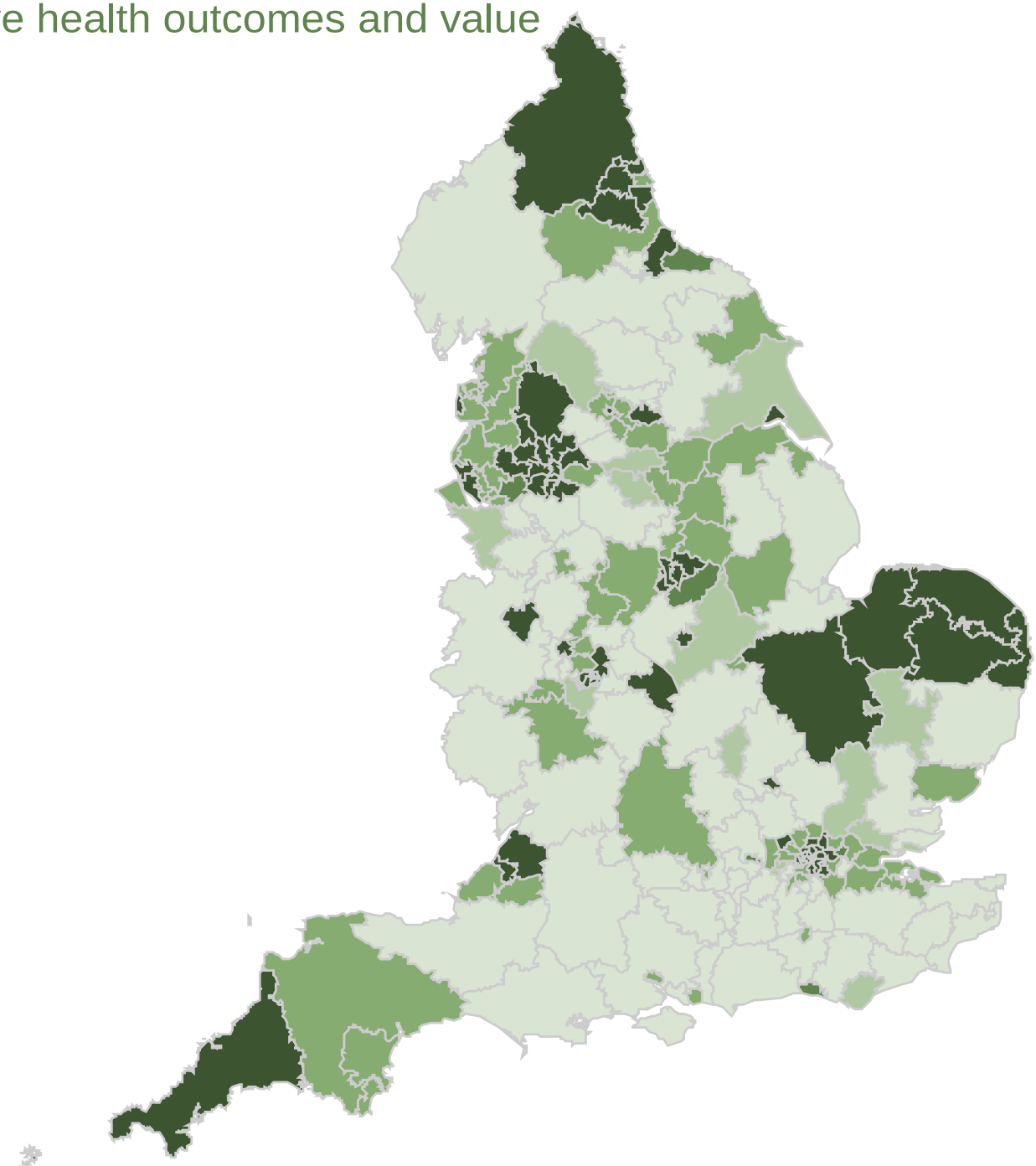
Public Health England

NHS RightCare

The 2nd Atlas of variation in risk factors and healthcare for liver disease in England

September 2017

Reducing unwarranted variation to improve health outcomes and value



http://fingertips.phe.org.uk/profile/atlas-of-variation

www.england.nhs.uk/rightcare

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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The 2nd Atlas of variation in risk factors and healthcare for liver disease in England

Reducing unwarranted variation to improve health outcomes and value

The 2nd Atlas of variation in risk factors and healthcare for liver disease in England has been prepared in partnership with a wide range of organisations:

Public Health England

Public Health England (PHE) exists to protect and improve the nation's health and wellbeing and reduce health inequalities. It does this through advocacy, partnerships, world-class science, knowledge and intelligence, and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.
www.gov.uk/phe

The **Cover of Vaccination Evaluated Rapidly (COVER)** surveillance scheme evaluates the childhood immunisation programme in England. In addition, Public Health England (PHE) in collaboration with the National Public Health Service for Wales, Public Health Agency, Northern Ireland and Health Protection Scotland, reports UK immunisation coverage data for children aged one, two and five years of age.
www.gov.uk/government/publications/cover-of-vaccination-evaluated-rapidly-cover-programme-information-standards

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The **National Drug Treatment Monitoring System (NDTMS)** collects, collates and analyses information from and for those involved in the drug treatment sector. The NDTMS is a development of the Regional Drug Misuse Databases (RDMDs), which have been in place since the late 1980s. NDTMS is controlled by PHE and provides intelligence to treatment providers, commissioners and other stakeholders on the population entering treatment and recovering from dependence.
www.ndtms.net/default.aspx

PHE leads the **NHS Screening Programmes** and hosts the **UK National Screening Committee** (UKNSC) secretariat. The UK NSC recommends that systematic, population screening in pregnancy is offered and recommended to all eligible women for HIV, hepatitis B and syphilis. **The NHS Infectious Diseases in Pregnancy Screening (IDPS) programme** worked collaboratively with the **PHE National Antenatal Infection Screening Monitoring (NAISM)** programme to obtain surveillance data until April 2016 when the screening programme commenced annual data returns from trusts. This is collated to support quality assurance of the IDPS programme, including metrics against national programme standards and key performance indicators.
www.gov.uk/topic/population-screening-programmes/infectious-diseases-in-pregnancy

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The **PHE Influenza Surveillance Team** has responsibility to co-ordinate and facilitate the national collection and reporting of data on the uptake of the influenza vaccine. The collection monitors, tracks and reports provisional vaccine uptake weekly and monthly during the annual vaccine campaign to provide a snapshot of the coverage in eligible groups who are registered in primary care on the day of data extraction, and final uptake at the end of the season. The collection is carried out using Immform, a secure online platform for vaccine uptake data collection for several immunisation surveys in England.
www.gov.uk/guidance/sources-of-uk-flu-data-influenza-surveillance-in-the-uk

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NHS RightCare is a national programme committed to reducing unwarranted variation to improve people's health and outcomes. It ensures that the right person has the right care, in the right place, at the right time, making the best use of available resources to help deliver a sustainable NHS. The RightCare approach identifies variation among similar healthcare communities and encourages health economies to focus efforts in these areas, leading to improvements in outcomes and quality, and the release of capacity and resources for future investment. NHS RightCare's Intelligence work includes Commissioning for Value and supporting knowledge management, ensuring local health economies have the data, evidence, tools and practical support to reduce unwarranted variation and deliver better value.
www.england.nhs.uk/rightcare

NHS England leads the NHS in England. It sets the priorities and direction of the NHS and encourages and informs the national debate to improve health and care. It wants everyone to have greater control of their health and their wellbeing, and to be supported to live longer, healthier lives by high-quality health and care services that are compassionate, inclusive and constantly improving. NHS England believes in health and high-quality care for all, now and for future generations.
www.england.nhs.uk

NHS Digital, previously the Health and Social Care Information Centre, is the national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care. Their work includes publishing more than 260 statistical publications per year, providing a range of specialist data services, and managing informatics projects and programmes, and developing and assuring national systems against appropriate contractual, clinical safety and information standards.
http://digital.nhs.uk/home

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

The **Office for National Statistics** (ONS) is the UK's largest independent producer of official statistics and the recognised national statistical institute of the UK. Their 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.
www.ons.gov.uk/ons/index.html

Children's Liver Disease Foundation (CLDF) is a national charity dedicated to fighting all liver diseases of childhood. They 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. They 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
www.childliverdisease.org

The **British Association for the Study of the Liver** (BASL) is a registered charity and is the National Association for hepatology. BASL is dedicated to advancing knowledge and understanding of the biology and pathology of the liver for the optimal care of patients. BASL is composed of interested individuals from clinical medicine, clinical and basic research and allied professions. BASL aims are to: Disseminate research findings and clinical expertise in liver disease; Promote and provide opportunities for collaboration in liver research; Provide a voice that can advise and interact with the media to raise awareness of liver disease within the UK. To advise policymakers within the health service how to advance the provision of care for patients with liver disease within the UK.
www.basl.org.uk

The British Liver Trust is the largest UK charity for all adults with liver disease. They tackle the serious and growing public health problem of liver disease. Liver disease is the third leading cause of premature death and more than one in five of us are at risk of developing the condition. The trust provide up to date information and support and campaign for improved services and care. Their Love Your Liver campaign encourages the best possible liver health for all through encouraging prevention, raising awareness of the risk factors and promoting early detection.
www.britishlivertrust.org.uk

***The Lancet* Liver Commission** was published in November 2014, and brings together partners from the British Liver Trust, Royal College of General Practitioners, Royal College of Physicians, British Association for the Study of the Liver, British Society of Gastroenterology, Children's Liver Disease Foundation and Foundation for Liver Research. This group is committed to recommending tangible targets and to monitoring progress towards improving liver disease in the UK.
www.thelancet.com/campaigns/liver

The Hepatitis C Trust is the only UK-wide charity focused on hepatitis C supporting the estimated 214,000 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.
www.hepctrust.org.uk

Sport England want everyone in England regardless of age, background or level of ability to feel able to engage in sport and physical activity. Some will be young, fit and talented, but most will not. Sport England need a sport sector that welcomes everyone – meets their needs, treats them as individuals and values them as customers.
www.sportengland.org/

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Foreword

We wholeheartedly welcome this update to the *Atlas of variation in risk factors and healthcare for liver disease in England*. Liver disease remains 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 helps service providers to learn from each other and develop a more effective service based on population planning and patient need. It highlights gaps in prevention initiatives and in the provision of health services and draws attention to localities where improvements are needed. Most importantly, it empowers patients not only to ask questions about the healthcare they receive and the options available to them but also to help identify ways in which services can be improved.

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 people receive on diagnosis, access to treatments, the support people are offered, and experiences with doctors and nurses, in hospitals and during end of life care. In an All-Party Parliamentary Hepatology Group (APPHG) audit of hepatitis C services in hospitals in England in 2010 entitled 'In the Dark'[1], 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 five-fold variation in the proportion of new hepatitis C patients being offered treatment in hospital, a range of 20% to 100%. It is likely that there is an even greater degree of variation in the proportion of people 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 continuing 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, clinicians and service 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.

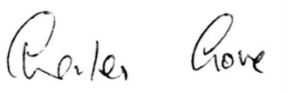
[1] The All-Party Parliamentary Hepatology Group. In The Dark: An audit of hospital hepatitis C services across England. 2010 Aug [cited 2017 Jul]. Available from: www.appghep.org.uk/reports

Of greatest concern in this update is that there is still 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 confer benefit on 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 people 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 person with liver disease 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 is not fit for purpose to answer the most important question for a person with liver disease: no matter where I seek it will I get a good service and the best possible outcome?

This update to the *Atlas of variation in risk factors and healthcare for liver disease in England* continues the publication of area-specific comparative disease data to highlight where variation exists and where commissioners, clinicians and service providers need to focus attention to eliminate waste and increase value. We continue to embrace the opportunity of working with Public Health England, NHS England, clinical commissioning groups (CCGs), local authorities, NICE 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.

Alison Taylor
Chief Executive
Children's Liver Disease Foundation



Charles Gore
Chief Executive
The Hepatitis C Trust

Andrew Langford
Chief Executive
British Liver Trust

Preface

This 2nd Atlas of variation in risk factors and healthcare for liver disease in England builds on five years of co-ordinated activity to raise awareness about the increasing and yet largely preventable toll of premature death and suffering from liver disease. In 2012, the Chief Medical Officer for England, in her Annual Report, identified liver disease as one of the three key issues for population health because it was 'the only major cause of mortality and morbidity which is on the increase in England whilst decreasing among our European neighbours'. Since then, The Lancet Commission on Liver Disease has published three reports in the Lancet outlining the evidence base for action on liver disease and in 2013, the first NHS Atlas of variation in Liver Disease was published. NICE has also published a range of guidance documents.

This Atlas of variation in risk factors and healthcare for liver disease in England presents 39 indicators which cover: the main risk factors for liver disease - alcohol, obesity and hepatitis B and C, which together may account for as much as 90% of liver disease; aspects of health service provision and outcomes. The Atlas contains some new indicators and some updated from the 2013 NHS Atlas of variation in liver disease. The data is presented in a new format to show not only a map of geographical variation for each indicator's range of values but also an accompanying map showing the statistical significance of this variation from the England value. Each indicator is also displayed using a column chart showing the distribution for the most recent period of data and a box and whisker plot showing the degree of variation. In each section the context is described for the indicator(s), options for action and a list of evidence –based resources to aid action. For 19 indicators it is statistically possible to analyse trend data over time both for the England value and degree of variation. Of these 10 indicators improved over time and 9 have shown a worsening over time.

Importantly for every indicator there is evidence of statistically significant variation across England: premature mortality from liver disease varies 7.7-fold by CCG and hospital admissions for cirrhosis, which have almost doubled over the past decade, vary 8.5 fold by CCG. Not only do outcomes vary geographically but so do the prevalence of risk factors for liver disease and aspects of health service provision. It is therefore essential that health service providers and commissioners use the data underpinning the presentation in this Atlas[1], the online interactive tool[2] as well as the Public Health England Local Authority Liver Disease Profiles[3] and other resources referred to within the Atlas to understand more about their local picture to determine priorities for action.

It is important to tackle variation in liver disease through better prevention of disease, recognition of those at risk and improved treatment not only to improve outcomes for individual patients but also to ensure optimal allocation and use of staff, capacity and other resources within the health system.

