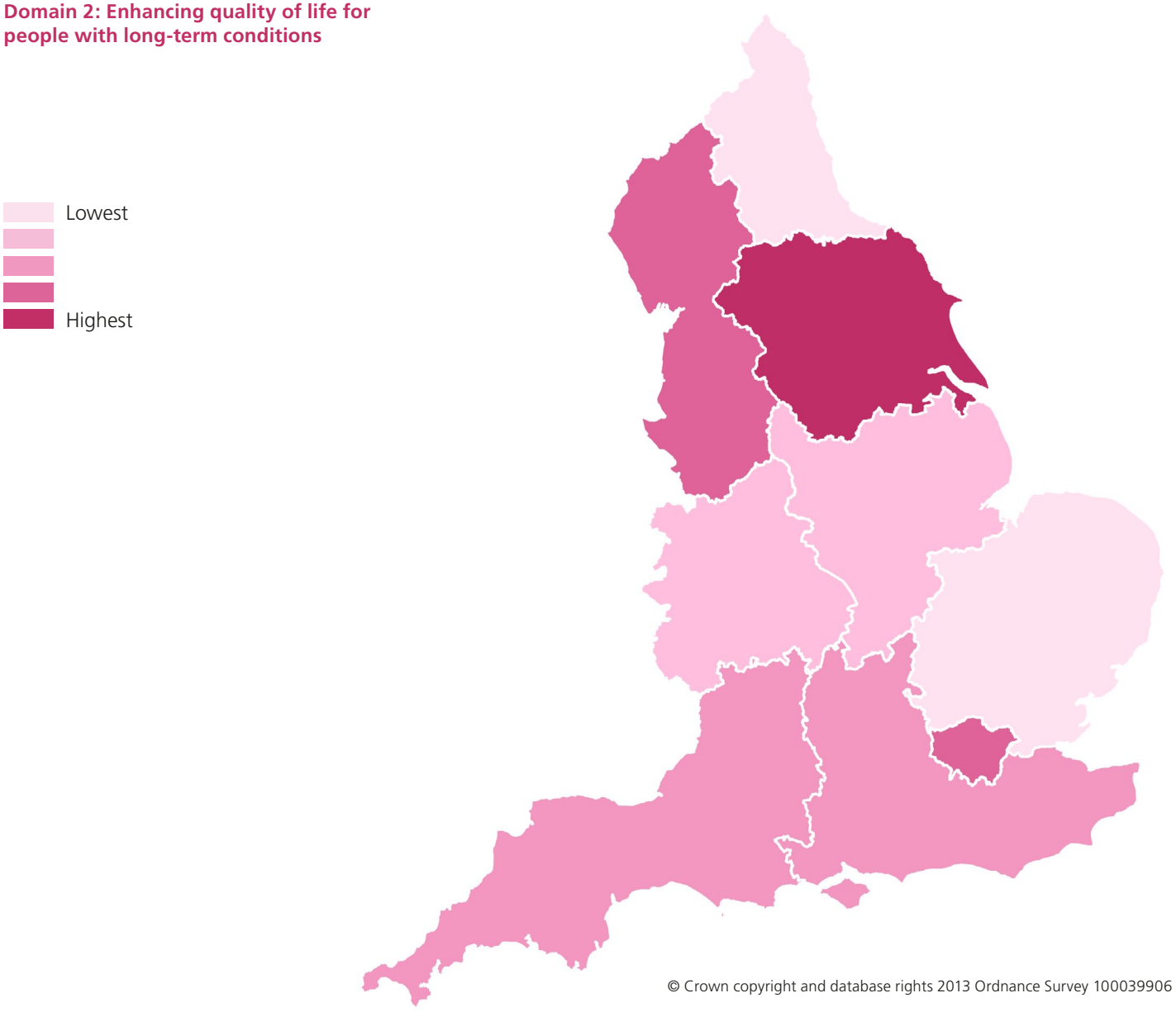
1 Data from 37 PCTs are missing due to incomplete data or no data available; data from 12 PCTs have been removed due to small numbers (<5).

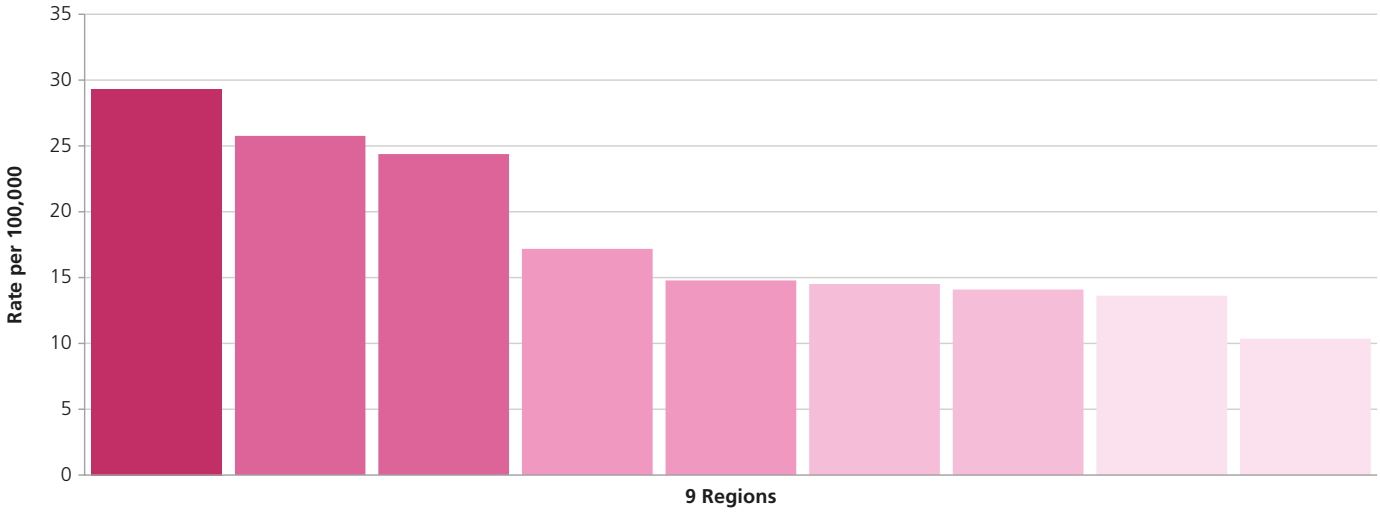
HEPATITIS C

Map 18: Rate of laboratory reports for confirmed hepatitis C per population by region

2011

Domain 2: Enhancing quality of life for people with long-term conditions





Context

In England, between 1995 and 2011, there was a steady sevenfold increase in the number of laboratory-confirmed reports of hepatitis C, from 1391 to 9908 per year. From 2010 to 2011, the number of laboratory reports of confirmed hepatitis C infection increased by 25.5%, from 7892 to 9908. More than two-thirds of laboratory reports (69%) were in men; almost 50% of all reports received were in individuals aged between 25 and 39 years. The marked increase in 2011 can probably largely be explained by the introduction of statutory laboratory reporting from October 2010, which would appear to confirm that considerable under-reporting of hepatitis C diagnoses is likely to have occurred in the past.[1]

Magnitude of variation

For regions in England, the rate of laboratory reports for confirmed hepatitis C ranged from 10.4 to 29.3 per 100,000 population, a 2.8-fold variation.

There are several possible reasons for the degree of variation observed, including differences in:

- the coverage of laboratory reporting;
- the amount of resource invested;
- the organisation of services;
- access to services for testing and counselling;
- the prevalence of newly diagnosed cases of hepatitis C, who may require treatment;
- the incidence of new cases, which may be affected by the effectiveness of local preventive measures, e.g. needle exchange and opioid substitution programmes;
- demography – some ethnic groups may have a higher prevalence.

Regional variation in the number of laboratory reports for hepatitis C in England has persisted. The percentage change in the number of reports between 2010 and 2011, however, also varied among regions. This is as a result of the introduction of statutory reporting in 2010, which led to the initiation of reporting at laboratories in regions that had not reported previously.

Options for action

When planning service improvement or development in laboratory reporting for hepatitis C, commissioners, clinicians and providers could consider:

- reviewing the completeness of reporting by laboratories responsible for reporting hepatitis C in the locality;
- identifying the level of increase in hepatitis C that has taken place in the local population over the last 5–10 years;
- reviewing the local demographic profile of people at risk and using the data to help improve the identification and treatment of people with hepatitis C;
- collaborating to introduce consistent methods of reporting, e.g. PCR results;
- ensuring that treatment outcomes, such as sustained viral response (SVR) rates, are measured against the number of people testing positive in the community, given that the purpose of testing is to identify patients who need treatment.

RESOURCES

- Health Protection Agency (2012) Hepatitis C in the UK: 2012 Report. http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1317135237627
- Department of Health (2010) Health Protection Legislation (England) Guidance 2010. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114510

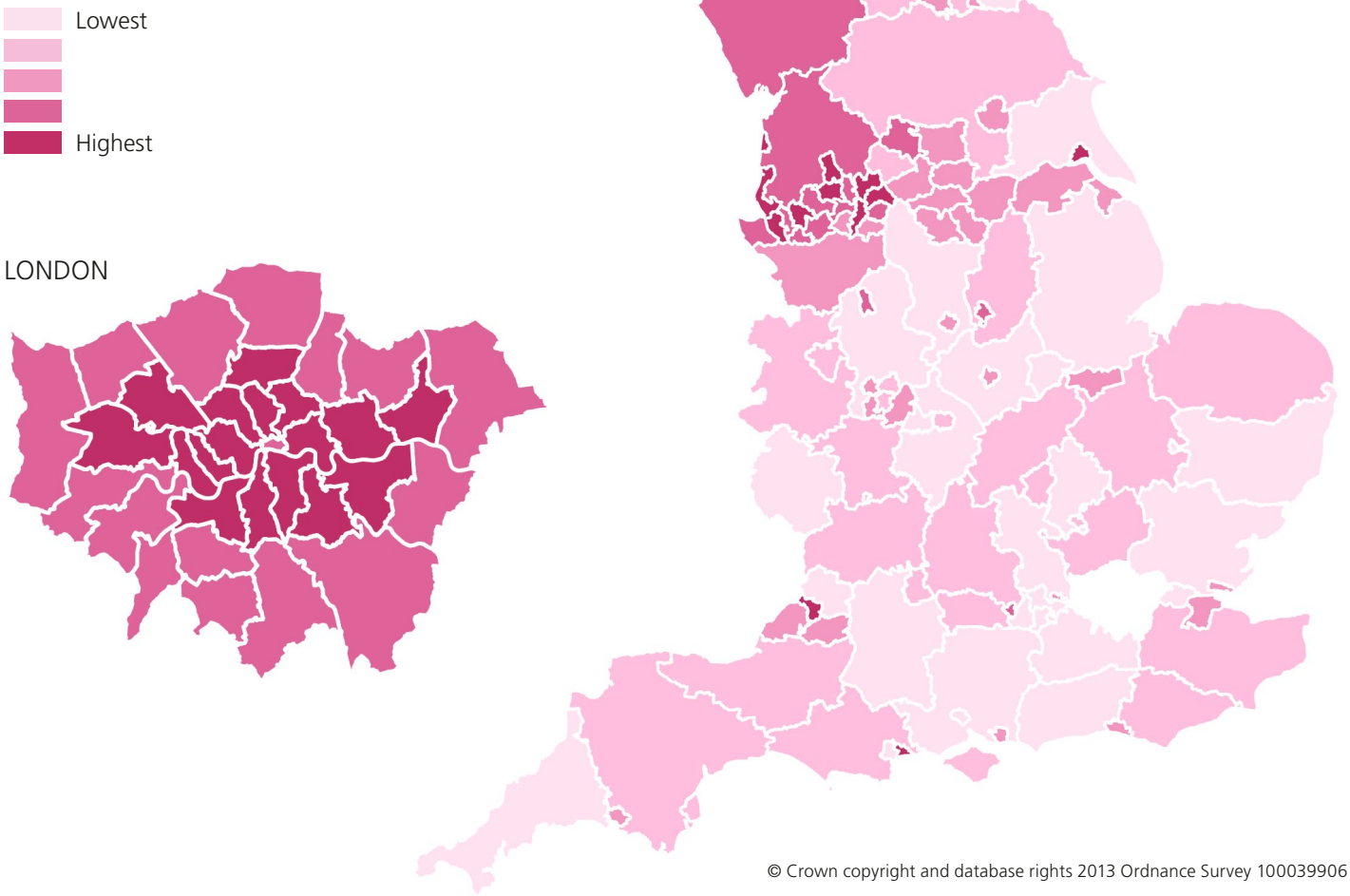
1 Health Protection Agency (2012) Hepatitis C in the UK: 2012 Report. http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1317135237627

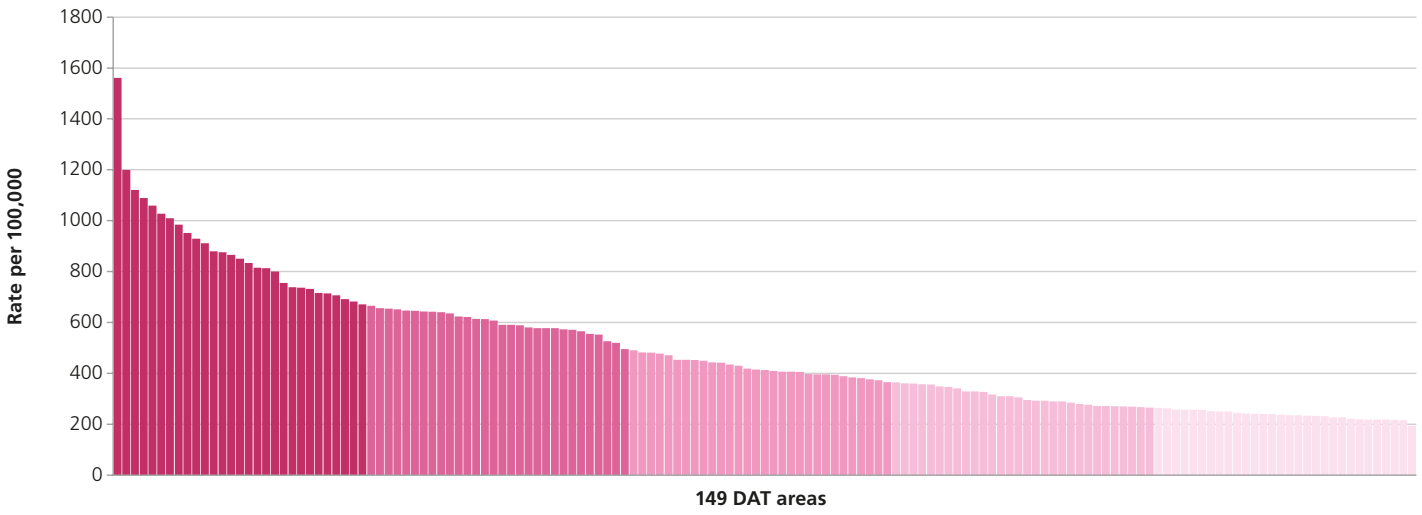
HEPATITIS C

Map 19: Estimated prevalence of chronic hepatitis C infection in people aged 15 years or older per population by drug action team (DAT) area

2005–2007

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions
Domain 3: Helping people to recover from episodes of ill health or following injury





Context

Exposure to hepatitis C (HCV) infection is largely preventable. Information about estimated prevalence helps to indicate the burden of hepatitis C when considered with the other relevant indicators in this Atlas (see Maps 18 and 20–27).

It is important to be able to predict the number of people likely to require treatment for chronic hepatitis C infection to facilitate effective planning and the commissioning of services.

The data for this indicator have been provided by the Health Protection Agency (HPA), and are derived from data in the HPA's commissioning template for estimating hepatitis C prevalence and numbers of people eligible for treatment by drug action team (DAT) area.[1]

The statistical model used in 2003 to estimate prevalence of hepatitis C antibodies in England was updated for 2005, including two refinements:

- data on ethnicity were used to estimate prevalence in non-injectors in South Asian and other ethnic groups separately;
- new estimates of the number of current injectors were used that cover England rather than London alone.

When an estimate for prevalence in people >60 years is included, the overall prevalence of hepatitis C antibody in the adult population (aged 15 years and older) in England is thought to be 0.54% [95% credible interval (CrI) 0.40, 0.75] or 218,000 individuals (95% CrI 163,000, 305,000).[2] Assuming a chronicity rate of 74%,[3] 161,320 adults would be living in England with chronic hepatitis C infection (0.40% of the adult population).

Magnitude of variation

For DAT areas in England, the estimated prevalence of chronic hepatitis C infection in people aged 15 years or older ranged from 194.3 to 1560.8 per 100,000 population (8-fold variation). When the five DAT areas with the highest estimated prevalence and the five DAT areas with the lowest estimated prevalence are excluded the range is from 218.8 to 1027.5 per 100,000 population, and the variation is 4.7-fold.

Potential reasons for the degree of variation observed include differences in:

- the prevalence of injecting drug users in the local population;
- the proportion of people from South Asian and other ethnic groups at increased risk of infection in the local population;
- availability of and access to services for testing at a local level;
- laboratory methods of processing samples.

Options for action

When planning service improvement or development for people with hepatitis C, drug action teams, commissioners and providers in a locality need to review:

- these estimates in relation to local data about chronic hepatitis C prevalence;
- local information systems and service contacts (i) to increase identification of people with chronic hepatitis C; (ii) to improve treatment and care of people with chronic hepatitis C; (iii) to facilitate identification of the barriers to treatment for people found to be positive for hepatitis C in the community; (iv) to refine ways to tackle the barriers to treatment.

RESOURCES

- Health Protection Agency (2012) Hepatitis C in the UK: 2012 Report. http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317135237219
- Health Protection Agency: Commissioning template for estimating HCV prevalence and numbers eligible for treatment by Drug Action Team area. http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HepatitisC/EpidemiologicalData/
- NICE (2012) Hepatitis B and C – ways to promote and offer testing (PH43). http://guidance.nice.org.uk/PH43
- NICE Pathway. Hepatitis B and C testing overview. http://pathways.nice.org.uk/pathways/hepatitis-b-and-c-testing

1 Health Protection Agency: Commissioning template for estimating HCV prevalence and numbers eligible for treatment by Drug Action Team area. http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HepatitisC/EpidemiologicalData/

2 Harris RJ, Ramsay M, Hope VD, Brant L, Hickman M, Foster GR, De Angelis D (2012) Hepatitis C prevalence in England remains low and varies by ethnicity: an updated evidence synthesis. *European Journal of Public Health* 22(2);187-92.

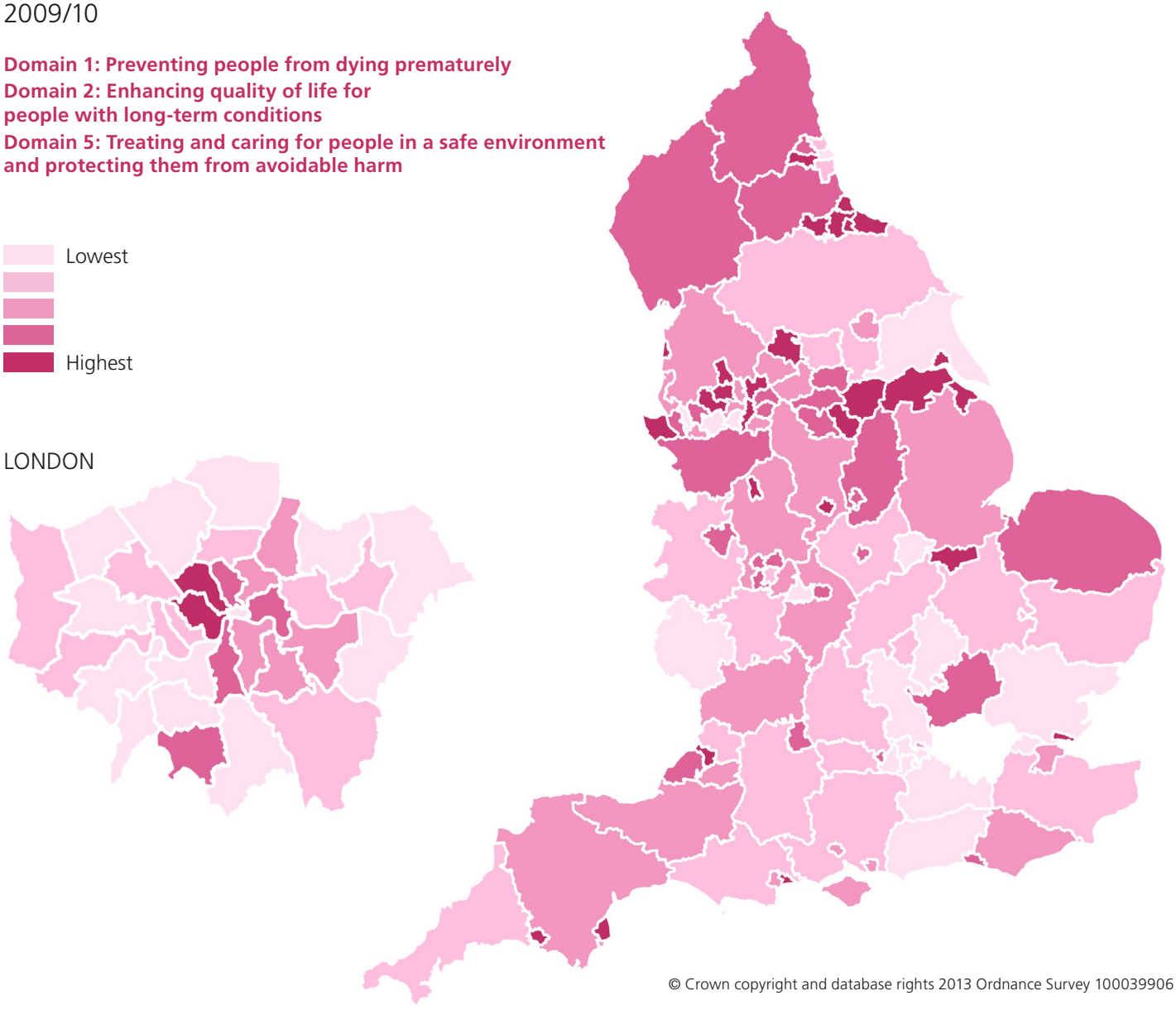
3 Micallef JM, Kaldor JM, Dore GJ (2006) Spontaneous viral clearance following acute hepatitis C infection: a systematic review of longitudinal studies. *Journal of Viral Hepatitis* 13; 34-41.

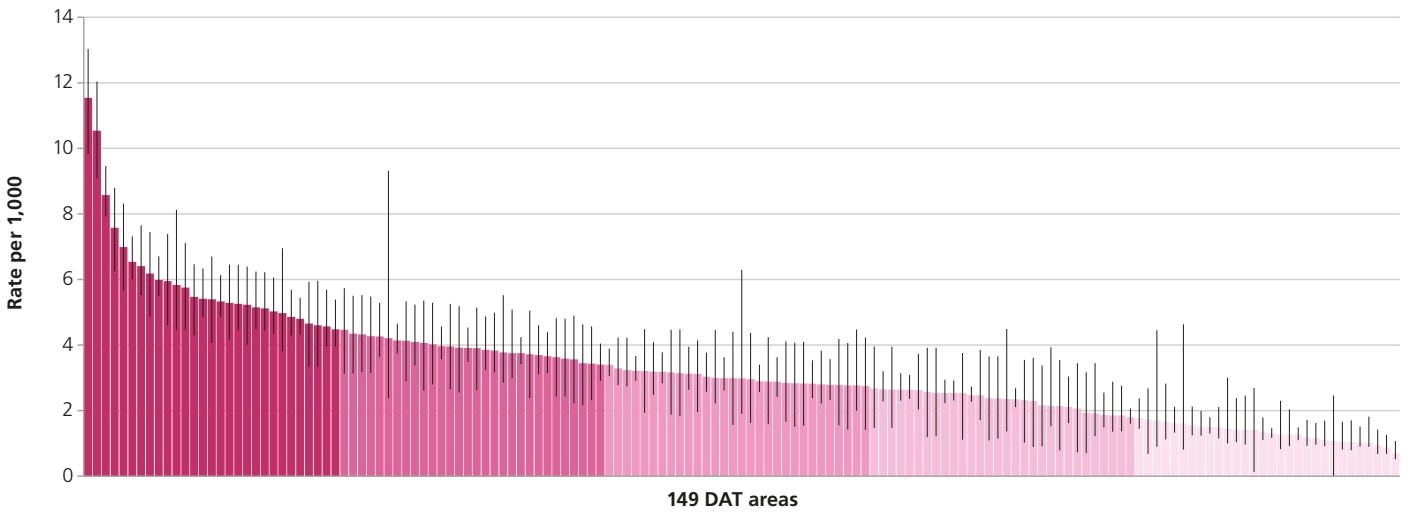
HEPATITIS C

Map 20: Estimated prevalence of opiate and/or crack cocaine injecting in people aged 15–64 years per population by drug action team (DAT) area

2009/10

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm





Context

In the UK, people who inject drugs are at the greatest risk of hepatitis C infection; they are also at risk of hepatitis B infection. A capacity to identify differences in the levels of injecting drug use in different areas of the country is important when assessing the disease burden and its implications for prevention and vaccination. Information about the number of people who inject drugs is also key to formulating effective policies for tackling related harms.

Undertaking direct counts of people engaged in a largely covert activity, such as the use of class A drugs, and particularly injecting drug use, is difficult. Indirect techniques that utilise various data sources tend to offer more reliability, although such prevalence estimates need to be used cautiously because they are difficult to validate.

The prevalence estimates for this indicator include people aged 15–64 years, resident in each DAT area, and known to be injecting heroin, methadone, other opiate drugs, or crack cocaine. These data are from the fifth round of a series of annual estimates of the prevalence of opiate and/or crack cocaine use and injecting in England at a national, regional and local level (see "Resources", item 2).

There has been a statistically significant decrease in the national estimate of opiate and/or crack cocaine use between 2008/09 and 2009/10, and in injecting drug use between 2006/07 and 2009/10.[1]

Other drugs that can be taken via injection include:

- other psycho-active drugs, such as cocaine and amphetamines;
- image- and performance-enhancing drugs, although this group of injecting drug users is likely to be at lower risk of hepatitis C and hepatitis B infection than people who inject psycho-active drugs.

In some areas of England, there may be large numbers of people who inject opiate and/or crack cocaine, other drugs or both.

Magnitude of variation

For DAT areas in England, the estimated prevalence of opiate and/or crack cocaine injecting in people aged 15–64 years ranged from 0.7 to 11.5 per 1000 population (17-fold variation). When the five DAT areas with the highest estimated prevalence and the five DAT areas with the lowest estimated prevalence are excluded, the range is 1.0–6.5 per 1000 population, and the variation is 6-fold.

Options for action

People who inject opiate and/or crack cocaine are at high risk of contracting hepatitis C and comprise a hard-to-reach group.

When planning service improvement and development for people who inject drugs, drug action teams, commissioners, clinicians and providers could consider reviewing:

- prevalence estimates for the locality;
- the degree of contact with this hard-to-reach, high-risk group;
- strategies for prevention and case-identification locally and their success in reducing the risk of hepatitis C;
- barriers to treatment for people found to be positive for hepatitis C in the community;
- ways to address barriers to treatment to reduce hepatitis C and liver disease in this hard-to-reach, high-risk group;
- access to the vaccine against hepatitis B.

RESOURCES

- Hay G, Gannon M, Casey J, Millar T. Estimates of the Prevalence of Opiate Use and/or Crack Cocaine Use, 2009/10: Sweep 6 report. The Centre for Drug Misuse Research, University of Glasgow, in collaboration with The National Drug Evidence Centre, University of Manchester. http://www.nta.nhs.uk/uploads/prevalencestats2009-10fullreport.pdf
- Hay G, Gannon M, Casey J, Millar T (2011) National and Regional Estimates of the Prevalence of Opiate and/or Crack Cocaine Use 2009-10: A Summary of Key Findings. National Treatment Agency for Substance Misuse. http://www.nta.nhs.uk/uploads/prevalencesummary0910.pdf

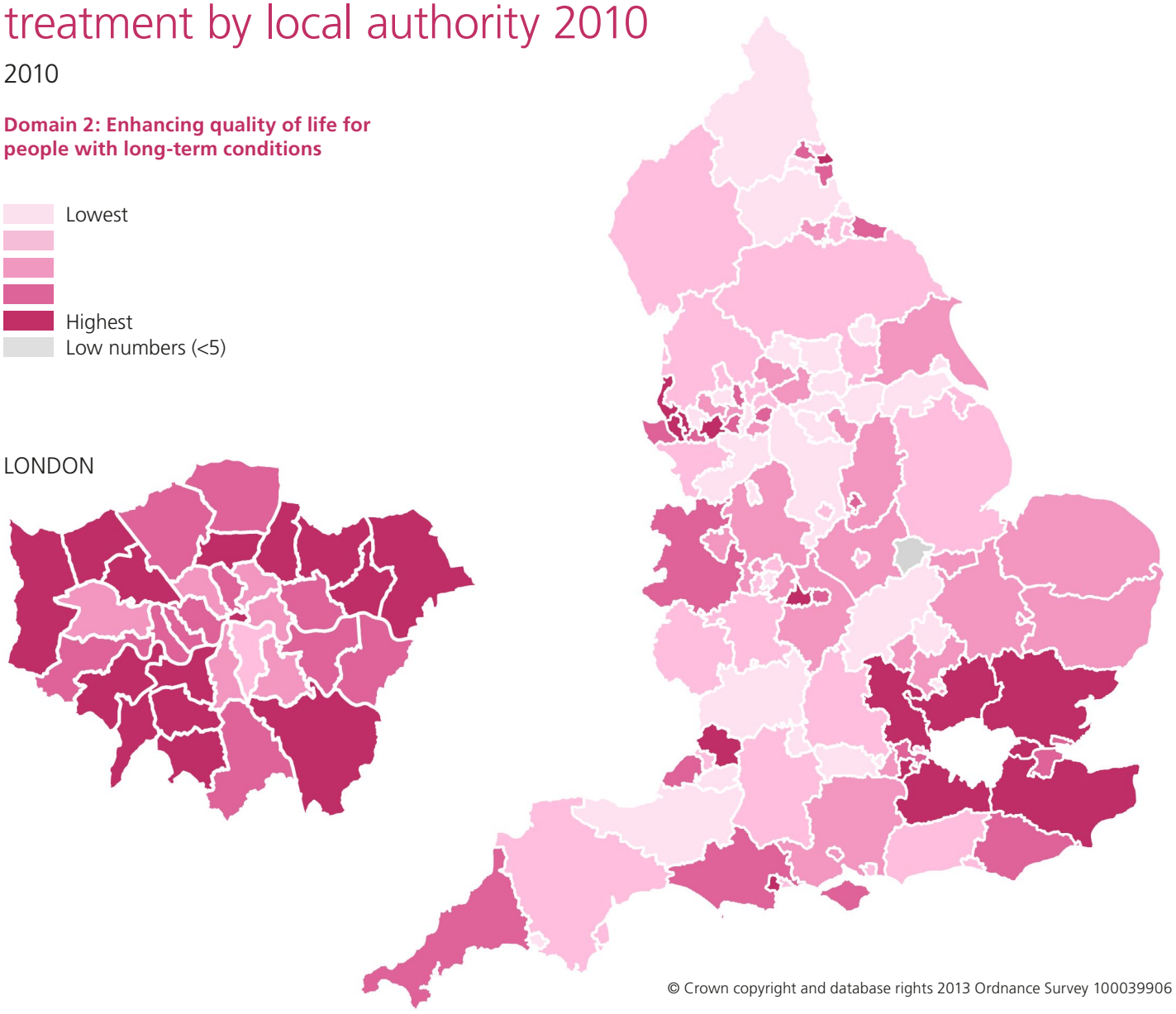
1 Further results and a detailed explanation of the methodology can be found on the NTA website. http://www.nta.nhs.uk/

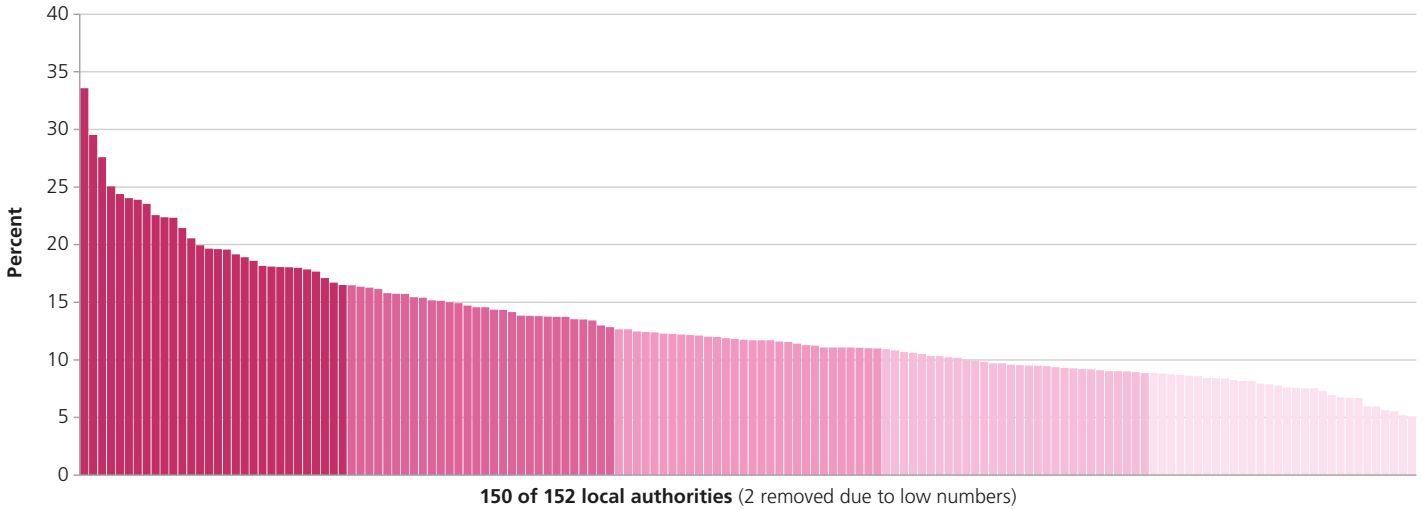
HEPATITIS C

Map 21: Number of drug users that left drug treatment successfully who do not then re-present to treatment again within 6 months as a proportion (%) of the total number in treatment by local authority 2010

2010

Domain 2: Enhancing quality of life for people with long-term conditions





150 of 152 local authorities (2 removed due to low numbers)

Context

In the UK, people who inject drugs are at greatest risk of hepatitis C infection. Infections are acquired when people share contaminated injecting equipment with infected individuals.

Around 200,000 people receive help for drug dependence in England every year, with about 135,000 being treated on any given day:

- some people have been in treatment before, and dropped out;
- some despite their best efforts will have relapsed;
- others are newcomers.[1]

Treatment is defined as successful when an individual no longer injects drugs. Successful treatment substantially reduces the risk of contracting hepatitis C and also of infecting other people with whom they come into contact.

The National Treatment Agency for Substance Misuse recently reported that:

- *Drug treatment is effective: over the last three years a third of users successfully completed, a third did not complete but did not return, and a third are still in treatment or have returned.*
- *Treatment is much better at getting people out now than it was: users starting treatment now are more likely to recover than those who started in 2005–06.*
- *There is an entrenched group of users – around 21,000 – who have been in continuous treatment. But they represent only 6% of the people who have been through the treatment system.*[1]

In the Public Health Outcomes Framework (PHOF), this is indicator 2.15, the importance of which is stressed because individuals with a successful treatment outcome demonstrate a significant improvement in several aspects of health and well-being:

- increased longevity;
- reduced blood-borne virus transmission;
- improved parenting skills;
- improved physical and psychological health.[2]

This indicator aligns with the Government's Drug Strategy 2010[3] and the ambition of public health to increase the number of individuals recovering from addiction.

Magnitude of variation

For upper-tier local authorities in England, the number of drug users that left drug treatment successfully who do not then re-present to treatment again within 6 months as a proportion of the total number in treatment ranged from 5.1% to 33.6% (7-fold variation).[4] When the five upper-tier local authorities with the highest proportions and five upper-tier local authorities with the lowest proportions are excluded, the range is 6.0–24.0%, and the variation is 4-fold.

When interpreting the magnitude of variation, it is important to note:

- lack of re-presentation does not always mean that treatment has been successful;
- some people who inject drugs are very mobile and may present to different services at different times;
- the indicator does not include people who do not start treatment at all and/or who are not in touch with services.

Options for action

As the most effective means of preventing transmission are needle–syringe exchange programmes (NSP) and opioid substitution therapy (OST), commissioners need to ensure that the mechanisms for the prevention of the future burden of hepatitis C in particular are aligned with locally commissioned drug treatment programmes.

Although the annual reports of the Health Protection Agency (HPA) show that testing for hepatitis C in people who use drugs has been improving, there are many barriers to gaining access to treatment programmes and achieving a successful outcome; both need to be addressed at a local level.[5]

Commissioners, clinicians and providers need to work with the local drug action team(s):

- to review treatment rates among people who inject drugs in the locality;
- to review the effectiveness of local drug treatment services in achieving recovery;
- to identify scope for improvement in local drug treatment services and systems.

RESOURCES

- National Treatment Agency (NTA) for Substance Misuse. http://www.nta.nhs.uk/
- National Treatment Agency (NTA) for Substance Misuse (2012) From Access to Recovery: Analysing Six Years of Drug Treatment Data. http://www.nta.nhs.uk/uploads/six-yearstudy.pdf

1 National Treatment Agency for Substance Misuse (2012) From Access to Recovery: Analysing Six Years of Drug Treatment Data. http://www.nta.nhs.uk/uploads/six-yearstudy.pdf

2 Department of Health (2012) Healthy Lives, Healthy People: Improving outcomes and supporting transparency. Part 2 Summary technical specifications of public health indicators, January 2012. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132358

3 Her Majesty's Government (2010) Drug Strategy 2010. Reducing Demand, Restricting Supply, Building Recovery: Supporting People to Live a Drug Free Life. Home Office. http://www.homeoffice.gov.uk/publications/alcohol-drugs/drugs/drug-strategy/drug-strategy-2010?view=Binary

4 Data from 2 upper-tier local authorities have been removed due to low numbers (<5), one of which is not visible on the map opposite.

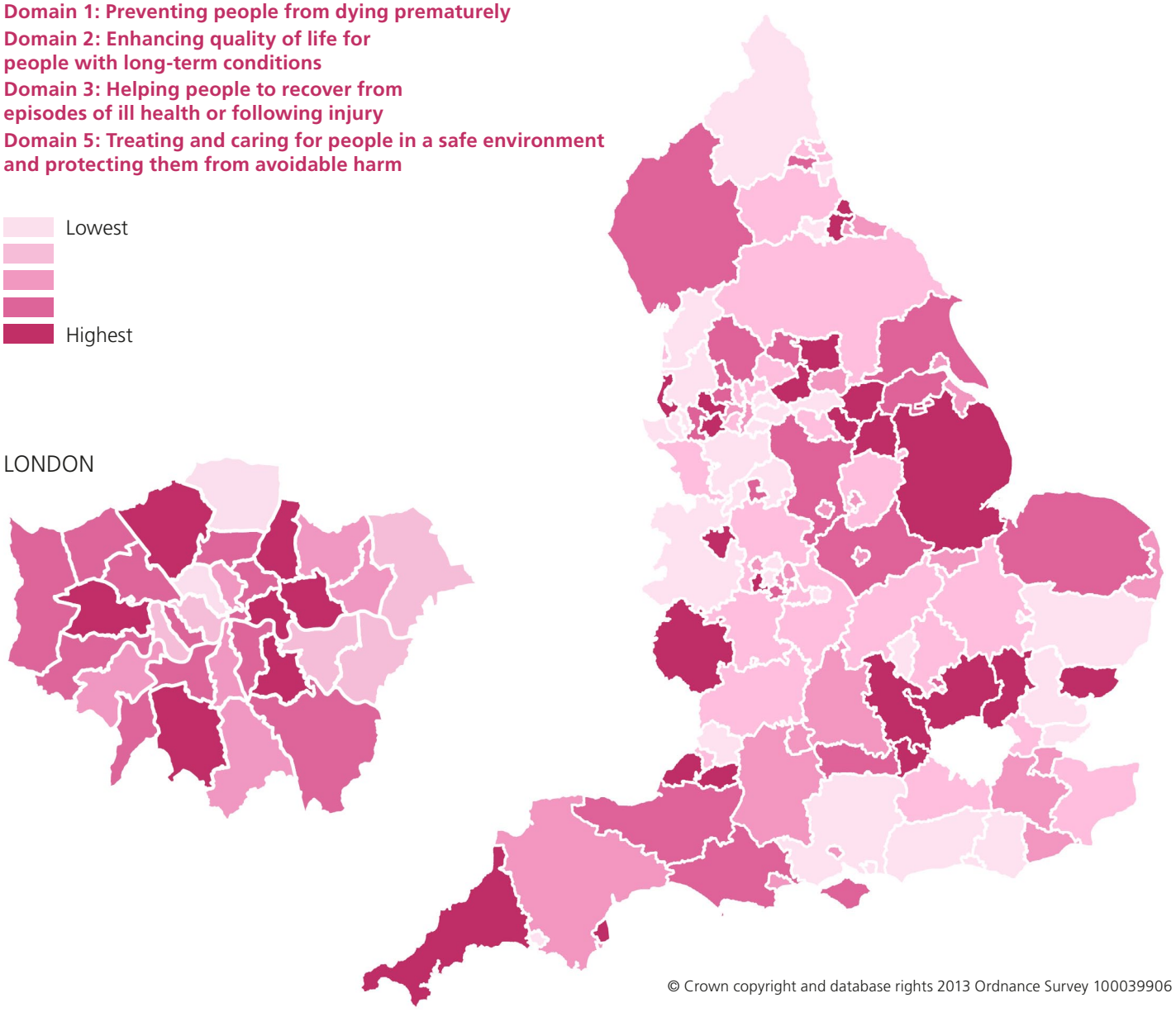
5 McGowan CE, Fried MW (2012) Barriers to hepatitis C treatment. *Liver International* 32 Suppl 1: 151-156. doi: 10.1111/j.1478-3231.2011.02706.x.

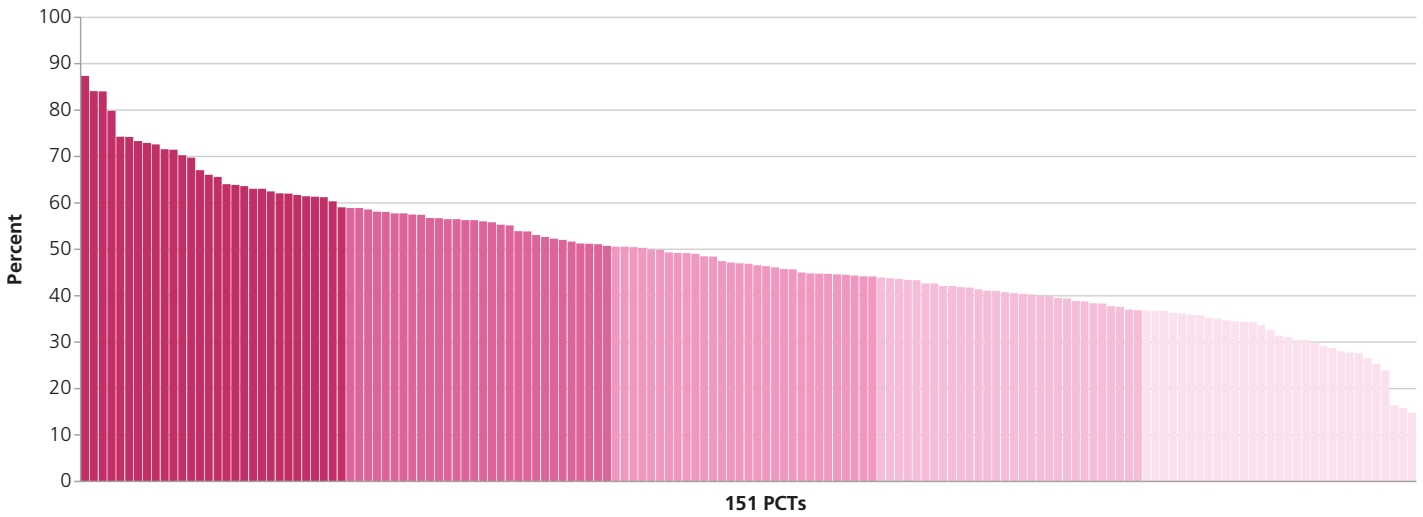
HEPATITIS C

Map 22: Percentage of hepatitis C test uptake among people who inject drugs receiving drug treatment by PCT

2011/12

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions
Domain 3: Helping people to recover from episodes of ill health or following injury
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm





Context

In the UK, people who inject drugs are at greatest risk of hepatitis C infection. Infections are acquired when people share contaminated injecting equipment with infected individuals.

Preventing the spread of blood-borne viruses such as hepatitis C is an important public health issue, and a key outcome in the Government's Drug Strategy 2010 (see "Resources"). Ensuring people who use drugs do not contract blood-borne viruses is one way of ensuring their safety and that of the local community before and during their recovery. Preventing transmission of blood-borne viruses also has benefits for civil society by reducing:

- harms to health;
- treatment costs.[1]

When people who inject drugs receive treatment for their addiction, it provides an opportunity to undertake hepatitis C testing to identify new cases. This can be an important step:

- to help patients understand the implications of the infection for their health;
- to address any barriers preventing access to treatment services;
- to deliver treatment with an intention to cure;
- to help prevent the spread of disease to other people with whom patients come into contact.

The National Treatment Agency (NTA) for Substance Misuse has a vital role in improving practice in testing for hepatitis C. As part of the annual planning process, the NTA regional teams ensure that access to hepatitis C testing and treatment provision is addressed in the treatment plans of commissioning partnerships across England.

NICE has developed public health guidance on the most cost-effective ways of offering tests to those at risk of infection from hepatitis B and C (see "Resources").

Magnitude of variation

For PCTs in England, the percentage of hepatitis C test uptake among people who inject drugs receiving drug treatment ranged from 14.8% to 87.4% (6-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 26.5–74.2%, and the variation is 2.8-fold.

When interpreting the magnitude of variation, it is important to note:

- the indicator does not include people who do not start treatment at all and/or who are not in touch with services;
- some people who inject drugs are very mobile and may present to different services at different times.

Options for action

When planning service improvement and development for people at increased risk of hepatitis C, commissioners need to work in partnership with the local drug action team(s), clinicians, providers and people who inject drugs:

- to review the percentage of people receiving drug treatment who are offered and accept hepatitis C testing;
- to ascertain the reasons why the current systems and treatment plans fail to deliver high rates of testing;
- to ensure that staff working in drug services understand the importance of and reasons for the offer of testing for hepatitis C;
- to agree and implement strategies for improving hepatitis C test uptake and access to treatment services.

RESOURCES

- National Treatment Agency for Substance Misuse. http://www.nta.nhs.uk/
- Advisory Council on the Misuse of Drugs (ACMD) (2009) The Primary Prevention of Hepatitis C Among Injecting Drug Users. Home Office. http://www.homeoffice.gov.uk/publications/agencies-public-bodies/acmd1/acmdhepcreport2?view=Binary
- National Treatment Agency for Substance Misuse (2012) From Access to Recovery: Analysing Six Years of Drug Treatment Data. http://www.nta.nhs.uk/uploads/six-yearstudy.pdf
- Harm Reduction Works – campaign materials. http://www.harmreductionworks.org.uk/
- Her Majesty's Government (2010) Drug Strategy 2010. Reducing Demand, Restricting Supply, Building Recovery: Supporting People to Live a Drug Free Life. Home Office. http://www.homeoffice.gov.uk/publications/alcohol-drugs/drugs/drug-strategy/drug-strategy-2010?view=Binary
- NICE (2012) Hepatitis B and C – ways to promote and offer testing (PH43). http://guidance.nice.org.uk/PH43
- NICE Pathway. Hepatitis B and C testing overview. http://pathways.nice.org.uk/pathways/hepatitis-b-and-c-testing

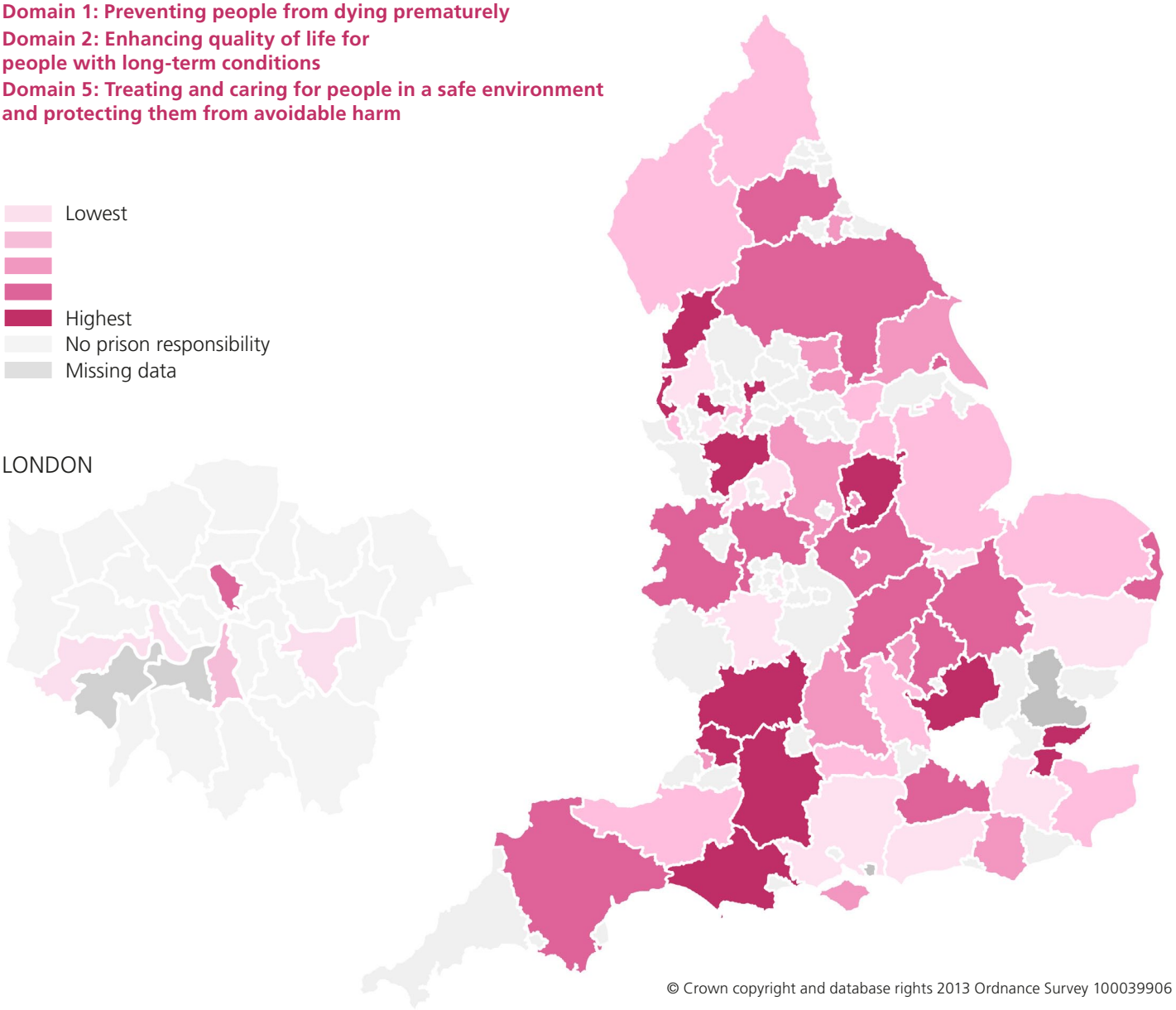
1 http://www.nta.nhs.uk/bbv.aspx

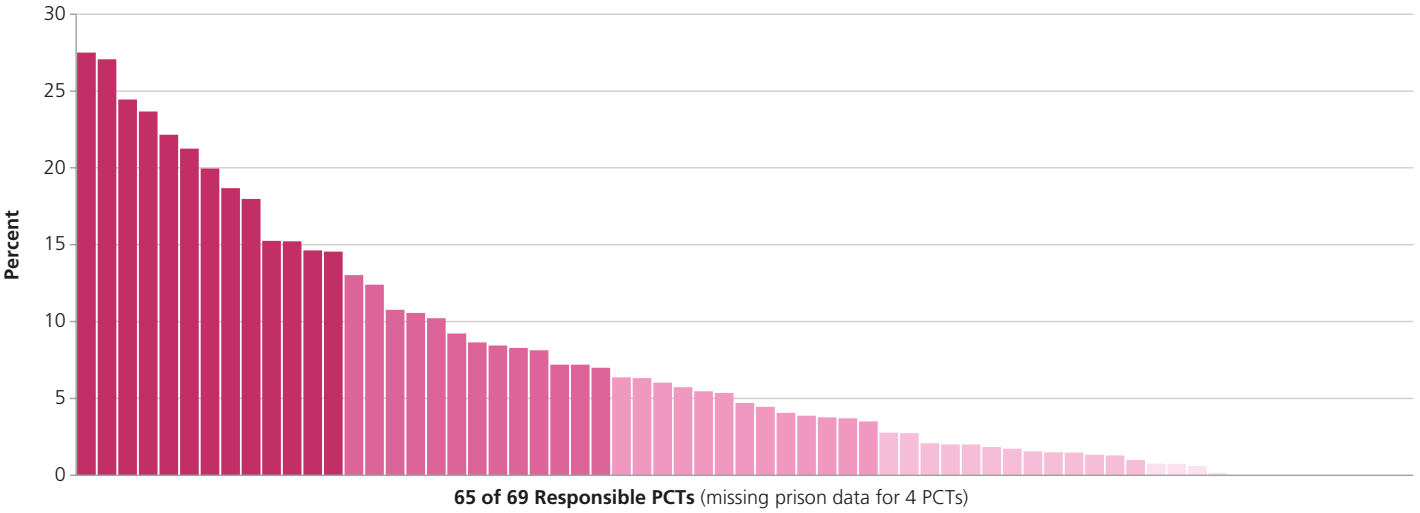
HEPATITIS C

Map 23: Percentage of hepatitis C test uptake among adult new prison receptions by responsible PCT

2011/12

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm





65 of 69 Responsible PCTs (missing prison data for 4 PCTs)

Context

Hepatitis C is a blood-borne viral infection. The virus is spread when blood from an infected person enters the bloodstream of another.[1] Injecting drug use is the most common way to acquire hepatitis C infection, whereby people who inject drugs share contaminated injecting equipment with infected individuals.

There is considerable overlap between the prison population and the population of injecting drug users in the community. Up to 60% of people who inject drugs have been in prison; in one study, 40–80% of newly sentenced adult offenders had used illicit substances.[2] Prison is a setting in which traditionally hard-to-reach populations can be tested and treated for hepatitis C infection.

No vaccine is available for protection against hepatitis C. Prevention is focussed on reducing the risk of transmission by increasing awareness among people potentially at risk of infection, improving access to and uptake of an offer of testing, and ensuring access to treatment with the objective of viral clearance for most people being treated.

Around half of injecting drug users with hepatitis C remain unaware of the infection. As many injecting drug users pass through the prison system, this provides a useful opportunity to increase active case-finding among high-risk individuals, and to offer opportunities for health education to those individuals.

Uptake of testing for hepatitis C is a Department of Health prison health performance and quality indicator (PHPQI),[3] based on data reported by prisons about testing for hepatitis C among offenders entering prison. Prison-specific data have been grouped by "responsible" PCT, i.e. PCTs that commission healthcare for one or more prisons, of which there are 69.

Magnitude of variation

For responsible PCTs, the percentage of hepatitis C test uptake among adult new prison receptions ranged from 0% to 27.5%.[4] When the two responsible PCTs with the highest percentages and the two responsible PCTs with the lowest percentages are excluded, the range is 0–24.5%.

Reasons for the variation observed could include differences in:

- data quality – testing is carried out by different teams at different points of care and some activity may not be reflected in the PHPQI data;
- the information provided about testing and offenders' decisions whether to take the test for hepatitis C;
- the point in the care pathway at which testing is offered;
- the ways in which risk is assessed and testing is offered and whether services are streamlined for testing.

Although not covered by this indicator, there is also likely to be variation in how the results are conveyed to offenders, and how follow-up arrangements for treatment are made.

Options for action

Testing offenders for hepatitis C on reception to prison or shortly thereafter provides an opportunity to identify and treat cases and to reduce the spread of the disease. When planning service improvement or development in testing new prison receptions for hepatitis C, commissioners, clinicians and providers with responsibility for one or more prisons need:

- To review testing rates with the relevant prisons and discuss improvements – testing should include automatic confirmation by PCR of an antibody-positive test;
- To identify prisons not yet submitting data and agree improvement measures;
- To commission improvements in service provision using the best practice guidance in the national survey of hepatitis C services in prisons (see Railton *et al*, "Resources");
- To review and improve referral *post* testing, and facilitate access to treatment;
- To ensure that arrangements for liaison between prisons, and between the prison and community, and for continuity of treatment, are in place; Department of Health modelling indicates that this is the single most important step that will make prison testing and treatment programmes cost-effective.

Improved coordination between commissioners and prisons and the development of a shared vision in local policies for offender health might increase the uptake of testing. Offenders also need education about the benefits of testing.

Offender Health with the National AIDS Trust have produced guidelines to improve blood-borne virus testing and treatment, which commissioners and service providers can use to audit performance against best-practice standards (see "Resources").

RESOURCES

- Health Protection Agency. Prison hepatitis B vaccination and hepatitis C testing monitoring. http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/PrisonInfectionPreventionTeam/PrisonHepBVaccAndHepCTestingProgramme/
- Health Protection Agency (2012) Hepatitis C in the UK: 2012 Report. http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1317135237627
- Health Protection Agency and Department of Health - Offender Health (2011) Prevention of infection and communicable disease control in prisons and places of detention. A manual for healthcare workers. http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1309970437635
- Railton C, Newton A, O'Moore E, Lombard M (2012) National survey of hepatitis C services in prisons in England. Department of Health & Health Protection Agency. http://www.dh.gov.uk/health/files/2012/07/Hep-C-Prison-Survey.pdf
- National AIDS Trust (2011) Tackling Blood-Borne Viruses in Prisons. A framework for best practice in the UK. http://www.nat.org.uk/Media%20library/Files/Policy/2011/NATBlood%20Borne%20VirusesPrisonsMay2011.pdf
- Humphreys C, Lombard M, Newton A, O'Moore É, Railton C (2013) An audit of the hepatitis C services in a representative sample of English prisons, 2013.

1 Health Protection Agency and Department of Health - Offender Health (2011) Prevention of infection and communicable disease control in prisons and places of detention. A manual for healthcare workers. http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1309970437635

2 Stewart D (2008) The problems and needs of newly sentenced prisoners: results from a national survey. Ministry of Justice Research Series 16/08. October 2008. http://webarchive.nationalarchives.gov.uk/20110201125714/http://www.justice.gov.uk/publications/problems-needs-prisoners.htm

3 Prison health performance and quality indicator report and guidance. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_133379

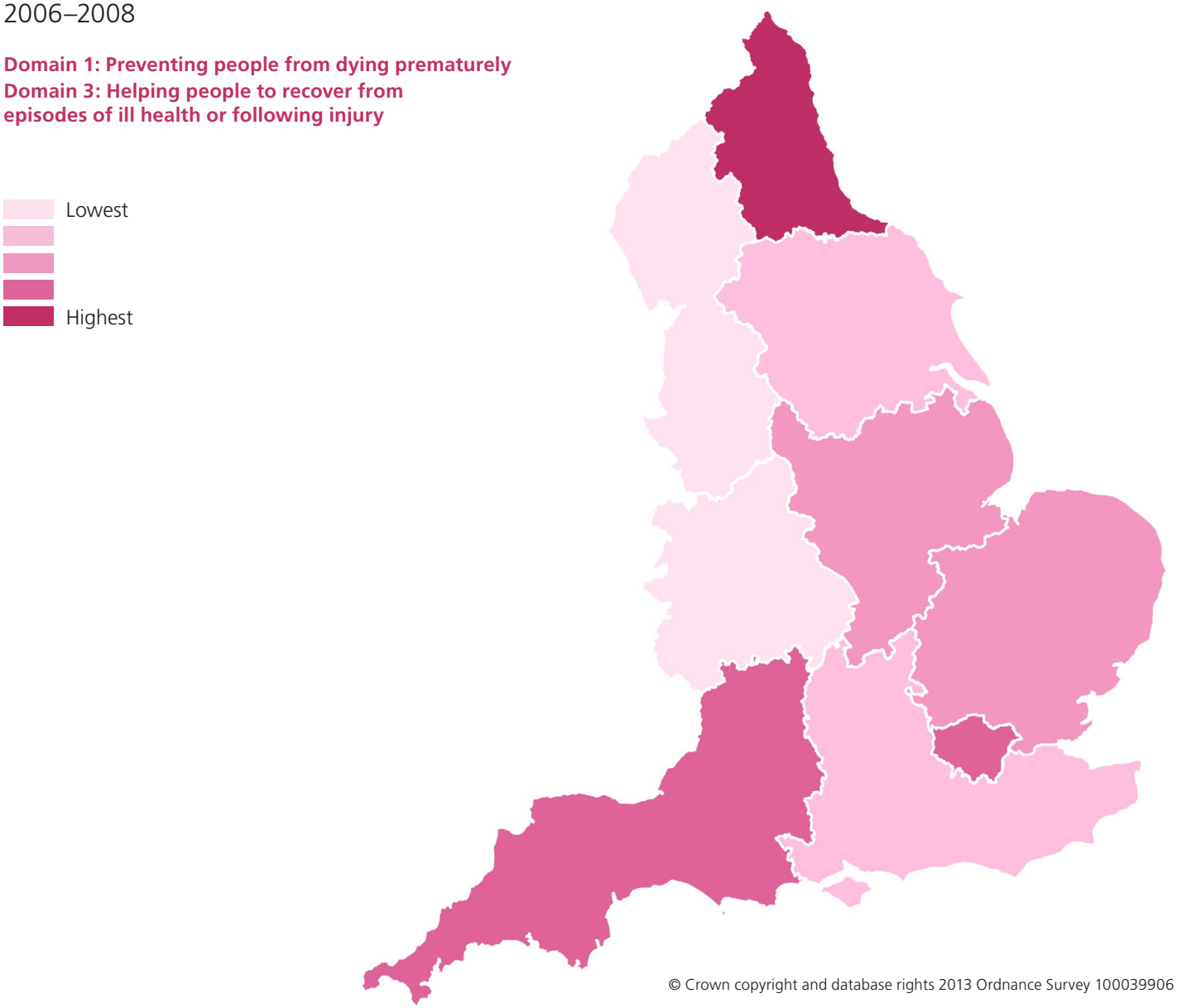
4 Eleven of the 137 (8%) prisons did not report rates of vaccination against hepatitis B for 2011/12, thus, data are missing for 4 PCTs and data are partial for 5 PCTs; some prisons reported >100% coverage of vaccinations due to calculation errors, but these have been reported as 100% in the map.

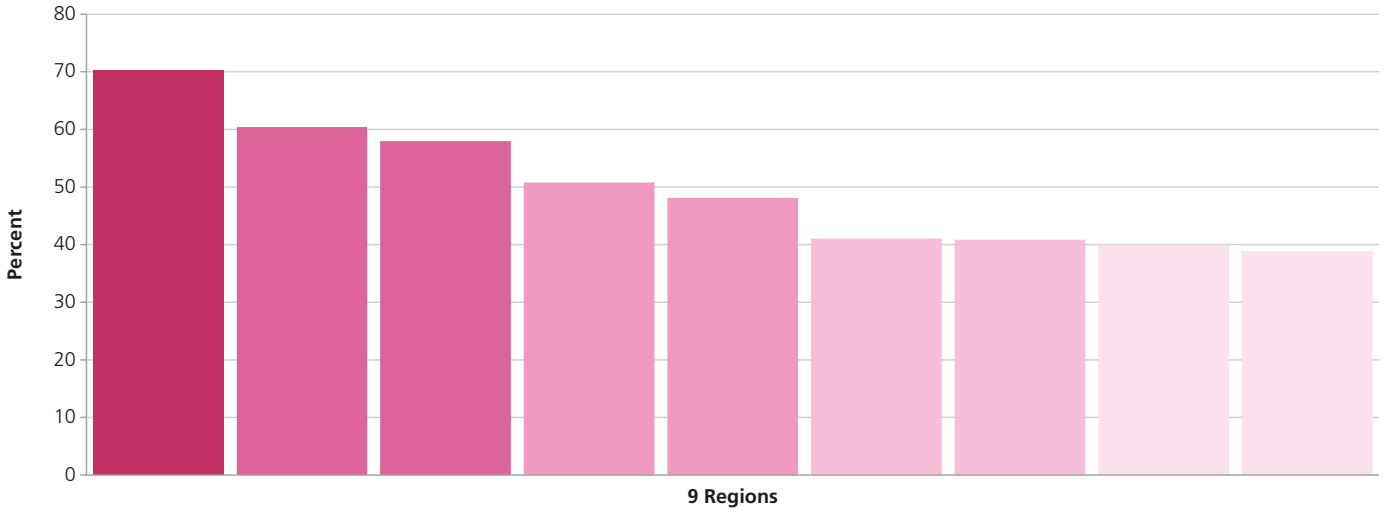
HEPATITIS C

Map 24: Estimated proportion (%) of people aged 15 years or older with chronic hepatitis C infection expected to access treatment who received treatment by region

2006–2008

Domain 1: Preventing people from dying prematurely
Domain 3: Helping people to recover from episodes of ill health or following injury





Context

NICE recommends that a combination of antiviral treatments that will successfully clear hepatitis C virus in the majority of patients is made available. There is a paucity of data on the number of individuals receiving antiviral treatment at a national level. Therefore, it is difficult to ascertain whether sufficient numbers of infected individuals are accessing treatment. This is an essential prerequisite to identify and address any unwarranted variation in hepatitis services.