Professor Julia Verne BSc, MBBS, MSc. PhD, FFPH
Head of Clinical Epidemiology, Public Health England

[1] Public Health England Atlas of variation. https://fingertips.phe.org.uk/profile/atlas-of-variation
[2] NHS RightCare, Intelligence Products, Atlas of variation. www.england.nhs.uk/rightcare/products/atlas
[3] Public Health England Liver Disease Profiles. https://fingertips.phe.org.uk/profile/liver-disease

Introduction

The publication of this Atlas of variation in risk factors and healthcare for liver disease, 2017 builds on five years of increasing interest and activity targeted at preventing and improving outcomes for liver disease.[1,2,3,4,5] This is a new version of the 2013 NHS Atlas of variation in liver disease. This Atlas updates some of the indicators in the 2013 Atlas, showcases some new ones and for the first time uses tests of statistical significance to describe the degree of geographical variation across England. It also shows trend data for many of the indicators. From 19 indicators in the Liver Atlas where the optimum value is stated and the median trend data is available, ten indicators showed an improvement over time and nine indicators showed that the situation has become worse. In addition, the overall variation between areas has narrowed for ten indicators and widened for nine indicators

The Atlas clearly demonstrates opportunities for prevention of liver disease, improving healthcare and improving outcomes for those with liver disease. This will require concerted effort at local and national level. It has been estimated that 90% of liver disease is preventable. The main risk factors are excess alcohol consumption, obesity and viral hepatitis (B&C). As demonstrated in this Atlas and the Public Health England Local Authority Liver Disease Profiles[6] these risk factors and their health consequences each vary significantly across the country with no one area having the same combination of challenges due to these three risk factors. Similarly healthcare provision and access for liver disease patients varies across the country. This is why the information contained in this Atlas, the supporting information at a local level which underpins this Atlas and the Public Health England Local Authority Liver Disease Profiles are so important for local commissioners and providers to understand their local picture.

Each map or series of maps, accompanying column charts and box and whisker plots (subsequently referred to as box-plots) for trend are followed by text which provides the context for the indicator(s), a description of the variation and trend data, options for action and a list of evidence-based resources to support action.

This Atlas of variation in risk factors and healthcare for liver disease demonstrates geographical variation in healthcare provision, access and outcomes which cannot be simply explained by the underlying prevalence of risk factors or liver disease. This type of variation is known as unwarranted variation. John Wennberg, who founded the pioneering Dartmouth Atlas of Health Care,[7] defined unwarranted variation in healthcare as:

> "*variation that cannot be explained on the basis of illness, medical evidence, or patient preference".*[8]

Addressing unwarranted variation in services to tackle risk factors and treat patients with liver disease would reduce mortality rates and the variation in these across the country. It could also potentially lead to significant cost savings to the NHS.

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[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. www.gov.uk/government/publications/cmo-annual-report-2011-volume-one-on-the-state-of-the-public-s-health
[2] Atlas of variation in Liver Disease, http://fingertips.phe.org.uk/documents/Atlas_2013%20Liver%20Disease.pdf
[3] Williams et al. (2014) Addressing liver disease in the UK: a blueprint for attaining excellence in health care and reducing premature mortality from lifestyle issues of excess consumption of alcohol, obesity, and viral hepatitis. Lancet; 384: 1953–97
[4] Williams et al. (2015) Implementation of the Lancet Standing Commission on Liver Disease in the UK. Lancet 2015; 386: 2098–111
[5] Williams et al. (2017) New metrics for the Lancet Standing Commission on Liver Disease in the UK. Lancet 2017; 389: 2053–80 first published online December 15, 2016
[6] Public Health England, Local Alcohol Profiles: http://fingertips.phe.org.uk/profile/local-alcohol-profiles
[7] Wennberg J et al (1996) *The Dartmouth Atlas of Health Care*. www.dartmouthatlas.org/downloads/atlases/96Atlas.pdf
[8] Wennberg J (2010) *Tracking Medicine: A Researcher's Quest to Understand Health Care*. Oxford University Press. www.dartmouthatlas.org

The burden of liver disease and inequalities

The *2011 Annual Report of the Chief Medical Officer (CMO), Volume 1*,[9] was the first national report to raise alarm bells about the largely preventable and increasing death toll and morbidity from liver disease. It was identified as one of three key issues for population health because it was:

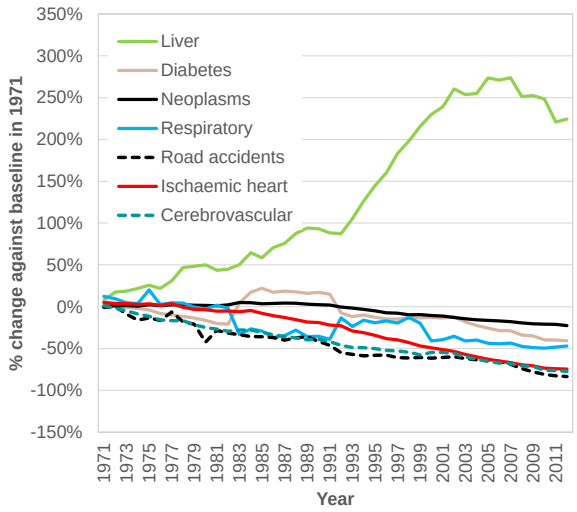
> *"the only major cause of mortality and morbidity which is on the increase in England whilst decreasing among our European neighbours."*

In recognition of the need for action to tackle liver disease the first NHS Atlas of variation in healthcare for people with liver disease was published in 2013 and liver disease has been the subject of three Lancet Commission Reports published in the Lancet in 2014, 2015 and 2016 [10],[11],[12] with the fourth report in preparation.

Figure A.1 shows the time trend in percentage change in mortality from liver disease compared with other major causes of premature mortality in England compared with a 1971 baseline. During this period liver disease mortality increased by over 250% whereas mortality from the other major causes reduced.

In England, liver disease is now the fourth most common cause of Years of Life Lost (YLL) in people aged 75 and under (after coronary heart disease and lung cancer).[13] However, for women of working age, liver disease is the second most common cause of YLL (after breast cancer).

Figure A.1: Trend in mortality from liver disease in relation to trends in mortality from other causes, United Kingdom, 1971–2013[14]



Maps 1a and 1b show geographical variation in YLL from chronic liver disease in persons age 1-64 years and 1-74 years respectively. They reveal not only the enormous absolute loss of life, but also importantly the considerable magnitude of variation across the Clinical Commissioning Groups (CCGs) in England (7.7-fold and 8.8-fold difference respectively). Deaths at a younger age have a disproportionate impact on YLL statistics.

These data emphasise the importance, when developing a strategy to tackle the rising burden of liver disease, of giving detailed consideration in the prevention of liver disease to younger adults and even children. As will be shown in Figures A.6 – A.8, the age at which people die from liver disease in England is low compared to other EU countries.

Figure A.2 shows the trend in mortality from chronic liver disease between 1995 and 2014, however in the latter years the rate and number of deaths has plateaued and may suggest a reversal of the earlier trend. When compared to liver disease mortality rates in

[9] 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. www.gov.uk/government/publications/cmo-annual-report-2011-volume-one-on-the-state-of-the-public-s-health

[10] Williams et al. (2014) Addressing liver disease in the UK: a blueprint for attaining excellence in health care and reducing premature mortality from lifestyle issues of excess consumption of alcohol, obesity, and viral hepatitis. Lancet; 384: 1953–97

[11] Williams et al. (2015) Implementation of the Lancet Standing Commission on Liver Disease in the UK. Lancet 2015; 386: 2098–111

[12] Williams et al. (2017) New metrics for the Lancet Standing Commission on Liver Disease in the UK. Lancet 2017; 389: 2053–80 first published online December 15, 2016

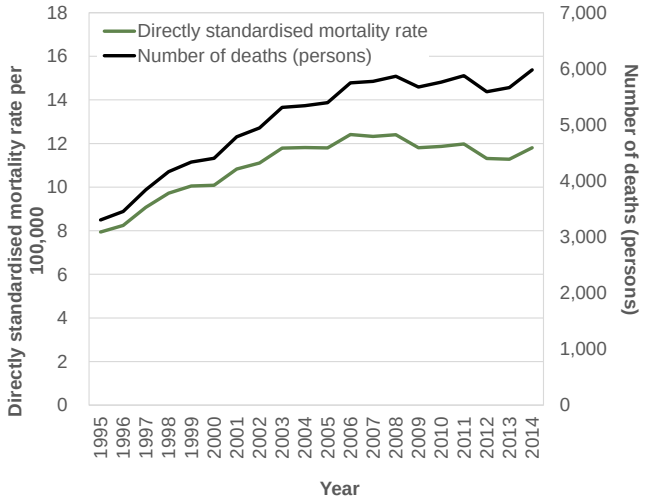
[13] Office for National Statistics. Mortality statistics: deaths registered in England and Wales (series DR), 2015. Office for National Statistics, Newport, UK; 2015. www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables

[14] World Health Organization. European health for all database (HFA-DB), July. www.euro.who.int/en/data-and-evidence/databases/european-health-for-all-family-of-databases-hfa-db

1995, there is an excess of approximately 4 deaths per 100,000 population in 2014.

Map 1c shows a 7.7-fold difference in premature (under 75 years) liver disease mortality rates across CCGs in England.

Figure A.2: Mortality from chronic liver disease including cirrhosis (ICD-10 K70, K73-K74 equivalent to ICD-9 571), 1995-2014[15]



In addition to significant geographical variation in risk factors, service provision and outcomes for liver disease, there are wide social inequalities across England. These inequalities, in part, explain the differences especially in risk factors across the country and consequent morbidity. Variation in deprivation does not explain the variation in health service provision although deprivation may influence access to services. See map A.1 for deprivation across England.

Figure A.3 shows that about 40% (R^2=0.433) of the variation in rate of YLL under the age of 75 due to liver disease can be explained by deprivation. This will include the impact that deprivation has on the prevalence of risk factors including alcohol misuse, obesity and Hepatitis B and C and a component of possible poorer access to services.

People in the most deprived population fifth who die from liver disease typically do so almost one decade earlier than those who die from liver disease in the most affluent population fifth (Figure A.4).

Figure A.3: 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 CCG 2013-15 in relation to the index of multiple deprivation (IMD) 2015 (1 = The least deprived; 100= The most deprived)[16],[17]

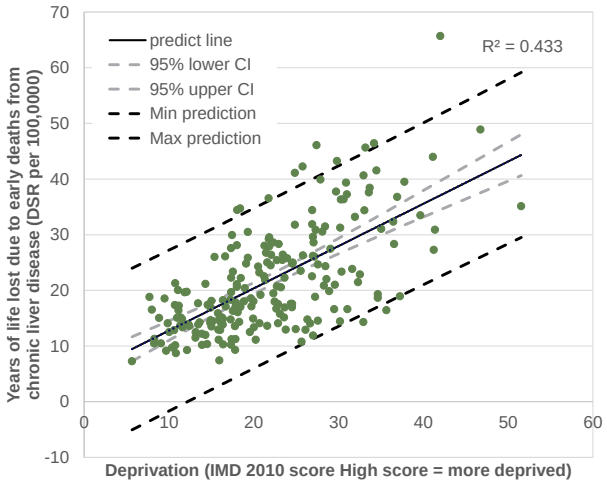
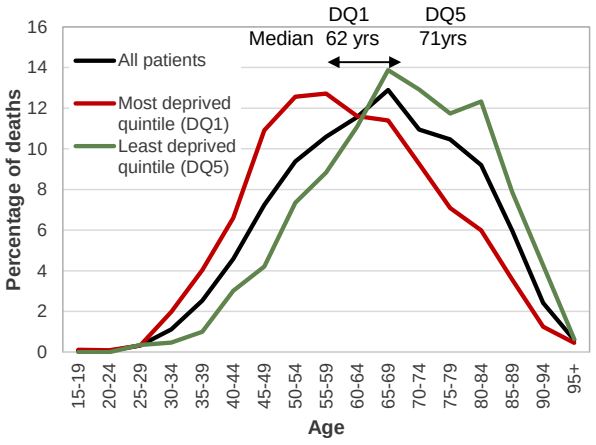


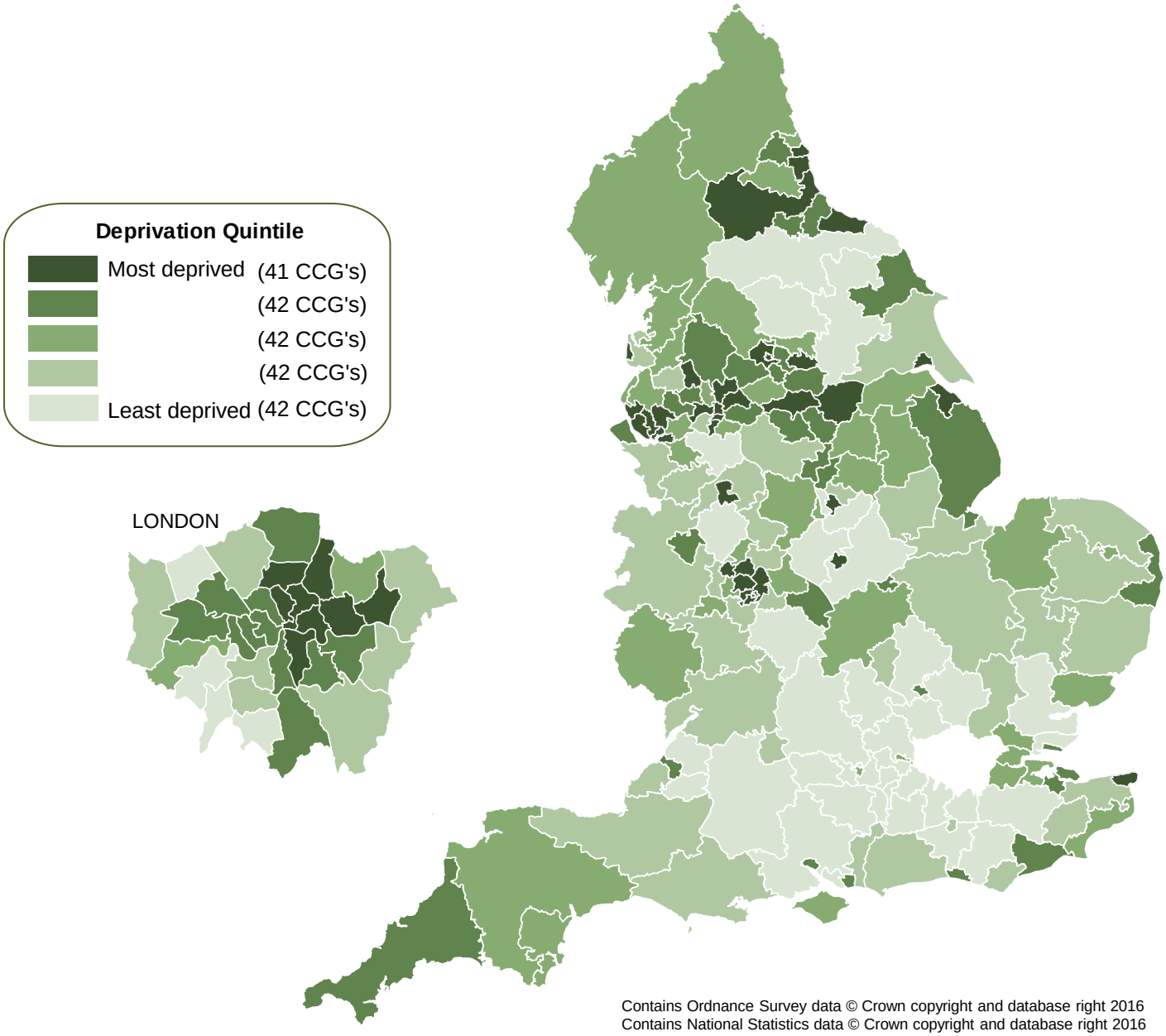
Figure A.4 shows a nine- year gap between the median ages at death for patients with liver disease who reside in the most deprived fifth (quintile) of an area compared to people from the least deprived fifth. There is a negative correlation between deprivation and age of death, this is even more pronounced for deaths from alcohol-related liver disease (Figure A.5)