In response to a national questionnaire issued by the Health Protection Agency in 2008 to 207 hospitals in England (response rate: 97%; 201/207), 130 hospitals reported treating patients with hepatitis C. Of the 85 hospitals that replied to a follow-up questionnaire about treatment, 65 (76%) reported starting 2788 patients on antiviral treatment that year, similar to the number reported in the previous year. Among 1714 patients for whom treatment outcome in 2008 had been reported, preliminary results suggest a sustained virologic response (SVR) of 72% was achieved overall (see Table 24.1). If, however, the number of patients achieving SVR (numerator) was expressed as a proportion of the number of all patients testing positive in any given locality (denominator), the outcome is not as promising as it would at first appear. Expressing the SVR as a proportion of all patients testing positive may help to highlight to commissioners, clinicians and providers that there are considerable upstream barriers to accessing treatment.

Table 24.1: Sustained virologic response (SVR) in patients for whom treatment outcome was reported in 2008[1]

Genotype	SVR (%)
1	60
2	85
3	82
4	59
Other or unknown	70

As some clinical centres reported not knowing how many individuals received antiviral treatment, or failed to respond to requests, the HPA used national data from pharmaceutical companies[2], pharmacy purchasing data (PharmEx[3]) and pharmacy prescribing data (IMS[4]) to estimate the number of individuals treated in England.[5] These calculations suggest that around 27,500 patients with hepatitis C could have been treated with pegylated interferon as part of the NICE recommended combination therapy between 2006 and 2011. This is sufficient to have treated about 20% of the estimated total of people with hepatitis C.

Magnitude of variation

For regions in England, the estimated proportion of people aged 15 years or older with chronic hepatitis C infection expected to access treatment who received treatment ranged from 38.9% to 70.2%, a 1.8-fold variation.

Options for action

When planning service improvement and development to increase the number of people with hepatitis C who receive treatment, commissioners, clinicians and providers could consider:

- reviewing the local estimates of hepatitis C prevalence and the percentage of people receiving treatment – providers of treatment services could reasonably be expected to report outcomes annually;
- following national guidelines on ways to promote and offer testing to people at increased risk of infection;[6]
- developing strategies to increase uptake of treatment and reduce barriers to access among high-risk groups;
- ensuring that, although treatment centres often report good outcomes in people who access treatment, outcomes and "intention to treat" at a local level are measured against the number of people testing positive, which may be a better indicator of whether treatment services are integrated given that the purpose of testing is to identify patients who need treatment.

RESOURCES

- Health Protection Agency (2012) Hepatitis C in the UK: 2012 Report. http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1317135237627
- NICE (2004) Interferon alfa (pegylated and non-pegylated) and ribavirin for the treatment of chronic hepatitis C (TA75). [Review and extension of Technology Appraisal Guidance No. 14, October 2000.] http://www.nice.org.uk/nicemedia/pdf/TA075guidance.pdf
- NICE (2006) Peginterferon alfa and ribavirin for the treatment of mild chronic hepatitis C. [Extension of the guidance in Technology Appraisal Guidance 75.] http://www.nice.org.uk/nicemedia/live/11590/33534/33534.pdf
- NICE (2010) Peginterferon alfa and ribavirin for the treatment of chronic hepatitis C (TA200). [Part review of Technology Appraisal Guidance 75 and 106.] http://www.nice.org.uk/nicemedia/live/13180/50856/50856.pdf
- NICE (2012) Telaprevir for the treatment of genotype 1 chronic hepatitis C (TA252). http://guidance.nice.org.uk/TA252
- NICE (2012) Boceprevir for the treatment of genotype 1 chronic hepatitis C (TA253). http://guidance.nice.org.uk/TA253

1 Health Protection Agency (2012) Hepatitis C in the UK: 2012 Report. http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1317135237627

2 Sales of interferon by Roche, and MSD, 2006–2008.

3 PharmEx data on interferon purchased, 2006–2008, from Department of Health Commercial Medicines Unit (CMU).

4 Interferon dispensing data supplied by IMS Health (source: IMS SCM data, published February 2009, showing units to hospital outlets, 2006–2008).

5 The following organisations provided data for the calculation of this indicator but bear no responsibility for their future analysis or interpretation: Roche; MSD; IMS Health; Commercial Medicines Unit, Department of Health.

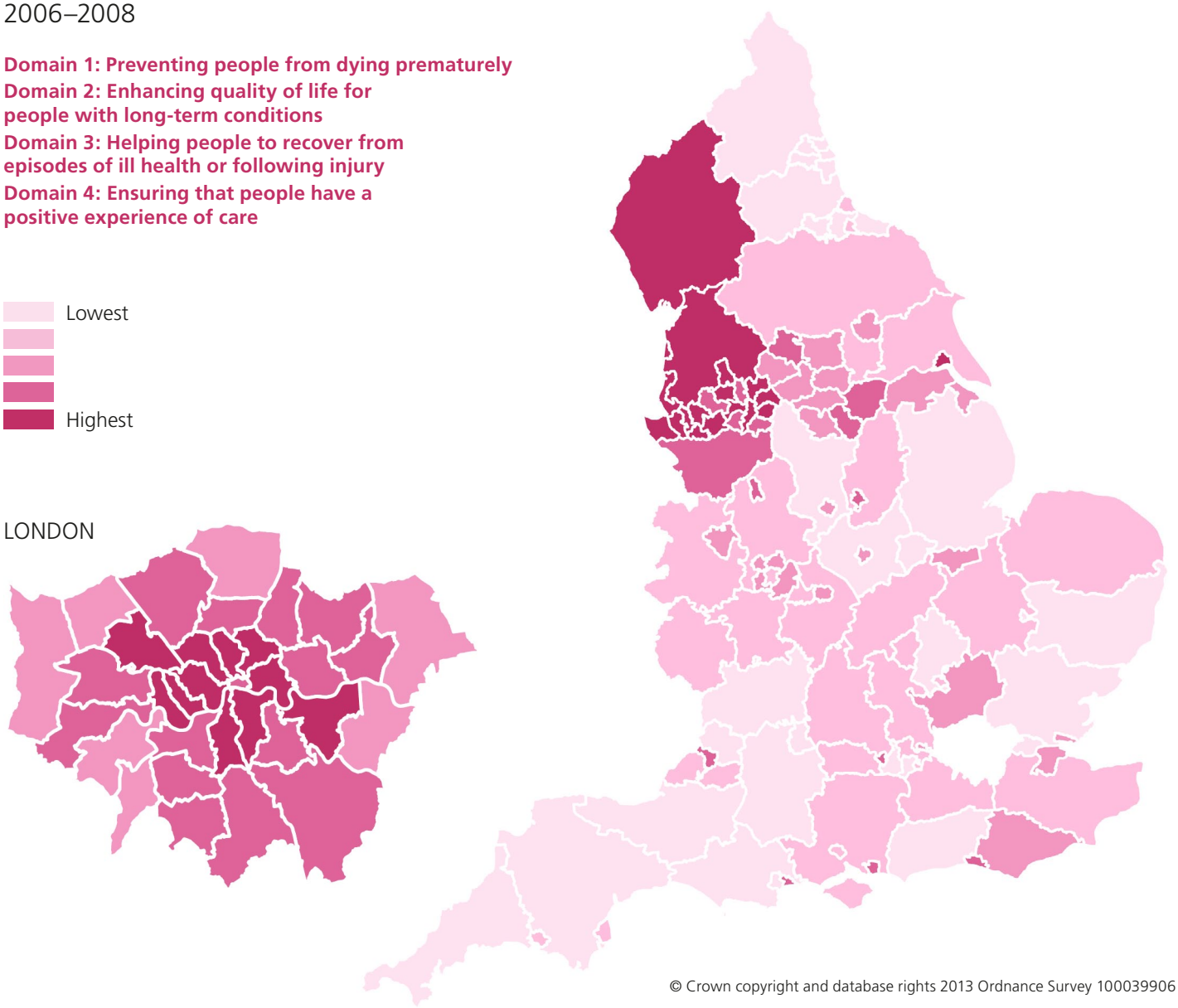
6 NICE (2012) Hepatitis B and C – ways to promote and offer testing (PH43). http://guidance.nice.org.uk/PH43

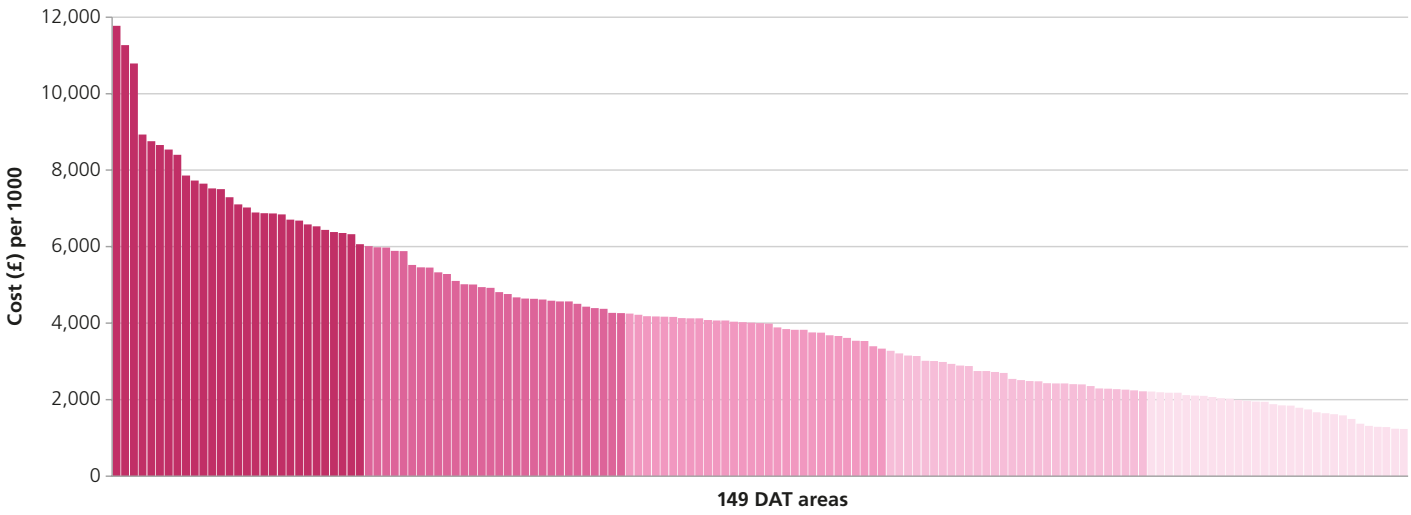
HEPATITIS C

Map 25: Estimated rate of cost to treat people with chronic hepatitis C who did not receive treatment per population by drug action team (DAT) area

2006–2008

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions
Domain 3: Helping people to recover from episodes of ill health or following injury
Domain 4: Ensuring that people have a positive experience of care





Context

At present, the most common cause of hepatitis C infection, and the commonest mode of transmission, is intravenous drug use or sharing drug equipment. Local estimates of the number of people who inject drugs are derived from estimates produced by the Home Office/National Treatment Agency at drug action team level. Data on the prevalence of ex-injectors are obtained from household surveys, corrected for under-reporting, and assigned to broad geographical areas (for further details, see Map 19). The availability of data on the progression of liver disease in individuals with hepatitis C is highly variable and progression is affected by many factors including co-morbidities, alcohol use, and age at infection. For this cost estimate, population-based progression rates are based on national data that are likely to be more representative of the whole infected population (including those who are asymptomatic).[1]

In the absence of robust data on the number of people with hepatitis C who have been treated, the number who are untreated, and the associated costs of care have been estimated for individuals embarking on and receiving the full course of treatment based on NICE recommendations for drug combinations, doses and duration of treatment. Costs of the initial assessment (including assessment, genotyping and biopsies where undertaken) were not included, although these are marginal because the staff and infrastructure are already in place to undertake assessments; costs were not adjusted for individuals who ceased treatment early due to lack of response or side-effects.

National data from pharmaceutical companies,[2] pharmacy purchasing data[3] and pharmacy prescribing data[4] were used to estimate the number of people treated in 2006–2008.[5]

Magnitude of variation

For DAT areas in England, the estimated rate of cost to treat people with chronic hepatitis C who did not receive treatment ranged from £1234 to £11,773 per 1000 population (10-fold variation). When the five DAT areas with the highest estimated rates and the five DAT areas with the lowest estimated rates are excluded, the range is £1367–£8657 per 1000 population, and the variation is 6-fold.

When interpreting the magnitude of variation, it is important to note:

- costings are based on prevalence estimates rather than counts of people with hepatitis C in each DAT area;
- treatment costs have increased since the estimates were produced;
- the proportion of people diagnosed is based on laboratory reports to the Health Protection Agency, adjusted for estimated under-reporting.

Options for action

When planning service improvement and development for people who need treatment for hepatitis C, drug action teams, commissioners, clinicians and providers could:

- review the cost estimates in relation to local data about chronic hepatitis C prevalence;
- review local information systems and service contacts (i) to increase identification, treatment and care of people with chronic hepatitis C, and (ii) to enhance patient engagement in the assessment process because non-engagement, non-attendance and non-adherence rates are very high for this group;
- quantify the extent of the discrepancy locally between the number of people who need to be treated and the resources necessary to provide treatment, and develop strategies to improve treatment coverage;
- record the outputs and assess the impact (i.e. numbers treated) and successful outcomes of investment;
- estimate in the calculation the costs saved by investment, including the impact and future cost of not treating patients whose liver disease is likely to progress.

RESOURCES

- Health Protection Agency (2012) Hepatitis C in the UK: 2012 Report. http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317135237219
- NICE (2004) Interferon alfa (pegylated and non-pegylated) and ribavirin for the treatment of chronic hepatitis C (TA75). [Review and extension of Technology Appraisal Guidance No. 14, October 2000.] http://www.nice.org.uk/nicemedia/pdf/TA075guidance.pdf
- NICE (2006) Peginterferon alfa and ribavirin for the treatment of mild chronic hepatitis C. [Extension of the guidance in Technology Appraisal Guidance 75.] http://www.nice.org.uk/nicemedia/live/11590/33534/33534.pdf
- NICE (2010) Peginterferon alfa and ribavirin for the treatment of chronic hepatitis C (TA200). [Part review of Technology Appraisal Guidance 75 and 106.] http://www.nice.org.uk/nicemedia/live/13180/50856/50856.pdf
- NICE (2012) Telaprevir for the treatment of genotype 1 chronic hepatitis C (TA252). http://guidance.nice.org.uk/TA252
- NICE (2012) Boceprevir for the treatment of genotype 1 chronic hepatitis C (TA253). http://guidance.nice.org.uk/TA253
- NICE (2012) Hepatitis B and C – ways to promote and offer testing (PH43). http://guidance.nice.org.uk/PH43
- NICE Pathway. Hepatitis B and C testing overview. http://pathways.nice.org.uk/pathways/hepatitis-b-and-c-testing

1 Health Protection Agency: Commissioning template for estimating HCV prevalence and numbers eligible for treatment by Drug Action Team area. http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HepatitisC/EpidemiologicalData/

2 Sales of interferon by Roche, and MSD, 2006–2008.

3 PharmEx data on interferon purchased, 2006–2008, from Department of Health Commercial Medicines Unit (CMU).

4 Interferon dispensing data supplied by IMS Health (source: IMS SCM data, published February 2009, showing units to hospital outlets, 2006–2008).

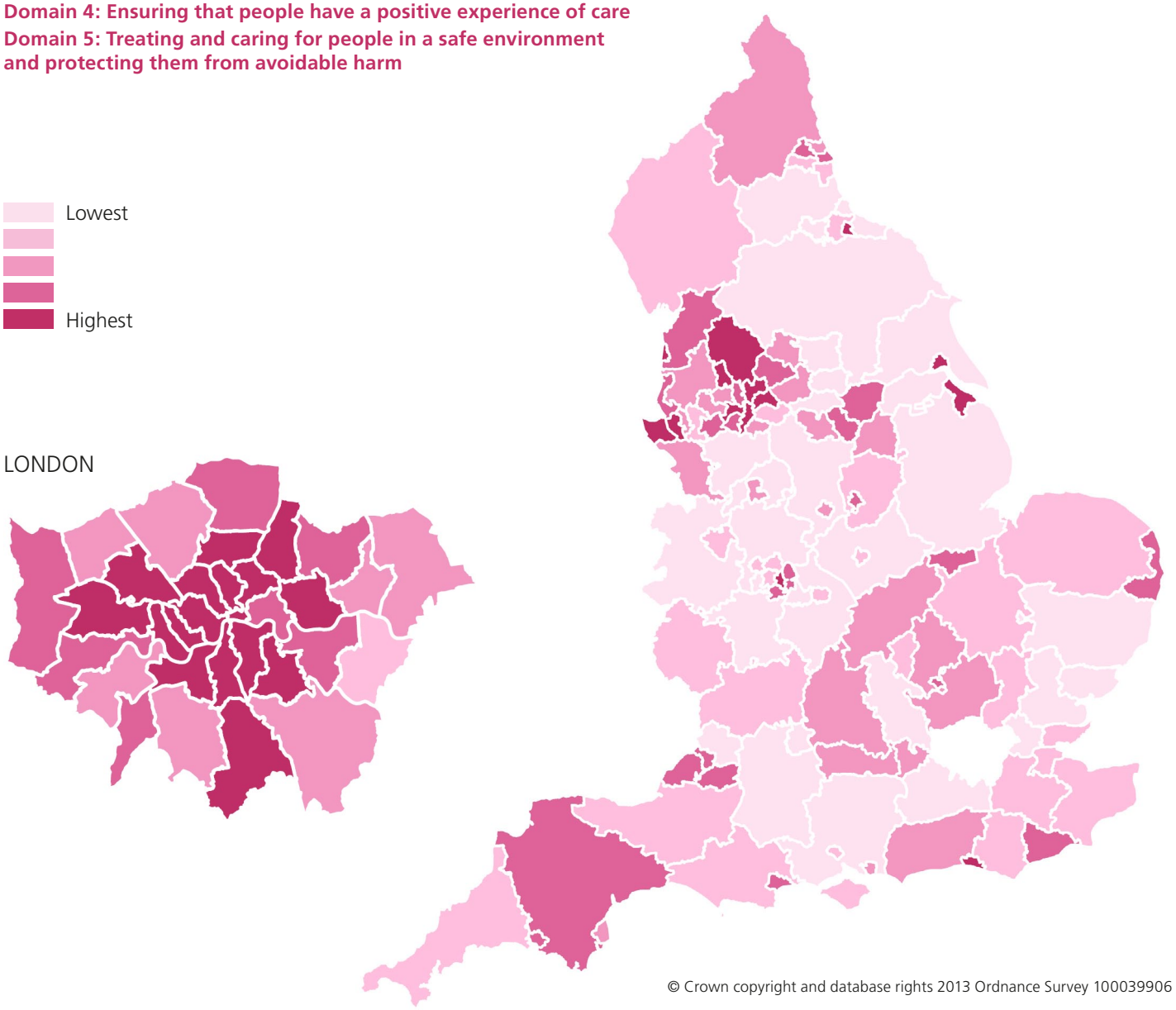
5 The following organisations provided data for the calculation of this indicator but bear no responsibility for their future analysis or interpretation: Roche; MSD; IMS Health; Commercial Medicines Unit, Department of Health.

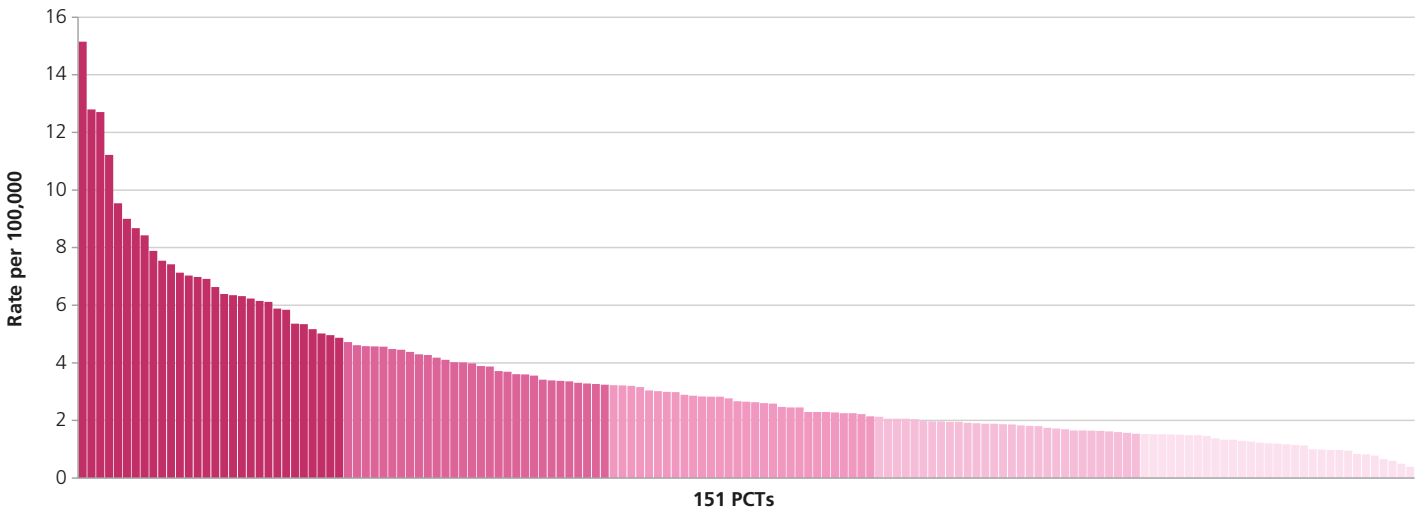
HEPATITIS C

Map 26: Rate of hospital admissions for hepatitis C-related end-stage liver disease per population by PCT

2008/09–2010/11

Domain 4: Ensuring that people have a positive experience of care
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm





Context

Although hepatitis C virus is a chronic infection, antiviral treatments are available that will successfully clear the virus in the majority of patients. However, unless there is a considerable increase in people receiving effective treatment, the future burden of hepatitis C-related disease will be substantial. All national data sources (hospital admissions for hepatitis C-related end-stage liver disease, liver transplants and deaths) show that hepatitis C-related liver disease is continuing to rise.[1] The Health Protection Agency predicts that, by 2020 in England, 15,840 individuals will be living with hepatitis C-related cirrhosis or hepatocellular carcinoma.[1] Admission to hospital for hepatitis C and end-stage liver disease (ESLD) is an outcome indicator of how successful the identification and care of people with hepatitis C and its prevention have been.

Hospital admissions with hepatitis C and ESLD have risen from 574 in 1998 to 2176 in 2011.[2]

Magnitude of variation

For PCTs in England, the rate of hospital admissions for hepatitis C-related ESLD ranged from 0.4 to 15.1 per 100,000 population (39-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 0.8 to 9.0 per 100,000 population, and the variation is 11-fold.

Reasons for the degree of variation observed include differences in:

- the prevalence of hepatitis C;
- disease progression, which in turn is affected by the presence of co-morbidities and level of alcohol use.

In addition, many patients who present with hepatitis C-related ESLD are not yet known to treatment services, although they may have accessed unplanned care in the past.

Unwarranted variation could be due to differences in:

- opportunities for testing and engagement with hepatitis C treatment services;
- access to drug treatment services and to social services.

Options for action

For individuals to receive the best possible care, it is essential that the aim of testing and treatment services is to prevent progression to ESLD. It is important for commissioners, clinicians and providers to make available specialised services for:

- local hepatitis C populations, in order to identify people at risk and offer testing with a view to treatment;
- patients with ESLD, in order to ensure they have access to expert care that will optimise their outcomes.

Commissioners need to work with all clinicians and providers:

- to set up and develop a clinical network, a model of service delivery pivotal to the assessment and treatment of patients with hepatitis C, including helping them to obtain access to accredited laboratory and other services;
- to ensure that patients receive appropriate and early intervention with effective combination therapy, which should reduce progression to ESLD (secondary prevention); treating ESLD will help to reduce mortality (supportive care and transplant).

A prerequisite to the provision of appropriate and early intervention with effective combination therapy is the development of local protocols between primary and secondary care. The use of such protocols will mean that:

- patient pathways for medical and social needs are in place;
- NHS staff receive appropriate skills development to enable them to deliver service improvements for patients with hepatitis C infection.

RESOURCES

- Health Protection Agency (2012) Hepatitis C in the UK: 2012 Report. http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317135237219
- Health Protection Agency (2011) Hepatitis C in the UK: 2011 Report. http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1309969906418
- NICE (2012) Hepatitis B and C – ways to promote and offer testing (PH43). http://guidance.nice.org.uk/PH43
- NICE Pathway. Hepatitis B and C testing overview. http://pathways.nice.org.uk/pathways/hepatitis-b-and-c-testing

1 Health Protection Agency (2012) Hepatitis C in the UK: 2012 Report. http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317135237219

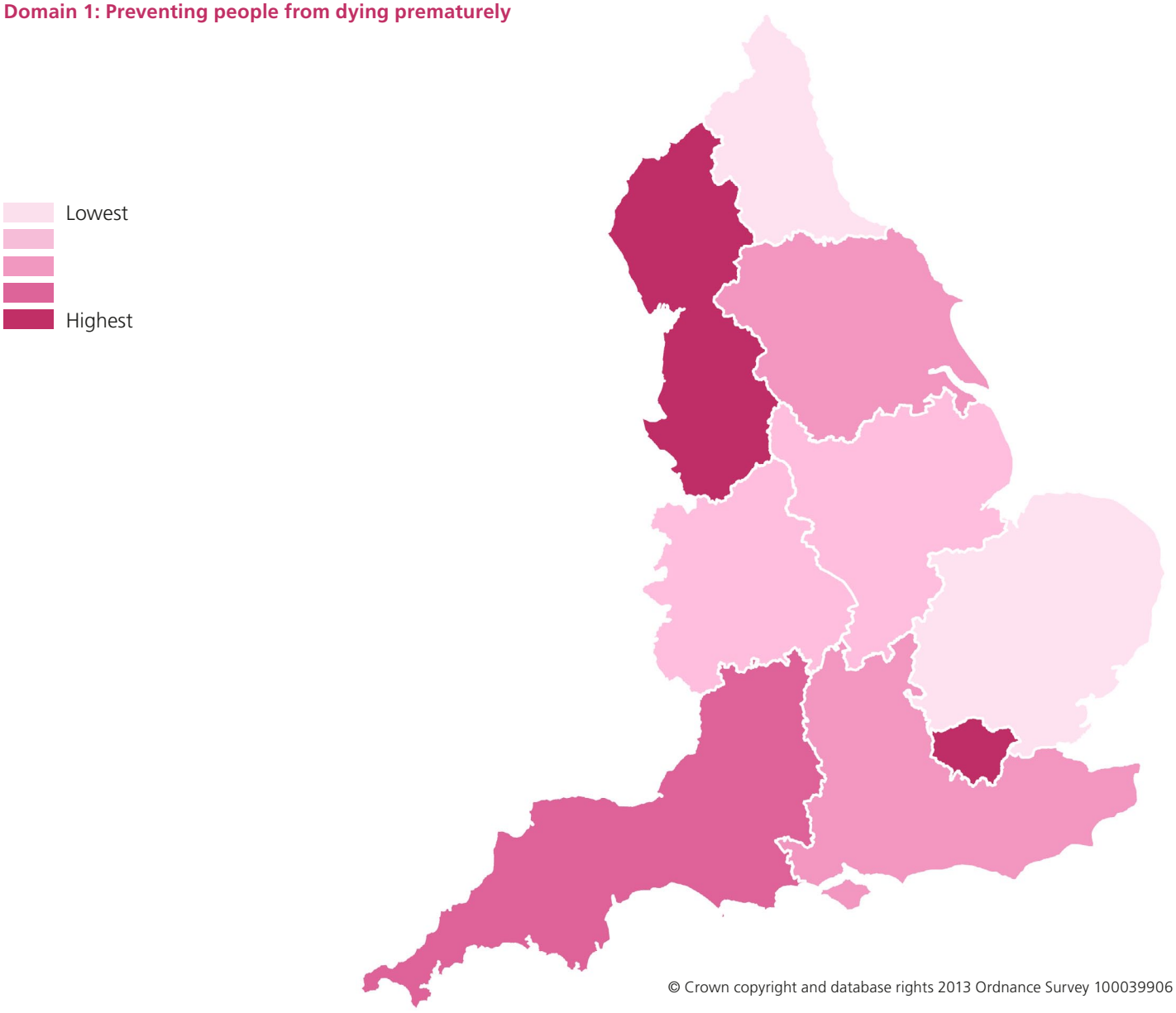
2 Provisional data up to November 2011.

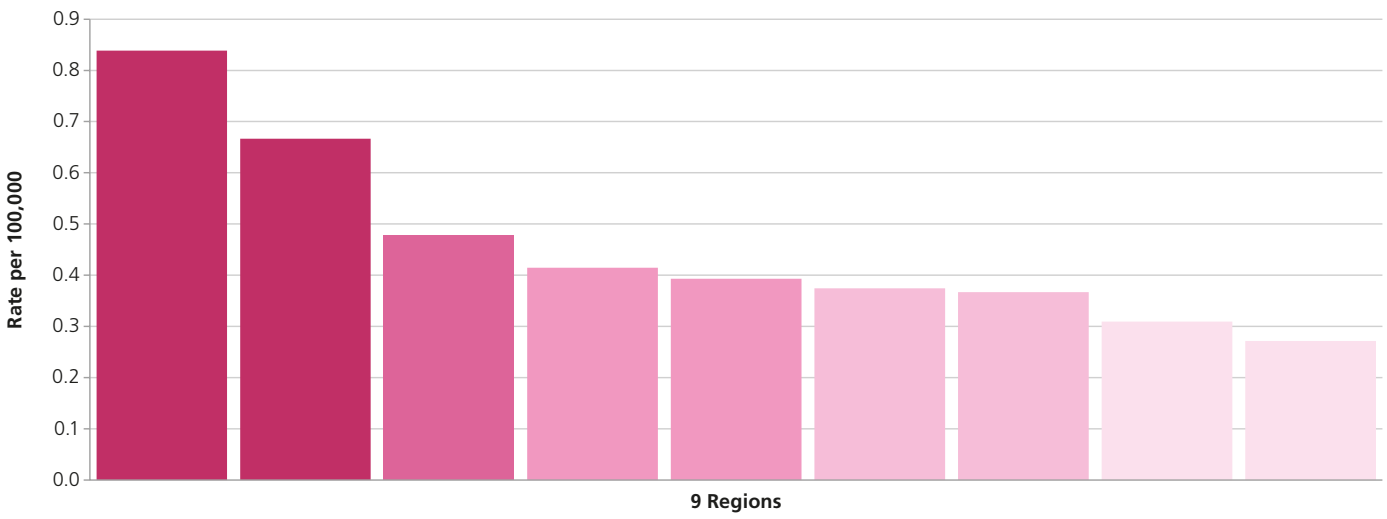
HEPATITIS C

Map 27: Rate of mortality from hepatitis C-related end-stage liver disease per population by region

2008–2010

Domain 1: Preventing people from dying prematurely





Context

Although hepatitis C virus is a chronic infection, antiviral treatments are available that will successfully clear the virus in the majority of patients. However, unless there is a considerable increase in people receiving effective treatment, the future burden of hepatitis C-related disease will be substantial. All national data sources (hospital admissions for hepatitis C-related end-stage liver disease, liver transplants and deaths) show that hepatitis C-related liver disease is continuing to rise.[1] It is predicted that, in 2020 in England, 15,840 individuals will be living with hepatitis C-related cirrhosis or hepatocellular carcinoma.[1]

Mortality from hepatitis C and end-stage liver disease (ESLD) is an outcome indicator of how successful the identification and care of people with hepatitis C and its prevention have been.

Data from the Office for National Statistics show the number of deaths from ESLD, in people with hepatitis C mentioned on their death certificate, has increased from 89 in 1996 to 296 in 2011.[2] As in previous years, the increase is occurring predominantly in men, with deaths in women remaining relatively stable.[1]

Magnitude of variation

For regions in England, the rate of mortality from hepatitis C-related ESLD ranged from 0.3 to 0.8 per 100,000 population, a 3.1-fold variation.[3]

Reasons for warranted variation are differences in:

- risk factors for hepatitis C;
- the prevalence of hepatitis C.

Other reasons for the degree of variation observed could include differences in:

- the level of investment in preventative services;
- the degree of compliance with prevention or treatment;
- the configuration of services;
- the timing of diagnosis.

Options for action

When planning service improvement or development to reduce mortality from hepatitis C-related ESLD, commissioners, clinicians and providers need to review:

- recent trends in mortality in the locality;
- whether there is sufficient focus upstream of these events to prevent infection, detect infection and prevent the development of advanced liver disease;
- treatment outcomes against the number of people testing positive for hepatitis C in the locality (intention-to-treat outcomes of people testing positive) in order to identify the barriers to a successful treatment outcome and the ways in which those barriers can be addressed;
- whether specialist services are working collaboratively with other agencies to obtain the best possible outcomes for this group of patients.

RESOURCES

- Health Protection Agency (2012) Hepatitis C in the UK: 2012 Report. http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317135237219
- Health Protection Agency (2011) Hepatitis C in the UK: 2011 Report. http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1309969906418
- NICE (2012) Hepatitis B and C – ways to promote and offer testing (PH43). http://guidance.nice.org.uk/PH43
- NICE Pathway. Hepatitis B and C testing overview. http://pathways.nice.org.uk/pathways/hepatitis-b-and-c-testing

1 Health Protection Agency (2012) Hepatitis C in the UK: 2012 Report. http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317135237219

2 Data for 2011 are provisional.

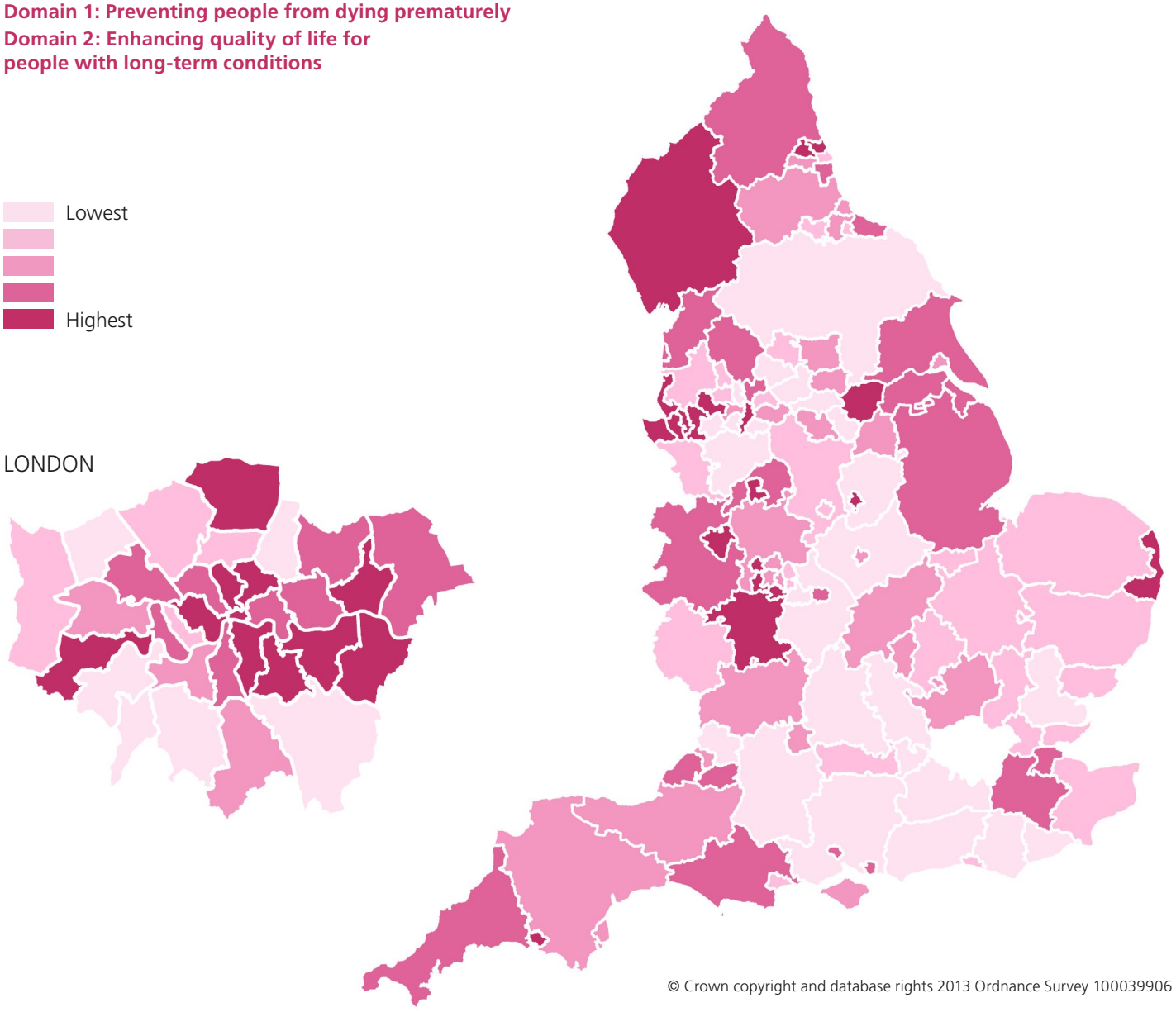
3 The Office for National Statistics (ONS) carried out the original collection and collation of the mortality data but bear no responsibility for their future analysis or interpretation.

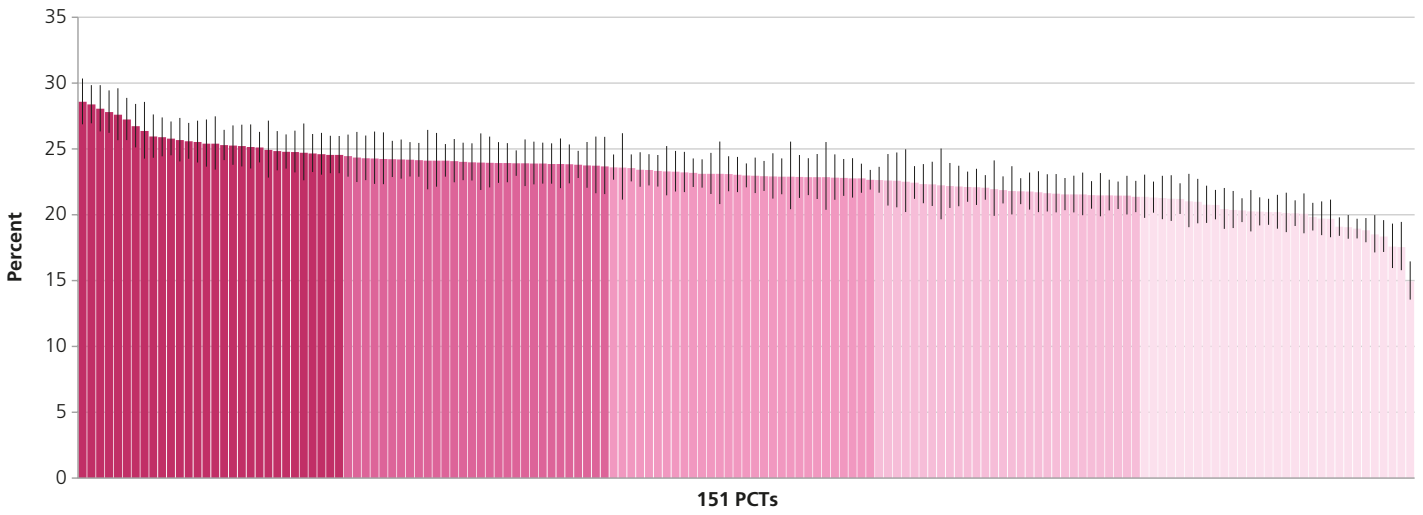
OBESITY

Map 28: Percentage of children in school reception year classified as overweight or obese by PCT

2010/11

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions





Context

In England, there are potentially 1.4 million adults with fatty liver disease which may in some cases lead to cirrhosis (non-alcoholic steatohepatitis) over the long term. Based on child measures of obesity, we also estimate that there are possibly 60,000 10-year-olds with fatty liver. Extrapolating this for children aged 5–15 years, up to 500,000 children may already be at risk of developing an underlying liver disease that could lead to cirrhosis in the future.[1]

The National Child Measurement Programme (NCMP; see "Resources") is undertaken annually in state-maintained schools in England. Over 1 million children in reception year (aged 4–5 years) and year 6 (aged 10–11 years) have their height and weight measured. The programme began in 2006, and is the most robust source of childhood obesity data in England (see Table 28.1).

Table 28.1: Proportion of children according to weight categories[2] (2010/11)

Weight category	Reception year	Year 6
Overweight and obese	22.6%	33.4%
Obese	9.4%	19.0%
- Boys	10.1%	20.6%
- Girls	8.8%	17.4%
Healthy weight – all children	76.4%	65.3%
- Boys	75.0%	64.0%
- Girls	77.9%	66.6%
Underweight – all children	1.0%	1.3%
- Boys	1.2%	1.1%
- Girls	0.8%	1.5%

In 2010/11:

- In reception, more than one in five children were overweight or obese; in year 6, one in three children were;
- The proportion of obese children in year 6 was more than double that in reception;
- The prevalence of children with a healthy weight was higher in reception year than in year 6; in both years, a higher percentage of girls were at a healthy weight than boys;
- The prevalence of underweight children is higher in year 6 than in reception. In reception, a higher percentage of boys were underweight than girls, whereas in year 6 a higher percentage of girls were underweight than boys.

Magnitude of variation

For PCTs in England, the percentage of children in school reception year classified as overweight or obese ranged from 14.9% to 28.6% (1.9-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 18.8–27.2%, and the variation is 1.4-fold.

The degree of variation observed is related to differences in the level of deprivation, which is associated with children's diet and physical activity. For both age-groups measured in the NCMP, there is a trend of widening inequalities. There is also variation by ethnic group, independent of level of deprivation.

Other potential reasons for the degree of variation observed include differences in:

- Access to preventive services;
- The local food and physical activity environments;
- Parental knowledge/education.

Options for action

When planning service improvement or development to reduce obesity in children, especially in view of the rising trend in most parts of England, commissioners, clinicians, providers and public health departments should consider working with their local health and wellbeing boards:

- to review local prevalence and trends for obesity;
- to refine and develop local strategies for reducing obesity in children, supported by guidance from NICE and other organisations.

RESOURCES

- National Obesity Observatory e-atlases. http://www.noo.org.uk/visualisation/eatlas
- National Obesity Observatory (2011) National Child Measurement Programme. Changes in children's body mass index between 2006/07 and 2010/11. http://www.noo.org.uk/uploads/doc/vid_13261_NCMP_Changes_in_childrens_BMI.pdf
- Health and Social Care Information Centre. National Child Measurement Programme: England, 2010/11 school year. http://www.ic.nhs.uk/catalogue/PUB09283

1 Cheung CRLH, Kelly DA (2011) Non-alcoholic fatty liver disease in children. *British Medical Journal* 343; d4460

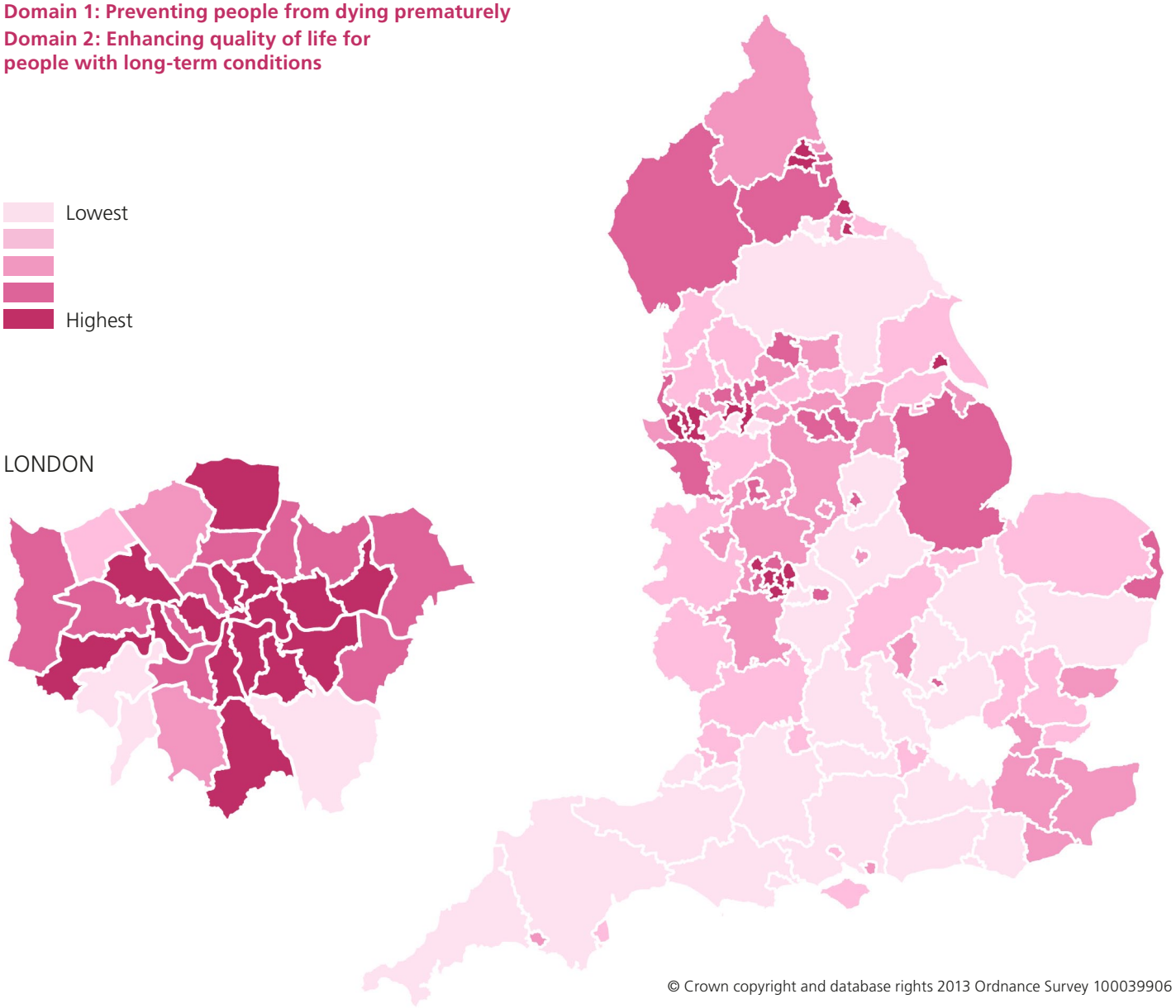
2 Children's body mass index (BMI) is categorised using the following thresholds in the British 1990 (UK90) growth reference: <2nd centile = underweight; 2nd to <85th centile = healthy weight; 85th to <95th centile = overweight; >95th centile = obese.

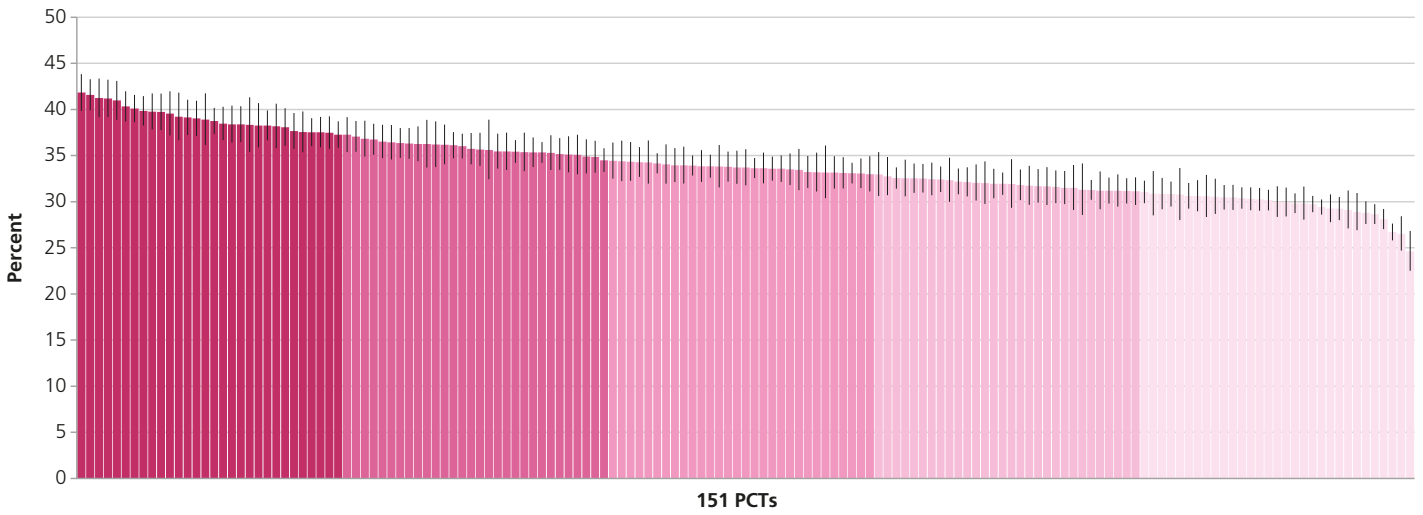
OBESITY

Map 29: Percentage of children in school year 6 classified as overweight or obese by PCT

2010/11

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions





Context

In England, there are potentially 1.4 million adults with fatty liver disease which may in some cases to lead to cirrhosis (non-alcoholic steatohepatitis) over the long term. Based on child measures of obesity, we also estimate that there could be 60,000 10-year-olds with fatty liver. Extrapolating this for children aged 5–15 years, up to 500,000 children may already be at risk of developing an underlying liver disease that could lead to cirrhosis in the future.[1]

The National Child Measurement Programme (NCMP; see "Resources") is undertaken annually in state-maintained schools in England. Over 1 million children in reception year (aged 4–5 years) and year 6 (aged 10–11 years) have their height and weight measured. The programme began in 2006, and is the most robust source of childhood obesity data in England (see Table 29.1)

Table 29.1: Proportion of children according to weight categories[1] 2010/11

Weight category	Reception year	Year 6
Overweight and obese	22.6%	33.4%
Obese	9.4%	19.0%
- Boys	10.1%	20.6%
- Girls	8.8%	17.4%
- In least-deprived decile		13.8%
- In most-deprived decile		23.7%
Healthy weight – all children	76.4%	65.3%
- Boys	75.0%	64.0%
- Girls	77.9%	66.6%
Underweight – all children	1.0%	1.3%
- Boys	1.2%	1.1%
- Girls	0.8%	1.5%

In 2010/11:

- In reception, more than one in five children were overweight or obese; in year 6, one in three children were;
- The proportion of obese children in year 6 was more than double that in reception;
- The prevalence of children with a healthy weight was higher in reception year than in year 6; in both years, a higher percentage of girls were at a healthy weight than boys.
- The prevalence of underweight children was higher in year 6 than in reception. In reception, a higher percentage of boys were underweight than girls, whereas in year 6 a higher percentage of girls were underweight than boys.

Magnitude of variation

For PCTs in England, the percentage of children in school year 6 classified as overweight or obese ranged from 24.6% to 41.8% (1.7-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 28.8–40.3%, and the variation is 1.4-fold.

The degree of variation observed is related to differences in the level of deprivation (see Figure 29.1), which is associated with children's diet and physical activity. For both age-groups measured in the NCMP, there is a trend of widening inequalities, particularly for children in year 6. The prevalence of obesity in the most-deprived 10% of areas is twice that in the least-deprived 10% of areas. There is also variation by ethnic group, independent of level of deprivation.

Other potential reasons for the degree of variation observed include differences in:

- Access to preventive services;
- The local food and physical activity environments;
- Parental knowledge/education.

Options for action

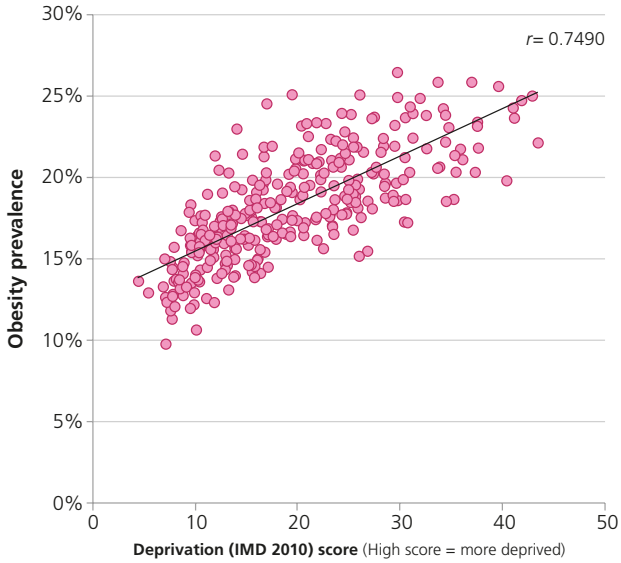
When planning service improvement or development to reduce obesity in children, especially in the context of a rising trend in most parts of England, commissioners, clinicians, providers and public health departments should consider working with their local health and wellbeing boards:

- to review local prevalence and trends for obesity;
- to refine and develop local strategies for reducing obesity in children, supported by guidance from NICE and other organisations.

RESOURCES

- National Obesity Observatory e-atlases. http://www.noo.org.uk/visualisation/eatlas
- National Obesity Observatory (2011) National Child Measurement Programme. Changes in children's body mass index between 2006/07 and 2010/11. http://www.noo.org.uk/uploads/doc/vid_13261_NCMP_Changes_in_childrens_BMI.pdf
- Health and Social Care Information Centre. National Child Measurement Programme: England, 2010/11 school year. http://www.ic.nhs.uk/catalogue/PUB09283

Figure 29.1: Obesity prevalence and deprivation (IMD 2010) in children in year 6 (aged 10–11 years) by PCT 2010/11



1 Cheung CRLH, Kelly DA (2011) Non-alcoholic fatty liver disease in children. *British Medical Journal* 343; d4460

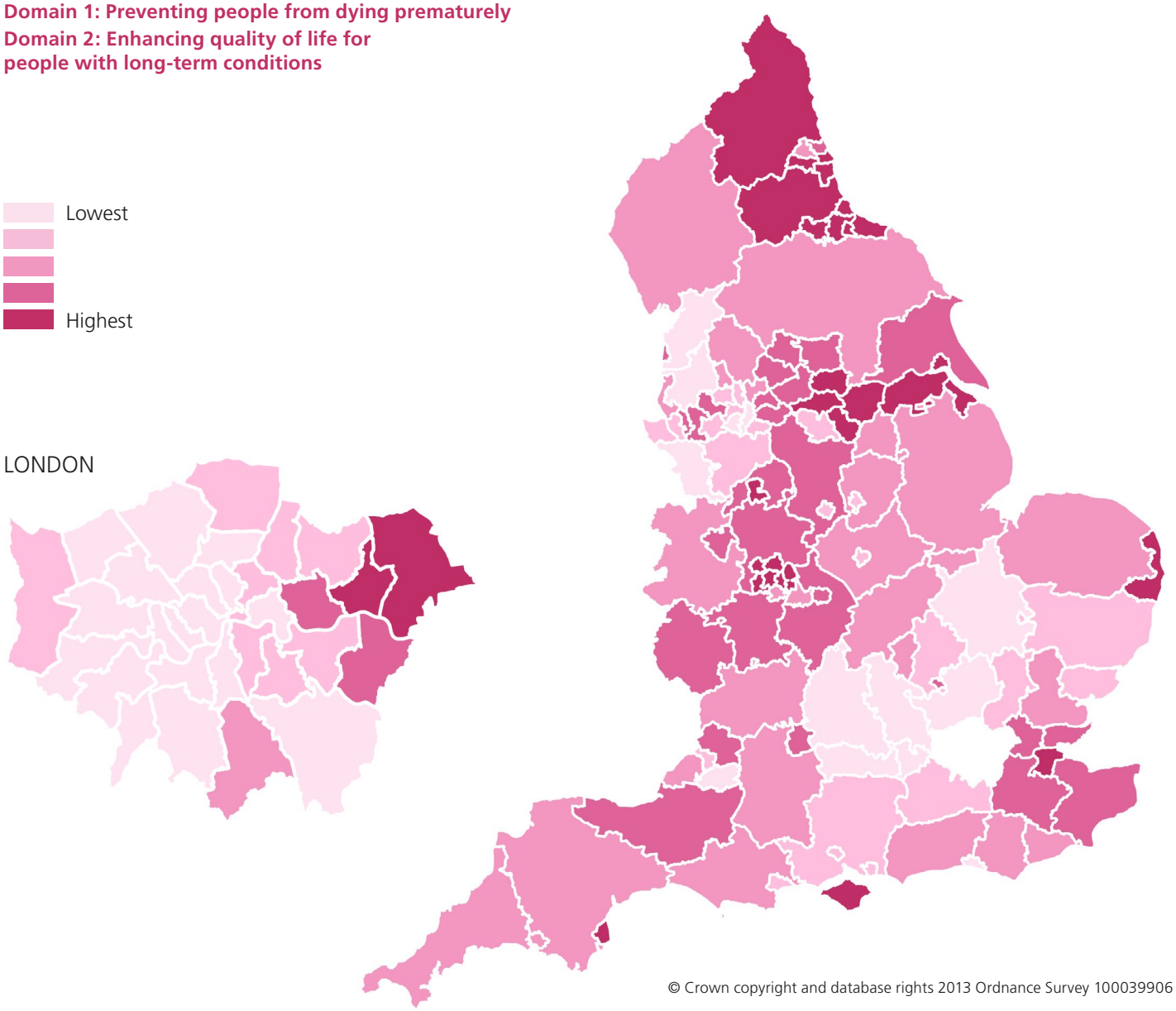
2 Children's body mass index (BMI) is categorised using the following thresholds in the British 1990 (UK90) growth reference: <2nd centile = underweight; 2nd to <85th centile = healthy weight; 85th to <95th centile = overweight; > 95th centile = obese.

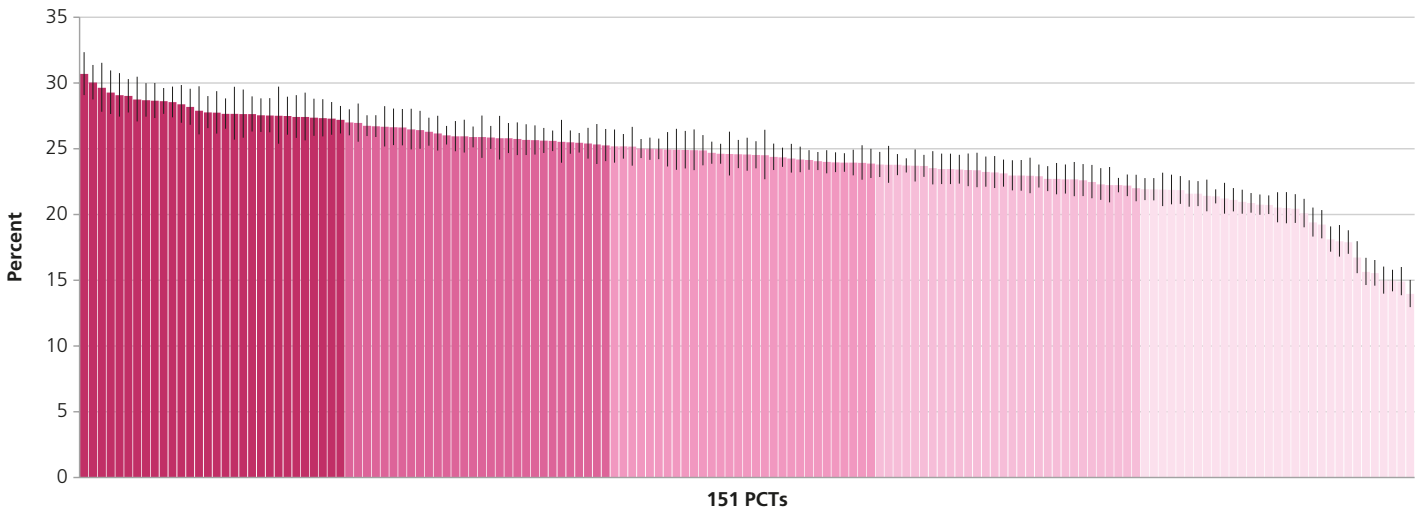
OBESITY

Map 30: Percentage of estimated adult obesity (body mass index ≥30 kg/m^2) by PCT

2006–2008

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions





Context

In recent years, it has been recognised that obesity contributes to the increasing burden of liver disease. Obesity is closely related to the development of fatty liver disease, and 26% of the adult population, around 14.3 million people in England, is thought to be obese.[1]

- On average, 50% of obese people (7.15 million) will have non-alcoholic fatty liver disease (NAFLD) – this probably includes the 2 million people with Type 2 diabetes, 90% of whom will have NAFLD;
- Of those 7.15 million people, 15%–20% will have the type of NAFLD known as non-alcoholic steatohepatitis (NASH), which may lead to cirrhosis in some cases.

The prevalence of obesity among adults has increased sharply during the 1990s and early 2000s (see Table 30.1).

Table 30.1: Proportion of adults categorised as obese (BMI ≥30 kg/m²) over time[2]

Population subgroup	Proportion categorised as obese		Proportion predicted to be obese in 2050
	1993	2010	
Men	13%	26%	60%
Women	16%	26%	50%
Children			25%

Obesity develops from an accumulation of excess body fat when energy intake from food and beverage consumption exceeds the energy expended through metabolism and physical activity. The causes of obesity are complex, and relate to a variety of societal and behavioural factors.[3]

Obesity is associated with various health risks including:

- Type 2 diabetes:
- cardiovascular disease;
- cancer;
- increased risk of skeletal and joint problems;
- increased risk of non-alcoholic fatty liver disease, gastro-oesophageal reflux and gall stones.[4]

The costs to the NHS attributable to overweight and obesity are projected to reach £9.7 billion by 2050, with the wider costs to society estimated to rise to £49.9 billion per year.[3] The prevention of obesity is a major public health challenge.

Magnitude of variation

For PCTs in England, the percentage of estimated adult obesity ranged from 14.0% to 30.7% (2.2-fold variation). When the five PCTs with the highest estimated percentages and the five PCTs with the lowest estimated percentages are excluded, the range is 15.6–29.0%, and the variation is 1.9-fold.

Prevalence of obesity in adults varies by age, sex, and ethnic group.[5] When compared with men, a higher proportion of women have a BMI >40 kg/m². Obesity prevalence increases with age up to approximately 70 years in both sexes. Health Survey for England data show women from Black African and Black Caribbean ethnic groups have a higher prevalence of obesity when compared with that in the general population, and men and women from Asian ethnic groups have a lower prevalence.

Obesity prevalence also varies by socio-economic status: higher levels of obesity are found in areas of greater deprivation.[6] The association is stronger for women than men, particularly when examining obesity prevalence by occupation-based social class.

Other potential reasons for the degree of variation observed are differences in access to:

- the local food and physical activity environments;
- preventive services.

When interpreting the magnitude of variation, it is important to note the data are modelled estimates rather than actual prevalence. These estimates, however, give the best indication of relative rates of obesity prevalence currently available.

Options for action

When planning service improvement or development to reduce obesity in adults, especially in view of the rising trend in most parts of England, commissioners, clinicians, providers and public health departments should consider working with their local health and wellbeing boards:

- to review local prevalence and trends for obesity;
- to refine and develop local strategies for reducing obesity in adults, supported by guidance from NICE and other organisations.