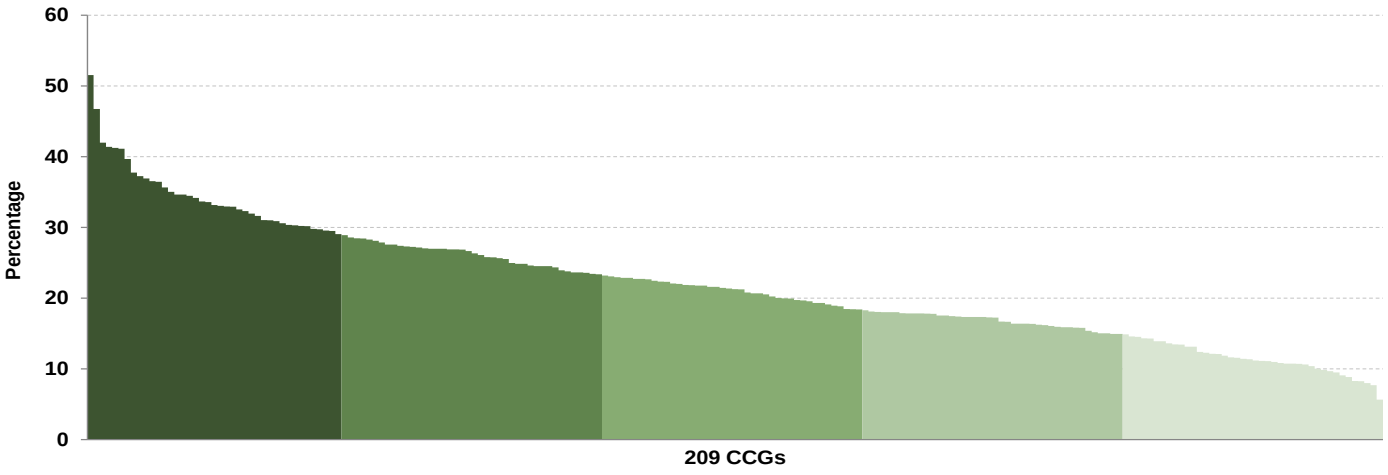
Figure A.4: Age at death by deprivation quintile, for all liver disease[18]



[15] NHS Digital Indicator Portal. https://indicators.hscic.gov.uk/webview
[16] NHS Digital Indicator Portal. https://indicators.hscic.gov.uk/webview
[17] Department of communities and local government. www.gov.uk/government/statistics/english-indices-of-deprivation-2015
[18] Reference: Hudson et al. Inequalities in death from liver disease in England in 2015, Conference Presentation, BASL Presentation, Abstract: www.baslannualmeeting.org.uk/uploads/Abstracts/End%20of%20Life/P18.pdf

Map A.1: **Index of Multiple Deprivation 2015 average LSOA score CCG quintiles**[19]

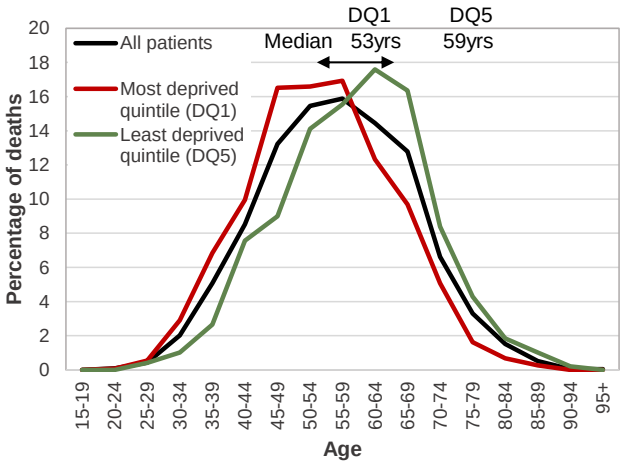




[19] Department for Communities and Local Government, Indices of Deprivation 2015

Figure A.5 shows a six year gap between the median age at death for patients who die from alcohol-related liver disease between those who live in the fifth most deprived areas compared with those who live in the least deprived fifth of areas. It is also important to note that there are more deaths from chronic liver disease in the most deprived quintile of the population.

Figure A.5: Percentage of deaths with a mention of alcoholic liver disease by age of death for all patients, most deprived quintile and the least deprived quintile, England 2015



Estimating the burden of liver disease in the population

People who die from liver disease usually present for the first time at a late stage with advanced disease with cirrhosis and its complications. The risk factors for liver disease are highly prevalent as is early stage, occult, liver disease. It can take up to 20 years for liver disease to progress to a stage where people would first appear in health service records. It is therefore only possible to estimate the burden of liver disease in the general population as shown in Table A.1. 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 or on acute presentation to hospital with complications. It has been estimated that between 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 A.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	15,120,000	Approx 27% of population are obese, Health Survey for England, 2015
At risk of alcohol-related liver damage	2,240,000	Approx 4% are higher risk drinkers (More than 35/50 units for men/women), Health Survey for England, 2015
With (at least) significant liver disease	600,000	Estimated from end-stage figures and natural history
With (at least) chronic viral hepatitis B and C	400,000	Estimated from HPA data 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)
Underlying cause of death is liver disease	13,937	(21,794 any mention of CLD), ONS deaths dataset, 2015
Have primary liver cancer	In 2014, there were 4,585 new cases of liver cancer in the England	PHE NCRAS
Liver organ transplants	925	NHS Organ Donation and Transplantation (2015/16) England

European comparisons

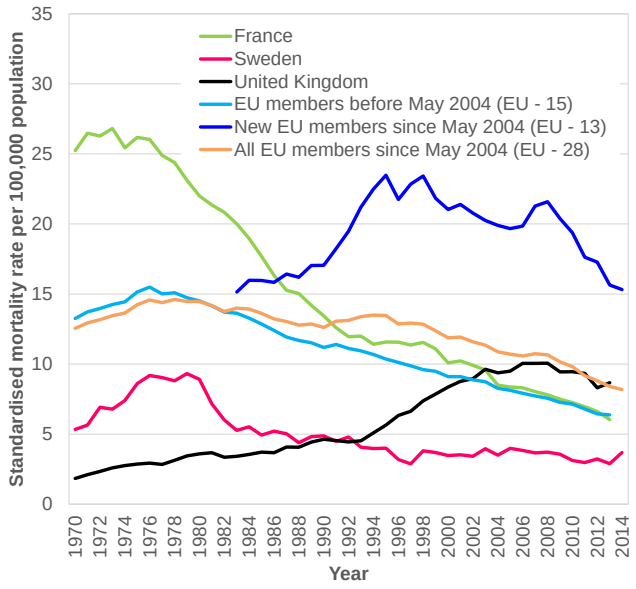
This Atlas compares geographical areas with the England value. Even some of the better performing localities in England cannot be complacent about the need to tackle liver disease because comparisons with other European Union countries reveal stark differences in mortality trends, age at death and age-specific standardised rates.

As highlighted in the Chief Medical Officer for England's 2011 Annual Report[20] the trend in premature mortality from liver disease in working age people in United Kingdom (UK) contrasts sharply with that in other European

[20] 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. www.gov.uk/government/publications/cmo-annual-report-2011-volume-one-on-the-state-of-the-public-s-health

Union members. In the UK it had been rising while in other countries the mortality rate had been falling as shown in Figure A.6.

Figure A.6: Premature mortality from chronic liver disease and cirrhosis in people aged under 65 in the UK and European Union (EU) countries before and after 2004, and France and Sweden, 1970-2014[21]

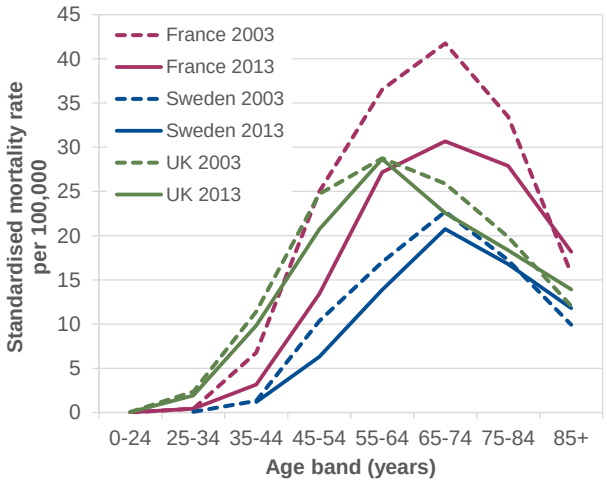


There is also a striking difference in the age at death and gender differences between the UK, France and Sweden. Figure A.7 shows that for all persons the peak of age–specific standardised mortality was much younger in the UK and has shown little change in the decade between 2003 and 2013 compared with France or Sweden.

This peak age-specific mortality at a younger age in the UK is reflected in graphs for men and women (Figures A.8a and A.8b). A comparison shows that the age-specific mortality rates in France have significantly reduced in the decade 2003-13 albeit from a higher baseline than in the UK and they have also reduced a little in Sweden.

The graph for women (A.8b) is especially shocking. Although a comparison of the y-axes reveals that the mortality rate for men is almost three-fold higher than that for women, the time period comparisons reveal that in France the female age-specific standardised mortality has

Figure A.7: Mortality from chronic liver disease and cirrhosis by age-band, 2003-2011 (Source: European detailed mortality database (DMDB) Updated: July 2016 World Health Organization Regional Office for Europe) [22]



reduced and the peak has moved to an older age group suggesting a particularly effective impact on young women. The peak age-standardised mortality rate for women in the UK is now higher than for both France and Sweden and also occurs in women 10-20 years younger.

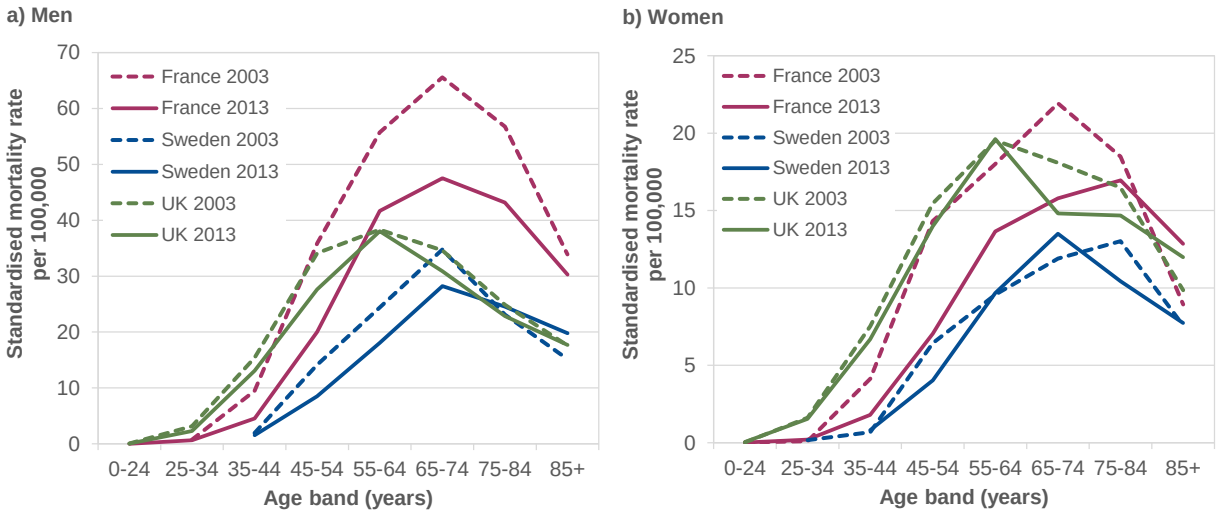
In contrast, in the UK there has been no overall reduction or shift in the peak age-group at death for men or women. The peak age-group at death in the UK is 10 years younger than both France and Sweden in 2013 (Figure A.7).

What is the importance of geographical variation?

The demonstration of geographical variation in health risk factors, treatment and outcomes is important because it highlights the need for local solutions. It enables commissioners, clinicians and providers to compare themselves with the national picture and their peers and highlight issues for more detailed investigation or the need for action. The NHS Compendium Atlases of variation in Healthcare, published in 2010, 2013 and 2015 and the first NHS Atlas of variation in healthcare for people with liver disease [23], demonstrated that unwarranted variation is ubiquitous in England across a range of indicators.

[21] European health for all database (HFA-DB) WHO/Europe July 2016 http://data.euro.who.int/hfadb
[22] World Health Organization. European Detailed Mortality Database (DMDB). http://data.euro.who.int/dmdb
[23] Right Care (2010, 2013, 2015) *The NHS Atlas of variation in Healthcare: Reducing unwarranted variation to increase value and improve quality, November 2010*. http://fingertips.phe.org.uk/profile/atlas-of-variation

Figures A.8a & A.8b: **Mortality from chronic liver disease and cirrhosis by age-band and gender, 2003 and 2013 (Source: European mortality database (MDB) Updated: July 2016 World Health Organization Regional Office for Europe)**



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*".[24]

It is for these reasons that in the NHS Atlas of variation in healthcare, November 2011 it was stated 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".[25]

This is not just a theoretical exercise. This Atlas helps to identify where resources may need to shift especially to place more emphasis on primary and secondary prevention.

The importance of variation to the public

The importance of variation to patients and their families cannot be overestimated as it may make the difference between developing a condition or not, or receiving a life-saving intervention or not.

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 pages 29-32). By this example, we hope that commissioners, providers and clinicians will also include patients and their carers in their deliberations when addressing unwarranted variation.

There are two ways to do this:

- by auditing services and outcomes against specified guidance or standards – an example would be the Liver Quality Enhancement Service Tool (Liver QuEST) project for accreditation of hospital services; a quality assurance framework that aims to improve the care

[24] Appleby J, Raleigh V (2011) *Variations in Health Care – the Good, the Bad and the Inexplicable*. The King's Fund. www.kingsfund.org.uk/publications/healthcare_variation.html
[25] Right Care (2011) *The NHS Atlas of variation in Healthcare: Reducing unwarranted variation to increase value and improve quality*, November 2011. https://fingertips.phe.org.uk/documents/Atlas_2011%20Compendium.pdf

of patients with liver disease across England.[26] The LiverQuEST pilot project has now been developed into a full accreditation programme called Improving Quality in Liver Services (IQILS) and is due to launch in 2017.

- by examining datasets in order to pose questions about services, the process of delivery, clinical practice, performance and outcomes.

The critical factors in addressing liver disease and to reduce premature mortality are:

- comprehensive programmes to tackle risk factors for liver disease
- 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
- seamless links between providers and specialist services for liver disease

Given the importance of liver disease prevention it is clear that the NHS alone cannot reduce mortality and all of the associated costs of treating liver disease.

The three Lancet Commission Reports[27,28,29] clearly set out what needs to be done to tackle liver disease from preventing dying prematurely to improving end-of-life care.

Local authorities have a significant role to play in the prevention of the three major risk factors for liver disease; alcohol, obesity and viral hepatitis. The prevention of liver disease will require close working between Local Authorities and local NHS services.

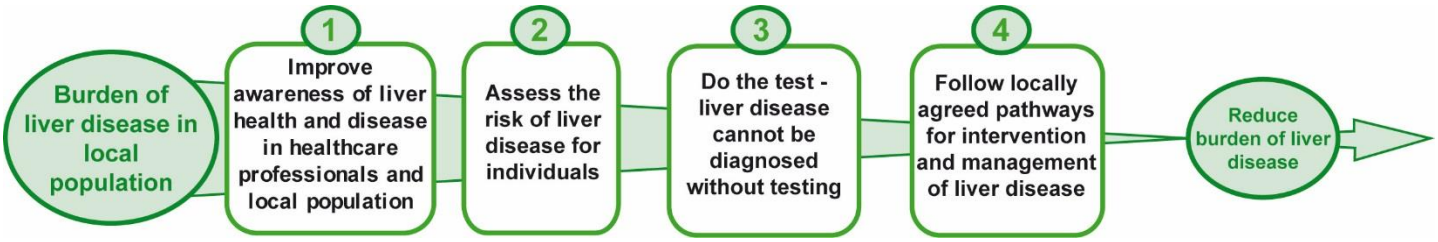
Tips for using the atlas of variation in risk factors and healthcare for liver disease in England to deliver healthcare improvement

The data shown in this Atlas can be used by a range of bodies including CCGs, Local Authorities, STPs, Specialised Commissioning, NHS England, NHS RightCare, Public Health England, The Lancet Commission on Liver Disease, National Policy Makers, Health Education England, the Royal Colleges and specialist societies such as the British Society for Gastroenterology and the British Association for the Study of the Liver (BASL) and Patient Representative Groups and Charities to identify the need for action.

Action can be targeted to specific areas which are identified through the maps to be statistically significant outliers. Firstly to identify the reasons why and then the appropriate action required.

The box-plots plots can be used to assess variation at a national level and whether improvements are occurring or indeed things having been getting worse over the past few years.

Figure A.9: **Basic steps in reducing the burden of liver disease**



[26] Royal College of Physicians. Liver QuEST for Excellence. www.liverquest.org.uk
[27] Williams et al. (2014) Addressing liver disease in the UK: a blueprint for attaining excellence in health care and reducing premature mortality from lifestyle issues of excess consumption of alcohol, obesity, and viral hepatitis. Lancet; 384: 1953–97
[28] Williams et al. (2015) Implementation of the Lancet Standing Commission on Liver Disease in the UK. Lancet 2015; 386: 2098–111
[29] Williams et al. (2017) New metrics for the Lancet Standing Commission on Liver Disease in the UK. Lancet 2017; 389: 2053–80 first published online December 15, 2016

The NHS RightCare Approach

Having identified a potential need for action the NHS RightCare Approach to improving outcomes and value in the NHS provides a helpful framework and set of tools for identifying what needs to change and how to change.

From December 2016 all local health economies will have been using the NHS RightCare approach to reduce unwarranted variation and deliver better value population healthcare. The NHS RightCare Approach has three phases and five key ingredients that build on strong evidence as a starting point as shown in Figure A.10 below.

"Where to Look"

Phase 1 of the NHS RightCare Approach begins with a review of data. This data highlights the top priorities and best opportunities for transformation and improvement at a local level by comparison with a CCGs most demographically similar peers. The Atlas of variation series, along with the suite of CCG products produced by NHS RightCare, used with local data and intelligence by local areas enables the identification of the greatest areas for improvement or opportunity.

This Atlas allows local areas to identify where they differ significantly from the England value, providing a starting point for furthur investigation into what is behind this variation.

Figure A.10: The NHS RightCare Approach

The underpinning dataset, which includes the data for every time period and organisation, is provided alongside this report.

Understanding the population and its associated needs will enable local health economies to commission appropriate services, including prevention, in order to address and reduce the burden of liver disease, thereby reducing unwarranted variation. Examples of questions local areas should consider are:

- Which risk factors for liver disease are particularly prevalent in my area eg alcohol, obesity or hepatitis B?
- Who is most at risk from alcohol related harm in my population? (adults, children, vulnerable groups such as migrants, homeless etc?)
- How accessible is alcohol in my population (number of outlets, bars, and clubs?)
- Are there services available to treat patients with liver disease in my population, and are they in the right place?
- How good is the quality of liver disease services for those that need them?
- How many people are dying from liver disease and what services do we have in place to support them at the end of their lives?

Alongside this comprehensive Atlas there is a wealth of other supporting data and profiles which are available from both PHE and NHS RightCare including:

- Local Alcohol Profiles for England[30]
- Obesity data[31]
- Viral hepatitis monitoring[32]
- The National Cancer Registry and Analysis Service (NCRAS) – data on liver cancer[33]
- National Antenatal Infections Screening.[34]
- NHS RightCare Where to Look packs[35]
- NHS RightCare Long Term Conditions packs[36]

These data and information sources provide a comprehensive picture of the opportunities for change, however, it is important to bear in mind that optimum values are usually unknown, therefore local areas may want to strive to be amongst the best performers rather than the England average. For example liver disease mortality rates are higher in the UK than other European countries as shown in Figure(s) A6, A7 and A8, and local areas may want to aim to reduce their rates to that of the best in Europe.

Data on expenditure

Data on commissioners' expenditure across healthcare conditions and care pathways is collated via a returns framework known as programme budgeting. The main purpose of the programme budgeting data is to provide benchmarking information to NHS organisations to enable evidence-based investment and prioritisation decisions to be made.[37] This information is a critical source of financial information, however the most recent publicly available data is from 2013/14[38]. Although these data are outdated, they are the most recently available and can still be used by commissioners to understand the links between investment, activity and healthcare outcomes for their populations. NHS RightCare also utilise these data to populate their intelligence packs.

Programme budgeting is used to:

- Show us how much we are spending
- Tell us where we are spending it
- Allow us to see what we are getting for it

This in turn should lead to:

- Improvements in efficiency – better value for money
- Improvements in effectiveness – better outcomes
- Improvements in equity – fairer distribution of resources and reductions in inequality of health outcomes

There are 23 programme budgeting categories[39], based on the World Health Organisation (WHO) International Classification of Disease (ICD10), which also splits the expenditure by care setting to cover the whole care pathway. Encouraging a consistent application of the programme budgeting framework means that any variation, demonstrated through benchmarking, is due to actual differences in spending patterns rather

[30] Local Alcohol Profiles for England. http://fingertips.phe.org.uk/profile/local-alcohol-profiles
[31] National Obesity Observatory (archived). http://webarchive.nationalarchives.gov.uk/20170210154603/http://www.noo.org.uk
[32] Viral Hepatitis Monitoring. www.gov.uk/government/statistics/people-who-inject-drugs-hiv-and-viral-hepatitis-monitoring
[33] National Cancer Registration and Analysis Service. PHE. www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/upper_gi_cancers
[34] National Antenatal Infections Screening Monitoring. www.gov.uk/government/publications/national-antenatal-infections-screening-monitoring-annual-data-tables
[35] NHS England, Where to Look Packs, Jan 2017. www.england.nhs.uk/rightcare/products/ccg-data-packs/where-to-look-packs
[36] NHS England, Long-term Conditions Pack. www.england.nhs.uk/rightcare/products/ccg-data-packs/long-term-conditions-packs
[37] NHS England, 2015/16 Programme Budgeting Guidance for CCGs https://nhs-digital.citizenspace.com/rocr/r01293/supporting_documents/R01293%20%20201516%20Programme%20Budgeting%20Guidance.docx
[38] NHS England Programme Budgeting Tool, 2013-14. www.england.nhs.uk/wp-content/uploads/2015/06/13-14-ccg-prog-bug-benchmarking-tool.xlsm
[39] NHS England Programme Budgeting Categories. http://webarchive.nationalarchives.gov.uk/20161103235253/https://www.england.nhs.uk/wp-content/uploads/2015/03/pb-cat-defins-mar15.pdf

than a slightly different approach to completing the returns.[37]

Liver disease sits within the hepatobiliary (HB) programme budget and unfortunately due to the way the data is collected it is not possible to disaggregate the expenditure to show solely liver disease. In 2013/14 the variation across CCGs in England for the HB programme ranged from £2,276 to £20,372 per 1,000 population (9-fold difference), with the national average spend being £12,526 per 1,000 population.

The majority of this spend nationally is on non-elective admissions (51%) followed by scheduled elective care (28%). The variation across CCGs is 3-fold for non-elective admissions and 5-fold for elective care.

Map A.2 shows this variation in expenditure across the country and although the direct costs for liver disease cannot be identified, areas where there is significantly higher or lower spend should reflect on the relationship between the overall HB budget and the relevant drivers for this expenditure. Examples of drivers for this expenditure are: are risk factors (maps 7, 9,16a-b,17), prevalence of disease (maps 8,12) service provision and/or use (maps 2, 4a-c, 5, 11a, 15a) and patient outcomes (maps 1c, 6, 22, 24 27a-d).

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 investigating 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 HB 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
- the potential reasons for unwarranted variation

Further exploration of the data profiles and sources shown on page 19, along with additional resources such as the CCG Spend and Outcome Factsheets and Tool (SPOT).[40] may yield further additional insights at a local level. A recent report from the Lancet Commission and Foundation for Liver Research describes the financial case for action on liver disease with an emphasis on tackling risk factors.[41]

Figures A.11 and A.12 identify options for action when investigating expenditure on the hepatobiliary budget.

Figure A.11: The potential for, and cost of intervention In relation to the course of liver disease

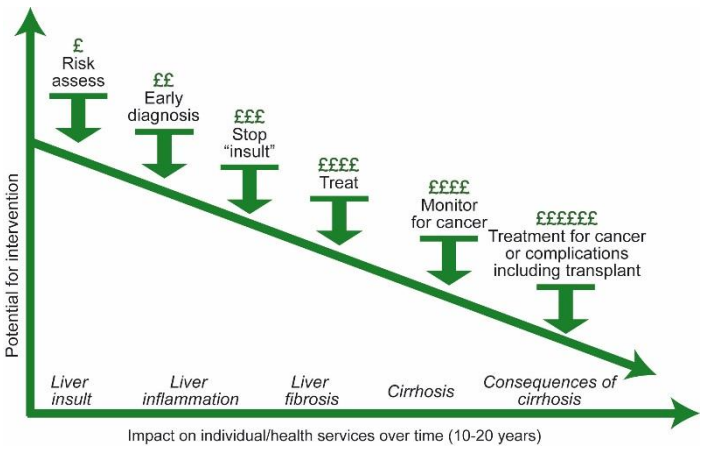
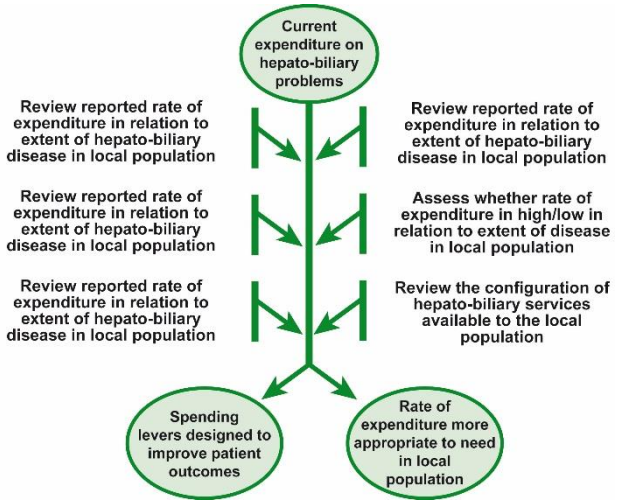
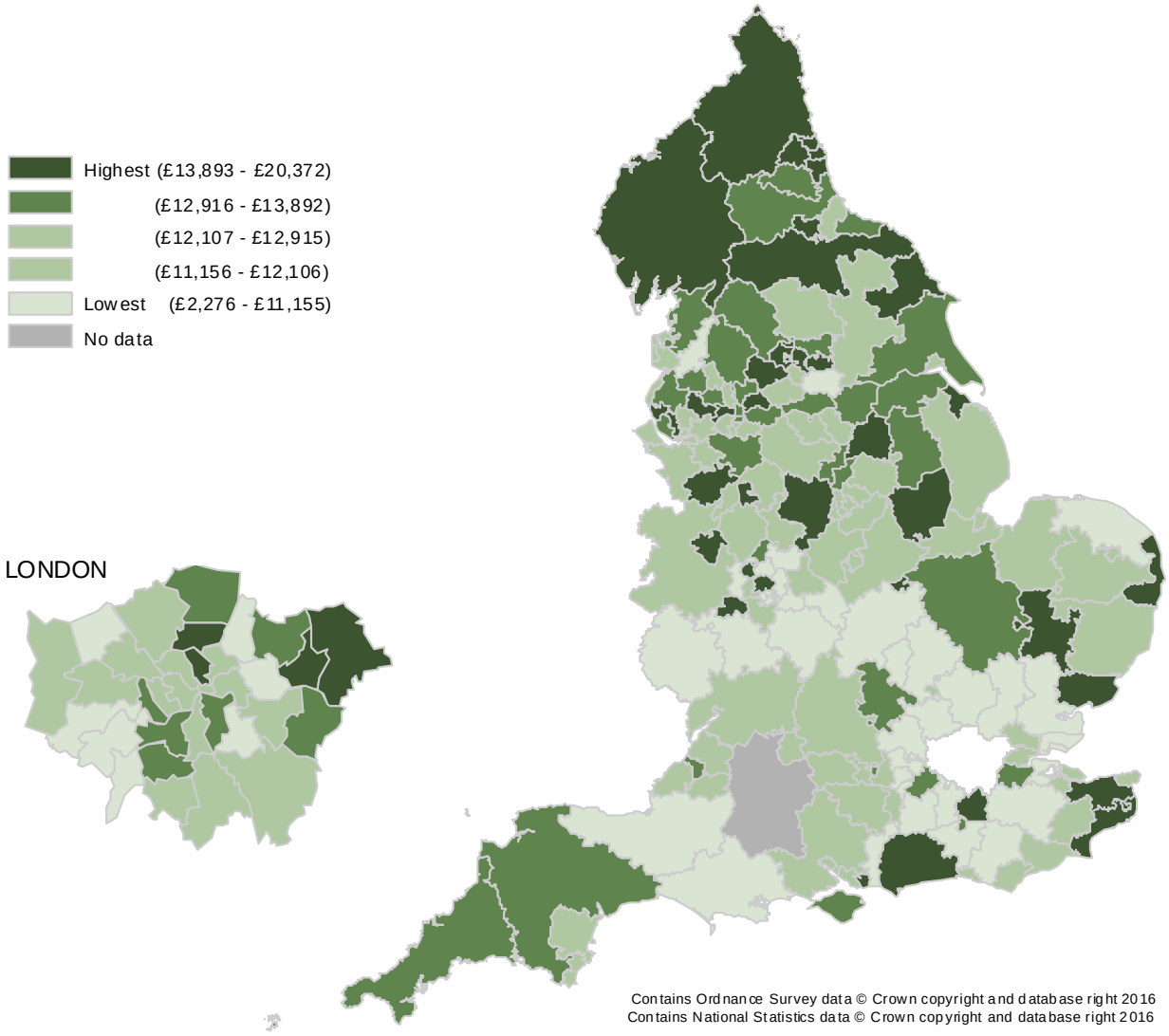