RESOURCES

- National Obesity Observatory. Wide-ranging authoritative information on data, evaluation and evidence related to weight status and its determinants. http://www.noo.org.uk/
- National Obesity Observatory. Adult obesity. http://www.noo.org.uk/NOO_about_obesity/adult_obesity
- NHS Information Centre (2009) Health Survey for England - 2008: Physical Activity and Fitness. http://www.ic.nhs.uk/pubs/hse08physicalactivity
- National Heart Forum (2010) New obesity data paints a bleak future for adults. http://www.heartforum.org.uk/resources/nhf-publications/?entryid30=3985&entryid43=21108&p=4

1 Health and Social Care Information Centre (2011) Health Survey for England – 2010: Trend tables. http://www.ic.nhs.uk/pubs/hse10trends

2 http://www.noo.org.uk/pages.php5?pg=375#d6828

3 Foresight (2007) Foresight - Tackling Obesities: Future Choices Project. http://www.bis.gov.uk/foresight/our-work/projects/published-projects/tackling-obesities/reports-and-publications

4 National Obesity Observatory. Health risks of adult obesity. http://www.noo.org.uk/NOO_about_obesity/obesity_and_health/health_risk_adult

5 National Obesity Observatory. Adult Weight. NOO data factsheet. http://www.noo.org.uk/uploads/doc/vid_16201_AdultWeightFactsheetJuly2012_v2.pdf

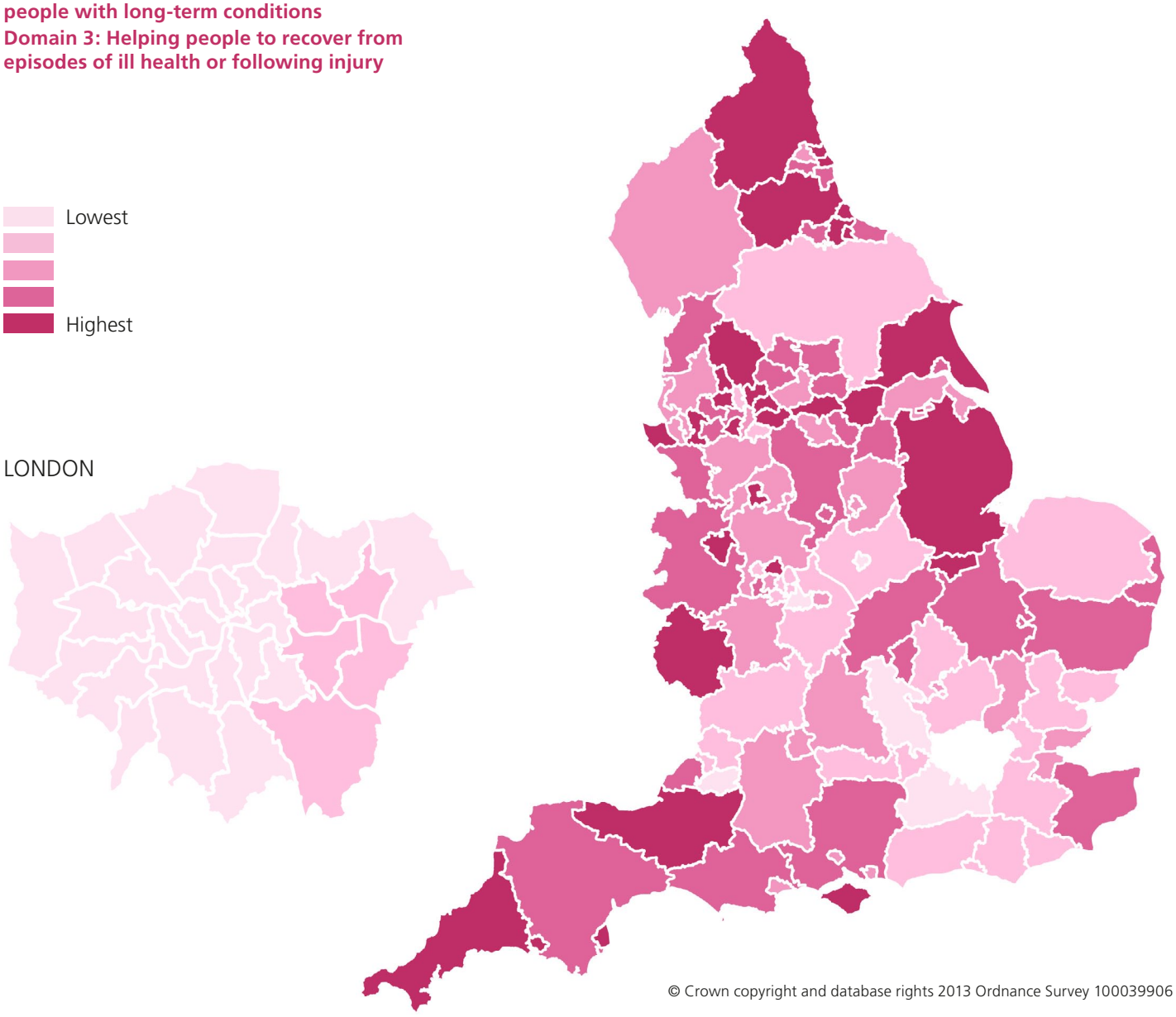
6 National Obesity Observatory. Adult Obesity and Socioeconomic Status. NOO data factsheet. http://www.noo.org.uk/uploads/doc/vid_16966_AdultSocioeconSep2012.pdf

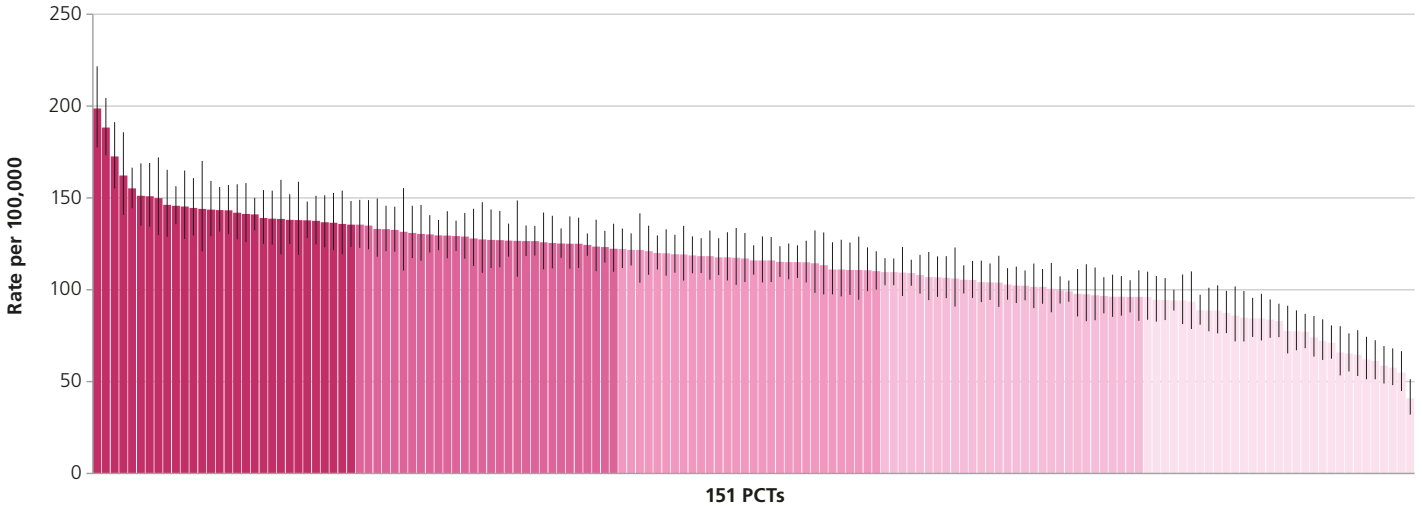
CHOLECYSTECTOMY

Map 31: Rate of cholecystectomies per population by PCT

Directly standardised rate 2010/11

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions
Domain 3: Helping people to recover from episodes of ill health or following injury





Context

Cholecystectomy is an operation performed to relieve the symptoms of cholelithiasis which may commonly present with the pain of biliary colic or the inflammation and infection of acute cholecystitis. If gallstones exit the gallbladder into the bile ducts, obstructive jaundice or pancreatitis may result. The cholecystectomy procedure has changed dramatically with the advent of laparoscopic surgery in the early 1990s, offering minimally invasive surgery rather than the traditional open technique. As a result, cholecystectomy can now be offered to patients with serious co-morbidities who formerly would have been considered unfit for open surgery.

Steiner et al[1] showed that laparoscopic cholecystectomy led to:

- an increase in the total number of people having operations;
- a reduction in the operative mortality rate.

Further advantages are a reduction in average length of stay and increased rates of day-case surgery. In England in 1999/2000, the average length of stay for removal of a gallbladder was 4.8 days and by 2010/11 it had been reduced to 2.8 days.

However, the number of people dying as a result of the procedure did not change because the overall number of people receiving an operation had increased. This exemplifies the way in which a change in technology leads to a change in clinical criteria for operation, which then alters the nature of the operation and management of the condition.

The data for this indicator comprise the combined total of open and laparoscopic cholecystectomies. The indications for both types of operation are the same, with the exception of the patient's fitness for operation in laparoscopic cholecystectomy.

Magnitude of variation

For PCTs in England, the rate of cholecystectomies ranged from 40.8 to 198.7 per 100,000 population (4.9-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 62.1–151.1 per 100,000 population, and the variation is 2.4-fold (see Table 31.1 for 2009/10 data).

The reasons for variation are not clear. It is unlikely that the degree of variation observed is due to differences in capacity or a lack of laparoscopic training. Trainee surgeons are trained in minimally invasive techniques, and laparoscopic surgery is now regarded as mainstream surgery.

Possible reasons for the degree of variation observed are differences in:

- criteria for referral from primary care;
- thresholds and criteria for admission.

There is little consensus on the appropriate rate of cholecystectomy. Data collected by the British Association of Day Surgery (BADS) suggest that at least 60% could be performed on a day-case basis (see Map 32, pages 108–109).

Options for action

When planning service improvement or development for patients undergoing cholecystectomy, commissioners, clinicians and providers need to review the ratio of laparoscopic to open cholecystectomy performed, and assess the potential to increase the rate of laparoscopic cholecystectomy (see Map 32). It is a safe and effective procedure[2,3] with good outcomes, that can be performed as a day case, thereby minimising patients' exposure to the risks of hospitalisation.

- Although laparoscopic surgery has a smaller morbidity and mortality risk when compared with the open procedure, the risk is not zero, and patients with serious co-morbidities will require appropriate counselling.
- Accurate and reproducible measurement of gallbladder symptoms would allow an assessment of the threshold for intervention to see if the procedure is now being offered to people with less severe disease.
- Specialists and GPs should consider developing guidelines for the management of upper abdominal pain, which may be a symptom of gallbladder disease.

Table 31.1: Rate of cholecystectomies per 100,000 population by PCT over two time-periods

Date of data	Range before exclusions	Fold difference before exclusions	Range after exclusions	Fold difference after exclusions	Notes
2009/10	51.1–170.8	3.3	60.2–150.7	2.5	Map 44, Atlas 2.0 (2011)
2010/11	40.8–198.7	4.9	62.1–151.1	2.4	

1 Steiner CA, Bass EB, Talamini MA et al (1994) Surgical rates and operative mortality for open and laparoscopic cholecystectomy in Maryland. *New England Journal of Medicine* 330: 403-408.

2 Dolan JP, Diggs BS, Sheppard BC, Hunter JG (2009) The national mortality burden and significant factors associated with open and laparoscopic cholecystectomy: 1997-2006. *J Gastrointest Surg* 13: 2292-2301.

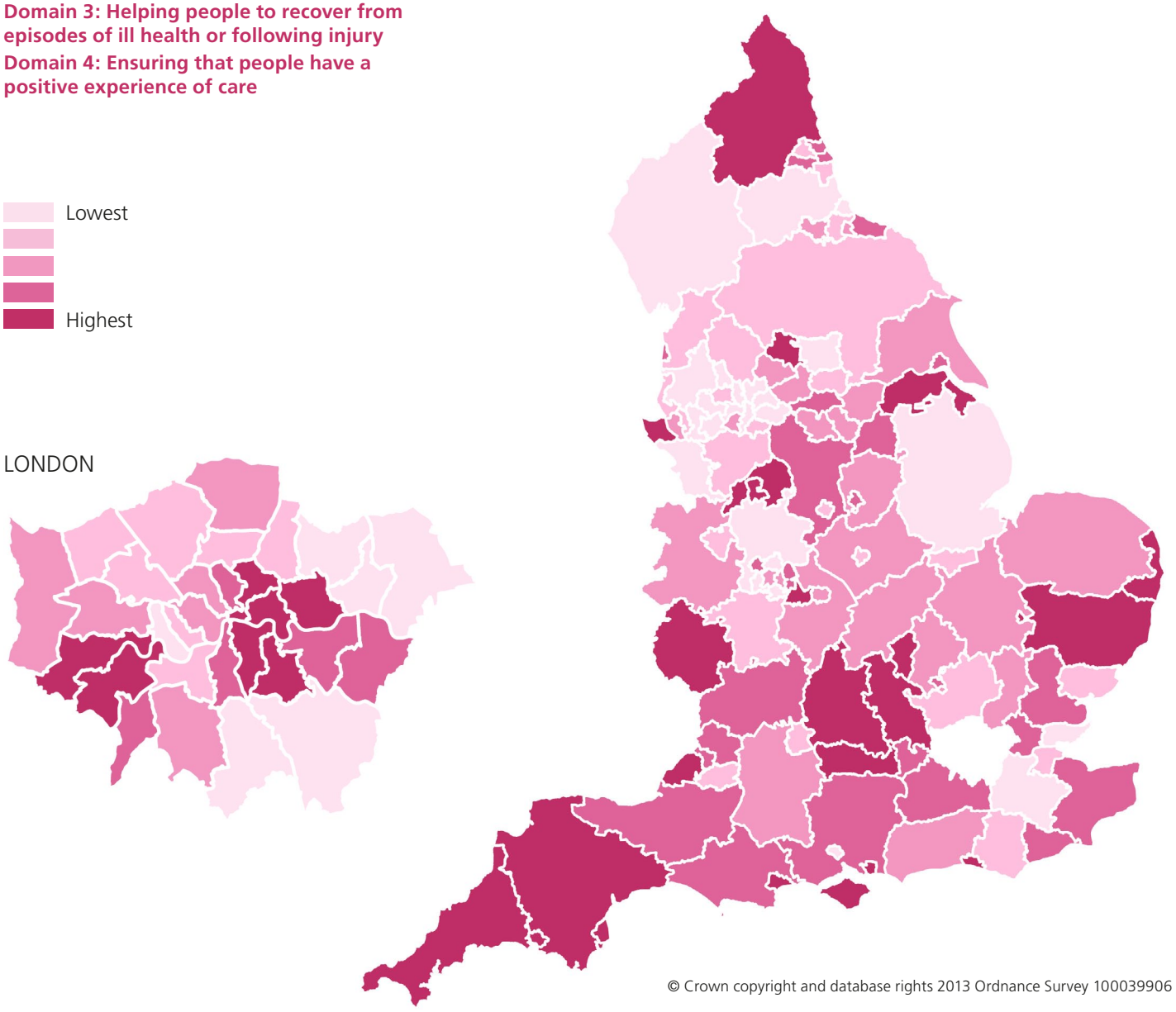
3 Hannan EL, Imperato PJ, Nenner RP, Starr H (1999) Laparoscopic and open cholecystectomy in New York State: mortality, complications, and choice of procedure. *Surgery* 125: 223-231.

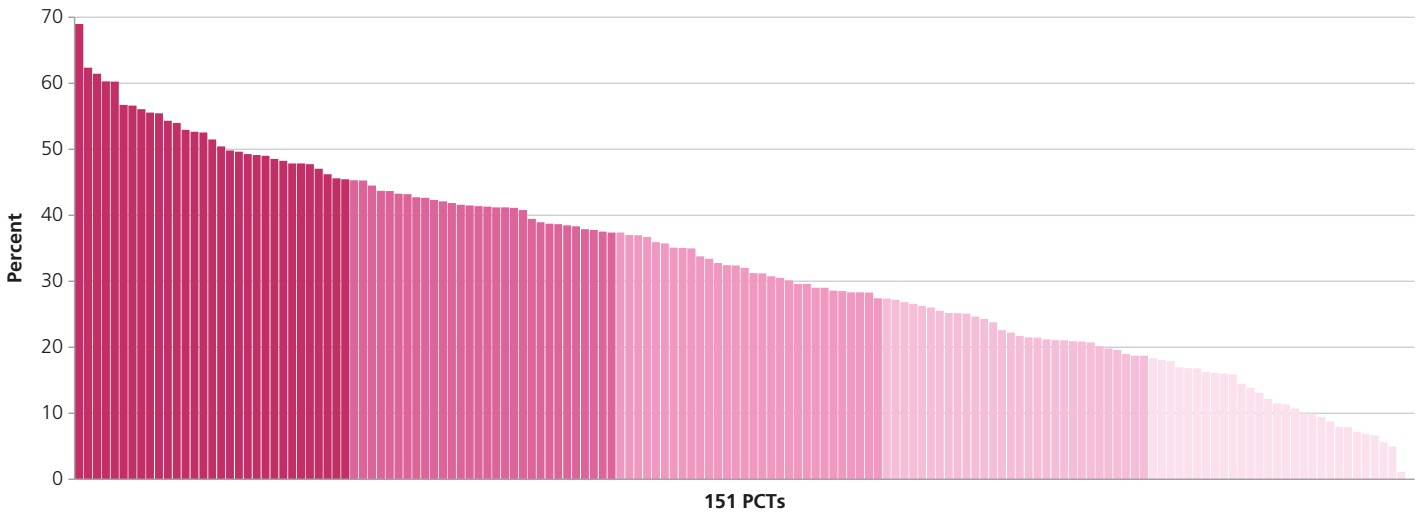
CHOLECYSTECTOMY

Map 32: Percentage of elective adult day-case laparoscopic cholecystectomy per all elective cholecystectomies by PCT

2010/11

Domain 3: Helping people to recover from episodes of ill health or following injury
Domain 4: Ensuring that people have a positive experience of care





Context

Day surgery is the management of a surgical procedure in which patient admission, operation and home discharge are completed on the same calendar day according to a planned pathway. Advances in surgical and anaesthetic techniques have resulted in a wider spectrum of procedures now feasible as day surgery.

The planned pathway commences in the GP's surgery based on good knowledge of the procedures that can be undertaken as ambulatory care. Patients are referred to a provider with the intention of day-surgery management. There is an expectation that the provider will deliver a quality-assured care process including booking, the period of admission, and follow-up support immediately after home discharge.

Day-surgery rates for many procedures in the British Association of Day Surgery (BADS) Directory of Procedures[1] are published on the 'NHS Better Care, Better Value Indicators' website.[2] If all providers in England were to match the performance of those in the upper quartile of day-case surgery rates for this set of procedures, the estimated annual saving could release more than £64 million.

Originally included in the Audit Commission's "Basket of 25 Procedures",[3] elective laparoscopic cholecystectomy has been promoted as suitable for day-case management for over 10 years. In the BADS Directory of Procedures, it is estimated that, with an optimised care pathway, up to 60% of patients could be managed on a day-stay basis.[1]

Magnitude of variation

For PCTs in England, the percentage of elective adult day-case laparoscopic cholecystectomy per all elective cholecystectomies ranged from 0% to 69.0%.[4] When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 6.9–56.7%, and the variation is 8-fold.

Reasons for the degree of variation observed include differences in:

- patient co-morbidities;
- the availability of home carer support.

However, much of the variation is unwarranted due to:

- suboptimal planning of the day-surgery pathway;
- conservative inclusion criteria;
- conservative clinical practices and/or culture.

The degree of variation observed in total rates of cholecystectomy after exclusion is 2.4-fold (see Map 31) whereas it is 8-fold for the percentage of elective adult day-case laparoscopic cholecystectomy per all elective cholecystectomies. If total rates of cholecystectomy are considered as a proxy for the burden of disease, it would appear that there is less variation in the burden of disease when compared with the variation in the type of care given. Further investigation is needed into the possible causes of lower rates of day-case surgery.

Options for action

Providers need to evaluate their care pathways for day surgery, and ascertain what level of transformational work might be needed.

Providers of day-surgery services could consider a "Default to Day Surgery" ethos as promoted by the NHS Institute for Innovation and Improvement ("Day Surgery – Treat Day Surgery as the Norm"; see "Resources").

Commissioners need to review their specifications for day-surgery services against the BADS guidelines for day-surgery service commissioning (see "Resources"), and could consider reinforcing a "Default to Day Surgery" ethos using CQUIN payment frameworks (see "Resources").

Commissioners, clinicians and providers need to collaborate to optimise the care pathway for patients undergoing laparoscopic cholecystectomy mindful of guidance in the NHS Institute for Innovation and Improvement documents (see "Resources").

RESOURCES

- British Association of Day Surgery (2012) Commissioning Day Surgery. A Guide for Clinical Commissioning Groups May 2012. http://www.daysurgeryuk.net/media/128969/commissioning2012.pdf
- NHS Institute for Innovation and Improvement. Focus On: Cholecystectomy. http://www.institute.nhs.uk/option,com_joomcart/Itemid,194/main_page,document_product_info/cPath,71/products_id,186.html
- NHS Institute for Innovation and Improvement. Quality and Service Improvement Tools. Day Surgery – Treat Day Surgery as the Norm. http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/day_surgery_-_treat_day_surgery_as_the_norm.html
- NHS Institute for Innovation and Improvement. Commissioning for Quality and Innovation (CQUIN) payment framework. http://www.institute.nhs.uk/world_class_commissioning/pct_portal/cquin.html

1 British Association of Day Surgery (2012) *Directory of Procedures*, 4th edition.

2 http://www.productivity.nhs.uk/Indicator/609/For/National/And/25th/Percentile

3 Audit Commission (2001) Day Surgery. Review of national findings. http://www.audit-commission.gov.uk/SiteCollectionDocuments/AuditCommissionReports/NationalStudies/daysurgery.pdf

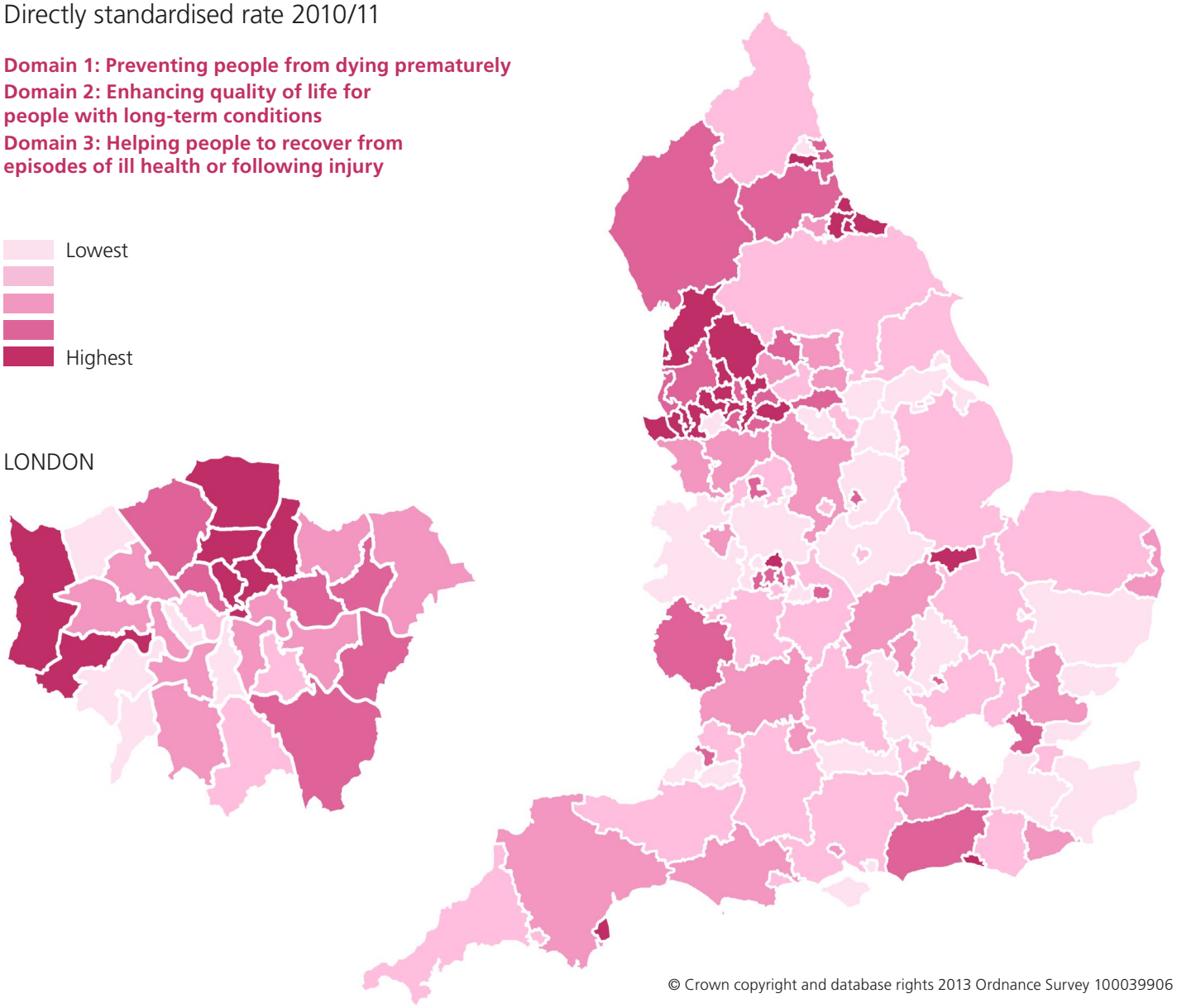
4 For one PCT, the value is 0%. In Atlas 2.0, page 157, this value was not included in the range.

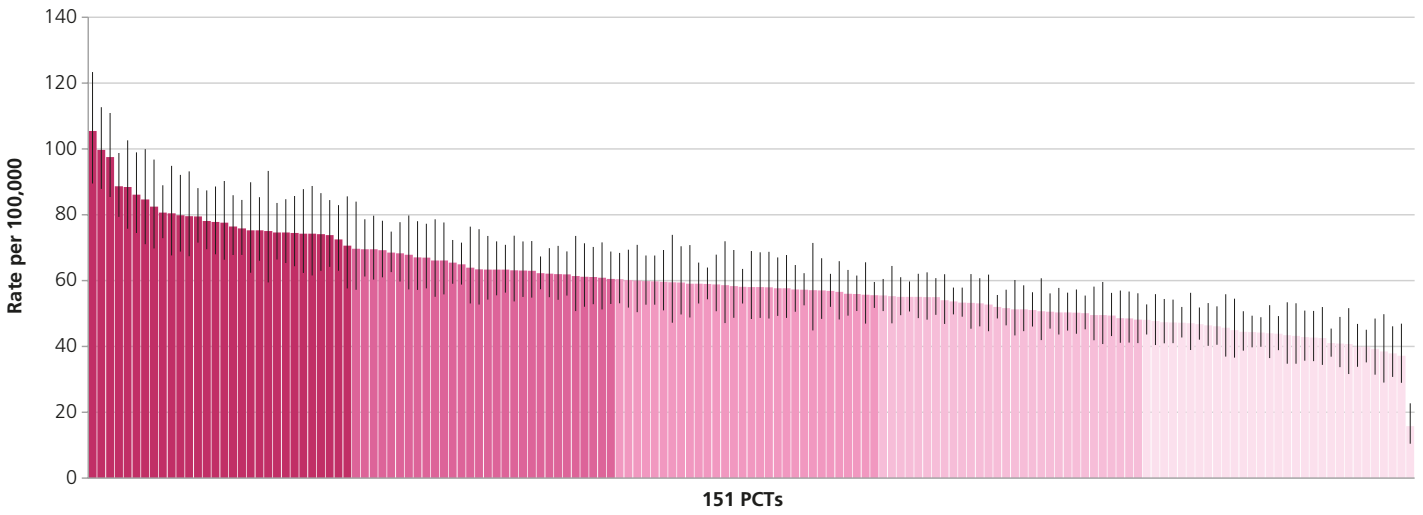
ENDOSCOPIC RETROGRADE CHOLANGIOPACREATOGRAPHY

Map 33: Rate of endoscopic retrograde cholangiopancreatography (ERCP) procedures per population by PCT

Directly standardised rate 2010/11

Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions
Domain 3: Helping people to recover from episodes of ill health or following injury





Context

Endoscopic retrograde cholangiopancreatography (ERCP) is a procedure in which an endoscope and X-rays are used to visualise the bile duct and the pancreatic duct. It can be used to diagnose or treat various conditions such as bile duct stones or pancreatic cancer; however, it should rarely be used for diagnosis because it is a potentially dangerous procedure and there are less invasive diagnostic procedures available.

This indicator is based on the combined total of diagnostic and/or treatment ERCP interventions.

Magnitude of variation

For PCTs in England, the rate of ERCP procedures ranged from 15.8 to 105.4 per 100,000 population (7-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 39.9–86.1, and the variation is 2.2-fold.

The reasons for variation are not clear. The ERCP rate should correspond to rates for cholecystectomy and pancreatic cancer, and is an indication of the burden of disease in local populations. However, Figure 33.1 shows that there is only a weak correlation between ERCP and cholecystectomy (r=0.2949). Low rates of ERCP in the context of high rates of cholecystectomy or pancreatic cancer may suggest that there are lower than optimum rates of intervention.

Options for action

When planning service improvement or development for patients undergoing ERCP, commissioners, clinicians and providers need to review the rate of ERCP in the context of local rates of cholecystectomy and pancreatic cancer.

The Association of Upper Gastrointestinal Surgeons, the British Society of Gastroenterology (BSG) and the Joint Advisory Group on endoscopy (JAG) have indicated that performance outcomes can be affected by case volumes for these procedures. The BSG and JAG recommend that:

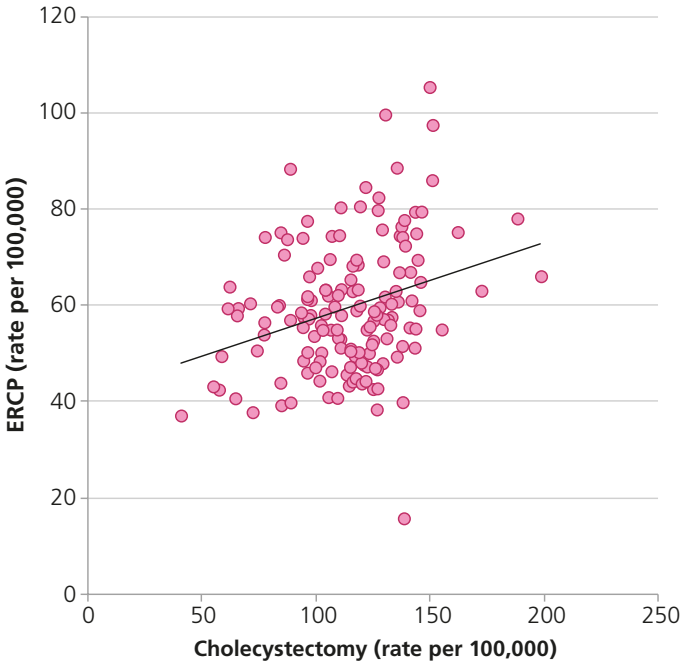
- clinicians undertaking ERCP should aim to achieve a minimum caseload of 75 per year;
- centres where ERCP is undertaken should perform an "absolute" minimum caseload of 150 a year.[1]

Commissioners need to ensure that patients are cared for at centres where the likelihood of a successful outcome is increased by the skill and experience gained as a result of a certain level of caseload.

RESOURCES

- Williams EJ, Green J, Beckingham I, Parks R, Martin D, Lombard M (2008) Guidelines on the management of common bile duct stones. Gut 57: 1004-1021. doi: 10.1136/gut.2007.121657 http://www.bsg.org.uk/attachments/127_cbds_08.pdf

Figure 33.1: Rate of ERCP procedures in relation to the rate of cholecystectomies per 100,000 population by PCT 2010/11



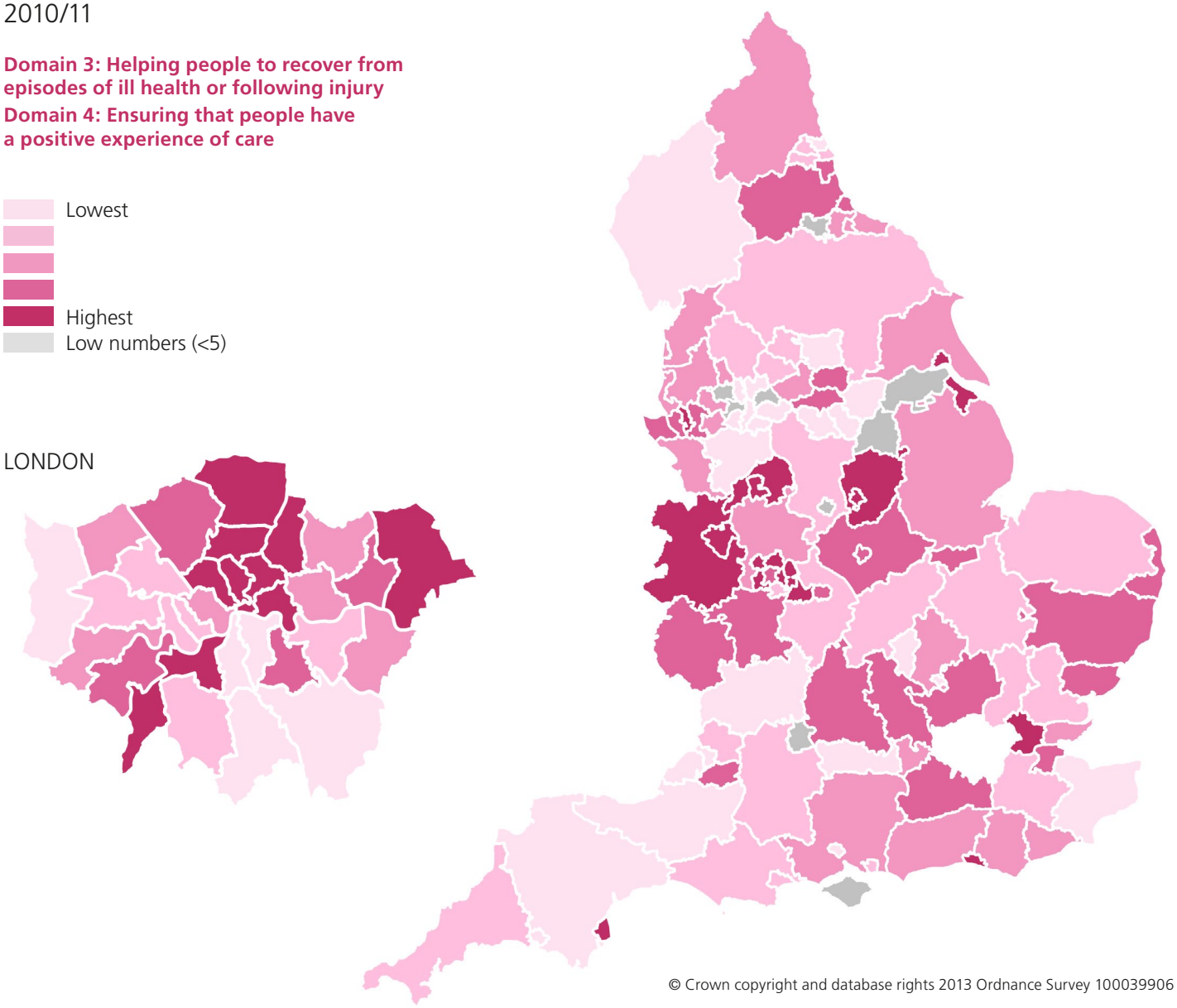
1 Green JRB and UK ERCP Stakeholders Working Party (2007) The Future of Service and Training in ERCP in the UK – A Strategy. http://www.bsg.org.uk/pdf_word_docs/ercp_stakeholders_08.doc

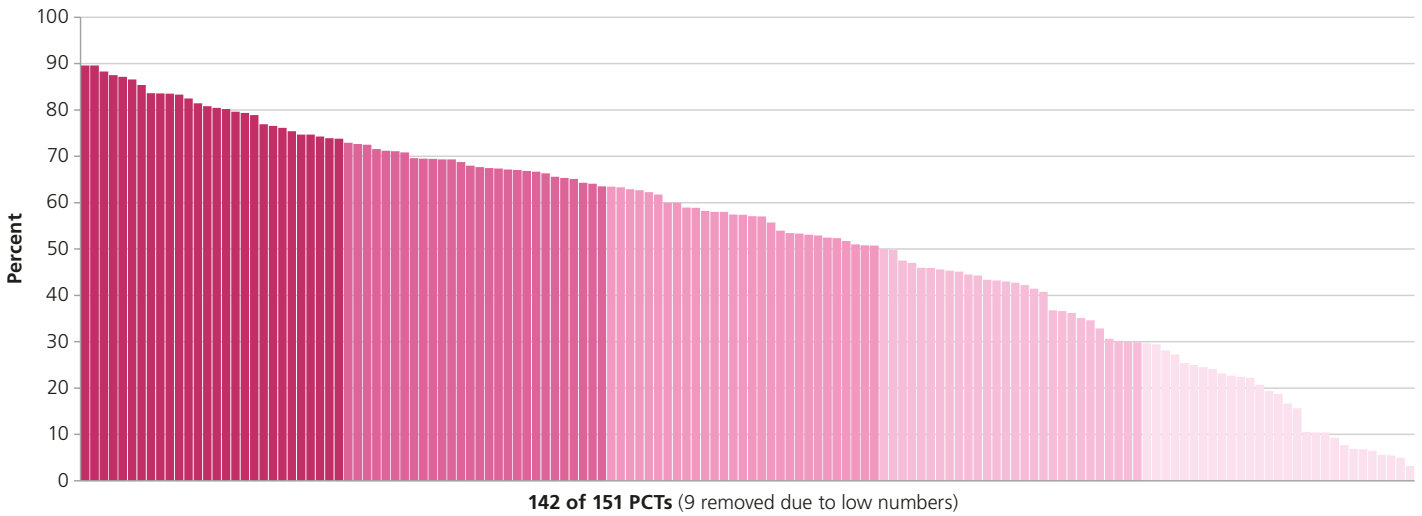
ENDOSCOPIC RETROGRADE CHOLANGIOPACREATOGRAPHY

Map 34: Percentage of elective endoscopic retrograde cholangiopancreatography (ERCP) procedures performed as day cases by PCT

2010/11

Domain 3: Helping people to recover from episodes of ill health or following injury
Domain 4: Ensuring that people have a positive experience of care





142 of 151 PCTs (9 removed due to low numbers)

Context

Endoscopic retrograde cholangiopancreatography (ERCP) is a procedure in which an endoscope and X-rays are used to visualise the bile duct and the pancreatic duct. It can be used to diagnose or treat various conditions such as bile duct stones or pancreatic cancer. Although the procedure has potential risks and complications that mandate scrupulous technique and assiduous early post-operative monitoring, there should be no reason why the majority of patients undergoing the intervention as an elective procedure require an overnight stay in hospital; it is feasible on a day-case basis, which is:

- popular with patients because they have to spend less time in hospital;
- of benefit to providers facing constraints in relation to capacity and cost.