Figure A.12: Options for action when investigating expenditure on hepatobiliary problems

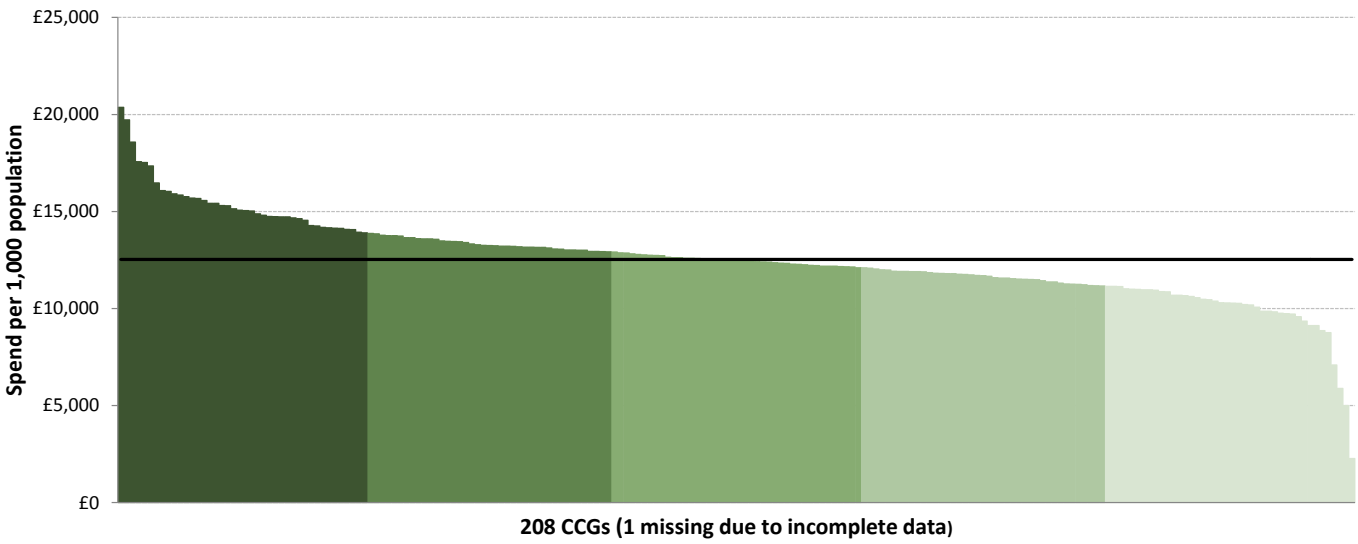


[40] Spend and Outcome Tool: www.gov.uk/government/publications/spend-and-outcome-tool-spot
[41] Liver Research Foundation, 2017. Financial case for action on liver disease. Escalating costs of alcohol misuse, obesity and viral hepatitis. www.liver-research.org.uk/liverresearch-assets/financialcaseforactiononliverdiseasepaper.pdf

Map A.2: **Rate of expenditure on hepatobiliary problems per 1000 population by CCG 2013/14**



Rate of expenditure on hepatobiliary problems per 1,000 population by CCG 2013/14



One reason for variation in expenditure could be the level of deprivation in a local population and the risk factors for liver disease especially alcohol, obesity and hepatitis C, which are also strongly correlated with deprivation. Figures A.13 and A.14 illustrate this.

Figure A.13: Association between alcohol-specific admissions and deprivation by CCG

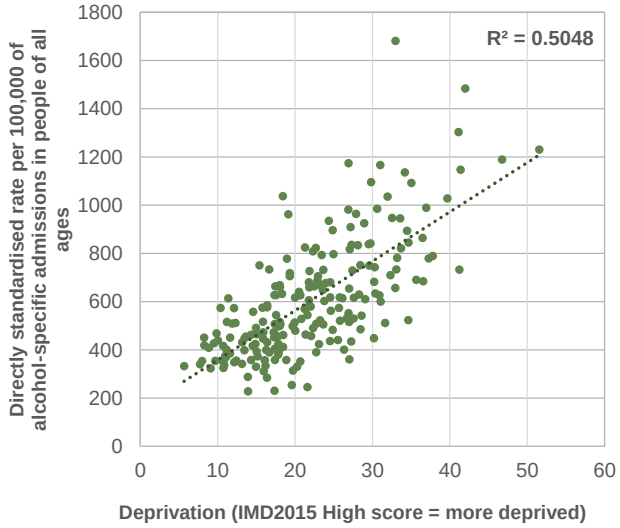
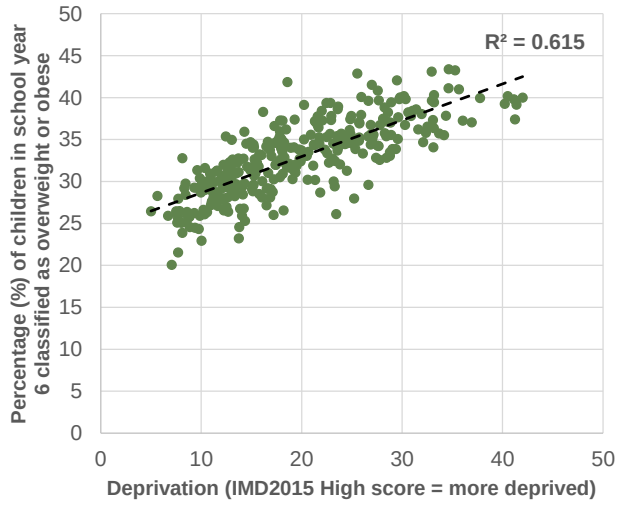


Figure A.14: Association between childhood obesity (year 6) and deprivation by lower tier local authority



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.[42]

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.

Organisation of liver services

Commissioners need to assess whether there is adequate provision to tackle liver disease for their population. Many patients may need care both in local hospitals and then onward referral to tertiary or transplant centres, so planning for liver services should consider larger geographical footprints such as Strategic Transformation Partnerships (STP) or regions to accommodate such needs.

Most patients with chronic liver disease will be under the care of a local gastroenterologist, until their disease becomes advanced or under the care of a specialist hepatologist in a non-transplanting centre.[43]

There is considerable variation in levels of current provision of liver disease services as defined by whole time equivalent (WTE) staffing levels (See box A.1 for definition). A recent survey found that there were 193.8 WTE hepatologists in England, however the expertise is not uniformly distributed, as almost two-thirds (64%) are either based within specialist regional centres or transplant centres. Only 16 district general hospitals met the criteria for an

[42] 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 www.biomedcentral.com/1471-2458/10/99

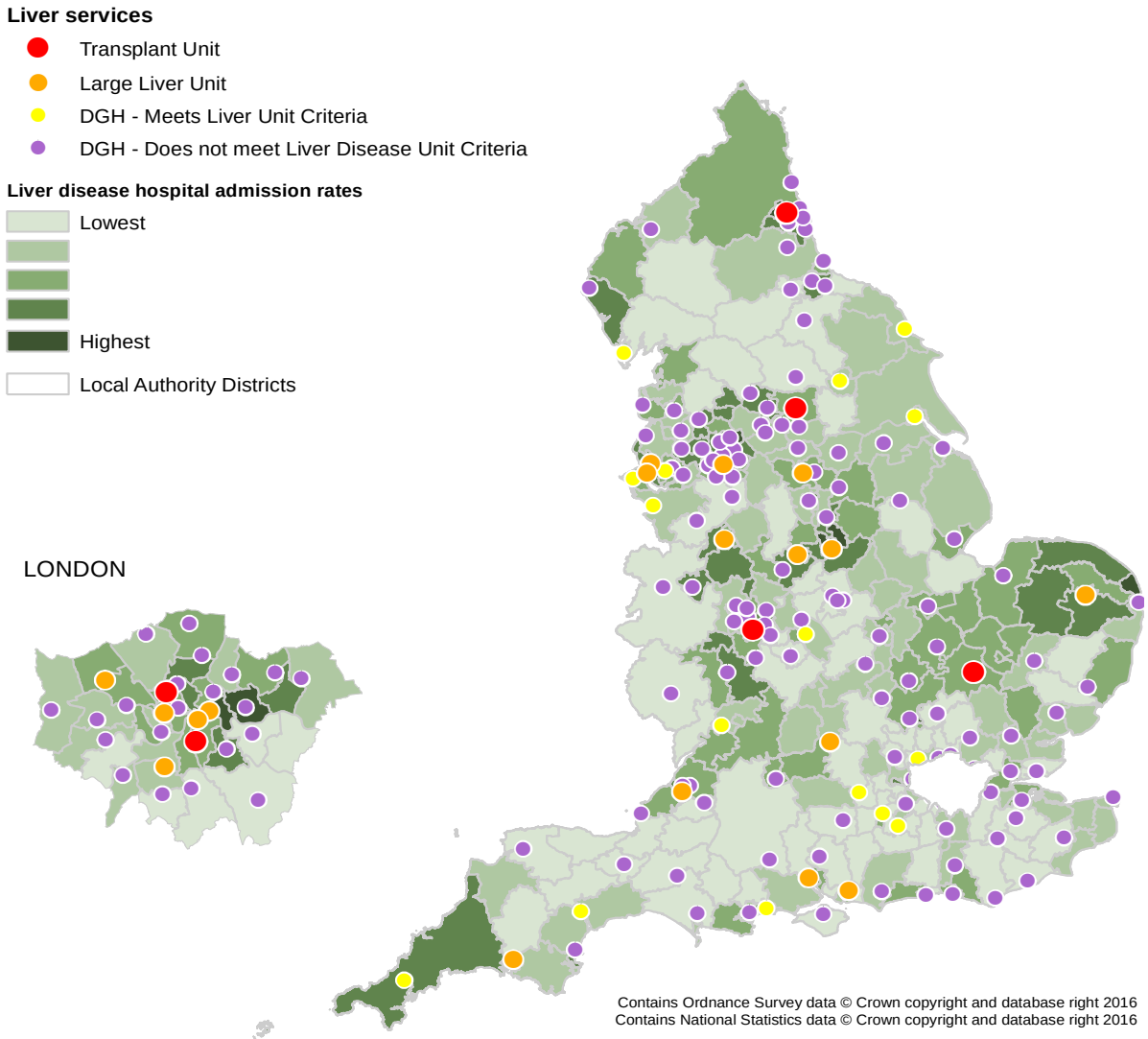
[43] NHS England Service specification for Liver Transplantation Service in Adults www.england.nhs.uk/wp-content/uploads/2017/04/liver-transplantation-service-adults.pdf

adequately staffed district general hospital acute service.[44]

Box A.1: Criteria for adequately staffed liver service	
Acute District General Hospital service	≥ 2 WTE hepatologists and ≥2 gastroenterologists with interest in hepatology
Large regional specialist liver units	≥ 3 WTE hepatologists

There are six liver transplant centres in England, and some centralisation of liver and related surgical services in a defined number of hospitals.[45] Maps A.3 and A.4 show the location of different levels of liver disease services in relation to background levels of liver disease admissions and mortality.