The British Association of Day Surgery (BADS) supports and encourages day-case surgery for a wide range of appropriate procedures and interventions. The Association's "Directory of Procedures" (see "Resources"), now the national benchmarking index for day surgery, includes a cited expectation of 75% of patients having an ERCP as an elective procedure being suitable for zero length stay. This recommendation is based on OPCS 4.6 codes for all ERCP procedures (includes diagnostic as well as therapeutic ERCP, although the former should now be undertaken only rarely). The same codes have been used to examine current day-case rates for this procedure.

Magnitude of variation

For PCTs in England, the percentage of ERCP procedures performed as day cases ranged from 3.2% to 89.6% (28-fold variation).[1] When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 6.8–86.6%, and the variation is 13-fold.

The reasons for the degree of variation observed are not clear, but could reflect differences in:

- routine practice in elective ERCP at different providers;
- coding of day cases.

In some cases, it is difficult to ascertain whether the procedure has been conducted as part of an emergency admission pathway or whether it has been combined in association with an elective surgical procedure such as laparoscopic cholecystectomy.

In some instances, in Trusts with a high percentage of day-case ERCP, patients may travel to a centre for ERCP as day cases but are likely to have an inpatient stay before and after at the referring Trust.

The degree of variation observed in total rates of ERCP after exclusion is 2.2-fold (see Map 33) whereas it is 13-fold for the percentage of elective ERCP procedures performed as day cases. If total rates of ERCP are considered as a proxy for the burden of disease, it would appear that there is less variation in the burden of disease when compared with the variation in the type of care given. Further investigation is needed into the possible causes of lower rates of day-case procedures.

Options for action

Service providers need to evaluate their care pathways for day surgery, and ascertain what level of transformational work might be needed.

Providers of day-surgery services could consider a "Default to Day Surgery" ethos as promoted by the NHS Institute for Innovation and Improvement ("Day Surgery – Treat Day Surgery as the Norm"; see "Resources").

In localities with low rates of day-case surgery, commissioners need:

- to review day-case rates for ERCP with providers;
- to discuss changes to the current patient pathway to implement a "best care" pathway which will achieve higher levels of day-case intervention for ERCP, as recommended by BADS and NHS Institute for Innovation and Improvement;
- to use the "best care" pathway as the standard for future commissioning.

RESOURCES

- British Association of Day Surgery. http://www.bads.co.uk
- British Association of Day Surgery (BADS) (2012) Directory of Procedures. 4th Edition.
- NHS Institute for Innovation and Improvement. Quality and Service Improvement Tools. Day Surgery – Treat Day Surgery as the Norm. http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/day_surgery_-_treat_day_surgery_as_the_norm.html
- British Association of Day Surgery (2012) Commissioning Day Surgery. A Guide for Clinical Commissioning Groups May 2012. http://www.daysurgeryuk.net/media/128969/commissioning2012.pdf
- Joint Advisory Group (JAG) on GI Endoscopy. http://www.thejag.org.uk/
- British Society of Gastroenterology (BSG). http://www.bsg.org.uk/
- Williams EJ, Taylor S, Fairclough P et al (2006) Are we meeting standards set for endoscopy? Results of a large scale prospective survey of ERCP practice. *Gut* doi: 10.1136/gut.2006.097543
- Cullinane M, Gray AJG, Hargreaves CMK et al (2004) Scoping our practice. The 2004 Report of the National Confidential Enquiry into Patient Outcome and Death. http://www.ncepod.org.uk/2004report/

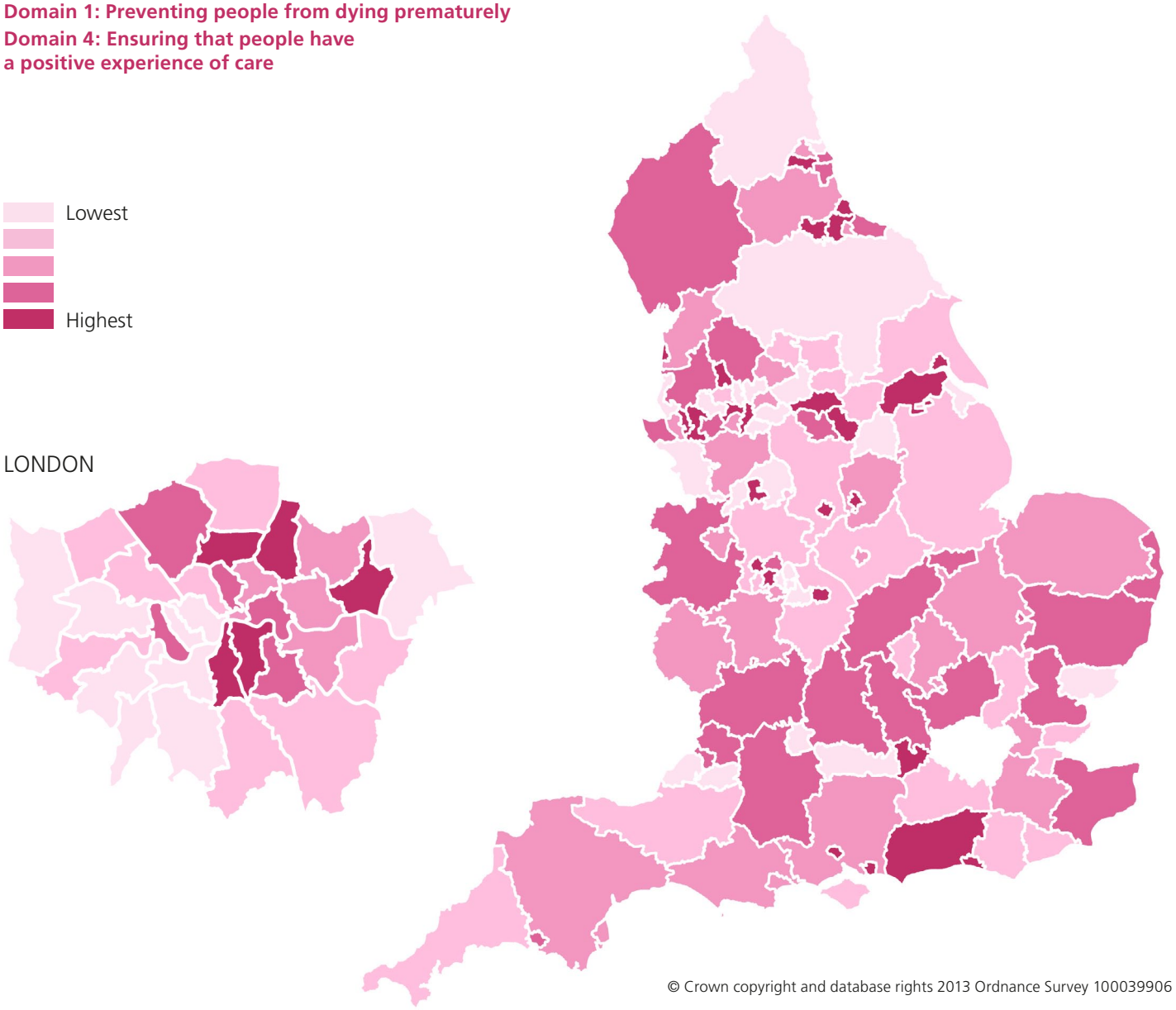
1 Data from 9 PCTs have been removed due to low numbers (<5).

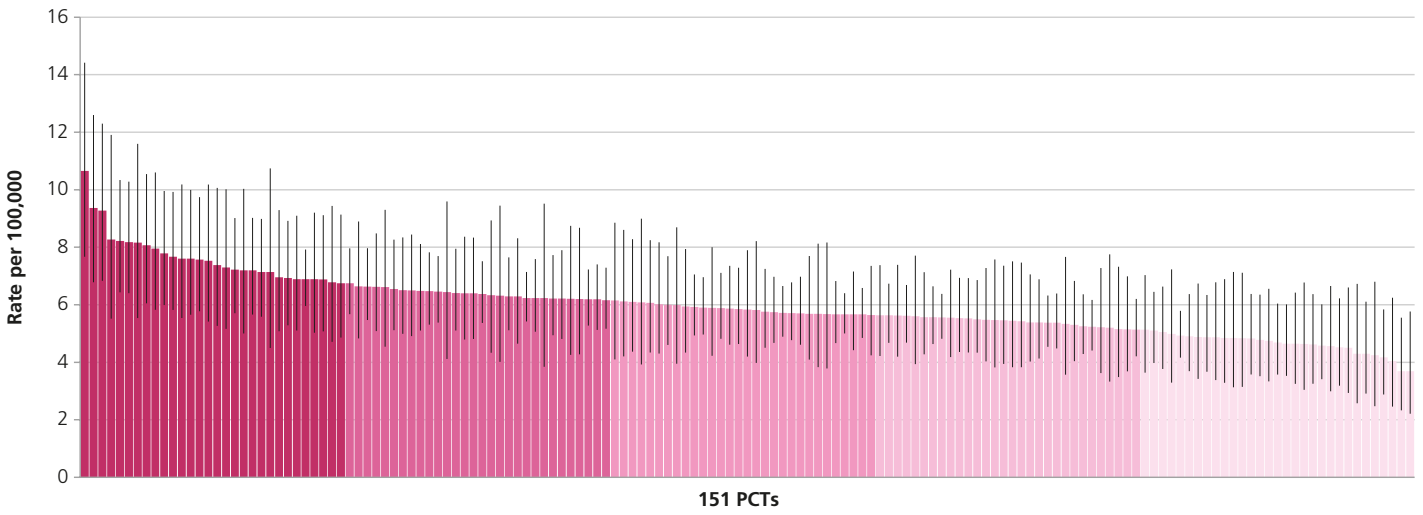
PANCREATIC CANCER

Map 35: Rate of mortality from pancreatic cancer in people aged under 75 years per population by PCT

Directly standardised rate 2008–2010

Domain 1: Preventing people from dying prematurely
Domain 4: Ensuring that people have a positive experience of care





Context

Pancreatic cancer is the ninth most common cancer in the UK: in 2009, more than 8350 people were diagnosed with pancreatic cancer, equivalent to around 160 new diagnoses each week of the year.[1]

Among men in the UK, there were around 4100 new cases of pancreatic cancer diagnosed in 2009, making it the eleventh most common cancer for men. In 2009, more than 4200 women in the UK were diagnosed with pancreatic cancer, making it the eighth most common cancer for women.

Onset tends to be later in life with over 80% of pancreatic cancer occurring in people aged 60 years and over. Pancreatic cancer rates in men have decreased slightly between the late 1970s and mid-1990s, but have remained stable since then. Pancreatic cancer rates for women declined between the late 1980s and late 1990s, but since then have gradually increased.

Overall, pancreatic cancer has a poor prognosis. The disease is often advanced by the time a person has symptoms, goes to the doctor and is diagnosed. Although survival rates for pancreatic cancer have increased by more than twofold since the 1970s, survival remains poor with less than one in five people surviving the disease for longer than one year after diagnosis. Around 4% of people survive pancreatic cancer for five years or more.

People with pancreatic cancer use some specialist hepatobiliary services, presenting with jaundice, or liver function tests, and use endoscopic retrograde cholangiopancreatography (ERCP) services for diagnosis and treatment.

Magnitude of variation

For PCTs in England, the rate of mortality from pancreatic cancer in people aged under 75 years ranged from 3.7 to 10.7 per 100,000 population (2.9-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 4.3–8.2 per 100,000 population, and the variation is 1.9-fold.[2]

Options for action

When planning service improvement or development to reduce mortality from pancreatic cancer, commissioners, clinicians and providers need:

- To review local mortality rates for pancreatic cancer;
- To identify whether there are opportunities for improving early diagnosis of pancreatic cancer locally;
- To ascertain whether there are local factors that contribute to differences in prevalence;
- To identify whether there are impediments to investigation or accessing expertise at a local level.

RESOURCES

- Cancer Research UK. Pancreatic cancer Key Facts http://info.cancerresearchuk.org/cancerstats/keyfacts/pancreatic-cancer/
- Cancer Research UK. Pancreatic cancer statistics http://info.cancerresearchuk.org/cancerstats/types/pancreas/

1 Cancer Research UK. Pancreatic cancer Key Facts.http://info.cancerresearchuk.org/cancerstats/keyfacts/pancreatic-cancer/

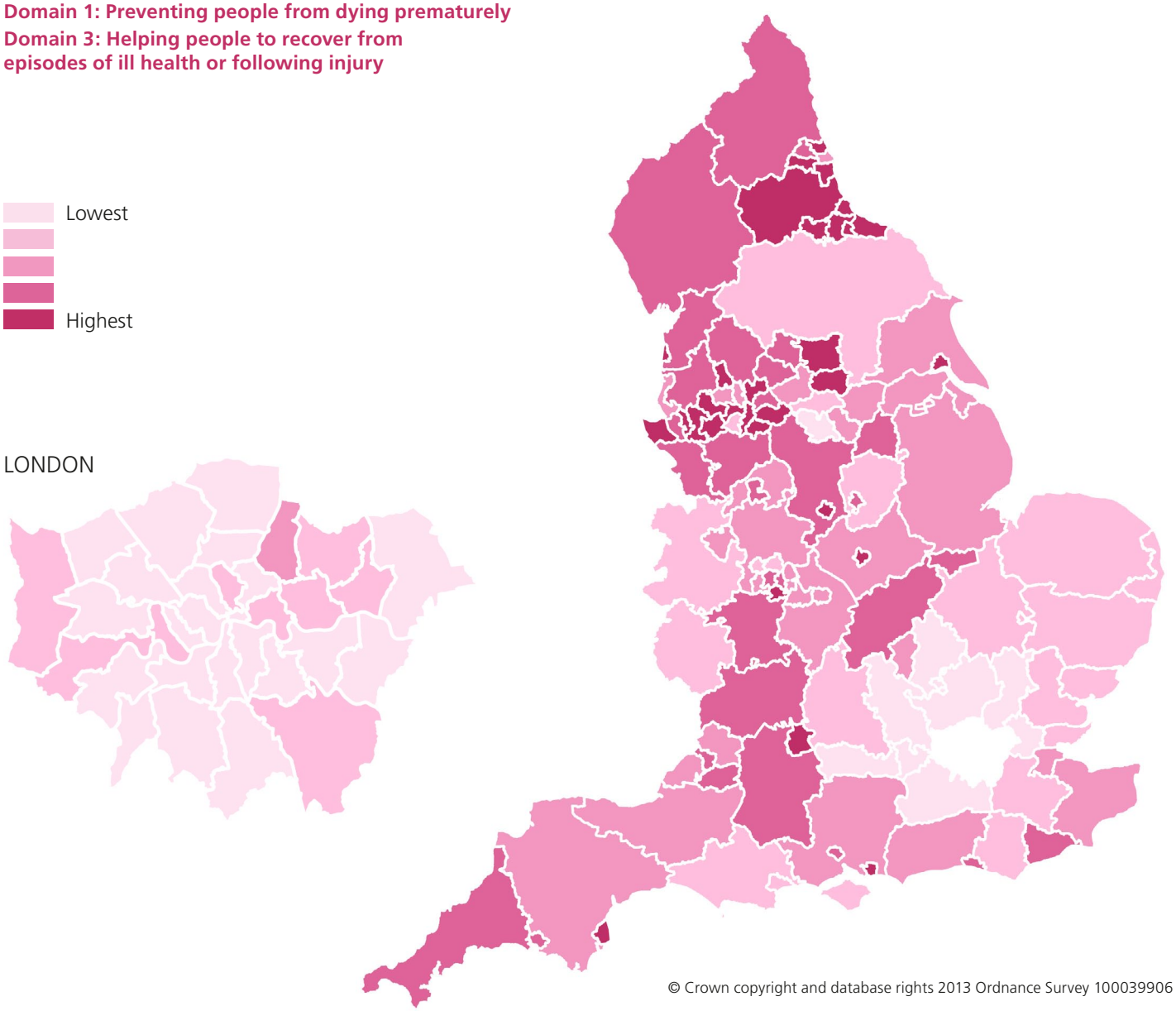
2 The Office for National Statistics (ONS) carried out the original collection and collation of the mortality data but bear no responsibility for their future analysis or interpretation.

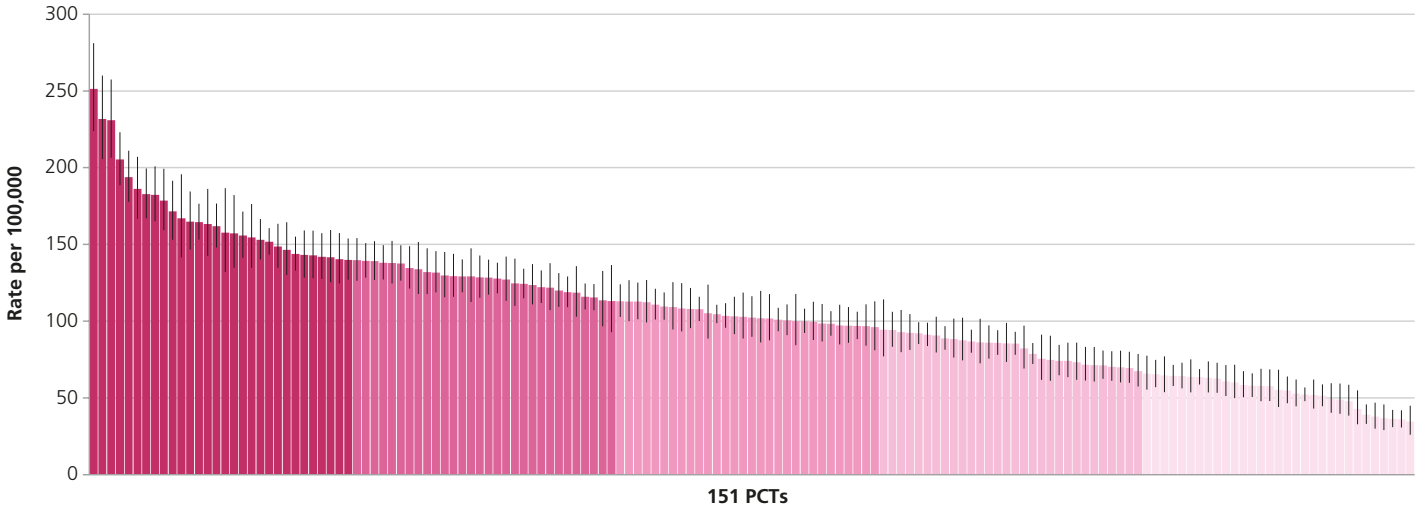
PARACETAMOL OVERDOSE AND POISONING

Map 36: Rate of admissions to hospital where diagnosis includes paracetamol overdose per population by PCT

Directly standardised rate 2010/11

Domain 1: Preventing people from dying prematurely
Domain 3: Helping people to recover from episodes of ill health or following injury





Context

Paracetamol is the most common drug taken in overdose in the UK. Although the management of early paracetamol poisoning should be straightforward, the management of late-presenting cases, cases presenting after a staggered overdose, and patients with risk factors for paracetamol poisoning can be much more complex.

The management of paracetamol overdose is a common problem which can test the linkages within secondary care services and between secondary and tertiary care pathways. In this context, 1 in 500 cases of paracetamol overdose results in liver failure, and potentially 1 in 300 is referred for a liver opinion.

Evidence-based treatment pathways can improve the chances of successful recovery from overdose. Wallace et al developed an evidence-based flowchart to guide clinicians through the investigation and treatment of all patients presenting to hospital after this common, but often difficult to manage, overdose. They suggest that:

> *"as well as a management guideline this flowchart can be used as an educational tool..."*.[1]

Magnitude of variation

For PCTs in England, the rate of admissions to hospital where diagnosis includes paracetamol overdose ranged from 34.6 to 251.3 per 100,000 population (7-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 39.0–186.1 per 100,000 population, and the variation is 4.8-fold.

The highest numbers of admissions are in the age-groups 15–24 years and 35–50 years. There is also an association with deprivation: there are higher rates of admission in areas with greater levels of deprivation.

Options for action

When planning service development or improvement to reduce non-elective admissions to hospital where the diagnosis includes a paracetamol overdose, commissioners, clinicians and providers need:

- To review local rates of hospital admission for paracetamol overdose;
- To identify whether there are particular age-groups in whom, and localities where, the problem is greatest;
- To develop joint approaches with social care agencies to reducing paracetamol overdose in areas of deprivation;
- To ensure evidence-based flowcharts in the treatment of paracetamol overdose (see "Resources") are used by all providers;
- To highlight the consequences of paracetamol overdose on more specialised services and ensure that guidelines and treatment pathways are followed.

RESOURCES

- Wallace CI, Dargan PI, Jones AL (2002) Paracetamol overdose: an evidence based flowchart to guide management. *Emerg Med J* 19:202-205 doi:10.1136/emj.19.3.202 http://emj.bmj.com/content/19/3/202.full

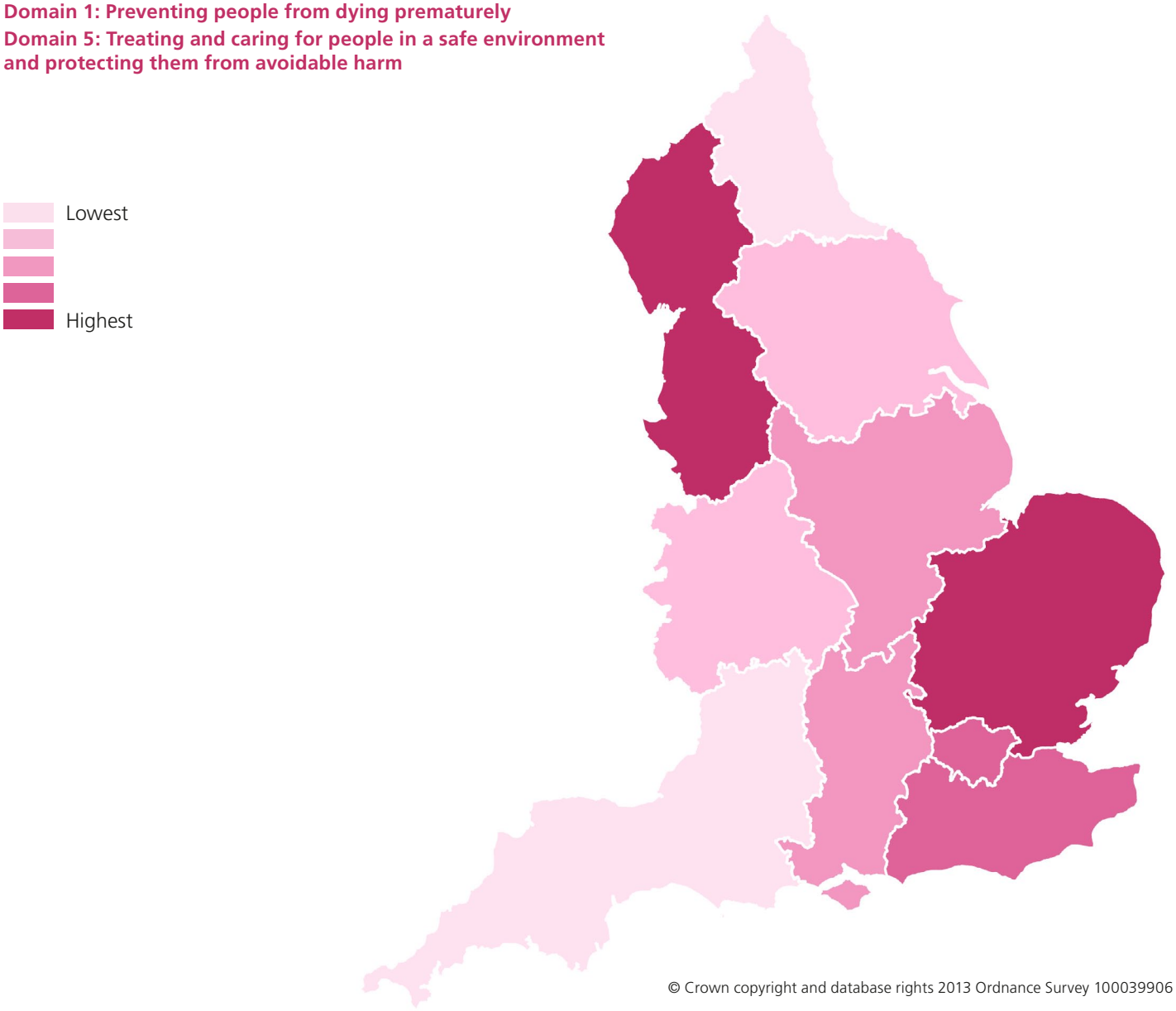
1 Wallace CI, Dargan PI, Jones AL (2002) Paracetamol overdose: an evidence based flowchart to guide management. *Emerg Med J* 19:202-205 doi:10.1136/emj.19.3.202 http://emj.bmj.com/content/19/3/202.full

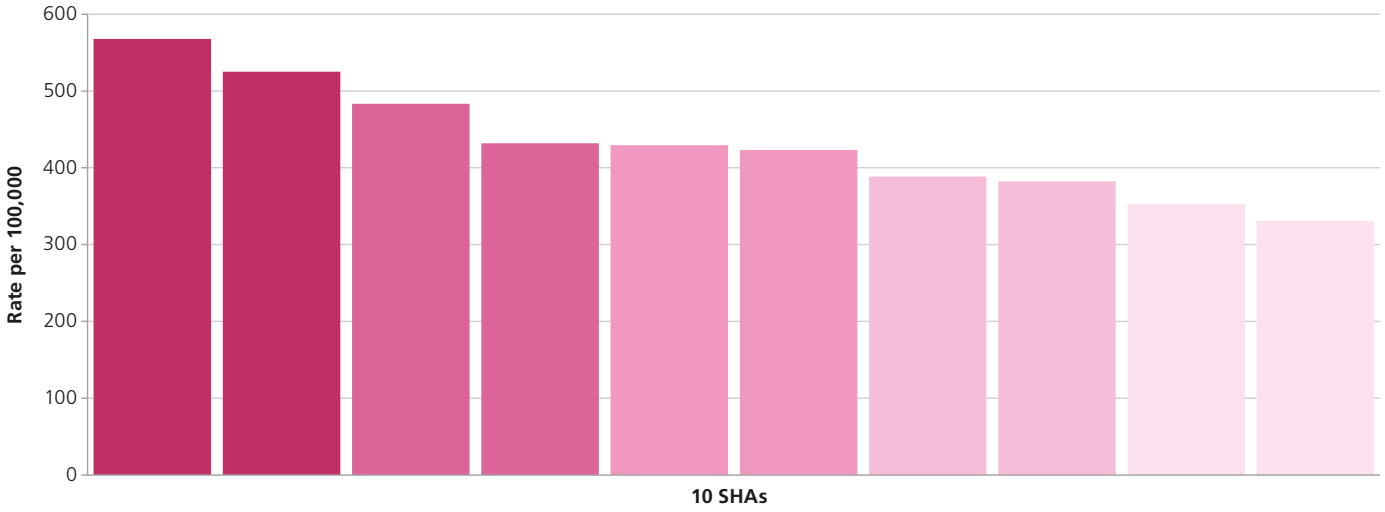
PARACETAMOL OVERDOSE AND POISONING

Map 37: Rate of mortality from paracetamol poisoning per admissions for paracetamol overdose by SHA

2008–2010

Domain 1: Preventing people from dying prematurely
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm





Context

When taken in its normal dosage, paracetamol is a safe and effective painkiller. It can also reduce the temperature of children and adults with fever, and is commonly used for this purpose. Taken in too high a dose, however, paracetamol can be dangerous and can cause fatal liver disease. Metabolites of paracetamol have a toxic effect on the cells of the liver (hepatocytes), which may be caused by as few as 12 tablets of paracetamol. However, it may take several days before symptoms develop.

The widespread availability of paracetamol makes it a commonly used means of attempting suicide or of parasuicide. In addition, a lack of awareness of the potential dangers of exceeding the recommended dose means that accidental poisoning is also an important cause of death from paracetamol. Initial symptoms after taking more than the recommended dosage are often no more than mild nausea and vomiting. As liver damage develops over the following days, right-sided abdominal pain may be experienced. If no treatment is given to halt or reverse the liver failure, a build-up of toxins in the body can lead to confusion, jaundice, an inability to clot blood, swelling of the brain and subsequent death.[1]

To limit the number of people who take an overdose of paracetamol as a means of attempting suicide or parasuicide, in November 1998, the Medicines Control Agency restricted the quantity of paracetamol that can be bought in one purchase.

As paracetamol alone does not immediately cause drowsiness or unconsciousness, and there is a delay in developing serious symptoms, both factors reduce the likelihood of a person seeking help at an early stage. Establishing a diagnosis of paracetamol poisoning as early as possible is vital because it is possible to prevent liver damage by administering an antidote. If treatment is given within six hours of taking paracetamol, death can usually be prevented.

Magnitude of variation

For SHAs in England, the rate of mortality from paracetamol poisoning per admissions for paracetamol overdose ranged from 330.9 to 567.6 per 100,000 population, a 1.7-fold variation.[2]

Although there are differences in rates of paracetamol overdose, these mortality rates have been calculated using hospital admissions for paracetamol overdose as the denominator. As a result, the degree of variation observed in mortality is more likely to be a reflection of the degree of variation in the speed of response and in treatment pathways between primary and secondary care. In cases of overdose, it is vital to secure rapid assessment and immediate treatment.