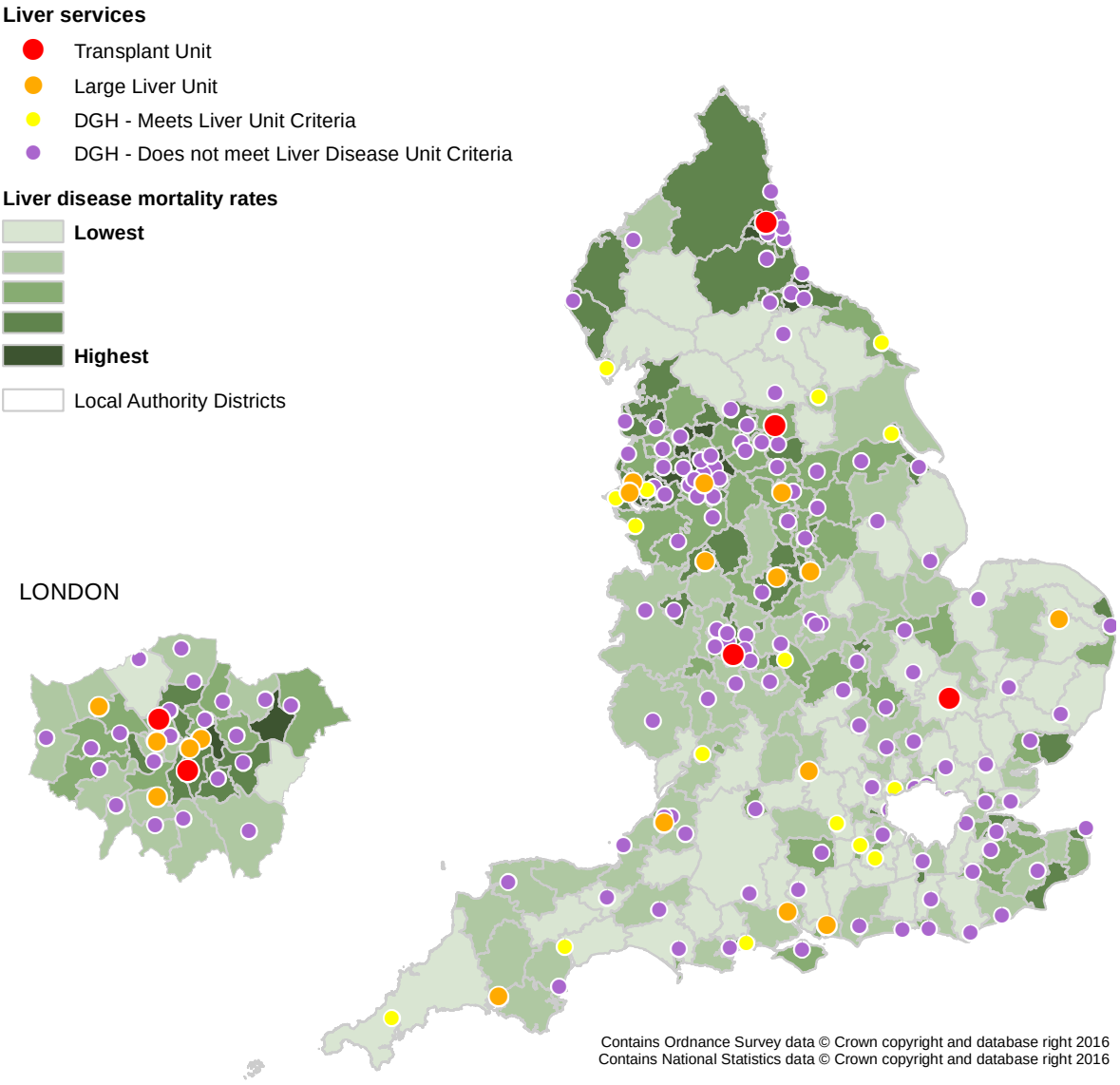
Map A.3: Liver services in England in relation to liver disease admissions in people of all ages, directly standardised rate per 100,000 population, 2014-15



[44] Williams et al. (2017) New metrics for the Lancet Standing Commission on Liver Disease in the UK. Lancet 2017; 389: 2053–80 first published online December 15, 2016

[45] A Census of Medical Workforce & Infrastructure for Liver Disease Strategy: Summary of Findings (Final 2011). www.hcvaction.org.uk/resource/census-medical-workforce-infrastructure-liver-disease-strategy-summary-findings

Map A.4: Liver services in England in relation to liver disease mortality in people of all ages, directly standardised rate per 100,000 population, 2014-15



Commissioners should consider maps A.3 and A.4 to understand whether locally:

- liver services may require further development
- there is the expertise available to 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.

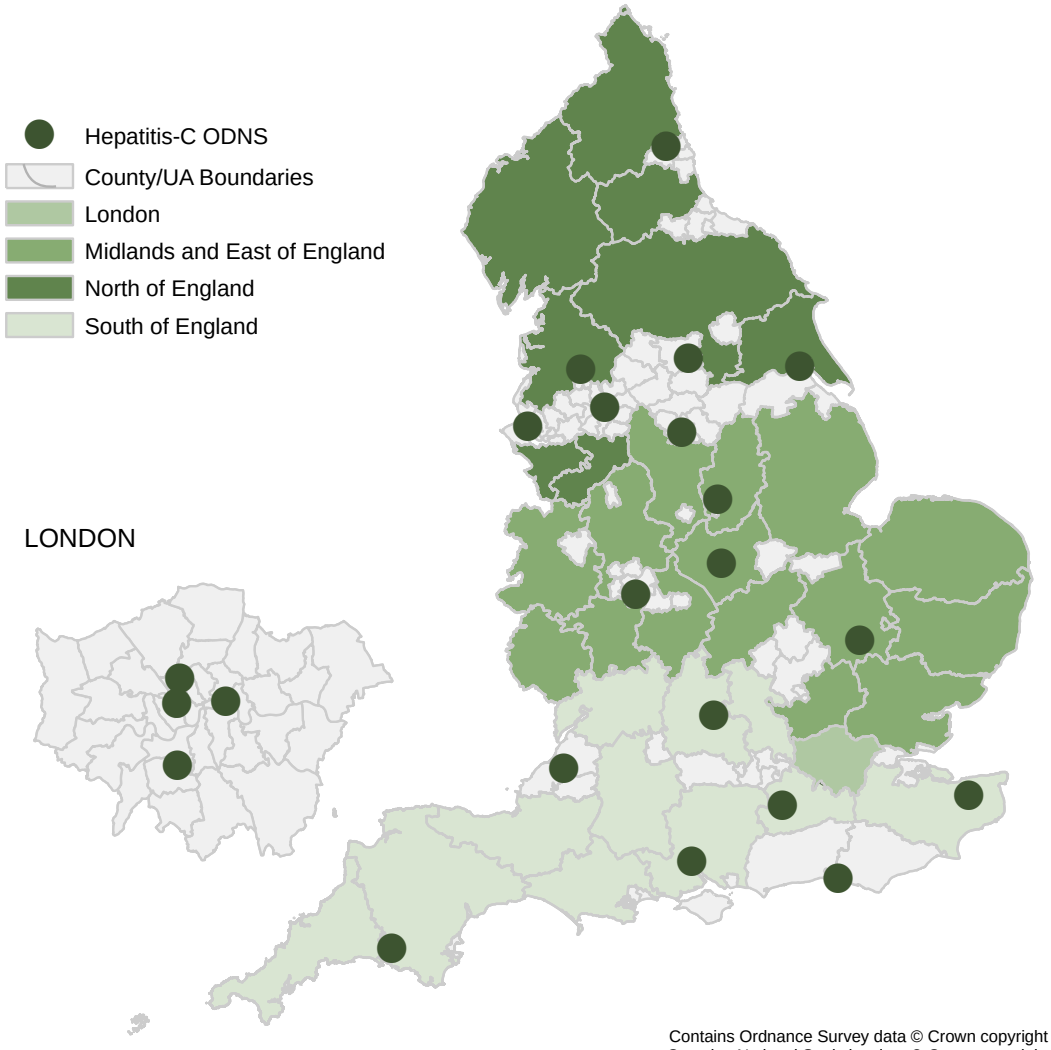
Liver transplant centres and the corresponding referral patterns can have a major impact on the quality of adult liver services and level of expertise available in the referring hospitals, especially as they play a central role in the training of hepatologists. Commissioners need to

ensure that the local population has access to appropriate expertise including transplant assessment.

The maps (A.3 & A.4) illustrate the need for greater provision of liver services in the deprived areas that have the highest rates of liver disease morbidity and mortality. The number of district general hospitals that do not meet the criteria for an acute liver service is unacceptable.

Map A.5 shows the location of the new operational delivery networks (ODNs) for hepatitis C.

Map A.5: Location of hepatitis C Operational Delivery Networks (ODNs) within the four NHS England regions



"What to Change"

Phase 2 of the NHS RightCare approach involves a more detailed review of specific areas, care pathways and optimal design to identify the options for improvement and testing viability.

Disease pathways developed by NHS RightCare (see Figure A.15 liver disease pathway) can highlight very specific points that require changes to be made to improve patient outcomes. Additionally, clinically led service reviews, for example Liver QUEST [26], and reviews of best practice guidelines and evidence will also inform the "what to change" phase.

Key questions for consideration are:

- Are there sufficient trained staff, equipment and facilities?
- Are there protocols for referral?
- Are there barriers to access for the population such as travelling times?
- Does the population at risk for liver disease have poor health literacy?
- Is there discrimination against liver disease patients because they are considered to have caused their condition through lifestyle choices?
- Is patient choice important?

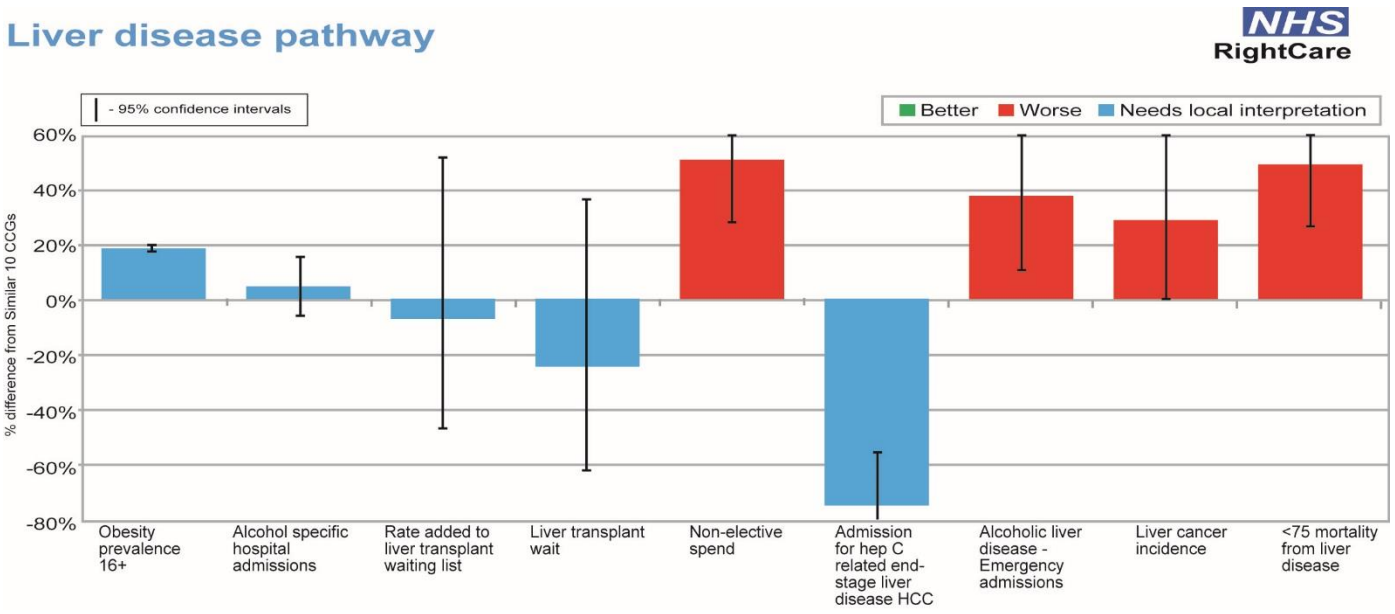
As the majority of admissions to hospital for people with liver disease are as an emergency there is significant scope for looking at alternative models for care which include more planned care for example in the management of oesophageal varices and ascites (maps 25 and 26). Good end-of-life care which may be introduced in parallel with life-saving interventions in acute decompensation (known as parallel planning)[47] has been shown to reduce emergency admissions, give more choice to patients regarding place of death and reduce costs (maps 27a – 27d).

"How to Change"

Phase 3 of the NHS RightCare approach involves taking forward opportunities and making them happen. This is achieved through outlining the case for change and making sure impact assessments and assumptions are explicit. This phase involves ensuring that there is clinical leadership of the change and that programmes of work are planned, delivered and monitored, using established and effective improvement processes – the fifth key ingredient of the NHS RightCare Approach.

As the aetiology of liver disease is complicated and care is provided in many sectors, commissioning of services to prevent, diagnose and treat the affected population requires careful consideration and coordination across a number

Figure A.15: NHS RightCare Liver Disease pathway[46]

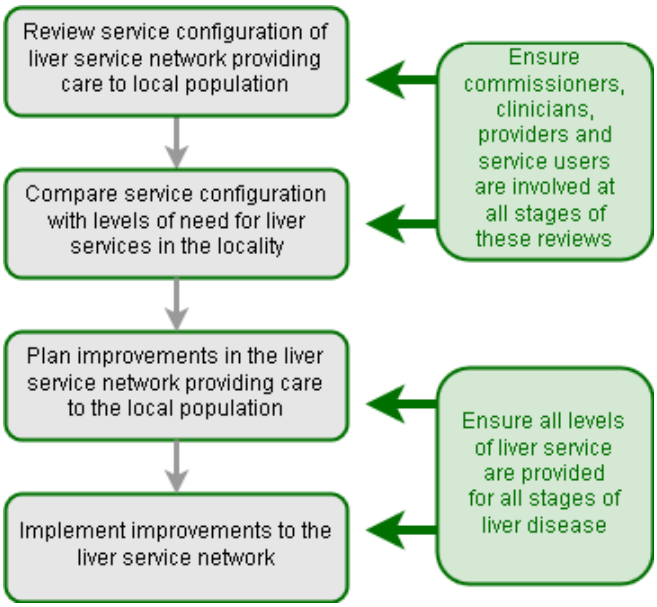


[46] NHS Rightcare, Where to Look packs - www.england.nhs.uk/rightcare/products/ccg-data-packs/where-to-look-packs

[47] Williams et al. (2015) Implementation of the Lancet Standing Commission on Liver Disease in the UK. Lancet 2015; 386: 2098–111

of organisations to ensure a seamless patient pathway. Figure A.16 illustrates some of the considerations.

Figure A.16: Options for action to ensure access to expertise in adult liver services



It is important when identifying where to focus efforts to make a change in the liver disease pathway that all affected organisations are involved in the design process. Local authorities, CCGs and clinicians needs to be brought together to understand how these data relate to each other and there should be processes in place to ensure that patients identified at risk or with early signs of liver disease can be referred into the relevant primary, secondary and tertiary care services for treatment. By identifying and treating patients early, the long-term effects of liver disease may possibly be mitigated and the subsequent use of costly emergency admissions and specialist services such as transplantation may be lowered.

Where patients are identified via an emergency route, access to brief intervention and appropriate onward referral to specialist services in a timely manner are essential as well as the use of referral protocols such as the BSG-BASL Bundle for assessment of decompensated patients with cirrhosis[48] in A&E to minimise adverse outcomes.

Service planning and/or reconfiguration needs to consider the balance between managing new referrals as well as the follow-up management of known patients. Issues that need to be factored in are local facilities and manpower, especially the number of hepatologists and liver specialist nurses available.

The need to plan for and co-ordinate liver disease services across local authority, community, district general and specialised services may mean that commissioners may wish to consider commissioning services on a bigger footprint such as at the STP or regional level. This will ensure equity in access to services at a local level and may also prove to be more cost effective and with better outcomes in the long term.