When interpreting the magnitude of variation, it is important to note that some people may have died from paracetamol poisoning before it was possible for any treatment to have been given in hospital.

Options for action

When planning service improvement or development to reduce deaths from paracetamol poisoning, commissioners, clinicians and providers need to work together to review:

- local mortality rates from paracetamol overdose;
- the speed of response and pathway of treatment and care in local services for people experiencing a paracetamol overdose;
- the education of patients;
- prevention measures within mental health services;
- the management of incidents that are near fatal.

RESOURCES

- Atcha Z, Majeed A (2000) Paracetamol related deaths in England and Wales, 1993-97. Health Statistics Quarterly 07, Autumn 2000. http://www.ons.gov.uk/ons/rel/hsq/health-statistics-quarterly/no--7--autumn-2000/paracetamol-related-deaths-in-england-and-wales--1993-97.pdf
- Office for National Statistics (2012) Deaths related to drug poisoning in England and Wales, 2011. http://www.ons.gov.uk/ons/rel/subnational-health3/deaths-related-to-drug-poisoning/2011/stb-deaths-related-to-drug-poisoning-2011.html

1 Atcha Z, Majeed A (2000) Paracetamol related deaths in England and Wales, 1993-97. Health Statistics Quarterly 07, Autumn 2000. http://www.ons.gov.uk/ons/rel/hsq/health-statistics-quarterly/no--7--autumn-2000/paracetamol-related-deaths-in-england-and-wales--1993-97.pdf

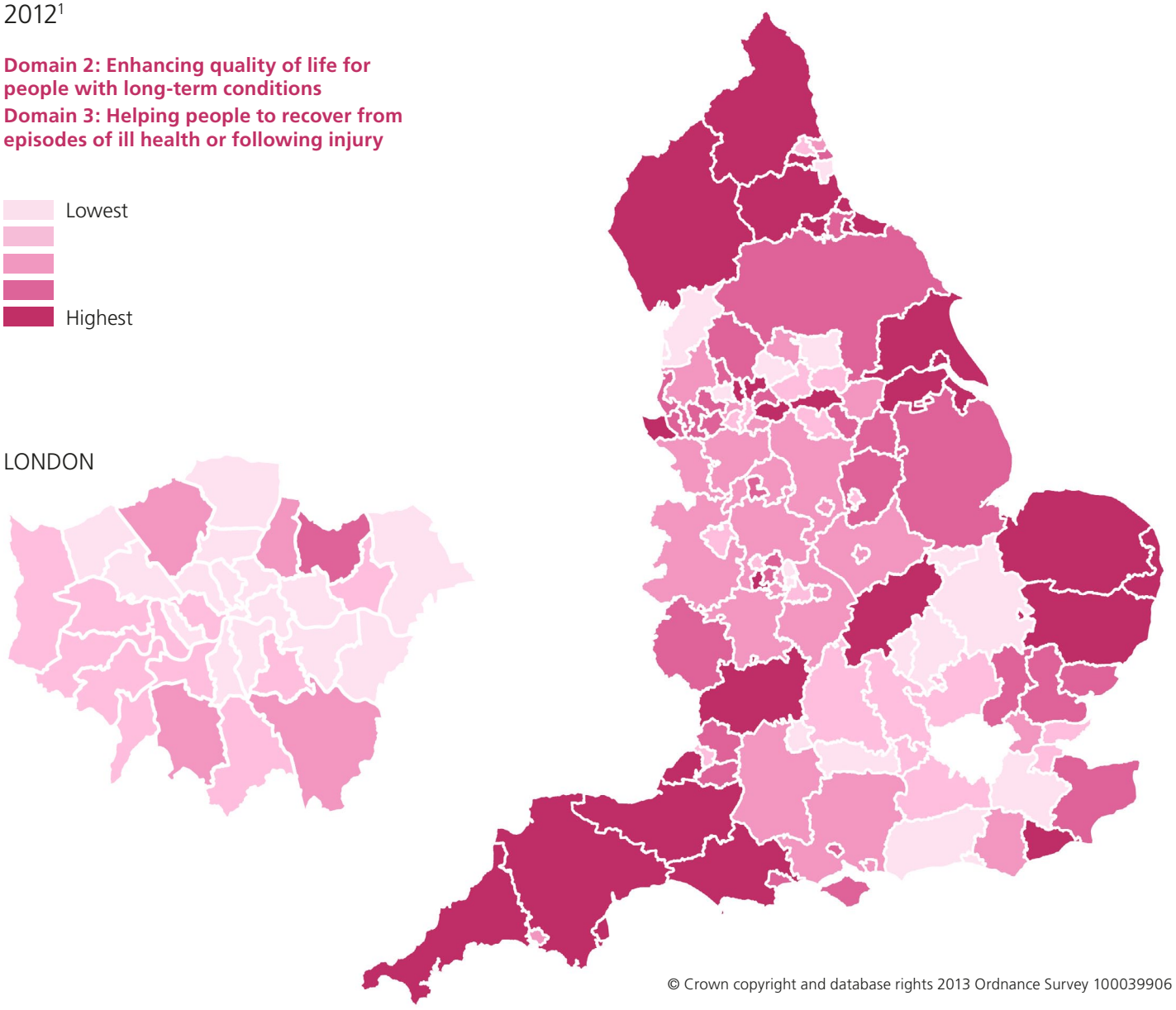
2 The Office for National Statistics (ONS) carried out the original collection and collation of the mortality data but bear no responsibility for their future analysis or interpretation.

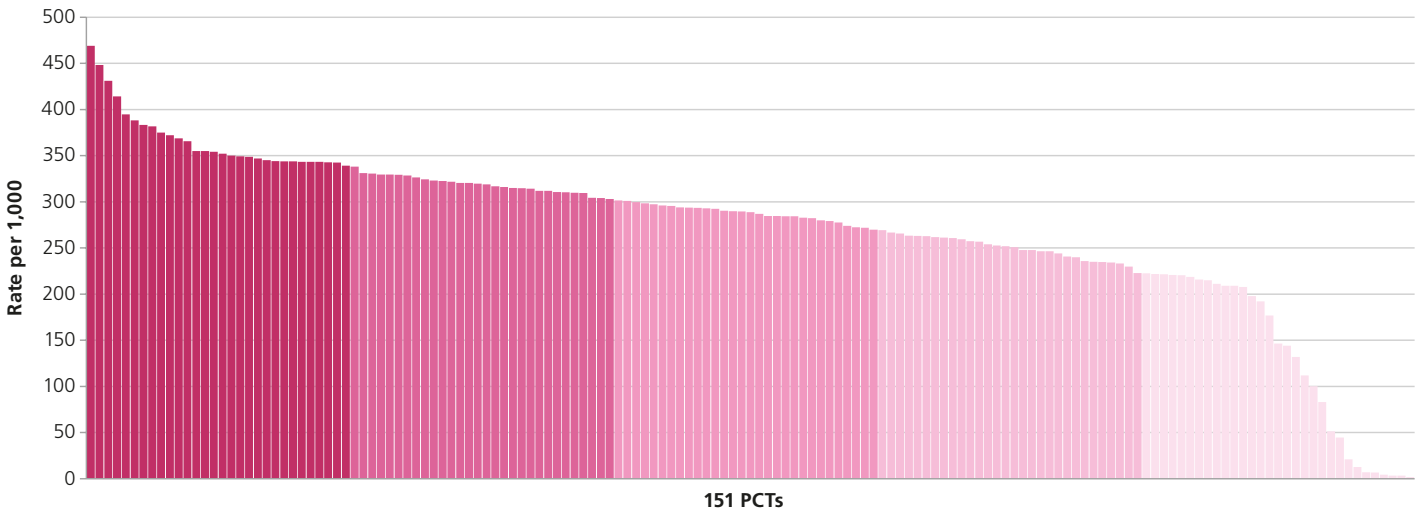
DIAGNOSTIC TESTING

Map 38: Estimated annual rate of use for alanine aminotransferase (ALT) tests ordered by GPs per practice population by PCT

2012[1]

Domain 2: Enhancing quality of life for people with long-term conditions
Domain 3: Helping people to recover from episodes of ill health or following injury





Context

The serum alanine aminotransferase (ALT) test is used as a test of liver disease.[2] When the liver is damaged, ALT is released into the bloodstream. The test is undertaken in the following circumstances:

- liver disease is suspected because of a risk factor, e.g. excess alcohol consumption;
- liver disease is assessed in the context of known or possible exposure to hepatitis viruses;
- disease of the bile duct or pancreas is suspected because of symptoms, e.g. jaundice, dark urine or ascites;
- a patient is known to have liver disease and requires monitoring;
- some guidance for other conditions or drugs suggests monitoring liver function, e.g. statins;
- incidental findings point to a potential liver disease, e.g. an abnormal ultrasound scan;
- a family history of liver disease.

The serum ALT test is usually requested in conjunction with other laboratory investigations such as alkaline phosphatase (ALP), gamma-glutamyl transferase (GGT) and sometimes aspartate aminotransferase (AST), a panel known as liver function tests (LFTs), which also includes albumin and bilirubin. ALT, ALP, GGT and AST are liver enzymes, and elevated values imply liver damage; albumin and bilirubin reflect actual liver function. Interpretation of these tests requires a level of knowledge and skill, which is often sub-optimal. There is some ethnic variation in serum ALT concentrations, and laboratory "norms" can also vary.

Liver function tests are used alone, or in conjunction with other tests, for investigation of people in whom a diagnosis is unclear. Given that liver disease is usually silent until it is at an advanced stage, these tests are often included in a "battery of tests" to explore potential diagnoses.

On average, laboratories report 10% of results as above their range of normal.[3] Liver enzymes are often abnormal in:

- diabetes mellitus or obesity due to fatty infiltration of the liver;
- cardiac failure because of congestion.

However, it is not clear how LFTs are used in these conditions.

The data for this indicator were extracted from an audit of pathology results sent to GPs in England arranged by Connecting for Health and the Royal College of Pathologists. The rate of testing per 1000 population is an estimated annual rate of use based on the extraxcted data about tests ordered by GPs and taken from population returns in QOF.

Magnitude of variation

For PCTs in England, the estimated annual rate of use for ALT tests ordered by GPs ranged from 1.9 to 468.9 per 1000 practice population (252-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 6.9–388.3 per practice population, and the variation is 56-fold.

It is difficult to understand the reason for the degree of variation observed:

- early liver disease is under-diagnosed and it is important to encourage consideration of its assessment and the potential to intervene at an early stage of the disease;
- there are often multiple repeats of tests, which appear to be inappropriate.

In addition, several laboratories report using inappropriate codes or uncoded test reports, which may distort the data, especially at the lower end of the returns.

When interpreting the degree of variation, it is important to note the indicator is an estimated annual rate from 23 days' data; however, there is no reason to believe the degree of variation would be reduced over a longer period of time.

The data and the degree of variation observed do not give any indication of:

- why tests were done;
- the numbers of repeat tests;
- the proportion of tests that are abnormal.

Options for action

Commissioners, clinicians and service providers in both primary and secondary care need to agree pathways for the investigation and management of liver disease at a local level; the Map of Medicine is a good place to start, and there are national guidelines for many of the pathways (see "Resources").

Agreement also needs to be reached on the following:

- mechanisms for interpreting tests;
- to which investigations and pathways each of the tests might lead if results are abnormal;
- within the pathways, protocols for repeating tests to avoid inappropriate duplication.

Shared IT systems among service providers will help to avoid the duplication of tests.

RESOURCES

- Map of Medicine. http://www.mapofmedicine.com/solution/editorialmethodology/currentpathways http://www.liver.nhs.uk/resources/map_of_medicine_pathways/
- British Society of Gastroenterology guidelines. http://www.bsg.org.uk/clinical-guidelines/liver/index.html

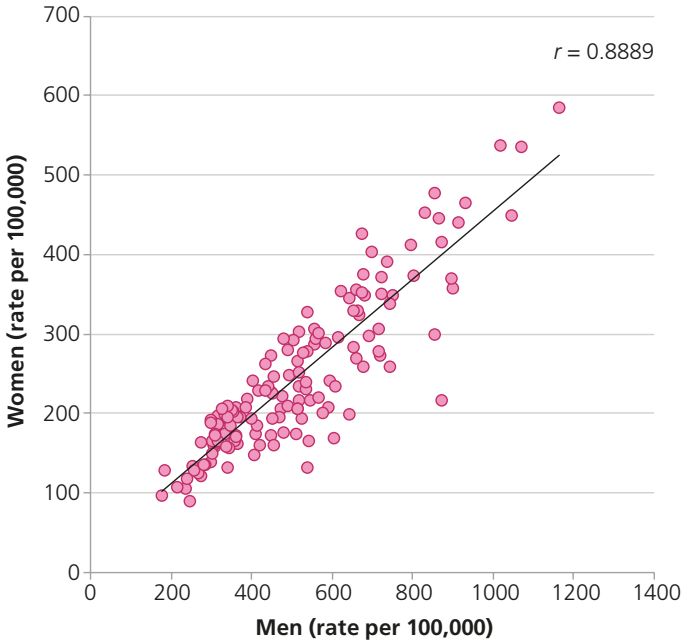
1 Data were extracted from 23 days at end of May–beginning of June 2012.

2 http://www.labtestsonline.org.uk/understanding/analytes/alt/tab/all?printpreview=1

3 Jones R, personal communication.

Additional visualisation for Map 11

Figure 11.1: Rate (directly standardised) of alcohol-specific admissions per 100,000 population for men in relation to women by PCT 2010/11

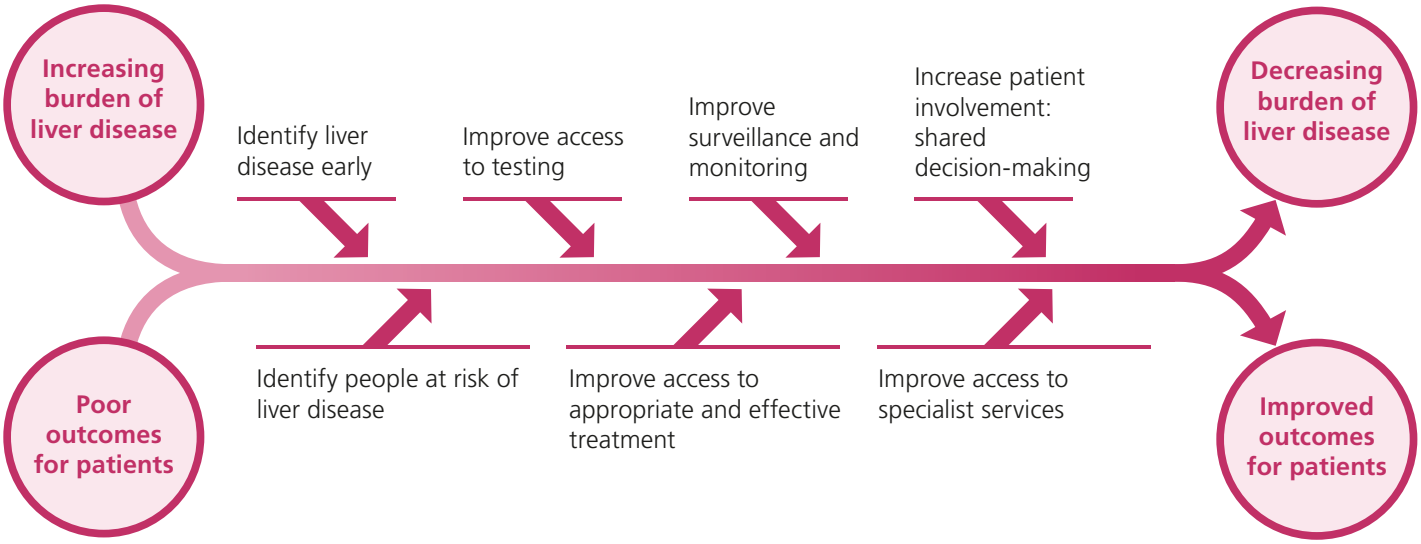


Innovations and models of good practice in services for people with liver disease

Introduction

While working on the National Liver Disease Strategy, many models of good practice and some innovations likely to be helpful in tackling unwarranted variation were identified (Figure CS.1). They are presented in this Atlas as exemplars so that commissioners, clinicians and service providers can consider how they may be applied in their locality.

FIGURE CS.1: GOOD PRACTICE IN SERVICES FOR PATIENTS WITH LIVER DISEASE



Identifying liver disease earlier

Liverpool is an area of high prevalence for liver disease, and in this locality many patients present late during the course of their disease. Risk assessment and early recognition of liver disease has been promoted by Liverpool PCT-CCG through the use of a locally enhanced service payment to minimise late diagnosis. Incentives are available to all participating primary care groups who:

- identify patients at risk;
- undertake relevant blood tests;
- refer only those patients who meet the criteria for referral that have been agreed with local secondary care services – other patients are managed entirely in the community.

The primary care medical director took the lead initially in auditing several hundred primary-care referrals. It was found that practices had different criteria and standards for referral within the PCT. Referral criteria and information standards were agreed with secondary-care providers who agreed to provide a consultant-level opinion together with full assessment of results. Up to 40% of patients can be discharged with an advisory care plan at first consultation.

Prior to the introduction of this locally enhanced service, a project had been set up to ensure that all of the information required was available at first consultation. There are similar models in Plymouth, Derby and Nottingham, where specialist nurses from the liver services ensure that patients have all the relevant tests and information arranged before an outpatient consultation, including blood tests, ultrasound tests and, when relevant, CT scans. All arrangements are

managed pro-actively and remotely by IT, telephone or via "Choose and Book". This ensures that patients have their consultation within six weeks. As a result, the quality of the consultation improved for patients and clinicians.

A variation of this type of service model was developed in Nottingham where all CCG referrals from individual practices were centralised at a single practice. A two-level triage system was used, in which a general practitioner with an interest in gastroenterology screened referrals. In cases where there was uncertainty, a brief synopsis of the case was emailed to 1 of 5 consultant hepatologists/gastroenterologists who screened the scenario and made clinical recommendations. Of a total of 354 potential referrals screened using this system during one year, 75% of hepatology referrals were dealt with by giving advice, blood tests, recommendations and appropriate community management plans. This outcome was achieved in conjunction with the introduction of new community guidelines for the management of abnormal liver function tests

Identifying people at risk of alcoholic liver disease and delivering brief interventions

The introduction of alcohol liaison nurses has been recommended by the British Society of Gastroenterology and accepted by NHS Evidence as a QIPP example. Approximately 40% of PCTs and an unknown number of Trusts have employed alcohol liaison nurses, but the models of care vary: in some localities, there are nurses in the medical admissions unit (MAU) or accident and emergency (A&E); in others, there are nurses who work across the community or in hospital wards. In Nottingham, the introduction of an alcohol liaison nurse reduced readmission rates and drinking rates during a 12-month follow-up period. Similar models have proved effective in Bolton and Liverpool. In Salford, an extension of this process has been used to identify frequent attendees at A&E who are also known to other local authority agencies: a coordinated approach with key workers has decreased attendances and readmission rates.

Improving access to testing and treatment for viral hepatitis

Pilot projects in Blackpool and Portsmouth, set up in collaboration with patient charities, have improved access to testing for hepatitis B and hepatitis C by providing tests at outlets in the community. The availability of testing at community outlets has increased access to testing in settings that are more acceptable to some patients, such as pharmacies or community centres. When setting up similar initiatives, it is important to ensure that mechanisms and pathways are in place to provide treatment in the community for people who have been positively identified. Too many patients face too many barriers when engaging with services that have been configured conventionally.

Inequity of access to services or expertise can be an issue for certain groups of people. As liver damage is silent for many years before it causes significant problems and as liver disease can be prevented, it is important for specialist services to provide outreach services to groups in the population for whom access is poor. In Newcastle and Newham, specialist services have worked with Imams and community leaders to provide information and increased access to testing for people from ethnic groups who may have acquired a hepatitis virus from a country where prevalence is high.

In Liverpool and London, community outreach teams work with homeless people and drug users to identify people with hepatitis C and to engage them in treatment. Many of these patients can be successfully treated and their virus eradicated despite the ongoing use of alcohol or drugs. The keys to successful treatment are:

- stability, supported by the ready availability of needle exchange programmes and opioid substitution programmes;
- engagement with treatment protocols in the community.

The benefits of this approach include a reduction in the virus pool and in the incidence of infections.

In Birmingham, a domiciliary care project for patients with chronic hepatitis B infection ("Homecare Study") arose from the recognition that large numbers of healthy, non-cirrhotic patients with chronic hepatitis B infection attend specialist viral hepatitis clinics when often they require only a blood test and a prescription of antiviral drug at each visit. Attending a hospital outpatient clinic may be disruptive to patients' lives, interfering with family and work commitments. Inevitably, outpatient clinics are over-booked and a consultation, blood test and the collection of a prescription may take up to three hours to complete.

In a pilot study to assess whether it is safe to monitor

and treat selected patients with chronic hepatitis B infection at home, without attendance at an outpatient department, 20 patients who were non-cirrhotic and already stabilised on the drug Tenofovir were enrolled. At three-monthly intervals during one year, each patient was visited by a community nurse to deliver the antiviral drug and take a blood test. Blood tests were analysed at The Queen Elizabeth Hospital, Birmingham, and reviewed by the viral hepatitis team at a multidisciplinary team meeting. None of 20 patients included in the pilot study was withdrawn as a result of compromised standards of clinical care (e.g. failed delivery of antiviral drugs, abnormal liver chemistry, or detectable hepatitis B virus DNA levels or drug toxicity). Patients completed externally validated questionnaires at 0, 3 and 9 months. The accessibility of care for selected patients with chronic hepatitis B infection was increased within the Trust by establishing a patient-centred care design, resulting in increased patient satisfaction and improved compliance with therapy.

In Nottingham, to improve the routine monitoring of patients with stable hepatitis B infection, two new models of follow-up were offered.

1. Telephone clinics run by nurse specialists, in which blood forms are posted to patients two weeks prior to a pre-booked telephone call. The venepuncture is undertaken in primary care or at a hospital site according to patient preference. The telephone clinics were organised via clinic booking in the usual way. Telephone consultations last 10–15 minutes and are conducted on a telephone number of the patient's choice. Letters are posted to the GP and the patient following consultation, together with a management plan and the test results.
2. A nurse clinic for patients who prefer face-to-face clinical contact, for reasons of language, understanding and up-to-date telephone contact for queries.

Currently, 140 patients are engaged in the new follow-up systems, with a decrease in the consultant-clinic new to follow-up ratios from 1:5 to 1:2. In total, 106 patients opted for telephone follow-up, with a decrease in "non-attendance" (defined in this model as not having blood results or not answering calls) from 18% (previously recorded) to 5%. Patient satisfaction with the telephone clinics is high: 85% regard the service as excellent; all patients perceive the telephone clinics as an improvement when compared with the previous model of a "standard" clinic.

Triage of patients to secondary care

In Southampton, a clinical "traffic light" system has been devised to determine which patients screened for liver disease are likely to have significant fibrosis or more advanced disease. Using a combination of three tests – hyaluronic acid, collagen P3 peptide, and platelet count – an algorithm was developed to triage patients to no fibrosis (green), cirrhosis (red), or an in-between group (amber) in whom interventions could be targeted to impede progression of scarring disease in the liver. Ten thousand people in primary care were contacted by their own GPs and had their alcohol intake assessed. The 10-item WHO AUDIT questionnaire[1] was used to identify hazardous and harmful drinkers, who were then offered the "traffic light" test. Alcohol intake was assessed again after one year. Approximately 650 people were enrolled in the traffic light system:

- just over 30% were assigned to the green category of risk of liver disease;
- just over 40% were assigned to the amber category of risk of liver disease;
- just under 30% were assigned to the red category of risk of liver disease.

After assessment at one year, it was found that the initial categorisation was accurate with respect to not only the proportion of people assigned to each category of risk but also the severity of liver disease attributed to each individual. By identifying people in each category, preliminary results suggest that the higher the risk category identified, the greater is the impact of interventions aimed at reducing alcohol consumption in each group. This and other evidence points to the importance of individualising the information and risk assessment for people at risk of liver disease.

Improving access to specialist services

Specialist services can be difficult for patients to access, and there are only six liver transplant centres in England, often located at a distance from where there are large populations of patients with liver disease. Outreach and satellite services from these centres of excellence are particularly important to ensure that expertise is made more widely available and access is improved. In

1 Babor TF, Higgins-Biddle JC, Saunders JB, Monteiro MG (2001) AUDIT. The Alcohol Use Disorders Identification Test. Guidelines for Use in Primary Care. 2nd edition. World Health Organization. http://whqlibdoc.who.int/hq/2001/who_msd_msb_01.6a.pdf

Plymouth, doctors and surgeons from the transplant team at King's College Hospital, London, run regular clinics for the population of the South West. As a result, assessment for transplantation and post-transplant care can be achieved at a local level without the need for patients to travel to a transplant centre.

Networks of care among service providers:

- ensure the spread of good practice;
- provide an element of peer-review;
- help to provide services at a more local level.

The liver network centred on Plymouth means that all of the hospitals in the South West, and all of the primary-care providers, can have access to the same liver transplant services as described above. Similar network arrangements for liver cancer exist throughout England centred on about 18 hospitals which host specialist multidisciplinary teams. Networks in Manchester and Leeds have developed successful programmes of providing increased access to treatment for hepatitis C in this way, including "in-reach" services to prisons. To address the rising burden of liver disease generally, there needs to be a greater number of local networks. In Yorkshire, a pilot programme involving secondary care services in Leeds and Bradford has been set up to address some of these issues and improve triage and management in primary care.

Surveillance and monitoring in liver disease

One of the principal reasons for follow-up of patients with liver disease in secondary care is to monitor for deterioration or complications. Bearing in mind the numbers of unplanned admissions, a system of routine follow-up appointments is not likely to be effective. Commissioners, clinicians and service providers need:

- to clarify the arrangements and indications for follow-up;
- to ensure that mechanisms are optimised to achieve the intended outcomes.

In Nottingham, a weekly nurse-led cirrhosis clinic began in 2009; to date, there are more than 200 regular patients registered. The clinic is run by a senior nurse specialist and supported by the hepatology consultants.

The aims of the clinic are:

- to improve and standardise the care of stable cirrhosis;
- to release capacity in the consultant clinics.

There is bidirectional flow between the nurse-led clinic and the consultant clinics. The majority of patients have alcohol as the primary aetiology of cirrhosis (80%). At the clinic, the following tasks are undertaken:

- an assessment of the progression of liver disease;
- organisation of the surveillance for the complications arising from cirrhosis;
- support for abstinence;
- provision of advice about nutrition.

The clinic was evaluated recently. After one year, the average Model for End Stage Liver Disease (MELD)[2] score, a measure of liver function and the severity of chronic liver disease, improved from 16.4 to 7.9, and abstinence from alcohol rates increased by 26.8%. When compared with a group of patients, matched by MELD, managed in a doctor-delivered service at another site, abstinence, admission to hospital and survival rates at one year were similar if not better for patients attending the nurse-led clinic.

Surveillance systems to monitor the progression of disease or the development of complications can be used to avoid unplanned admissions, to prevent the unnecessary deterioration of patients' health and to detect progression or cancer at a stage when the disease is still amenable to intervention. The keys to surveillance programmes are the appropriate selection of patients and automating the system such that its purpose is achieved and is not reliant upon the serendipity of follow-up appointments. In Liverpool, an automated surveillance programme for primary liver cancer in patients at risk has improved detection at a potentially curative stage from fewer than 20% to more than 65% of patients overall, and to 90% in the surveillance subgroup. Although the number of patients is small, survival appears to have been improved.

End-of-life care scenarios are difficult for patients, families and clinicians, especially when it becomes obvious that survival will be limited by liver disease, or following deterioration when the poor prognosis

2 Mayo Clinic. The MELD Model: http://www.mayoclinic.org/meld/mayomodel5.html; the MELD Model, UNOS Modification (for implementation in organ allocation for liver transplantation): http://www.mayoclinic.org/meld/mayomodel6.html

becomes acutely apparent. The aim of the Government's End of Life Care Strategy[3] is to address these difficulties. For patients with liver disease, however, there are additional difficulties:

- they die at a relatively young age – 90% die before the age of 65 years whereas 77% of cancer deaths occur over the age of 65 years;
- they often feel there is a stigma attached to their diagnosis of liver disease;
- they can have problematic social circumstances.

The trajectory for liver disease is punctuated by acute exacerbations or complications, for which the patient can be treated, but sometimes the respite is only temporary and patients and carers may need to be better informed about the limits to life-expectancy. The aim of initiatives by Newcastle PCT, or the Amber care programme at King's College Hospital, London, is to address this issue, and these approaches need to be adopted more widely. An end-of-life care practice module entitled "Getting it Right: Improving End of Life Care for People Living with Liver Disease" is now available at: http://www.liver.nhs.uk/publications/.

Patient involvement: shared decision-making

The modern NHS should enable patients to be fully involved in their own healthcare by engaging them in shared decision-making. The involvement of patients in the decision-making process leads to higher satisfaction, improved outcomes, greater knowledge of their condition and increased adherence to treatments.

At University Hospitals Birmingham, patients were provided with the tools to engage in the decision-making process, including access to their own health records, the ability to communicate with patients who have similar conditions and access to appropriate healthcare resources. A shadow hospital IT system was created known as "myhealth@qehb" that included the electronic prescribing and electronic outpatient note-keeping systems, so that patients could view their letters, appointments and blood-test results. As well as being able to access their health records, patients can also communicate with their healthcare team and learn about their long-term condition and its management.

As this system is accessed via the Internet, patients are able to log in at home or when they are on the move. After successful feedback about the pilot, the system went live in July 2012 to patients being treated within the entire liver medicine specialty and also 10 other specialities within the Trust. After this initial roll-out phase, there will be an external evaluation of the project. This is the first such project for patients with liver disease, although patients with kidney disease have experienced the benefits of a similar system, known as Renal Patient*View*[4], for many years.

Even in the absence of an elaborate IT system, support groups are able to provide information and support to patients and their families. There are many examples across England of valuable support services provided for people with liver disease or for particular subsets of patients with liver disease. Some support services, in particular specialist nurse services, have been set up and are maintained by patient charities and others by secondary care service providers. Commissioners may wish to take account of the added value generated by such groups when giving feedback on the support services that have been commissioned for a locality.

3 Department of Health (2008) End of Life Care Strategy – promoting high quality care for all adults at the end of life. http://www.dh.gov.uk/health/2011/07/end-of-life-care-strategy/ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

4 http://www.renalpatientview.org

Glossary of Terms Relating to Liver Disease

Acamprosate

Acamprosate is a medication used to help maintain abstinence in people who have successfully overcome drinking problems.

Ascites

Ascites is the accumulation of fluid in the abdomen. It is a complication of advanced liver disease.

Blood-borne viruses (BBVs)

Hepatitis B and hepatitis C are two of the most common blood-borne viruses. The viruses are found in blood and other body fluids in varying amounts. Other BBVs include human immunodeficiency virus (HIV) and the other hepatitis viruses.

Body mass index (BMI)

See also ***Overweight*** *and* ***Obesity***

Body mass index is a measure of body fat, calculated by dividing a person's weight in kilograms by their height in metres squared. An alternative measure is visceral fat storage, which can be ascertained by measuring waist circumference.

Child–Pugh score

The Child–Pugh score, or the Child–Pugh grade, can be used in patients with liver cirrhosis to assess the severity of the clinical condition. Five variables are considered (severity of ascites and of encephalopathy, abnormality in the serum bilirubin, serum albumin and clotting times), and a score (of between 1 and 3) is accordingly assigned to each of these factors. The sum of the scores provides the Child–Pugh score, which corresponds to a Child–Pugh grade (or Child's grade) of A, B or C. This grade is used as a general means to verify the prognosis of the patient. For example, it can be used to determine the risk to a patient with regard to possible surgery, and also, to suggest the perceived survival of the patient over a period of time. Pharmaceutical manufacturers may use the Child–Pugh grade to suggest dose reductions, or to contraindicate the use of the drug, dependent on the degree of dysfunction of the cirrhotic liver.

Source: Iqbal A (2012) What is the Child–Pugh score? National electronic Library for Medicines. http://www.nelm.nhs.uk/en/NeLM-Area/Evidence/Medicines-Q--A/What-is-the-Child-Pugh-score/

Cholecystectomy

Cholecystectomy is the surgical removal of the gallbladder. It is one of the most common operations performed by the NHS. More than 60,000 gallbladder removals are performed each year.

Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy is a therapeutic approach that changes maladaptive thinking to lead to a change in effect and behaviour.

Cirrhosis

Cirrhosis is widespread scarring of the liver as a result of continuous, long-term liver damage. Scar tissue replaces healthy tissue in the liver and prevents the liver from working properly. The damage caused by cirrhosis is permanent and cannot be reversed. Cirrhosis increases the risk of liver failure, internal bleeding and development of liver cancer.

Delirium tremens

Delirium tremens is a severe form of alcohol withdrawal that involves sudden and severe mental or nervous system changes.

Dependent drinking

See also ***Harmful drinking*** *and* ***Hazardous drinking***

Alcohol is habit-forming both physically and psychologically. Being dependent on alcohol means that a person feels they are unable to function without alcohol. Severely dependent drinkers usually experience severe withdrawal symptoms, and can fall into a pattern of "relief drinking", whereby drinking occurs in order to avoid withdrawal symptoms. Severely dependent drinkers are often able to tolerate very high levels of alcohol.

Disulfiram

Disulfiram is a medication used as a deterrent to drinking alcohol. It is prescribed together with other treatments in alcohol dependence.

Encephalopathy

Hepatic encephalopathy is the occurrence of confusion, altered level of consciousness, and coma as a result of liver disease.

End-stage liver disease (ESLD)

End-stage liver disease is an irreversible condition that leads to the imminent complete failure of the liver. It is often a consequence of chronic liver diseases, and is one of the most extended causes of death in the Western hemisphere. The most common causes of chronic liver disease are alcohol, obesity and viral hepatitis.

Endoscopic retrograde cholangiopancreatography (ERCP)

Endoscopic retrograde cholangiopancreatography is a procedure to investigate problems in the bile duct or pancreatic duct using a flexible telescope and X-ray dye. Gallstones in the bile duct or a narrowing of the bile duct are common problems, both of which can cause jaundice (in which the skin turns yellow).

Haemochromatosis

Haemochromatosis is the result of too much iron in the body. It is also called iron overload. Untreated, iron overload can lead to liver damage. Extra iron may also build up in other areas of the body, including the thyroid gland, testicles, pancreas, pituitary gland, heart, or joints. Early treatment can help to prevent complications such as liver disease, heart disease, arthritis or diabetes.

Harmful drinking

See also ***Dependent drinking*** *and* ***Hazardous drinking***

Harmful drinking is when a person experiences health problems that are directly related to alcohol. These include high blood pressure (hypertension), cirrhosis (scarring of the liver), some types of cancer, such as mouth cancer and bowel cancer, and heart disease. Many of the health problems that occur as a result of harmful drinking do not cause any symptoms until they reach their most serious stages. This means it can be easy to under-estimate the levels of physical damage caused by harmful drinking.

Hazardous drinking

See also ***Dependent drinking*** *and* ***Hazardous drinking***

Hazardous drinking is when a person drinks more than the recommended weekly amount of alcohol (21 units per week for men and 14 units for women). Drinking below these levels is regarded as safe. In some cases, there may be obvious problems such as depression. Consuming alcohol can be an unwisely chosen coping mechanism for life-events or may simply be habitual.

Hepatocellular carcinoma (HCC)

Hepatocellular carcinoma is also sometimes called hepatoma. It is the most common type of primary liver cancer. This type of liver cancer develops from the main liver cells and is usually confined to the liver, although occasionally it spreads to other organs. It is most common in people who have a damaged liver from cirrhosis.

Hepatitis B

Hepatitis B is a viral infection of the liver. In adults, the virus can cause an acute illness that usually resolves quickly without causing long-term liver damage. However, when acquired in infancy or early childhood, the infection becomes chronic in 90% of individuals who are most at risk of developing liver disease as adults. In 15–40% of people with chronic infection, cirrhosis, liver cancer or liver failure will develop, and so the infection may eventually be fatal.

Hepatitis C

Hepatitis C is an infectious disease caused by the hepatitis C virus (HCV). The virus causes inflammation of the liver and, when left untreated, can result in chronic liver disease, liver failure, or even death. As the liver is able to work even when damaged, many people are unaware they have the disease at first because they have no symptoms. In the UK, people who inject drugs are the main group at risk of infection from hepatitis C. There is no vaccination to prevent hepatitis C and infection remains chronic in approximately 75% of people.

Hepatitis C antibody test, polymerase chain reaction (PCR) test and genotyping

Hepatitis C antibody tests detect the presence of antibodies to the virus, indicating exposure to hepatitis C. These tests cannot identify whether there is an active viral infection, only that someone was exposed to the virus in the past. A polymerase chain reaction (PCR) test identifies whether the virus is present in the blood, indicating there is an active infection with HCV. Viral genotyping is used to determine the kind, or genotype, of the virus present. There are 6 major types of hepatitis C virus: the most common is genotype 1, which is less likely to respond to treatment than genotypes 2 or 3 and usually requires longer-term therapy. Genotyping is often ordered before the start of treatment to indicate the likelihood of success and the length of time for which treatment may be needed.

Hepatorenal syndrome

Hepatorenal syndrome is a condition in which there is progressive kidney failure in a person with cirrhosis of the liver. It is a serious and often life-threatening complication of cirrhosis.

Non-alcoholic fatty liver disease (NAFLD)

Non-alcoholic fatty liver disease (NAFLD) is the term for a wide range of conditions caused by an accumulation of fat within the liver cells. It is usually seen in people who are overweight or obese.

Obesity

See also ***Body mass index*** *and* ***Overweight***

Obesity is when a person is carrying excess body fat, usually detected by assessing their weight in relation to their height, i.e. they have a body mass index (BMI) of 30 kg/m^2 or greater. A person is considered to be obese when they have a body mass index of between 30 kg/m^2 and 39.9 kg/m^2; if their body mass index is >40 kg/m^2, they are considered to be "morbidly obese". Morbid obesity confers a very significant risk of adverse health. Obesity can cause Type 2 diabetes (when there is excess glucose in the blood), heart disease (when the heart's blood supply is blocked) and liver disease. If using the alternative measure of visceral fat storage (size of waist circumference), men are considered at risk of abdominal obesity if their waist circumference is >94 cm, and women are considered at risk if their waist circumference is >80 cm (37 inches and 32 inches, respectively).

Oesophageal varices

Oesophageal varices are abnormal, enlarged veins in the lower part of the oesophagus – the tube that connects the throat and stomach. Oesophageal varices occur most often in people with serious liver diseases.

Overweight

See also ***Body mass index*** *and* ***Obesity***

A person is considered overweight when they have a body mass index (BMI) of between 25 kg/m^2 and 29.9 kg/m^2.

Pancreatitis

Pancreatitis is inflammation of the pancreas. The pancreas is a gland located behind the stomach. Acute pancreatitis is sudden swelling and inflammation of the pancreas. The condition is most often caused by alcoholism and alcohol abuse. There are other causes including bile duct stones, damage after ERCP and auto-immune factors. Most cases resolve in one week. However, some cases develop into a life-threatening illness.

Spironolactone

Spironolactone is a diuretic (also known as a water tablet), commonly used to treat fluid build-up (oedema and ascites) in patients with liver disease. Spironolactone is a potassium-sparing diuretic because, unlike some other diuretics, it does not cause the body to lose potassium.

Sustained virological response (SVR)

Sustained virologic response is the goal of hepatitis C treatment; it means there is no detectable virus in the blood on completion of treatment. Studies have shown that with a six-month SVR (i.e. no detectable virus in the blood for 6 months after finishing treatment), relapse occurred in only 1–2% of patients.

Wernicke's encephalopathy

Wernicke's encephalopathy is a disease resulting from thiamine deficiency. The classic symptoms are confusion, imbalance and paralysis or weakness of the eye muscles. Unless treated, it progresses to a permanent psychosis.

Glossary of Essential Terms

Introduction

Much of the disagreement that occurs during the commissioning or management of services arises because different people use the same term but have a different understanding of its meaning. This Glossary is provided to help develop a shared or common language. If there is a clear, short or memorable definition from the literature, this has been cited and presented in italics; where definitions in the literature do not meet any of these criteria, Right Care has composed and provided a definition.

Access to healthcare

Facilitating access is concerned with helping people to command appropriate health care resources in order to preserve or improve their health. There are at least four aspects.

1. *If services are available, in terms of adequate supply of services, then a population may 'have access' to health care.*
2. *The extent to which a population 'gains access' to health care also depends on financial, organisational and social or cultural barriers that limit utilisation. Thus utilisation is dependent on the affordability, physical accessibility and acceptability of services and not merely the adequacy of supply.*
3. *The services available must be relevant and effective if the population is to 'gain access to satisfactory health outcomes'.*
4. *The availability of services, and barriers to utilisation, have to be evaluated in the context of differing perspectives, health needs and the material and cultural settings of diverse groups in society.*

Source: Gulliford M et al (2001) *Access to Health Care. Report of a Scoping Exercise for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO).* http://www.netscc.ac.uk/hsdr/files/project/SDO_ES_08-1009-005_V01.pdf

Appropriate

A procedure is termed appropriate if its benefits sufficiently outweigh its risks to make it worth performing …

Source: Kahan JP et al (1994) Measuring the necessity of medical procedures. *Medical Care* 32: 352-365.

Audit

While inspection has traditionally focused on organizational systems and processes, rather than the assessment of internal control systems, audit has usually been the mechanism for examining internal controls (…). However, audit is more associated with stewardship of resources, whereas inspection traditionally is primarily concerned with 'professional and service standards' (…).

Source: Scrivens E (2005) *Quality, Risk and Control in Health Care*. Open University Press (page 128).

Average, *see* ***Mean***

British National Formulary (BNF)

The British National Formulary is a joint publication of the British Medical Association and the Royal Pharmaceutical Society. It provides prescribers, pharmacists and other healthcare professionals with up-to-date information about the use of medicines.

Burden of disease

The burden of disease is a measurement of the gap between a population's current health and the optimal state where all people attain full life expectancy without suffering major ill-health.

Source: World Health Organization. Health Promotion Glossary Update. [Modified definition (WHO, 2000).] http://www.who.int/healthpromotion/about/HPR%20Glossary_New%20Terms.pdf

Care pathway

... the expected course of events in the care of a patient with a particular condition, within a set timescale.

Source: Kitchiner D, Davidson D, Bundred P (1996) Integrated Care Pathways: effective tools for continuous evaluation of clinical practice. *J Eval Clin Pract* 2; 65-69.

Clinical guidelines

Systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific circumstances.

Source: Cited in Thompson C, Dowding D (2002) *Clinical Decision Making and Judgement in Nursing* Elsevier Limited (page 148).

Commissioner

... to be the advocate for patients and communities, securing a range of appropriate high-quality health care services for people in need [and] to be the custodian of tax-payers' money; this brings a requirement to secure best value in the use of resources.

Source: House of Commons Health Committee (2010) Commissioning. Fourth Report of Session 2009-10. Volume 1. http://www.publications.parliament.uk/pa/cm200910/cmselect/cmhealth/268/268i.pdf

Commissioning

Commissioning in the NHS is the process of ensuring that the health and care services provided effectively meet the needs of the population. It is a complex process with responsibilities ranging from assessing population needs, prioritising health outcomes, procuring products and services, and managing service providers.

Source: Department of Health (2010) Commissioning [Archived content]. http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/managingyourorganisation/commissioning/index.htm

Confidence intervals

Confidence intervals give the range within which the true size of a treatment effect (which is never precisely known) lies, with a given degree of certainty (usually 95% or 99%).

Source: Evans I, Thornton H, Chalmers I (2006) *Testing Treatments. Better Research for Better Healthcare.* The British Library.

Costs

Cost is not solely financial. Cost may be measured as the time used, the carbon produced, or the benefit that would be obtained if the resources were used for another group of patients (i.e. the opportunity cost).

Credible intervals

A credible interval (or Bayesian confidence interval) is an interval in the domain of a posterior probability distribution used for interval estimation.

Source: Edwards W, Lindman H, Savage LJ (1963) Bayesian statistical inference in statistical research. *Psychological Review* 70; 193-242.

Culture

Culture is the shared tacit assumptions of a group that it has learned in coping with external tasks and dealing with internal relationships.

Source: Schein EH (1999) *The Corporate Culture Survival Guide*. John Wiley & Sons (page 186).

Deprivation

Deprivation is a concept that overlaps, but is not synonymous with poverty. Absolute poverty can be defined as the absence of the minimum resources for physical survival, whereas relative poverty relates to the standards of living in a particular society at a specific time. The different concepts of deprivation include the following:

- *Material deprivation, which reflects the access people have to material goods and resources. Access to these goods and resources enables people "to play the roles, participate in relationships and follow the customary behaviour which is expected of them by virtue of their membership in society" (as described by Townsend).*
- *Social deprivation has been separately distinguished as relating to people's roles and relationships, membership and social contacts in society.*
- *Multiple deprivation relates to the occurrence of several forms of deprivation concurrently, such as low income, poor housing, and unemployment. This can be particularly stressful for families.*

Source: http://www.show.scot.nhs.uk/publications/isd/deprivation_and_health/background.HTM

Effective care

The extent to which an intervention, procedure regimen, or service produces a beneficial outcome under ideal circumstances (e.g., in a randomized controlled trial).

Source: Canadian Agency for Drugs and Technologies in Health (2009) *Optimal Therapy Report: Cost effectiveness of blood glucose test strips in the management of adult patients with diabetes mellitus*. Volume 3, Issue 3.

Efficiency

See also ***Productivity***

… efficiency can be defined as maximising well-being at the least cost to society.

Source: Mitton C, Donaldson C (2004) *Priority setting toolkit. A guide to the use of economics in healthcare decision making*. BMJ Publishing Group.

Equity

Equity is a subjective judgment of fairness.

Evidence

Evidence is generally considered to be information from clinical experience that has met some established test of validity, and the appropriate standard is determined according to the requirements of the intervention and clinical circumstance. Processes that involve the development and use of evidence should be accessible and transparent to all stakeholders.

Source: Olsen LA, Goolsby WA, McGinnis JM; Roundtable on Evidence-Based Medicine (2009) *Leadership Commitments to Improve Value in Health Care: Finding Common Ground: Workshop Summary*. National Academies Press. Free to download at: http://www.nap.edu/catalog.php?record_id=11982

Health

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

Source: Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19 June–22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. The definition has not been amended since 1948. http://www.who.int/suggestions/faq/en/index.html

Health needs

… objectively determined deficiencies in health that require health care, from promotion to palliation.

Source: World Health Organization (WHO) Health Systems Strengthening Glossary. http://www.who.int/healthsystems/hss_glossary/en/index.html

Healthy life-expectancy

See also ***Life-expectancy*** *and* ***Life-expectancy at birth***

Average number of years that a person can expect to live in "full health" by taking into account years lived in less than full health due to disease and/or injury.

Source: World Health Organization (WHO) Health statistics and health information systems. Health Status Statistics: Mortality. http://www.who.int/healthinfo/statistics/indhale/en/

Index of Multiple Deprivation (IMD) 2010

See also ***Deprivation***

The Index of Multiple Deprivation 2010 (IMD 2010) is a measure of multiple deprivation at the small area level. The model of multiple deprivation which underpins the IMD 2010 is … based on the idea of distinct dimensions of deprivation which can be recognised and measured separately. These are experienced by individuals living in an area. People may be counted as deprived in one or more of the dimensions, depending on the number of types of deprivation that they experience. The overall Index of Multiple Deprivation is conceptualised as a weighted area level aggregation of these specific dimensions of deprivation.

Source: McLennan D, Barnes H, Noble M, Davies J, Garratt E, Dibben C (2011) The English Indices of Deprivation 2010. Department for Communities and Local Government. https://www.gov.uk/government/publications/english-indices-of-deprivation-2010-technical-report

Inequalities in health

Inequalities in health are objectively measured differences in health status, healthcare access and health outcomes.

Input, Output and Outcome

Input is a term used by economists to define the resources used, such as the number of hospital beds, to produce the output, such as the number of patients admitted per bed per year.

The economists' terminology is different from the language utilised in quality assurance, in which the terms structure, process and outcome are used. Input equates to structure and process, i.e. the number of beds and the number of admissions per bed, respectively. However, the outcome is distinct from the output. Outcome includes some measure of the effect the process has had on the patients, for example, the number of patients who were discharged to their own home.

Integrated care

Clinical integration, where care by professionals and providers to patients is integrated into a single or coherent process within and/or across professions such as through use of shared guidelines and protocols.

Source: Kodner DL, Spreeuwenberg C (2002) Integrated care: meaning, logic, applications and implications – a discussion paper. *International Journal of Integrated Care* 2: 1-6.

International Classification of Diseases (ICD)

The International Classification of Diseases is the standard diagnostic tool for epidemiology, health management and clinical purposes. This includes the analysis of the general health situation of population groups. It is used to monitor the incidence and prevalence of diseases and other health problems.

It is used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and health records. In addition to enabling the storage and retrieval of diagnostic information for clinical, epidemiological and quality purposes, these records also provide the basis for the compilation of national mortality and morbidity statistics by WHO Member States. It is used for reimbursement and resource allocation decision-making by countries.

ICD-10 was endorsed by the Forty-third World Health Assembly in May 1990 and came into use in WHO Member States as from 1994. The 11th revision of the classification has already started and will continue until 2015.

Source: World Health Organization. International Classification of Diseases (ICD).
http://www.who.int/classifications/icd/en/

Life-expectancy

See also ***Healthy life-expectancy*** *and* ***Life-expectancy at birth***

Life-expectancy at a specific age is the average number of additional years a person of that age could expect to live if current mortality levels observed for ages above that age were to continue for the rest of that person's life.

Source: Population Division, DESA, United Nations. *World Population Ageing 1950–2050*, Annex 1.
http://www.un.org/esa/population/publications/worldageing19502050/pdf/95annexi.pdf

Life-expectancy at birth

See also ***Healthy life-expectancy*** *and* ***Life-expectancy***

... , life-expectancy at birth is the average number of years a newborn would live if current age-specific mortality rates were to continue.

Source: Population Division, DESA, United Nations. *World Population Ageing 1950–2050*, Annex 1.
http://www.un.org/esa/population/publications/worldageing19502050/pdf/95annexi.pdf

Mean (average)

The mean is the sum of values, e.g. size of populations, divided by the number of values, e.g. number of populations in the sample.

Medical care epidemiology

... studies the use of health care services among populations living within the geographic boundaries of "natural" health care [populations].

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

Network

If a system is a set of activities with a common set of objectives, the network is the set of organisations and individuals that deliver the systems.

Outcome, *see* ***Input***

Output, *see* ***Input***

Patient decision aid

Patient decision aids are … intended to supplement rather than replace patient–practitioner interaction. They may be leaflets, interactive media, or video or audio types. Patients may use them to prepare for talking with a clinician, or a clinician may provide them at the time of the visit to facilitate decision making. At a minimum, patient decision aids provide information about the options and their associated relevant outcomes.

Source: Elwyn G (2006) Developing a quality criteria framework for patient decision aids; online international Delphi Consensus process. *British Medical Journal*, 333: 417-427.

Population medicine

Population medicine is a style of clinical practice in which the clinician is focused not only on the individual patients referred but also on the whole population in need.

Preference-sensitive care

… elective, or "preference-sensitive" care, interventions for which there is more than one option and where the outcomes will differ according to the option used because patients delegate decision making to doctors, physician opinion rather than patient preference often determines which treatment patients receive. I argue that this can result in a serious but commonly overlooked medical error: operating on the wrong patients – on

those who, were they fully informed, would not have wanted the operation they received.

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

Preference-sensitive treatment decisions

Preference sensitive treatment decisions involve making value trade-offs between benefits and harms that should depend on informed patient choice.

Source: O'Connor AM et al (2007) Toward the 'Tipping Point': Decision aids and informed patient choice. *Health Affairs* 26: 716-725.

Productivity

See also ***Efficiency***

Productivity is the relationship between inputs and outputs, such as the number of operations per theatre per year; efficiency is the relationship between outcomes and inputs, such as the number of successful operations per theatre per year.

Protocol

… protocols are the descriptions of steps taken to care for and treat a patient. They are sometimes called the 'integrated care pathway' and are designed to:

- *Implement national standards such as national service frameworks and guidelines and appraisals produced by the National Institute for [Health and] Clinical Excellence (NICE)*
- *Determine care provision by using best available evidence if national standards are not available*

… They identify who carries out key parts of the care or treatment and where they should be delivered.

Source: NHS Institute for Innovation and Improvement. Quality and Service Improvement Tools. Protocol Based Care. http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/protocol_based_care.html

Quality

Quality is the degree to which a service meets pre-set standards of goodness.

Source: Donabedian A, personal communication.

Quality of life[1]

… individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment.

Source: World Health Organization (WHO) Programme on Mental Health. WHOQOL: Measuring Quality of Life. The World Health Organization Quality of Life Instruments (The WHOQOL-100 and the WHOQOL-BREF). http://www.who.int/mental_health/media/68.pdf

Range

The range is the difference between the highest and lowest value in the sample. The range provides a crude measure of the spread of the data.

Safety

Patient safety can, at its simplest, be defined as: The avoidance, prevention and amelioration of adverse outcomes or injuries stemming from the process of healthcare. … the reduction of harm should be the primary aim of patient safety, not the elimination of error.

Source: Vincent C (2006) *Patient Safety*. Churchill Livingstone.

Self-management

… self-management is especially important for those with chronic disease, where only the patient can be responsible for his or her day-to-day care over the length of the illness. For most of these people self-management is a lifetime task.

Source: Lorig KR, Holman HR (2003) Self-Management Education: History, Definition, Outcomes, and Mechanisms. *Annals of Behavioural Medicine* 26; 1-7. doi 10.1207/S153124796ABM2601_01

Shared decision-making

In a shared decision, a health care provider communicates to the patient personalized information about the options, outcomes, probabilities, and scientific uncertainties of available treatment options, and the patient communicates his or her values and the relative importance he or she places on benefits and harms.

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

1 Examples of other quality of life definitions can be found at: http://www.scotland.gov.uk/Publications/2006/01/13110743/11

Standard deviation

See also ***Variance***

The standard deviation is a measure of spread, and is the square root of the variance.

Standards

A minimum level of acceptable performance or results or excellent levels of performance or the range of acceptable performance or results.

Source: Kohn LT, Corrigan JM, Donaldson MS (eds) Committee on Quality of Health Care in America, Institute of Medicine (2000) *To Err is Human. Building a Safer Health System.* National Academy Press, Washington.

Structure

Structure comprises the inter-relation of healthcare facilities through which health services are provided. Healthcare is a localised activity, provided by the organisations that form the general healthcare structure, including hospitals, GP practices, clinics, ambulatory care, rehabilitation centres, home care and long-term-nursing care.

Supply-sensitive care

It differs in fundamental ways from both effective care and preference-sensitive care. Supply-sensitive care is not about a specific treatment per se; rather, it is about the frequency with which everyday medical care is used in treating patients with acute and chronic illnesses. Remedying variation in supply-sensitive care requires coming to terms with the "more care is better" assumption. Are physician services and hospitals in high-cost, high-use regions overused?

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

System

A system is a set of activities with a common set of objectives for which an annual report is produced.

Unwarranted variation

Variation in the utilization of health care services that cannot be explained by variation in patient illness or patient preferences.

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

Value

… value is expressed as what we gain relative to what we give up – the benefit relative to the cost.

Source: Institute of Medicine of the National Academies (2008) Learning Healthcare System Concepts v. 2008. The Roundtable on Evidence-Based Medicine, Institute of Medicine. Annual Report.

Value for money

Value for money is achieved *"by focusing on the productivity of staff and on prevention rather than cure, as well as by carefully allocating resources to people in greatest need and by adopting the most effective approaches."*

Source: The Cabinet Office (2008) Excellence and fairness: achieving world class public services (page 12).

Variation

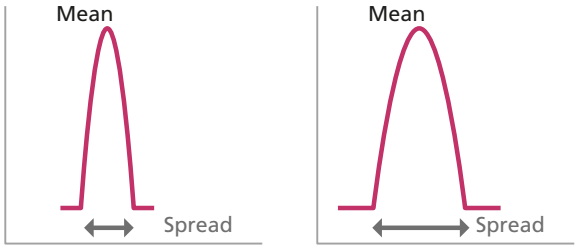
Everything we observe or measure varies. Some variation in healthcare is desirable, even essential, since each patient is different and should be cared for uniquely. New and better treatments, and improvements in care processes result in beneficial variation.

Source: Neuhauser D, Provost L, Bergman B (2011) The meaning of variation to healthcare managers, clinical and health-services researchers, and individual patients. *BMJ Qual Saf* 20 (Suppl 1); i36-i40. doi: 10.1136/bmjqs.2010.046334

Variance

See also ***Range***

The variance is another measure of spread, which describes how far the values in the sample lie away from the mean value. It is the average of the squared differences from the mean and is a better measure of spread than the range.



This figure illustrates how two populations may have the same mean value, but different degrees of variation or spread: the second population shows greater variation than the first.

Glossary of Organisations

Clinical commissioning groups (CCGs)

Clinical commissioning groups (CCGs) are groups of general practitioners (GPs) which, from April 2013, will be responsible for planning and designing local health services in England. They will commission a range of health and care services including planned hospital care, urgent and emergency care, rehabilitation care, community health services, and mental health and learning disability services. Clinical commissioning groups will retain legal accountability and responsibility for meeting their statutory functions, and commissioning decisions cannot be delegated to other organisations.

Department of Health (DH)

The Department of Health (DH) is the government department responsible for improving England's health and well-being. It provides strategic leadership for public health, the NHS and adult social care in England.

Health Protection Agency (HPA)

The Health Protection Agency (HPA) is an independent organisation set up in 2003 to protect the public from threats to health from infectious diseases and environmental hazards. It provides advice and information to the general public, to health professionals and to national and local government. From April 2013, the HPA will become part of Public Health England (PHE).

Health and Wellbeing Boards (HWBs)

Health and wellbeing boards (HWBs) will bring together local commissioners across the NHS, public health and social care, elected representatives and representatives of HealthWatch to deliver integrated health and care services with the aim of improving the health and wellbeing of people in their area. Shadow health and wellbeing boards will be in place from April 2012. Fully fledged boards will commence operation in April 2013.

NHS Commissioning Board (NHS CB)

The NHS Commissioning Board (NHS CB) plays a key role in the Government's vision to modernise the health service with the aim of securing the best possible health outcomes for patients by prioritising them in every decision it makes. Formally established as an independent body, at arm's length to the Government, on 1 October 2012, it will carry forward the preparatory work begun as the NHS Commissioning Board Authority while taking on initial statutory responsibilities. Notable among these responsibilities is the authorisation of clinical commissioning groups (CCGs), the drivers of the new, clinically led commissioning system introduced by the Health and Social Care Act 2012. The NHS Commissioning Board will take up its full statutory duties and responsibilities on 1 April 2013.

NHS Commissioning support units (CSUs)

NHS Commissioning support units (CSUs) are being designed to offer an efficient locally sensitive and customer-focussed service to clinical commissioning groups (CCGs), which are likely to need support for:

- Transformational commissioning functions, e.g. service re-design;
- Transactional commissioning functions, e.g. market management, healthcare procurement, contract negotiation and monitoring, information analysis and risk stratification.

NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme

The NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme in England is responsible for ensuring that all pregnant women are routinely offered screening for hepatitis B, HIV, syphilis and susceptibility to rubella infection. The aim of this Programme is to ensure that women with hepatitis B, HIV and syphilis are identified and offered appropriate assessment and management for their health, as well as ensuring that strategies are put in place to reduce the risk of mother-to-child transmission of these conditions. In addition, the Programme identifies women susceptible to rubella, for whom post-natal MMR vaccination could protect future pregnancies.

National Institute for Health and Clinical Excellence (NICE)[2]

The National Institute for Health and Clinical Excellence (NICE) was set up to help professionals working in the NHS, local authorities and the wider community deliver high-quality healthcare. It develops evidence-based guidelines on the most effective ways to diagnose, treat and prevent disease and ill-health; it also publishes patient-friendly versions of these guidelines which can help to educate and empower patients and carers. NICE also sets quality standards which define high-quality care for a specific disease, condition or clinical area.

National Treatment Agency for Substance Misuse (NTA)

The National Treatment Agency for Substance Misuse (NTA) was created as a Special Health Authority in 2001 to improve the availability, capacity and effectiveness of drug treatment in England. The NTA ensures that treatment services in England deliver on both the public health and criminal justice agendas, reflecting the interests of the Department of Health, responsible for funding the NHS as well as public health services, and the Home Office, the lead Whitehall department on drugs policy and crime reduction. The NTA allocates central funding, provides support and guidance to local areas, and measures outcomes to ensure value for money. In 2013, the critical functions of the NTA will be transferred to Public Health England (PHE).

Public Health England (PHE)

Public Health England (PHE) will be operational from April 2013. It will work collaboratively to provide a range of health protection services across the country. Public Health England will provide both strong strategic leadership and lead on the vision for the protection and improvement of the public's health. It will play a key role in health protection services, establishing and maintaining internationally benchmarked best practice, while also providing professional advice to Government, local authorities, the NHS, the devolved administrations and internationally. Through the health improvement and population health directorate, PHE will also be responsible for the development of a 21st century health and wellbeing service, supporting local authorities and the NHS to deliver the greatest possible improvements in the public's health, and acting as professional advocate for the public's health. Additionally, PHE will deliver an internationally recognised, high-performing evidence and intelligence service encompassing research, statistics and know-how. This knowledge will inform and support the practice of public health and drive improvements in the public's health. PHE will also design, develop and implement cross-cutting programmes, commissioning services from statutory and third sector bodies.

1 In 2013, NICE will keep its acronym but change its name to the National Institute for Health and Care Excellence.

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Alexander Gimson
Stephen Green
Andrew Hughes
Rachel Johnson
Kevin Watson

MAP 7
Stephen Green
Andrew Hughes
Rachel Johnson
James Neuberger
Chris Rudge

MAP 8
Alexander Gimson
Stephen Green
Erica Ison
Andrew Hughes
Rachel Johnson
Chris Rudge

MAP 9
Erica Ison
Stephen Green
Caryl Beynon
Diane Draper
Chris Gibbins
Clive Henn
Robert Phillips
Alanna Wolff

MAP 10
Stephen Green
Caryl Beynon
Chris Gibbins
Clive Henn
Don Lavoie
Michela Morleo

MAP 11
Stephen Green
Caryl Beynon
Chris Gibbins
Clive Henn
Don Lavoie
Michela Morleo
Robert Phillips
Kevin Watson

MAPS 12–14
Stephen Green
Sue Faulding
Andrew Hughes
David Lloyd
Rosemary Matheson
Kevin Watson

MAP 15
Stephen Green
Fortune Ncube
Hilary Phelps
Sandra Smith
Suzan Trienekens

MAP 16
Stephen Green
John Hastings
Autilia Newton
Eamonn O'Moore
Cathie Railton

MAP 17
Stephen Green
Mary Ramsay
Joanne White

MAP 18
Stephen Green
Koye Balogun
Mary Ramsay

MAP 19
Stephen Green
Helen Harris
Mary Ramsay

MAP 20
Stephen Green
Gordon Hay
Vivian Hope
Fortune Ncube
Kevin Shelton

MAP 21
Stephen Green
Mary Ramsay
Malcolm Roxburgh
Kevin Shelton
John Newton

MAP 22
Stephen Green
Sarah Collins
Sam Lattimore
Mary Ramsay
Malcolm Roxburgh
Kevin Shelton
John Newton

MAP 23
Stephen Green
Sarah Collins
John Hastings
Sam Lattimore
Autilia Newton
Eamonn O'Moore
Cathie Railton
Mary Ramsay

MAPS 24 AND 25
Stephen Green
Clint Botha
Richard Burns
Annastella Costella
Helen Harris
Steve Mason
Mary Ramsay
Matt Stone
Brenda Thomas

MAPS 26 AND 27
Stephen Green
Annastella Costella
Helen Harris
Mary Ramsay

MAP 28
Stephen Green
Caroline Hancock
Caroline Ridler
Harry Rutter

MAP 29
Stephen Green
Caroline Hancock
Andrew Hughes
Caroline Ridler
Harry Rutter
Kevin Watson

MAP 30
Stephen Green
Caroline Hancock
Andrew Hughes
Caroline Ridler
Harry Rutter

MAP 31
Douglas McWhinnie
Muir Gray
Mark Skues
Stephen Green
Andrew Hughes
Kevin Watson

MAP 32
Mark Skues
Heather Walker

MAP 33
Stephen Green
Kevin Watson
James Ferguson

MAP 34
Stephen Green
Andrew Austin
Paul Edwards
Adam Lawson
Stephen Ryder
Mark Skues

MAP 35
Stephen Green
Victoria Coupland
Andrew Hughes

MAP 36
Stephen Green
John O'Grady
Kevin Watson

MAP 37
Stephen Green
Vanessa Fearn
Laura Mulcahy
Kevin Watson

MAP 38
Stephen Green
Gifford Batstone
Ed Cate
Erica Ison
Rick Jones
Simon Richards

INNOVATION AND MODELS OF GOOD PRACTICE
Geoffrey H Haydon
Sally Bufton
Katrina O'Donnell
David Mutimer
James Ferguson
Helen Caldwell
Martin Lombard
Diane Exeley
Jayne Wilkie
Simon Bowers
Nick Stern
Paul Richardson
Matthew Cramp
Amanda Clements
Graham Foster
Mark Hudson
Elizabeth Kendrick
Steve Ryder
Kieran Moriarty
Martin Smith
Nick Sheron

GLOSSARY OF ESSENTIAL TERMS
Muir Gray
Erica Ison
Anant Jani
Mehrunisha Suleman
James Ferguson

GLOSSARY OF TERMS RELATING TO LIVER DISEASE AND GLOSSARY OF ORGANISATIONS
James Ferguson

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From 1 April 2013, NHS Liver Care will become part of NHS Improving Quality.

Information and resources can still be accessed at:

www.livermatters.nhs.uk

www.liver.nhs.uk

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