The South West region[49] and West Midlands region[50] have produced reports based on their reviews of liver disease prevention and treatment for their regions.

At a national level, clinical leadership in liver disease has come together under the Lancet Commission on Liver Disease which has produced evidence-based guidelines in its three Lancet Commission Reports. [51,52,53]

The Lancet Commission has published evidence-based recommendations to tackle liver disease in the UK (Box A.2) [53] and overarching recommendations were made for increased awareness and understanding of liver disease for the public and healthcare professionals.

[48] BSG - BASL Decompensated Cirrhosis Care Bundle - First 24 Hours, British Society of Gastroenterology. www.bsg.org.uk/care-bundles/care-bundles-general/decompensated-cirrhosis-care-bundle-first-24-hours.html
[49] Public Health England (2015). Review of Liver Disease in the South West: a health needs assessment. https://www.gov.uk/government/publications/liver-disease-in-the-south-west-a-health-needs-assessment
[50] Public Health England, LKIS West Midlands (2015). Liver Disease in the West Midlands: an epidemiological study. https://khub.net/web/phewestmidlands
[51] Williams et al. (2014) Addressing liver disease in the UK: a blueprint for attaining excellence in health care and reducing premature mortality from lifestyle issues of excess consumption of alcohol, obesity, and viral hepatitis. Lancet; 384: 1953–97
[52] Williams et al. (2015) Implementation of the Lancet Standing Commission on Liver Disease in the UK. Lancet 2015; 386: 2098–111
[53] Williams et al. (2017) New metrics for the Lancet Standing Commission on Liver Disease in the UK. Lancet 2017; 389: 2053–80 first published online December 15, 2016

Box A.2: Summary of key recommendations from Lancet Commission[53]

- Improving the expertise and facilities in primary care to strengthen detection of early disease and its treatment, and screening of high-risk patients in the community
- Establishment of acute liver services in district general hospitals linked with 30 regional specialist centres for complex investigations and treatment, and increased provision of medical and nursing training in hepatology
- A national review of liver transplantation to ensure better access for patients to increase capacity
- Specialist paediatric services and continuity of care in transition arrangements for children with liver disease reaching adult life
- Measures to reduce overall alcohol consumption in the country
- Promotion of healthy lifestyles to reduce obesity and the burden of non-alcoholic fatty liver disease
- Eradication of chronic hepatitis C as a major public health threat by 2030 and a major reduction in the burden of hepatitis B
- Increasing awareness of liver disease in the general population and within the National Health Service (NHS), including the work of liver patient support groups

In the most recent report, the initial ten recommendations have been reduced to eight because of some overlap between the original points. Significant progress has been made towards these recommendations.[52] Notable developments include the publication of NICE guidance for Non-Alcoholic Fatty Liver Disease[54] and Cirrhosis[55] to improve and standardise care nationally. Progress towards the eradication of hepatitis C has been marked due to introduction of efficacious antiviral drugs, however this is not yet the case for hepatitis B.

Significant future efforts are required in order to successfully address all of these recommendations.

Each indicator in this Atlas contains sections entitled “Context”, (which provides the background to the indicator), “Options for Action” (what providers and commissioners can do) and “Resources” (references to guidelines and policy statements).

This information together with the information of local performance can be used to highlight and improve services.

The way forward: increasing value

This Atlas of variation in risk factors and healthcare for liver disease in England shows a clear need to increase efforts to prevent, detect early and improve treatment for people with liver disease. It highlights opportunities for more proactive ways of managing patients with chronic liver disease as day cases and outpatients to try to reduce the large numbers of costly emergency admissions.

Ideally, it would be possible to look at the patient pathway(s) and move some funding to the prevention and early diagnosis phase of the pathway with the intention of saving costs in treatment further down the line.

Some of the maps highlight that there is still a significantly increasing trend on the burden placed on secondary care services in treating the effects of liver disease. Collective actions across developing policy, implementation of community interventions and working with relevant clinical teams to increase primary and secondary prevention interventions is crucial to help reduce this costly burden to the NHS.

In the three years since the publication of the first NHS Atlas of variation in healthcare for people with liver disease in 2013 it is apparent from this update that there is still unwarranted variation in the risk factors for, treatment of and outcomes of liver disease. Collaborative working across all sectors is paramount in tackling liver disease and this must be a priority for the forthcoming years.

[54] NICE guidance (July 2016) Non-alcoholic fatty liver disease (NAFLD): assessment and management www.nice.org.uk/guidance/ng49
[55] NICE guidance (July 2016) Assessment and Management of Cirrhosis www.nice.org.uk/guidance/indevelopment/gid-cgwave0683

A patient's view of the ideal pathway

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. 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 services for people 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'm not aware that babies get liver disease. I'd like 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 things like 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. • People need signposting to online information that is 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 if it is urgent to check whether I have existing liver damage. I am not aware of how it could 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 people 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 people to identify their personal risk factors and the implications of those risk factors.

Narrative	Care-planning considerations/implications
Early identification:	
I am not thought 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 either to be able 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 feeling 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 people 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 people 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 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 people 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.
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 I should 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 any stage in the pathway if and when needed and irrespective of where I live. I don't want to be caught up in	• 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. • People should be encouraged and supported to take responsibility for their liver condition

Narrative	Care-planning considerations/implications
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. If I am 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? If I am 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.	and make informed decisions about treatment options. • Protocols for shared care must be developed and clear 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.
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.	• 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 further information and support. • Access to social work support also needs to be provided. • Data on transplantation, waiting times and outcomes need to be made available to patients.

Narrative	Care-planning considerations/implications
I want to be made aware of the financial support and other help that I and my family are entitled to.	
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, fully informed of 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 further information and support. • Access to social work and other support services 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 timely access to expert teams such as those involved in specialist palliative care and pain management. • It is important to provide patients with signposting to other agencies, charities, voluntary bodies and other services.
Carers and relations:	
We are 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.

Table S1: Magnitude of variation summary

Map	Geography	Title	Optimum value	Range	Fold difference*	Number of areas significantly higher than England (99.8% level)	Number of areas significantly lower than England (99.8% level)	Variation trend	Median trend
1a	CCG of residence	Variation in rate of years of life lost in people aged 1 to 64 years from chronic liver disease including cirrhosis per population by CCG (2013-15), Directly standardised rate per 10,000	Low	9.3 - 71.5	7.7	26 (from 209)	34 (from 209)	Maximum to minimum range and 95th to 5th percentile gap narrowed significantly	Significant decrease
1b	CCG of residence	Variation in rate of years of life lost in people aged 1 to 74 years from chronic liver disease including cirrhosis per population by CCG (2013-15), Directly standardised rate per 10,000	Low	7.5 - 65.7	8.8	28 (from 209)	42 (from 209)	Maximum to minimum range and 95th to 5th percentile gap narrowed significantly	Significant decrease
1c	CCG of residence	Variation in mortality rate in people aged under 75 years from chronic liver disease including cirrhosis per population by CCG (2013-15), Directly standardised rate per 100,000	Low	3.9 - 30.1	7.7	36 (from 209)	30 (from 209)	Maximum to minimum range narrowed significantly	Significant decrease
2	CCG of residence	Variation in rate of admissions to hospital at least once for cirrhosis in people aged 18 years and over per population by CCG (2014/15), Directly standardised rate per 100,000	Low	36.5 - 308.3	8.5	58 (from 209)	69 (from 209)	Significant widening of all three measures of variation	Significant increase
3	CCG of residence	Experimental Statistic: Variation in rate of hospital admissions for liver disease in children and young people aged 18 years and under per population by CCG (2010/11-2014/15), Crude rate per 100,000	Requires local interpretation	12.2 - 374.5	30.7	39 (from 209)	99 (from 209)	Significant widening of all three measures of variation	Significant increase
4a	CCG of residence	Variation in rate of alcohol-specific admissions in people of all ages per population by CCG (2015/16), Directly standardised rate per 100,000	Low	228.6 - 1,681.0	7.4	81 (from 209)	95 (from 209)	Significant widening of all three measures of variation	Significant increase
4b	CCG of residence	Variation in rate of alcohol-specific admissions in men of all ages per population by CCG (2015/16), Directly standardised rate per 100,000	Low	336.3 - 2,758.0	8.2	78 (from 209)	97 (from 209)	Significant widening of all three measures of variation	Significant increase
4c	CCG of residence	Variation in rate of alcohol-specific admissions in women of all ages per population by CCG (2015/16), Directly standardised rate per 100,000	Low	133.5 - 1,015.5	7.6	59 (from 209)	71 (from 209)	Significant widening of all three measures of variation	Significant increase
5	CCG of residence	Variation in rate of alcohol-specific admissions in people aged under 18 years per population by CCG (2015/16), Crude rate per 100,000	Low	8.0 - 106.8	13.4	14 (from 209)	10 (from 209)	Significant narrowing of all three measures of variation	Significant decrease

* The fold-difference value may differ from the ratio of the maximum and minimum values presented in the 'Range' column due to rounding.

Map	Geography	Title	Optimum value	Range	Fold difference*	Number of areas significantly higher than England (99.8% level)	Number of areas significantly lower than England (99.8% level)	Variation trend	Median trend
6	UTLA	Variation in percentage of people aged 18 to 75 with alcohol use who completed structured treatment successfully and did not re-present to treatment within 6 months by upper-tier local authority (2015)	High	16.8 - 64.9	3.9	29 (from 152)	32 (from 152)	No significant change in any variation measure	Significant increase
7	LTLA	Variation in rate of premises licensed to sell or supply alcohol per population aged 18 years and over by lower-tier local authority per population (2016), Crude rate per 1,000	Low	1.9 - 12.0	6.3	104 (from 326)	45 (from 326)	Trend data unavailable	Trend data unavailable
8	Region	Variation in rate of laboratory reports for confirmed hepatitis C per population by region (2015), Crude rate per 100,000	Requires local interpretation	8.6 - 47.2	5.5	2 (from 9)	6 (from 9)	Maximum to minimum range widened significantly	Significant increase
9	UTLA	Variation in estimated prevalence of injecting of opiate and/or crack cocaine in people aged 15 to 64 years per population by upper-tier local authority (2011/12), Crude rate per 1,000	Low	0.3 - 8.7	33.7	No data	No data	No significant change in any variation measure	No change
10	UTLA	Variation in percentage of hepatitis C test uptake among people who inject drugs receiving drug treatment by upper-tier local authority (2015/16)	High	55.6 - 96.6	1.7	44 (from 152)	36 (from 152)	95th to 5th percentile gap and 75th to 25th percentile gap narrowed significantly	Significant increase
11a	STP	Variation in rate of hospital admissions for hepatitis C-related end-stage liver disease or hepatocellular carcinoma per population by Sustainability Transformation Partnerships (STP) (2012/13 - 2014/15), Crude rate per 1,000,000	Low	4.4 - 21.0	4.8	6 (from 44)	16 (from 44)	Maximum to minimum range narrowed significantly, 95th to 5th and 75th to 25th percentile gaps widened significantly	Significant increase
11b	STP	Variation in rate of mortality from hepatitis C-related end-stage liver disease or hepatocellular carcinoma per population by Sustainability Transformation Partnerships (STP) (2011-2015), Crude rate per 100,000	Low	0.2 - 1.1	4.6	4 (from 44)	1 (from 44)	95th to 5th percentile gap widened significantly	Significant increase
12	Region	Variation in percentage of women who tested positive for hepatitis B in the NHS Infectious Diseases in Pregnancy Screening Programme by region (2015)	Requires local interpretation	0.2 - 0.8	4.4	1 (from 9)	6 (from 9)	Maximum to minimum range and 95th to 5th percentile gap narrowed significantly	No change

* The fold-difference value may differ from the ratio of the maximum and minimum values presented in the 'Range' column due to rounding.

Map	Geography	Title	Optimum value	Range	Fold difference*	Number of areas significantly higher than England (99.8% level)	Number of areas significantly lower than England (99.8% level)	Variation trend	Median trend
13	UTLA	Variation in percentage of infants immunised for hepatitis B by their first birthday who were born to mothers with persistent hepatitis B infection by upper-tier local authority (2015/16)	High	0 - 100	-	No data	No data	Trend data unavailable	Trend data unavailable
14	Region	Variation in rate of laboratory reports for acute or probable acute hepatitis B per population by region (2015), Crude rate per 100,000	Requires local interpretation	0.3 - 1.5	4.5	1 (from 9)	0 (from 9)	75th to 25th percentile gap narrowed significantly	Significant decrease
15a	STP	Variation in rate of hospital admissions for hepatitis B-related end-stage liver disease or hepatocellular carcinoma per population by Sustainability Transformation Partnerships (STP) (2012/13 - 2014/15), Crude rate per 1,000,000	Low	1.2 - 8.9	7.4	5 (from 44)	4 (from 44)	No significant change in any variation measure	No change
15b	STP	Variation in mortality rate from hepatitis B-related end-stage liver disease or hepatocellular carcinoma per population by Sustainability Transformation Partnerships (STP) (2011-2015), Crude rate per 100,000	Low	0.1 - 0.4	7.4	4 (from 44)	0 (from 44)	Maximum to minimum range narrowed significantly	No change
16a	LTLA	Variation in percentage of children in school reception year classified as overweight or obese by lower-tier local authority (school year 2015/16)	Low	12.9 - 30.1	2.3	40 (from 326)	49 (from 326)	Maximum to minimum range and 95th to 5th percentile gap narrowed significantly	Significant decrease
16b	LTLA	Variation in percentage of children in school year 6 classified as overweight or obese by lower-tier local authority (school year 2015/16)	Low	20.1 - 43.4	2.2	52 (from 326)	90 (from 326)	Significant widening of all three measures of variation	Significant increase
17	LTLA	Variation in percentage of adults aged 16 and over classified as obese (body mass index ≥30 kg/m^2) by lower-tier local authority (2013-2015)	Low	11.0 - 34.0	3.1	53 (from 326)	60 (from 326)	Trend data unavailable	Trend data unavailable
18	NHS Area Team	Variation in percentage of people aged 6 months to 65 years with chronic liver disease who have received the influenza vaccine by NHS Area Team (2015/16)	High	34.1 - 50.0	1.5	10 (from 25)	7 (from 25)	Trend data unavailable	Trend data unavailable
19a	CCG of residence	Variation in rate of hospital admissions where the primary diagnosis is paracetamol overdose per population by CCG (2013/14 - 2014/15), Directly standardised rate per 100,000	Low	30.7 - 304.9	9.9	33 (from 209)	110 (from 209)	Maximum to minimum range and 75th to 25th percentile gap widened significantly	Significant increase
19b	Region	Variation in percentage of deaths from paracetamol poisoning per hospital admissions for paracetamol overdose by region (2012-2014)	Low	0.2 - 0.5	2.0	0 (from 9)	0 (from 9)	95th to 5th percentile gap narrowed significantly	Significant decrease

* The fold-difference value may differ from the ratio of the maximum and minimum values presented in the 'Range' column due to rounding.

Map	Geography	Title	Optimum value	Range	Fold difference*	Number of areas significantly higher than England (99.8% level)	Number of areas significantly lower than England (99.8% level)	Variation trend	Median trend
20	STP	Variation in mortality rate in people aged under 75 years due to hepatocellular carcinoma per population by Sustainability Transformation Partnerships (STP) (2011-2015), Directly standardised rate per 100,000	Low	1.2 - 3.0	2.6	6 (from 44)	1 (from 44)	No significant change in any variation measure	Significant increase
21	Region	Variation in percentage of people aged 15 years and over with hepatocellular carcinoma that have had treatment with curative intent (liver transplantation, major liver resection or ablation) by region (2010-2014)	High	11.4 - 17.3	1.5	0 (from 9)	0 (from 9)	Trend data unavailable	Trend data unavailable
22	CCG of residence	Variation in rate of liver transplants from all donors per population by CCG (2010/11 - 2014/15), Crude rate per 1,000,000	Requires local interpretation	4.5 - 25.4	5.7	2 (from 209)	0 (from 209)	Trend data unavailable	Trend data unavailable
23a	SHA	Variation in rate of organ donation from deceased donors per population by Strategic Health Authority (2014/15), Crude rate per 1,000,000	Requires local interpretation	15.4 - 24.9	1.6	0 (from 10)	0 (from 10)	No significant change in any variation measure	Significant increase
23b	SHA	Variation in rate of liver donation from deceased donors per population by Strategic Health Authority (2014/15) , Crude rate per 1,000,000	Requires local interpretation	11.8 - 17.3	1.5	0 (from 10)	0 (from 10)	No significant change in any variation measure	Significant increase
24	SHA	Variation in rate of liver transplants from deceased donors per population by Strategic Health Authority (2014/15), Crude rate per 1,000,000	Requires local interpretation	9.3 - 14.7	1.6	0 (from 10)	0 (from 10)	No significant change in any variation measure	Significant increase
25	CCG of residence	Variation in percentage of admissions for oesophageal varices procedure that were emergency admissions by CCG (2014/15)	Low	0.0 - 85.7	-	8 (from 209)	5 (from 209)	No significant change in any variation measure	Significant decrease
26	CCG of residence	Variation in percentage of admissions for paracentesis procedure that were emergency admissions by CCG (2014/15)	Low	13.9 - 100.0	7.2	51 (from 209)	33 (from 209)	No significant change in any variation measure	Significant decrease
27a	SCN	Variation in mean number of bed-days per liver disease patient admitted to hospital in the last year of life by Strategic Clinical Network (SCN) (2015)	Requires local interpretation	12.1 - 20.2	1.7	2 (from 12)	8 (from 12)	Trend data unavailable	Trend data unavailable
27b	SCN	Variation in percentage of liver disease patients who died without being admitted to hospital in the last year of life by Strategic Clinical Network (SCN) (2015)	Requires local interpretation	10.1 - 16.1	1.6	0 (from 12)	0 (from 12)	Trend data unavailable	Trend data unavailable
27c	SCN	Variation in percentage of liver cancer deaths that occurred in hospital among all care facilities by Strategic Clinical Network (SCN) (2015)	Low	29.3 - 45.5	1.6	0 (from 12)	1 (from 12)	Trend data unavailable	Trend data unavailable
27d	SCN	Variation in percentage of liver non-cancer deaths that occurred in hospital among all care facilities by Strategic Clinical Network (SCN) (2015)	Low	73.3 - 82.1	1.1	0 (from 12)	0 (from 12)	Trend data unavailable	Trend data unavailable

* The fold-difference value may differ from the ratio of the maximum and minimum values presented in the 'Range' column due to rounding.

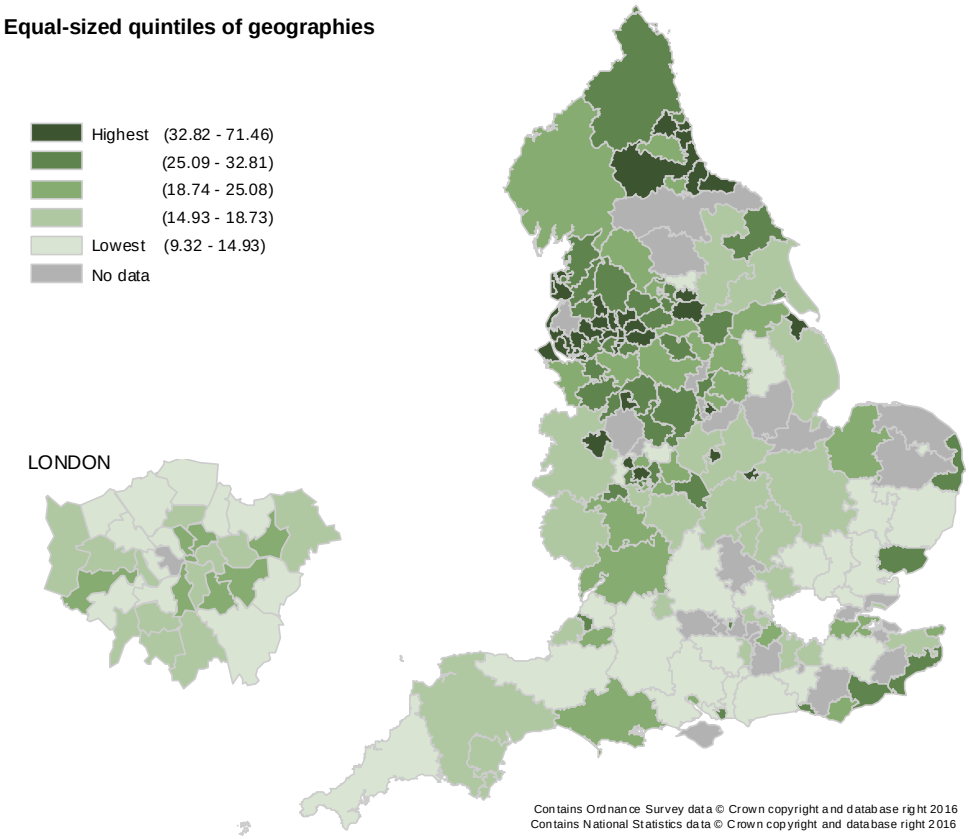
CHRONIC LIVER DISEASE

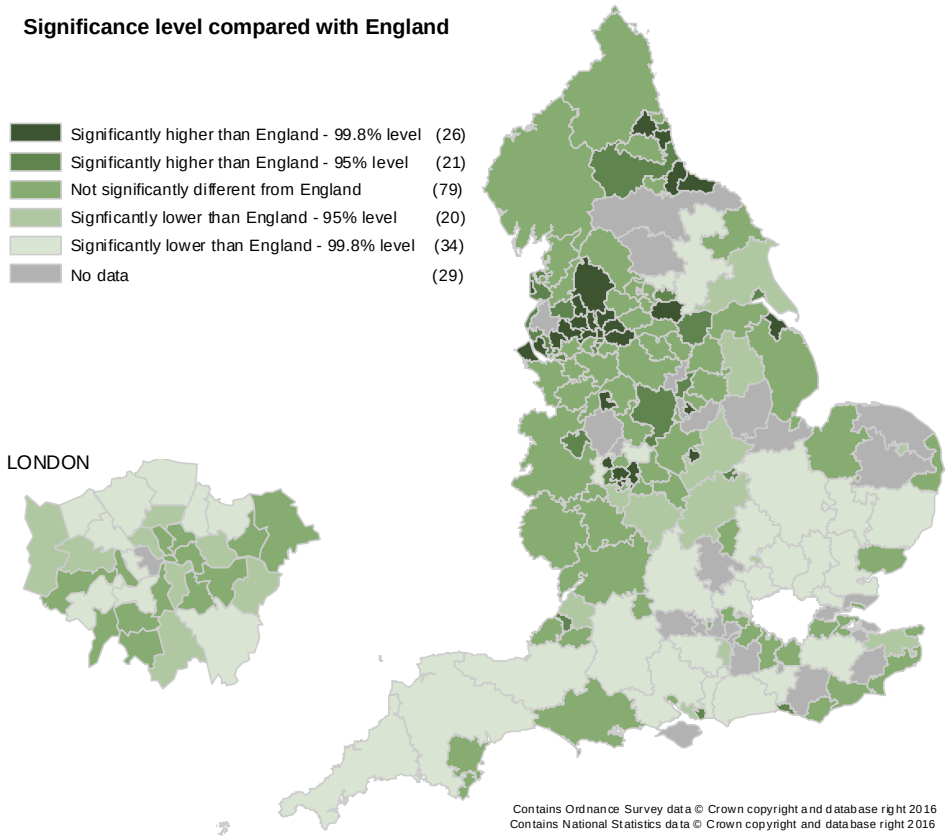
Map 1a: Variation in rate of years of life lost in people aged 1 to 64 years from chronic liver disease including cirrhosis per population by CCG (2013-15)

Directly standardised rate per 10,000

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long-term conditions
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW





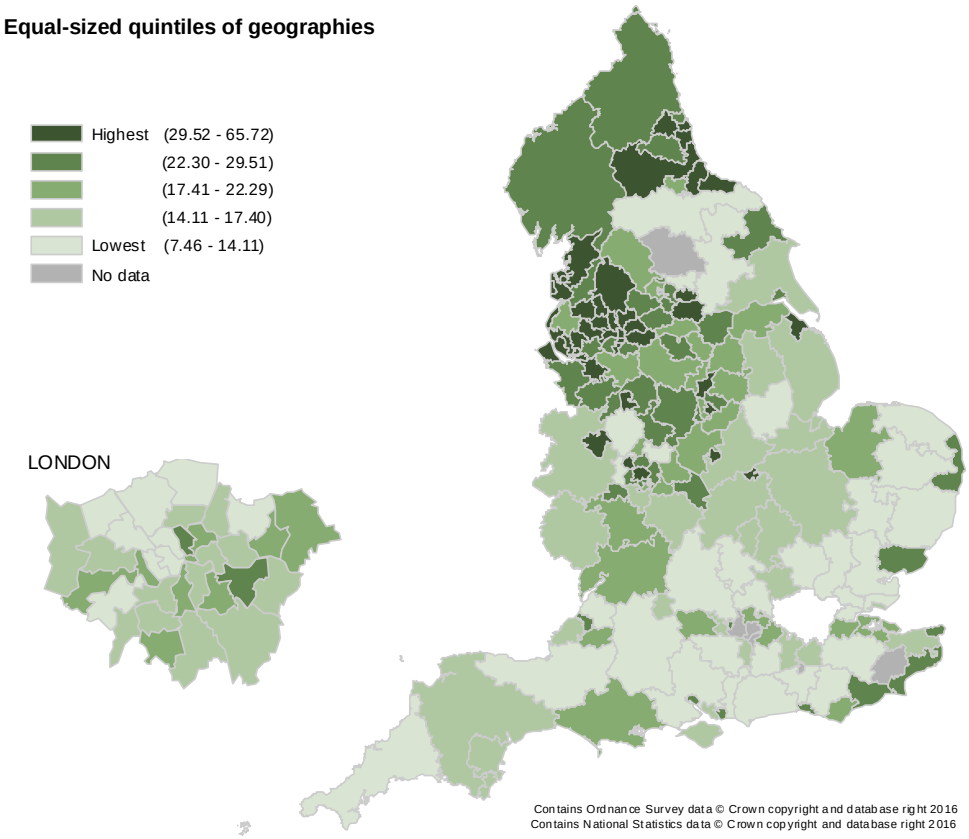
CHRONIC LIVER DISEASE

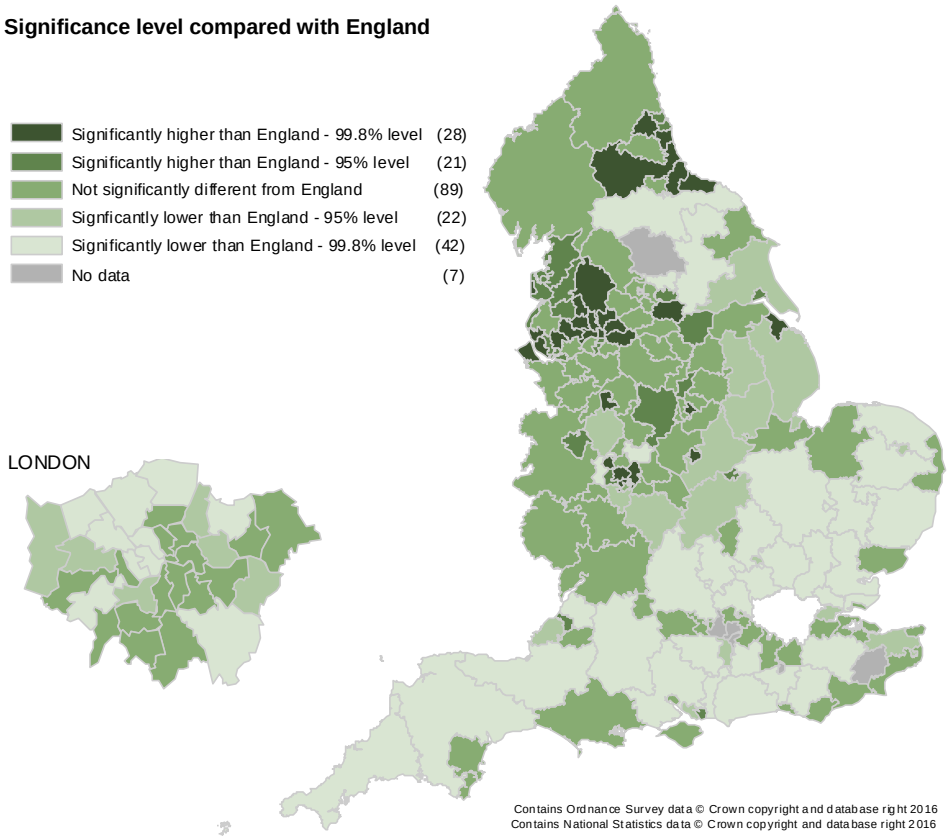
Map 1b: Variation in rate of years of life lost in people aged 1 to 74 years from chronic liver disease including cirrhosis per population by CCG (2013-15)

Directly standardised rate per 10,000

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long-term conditions
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW





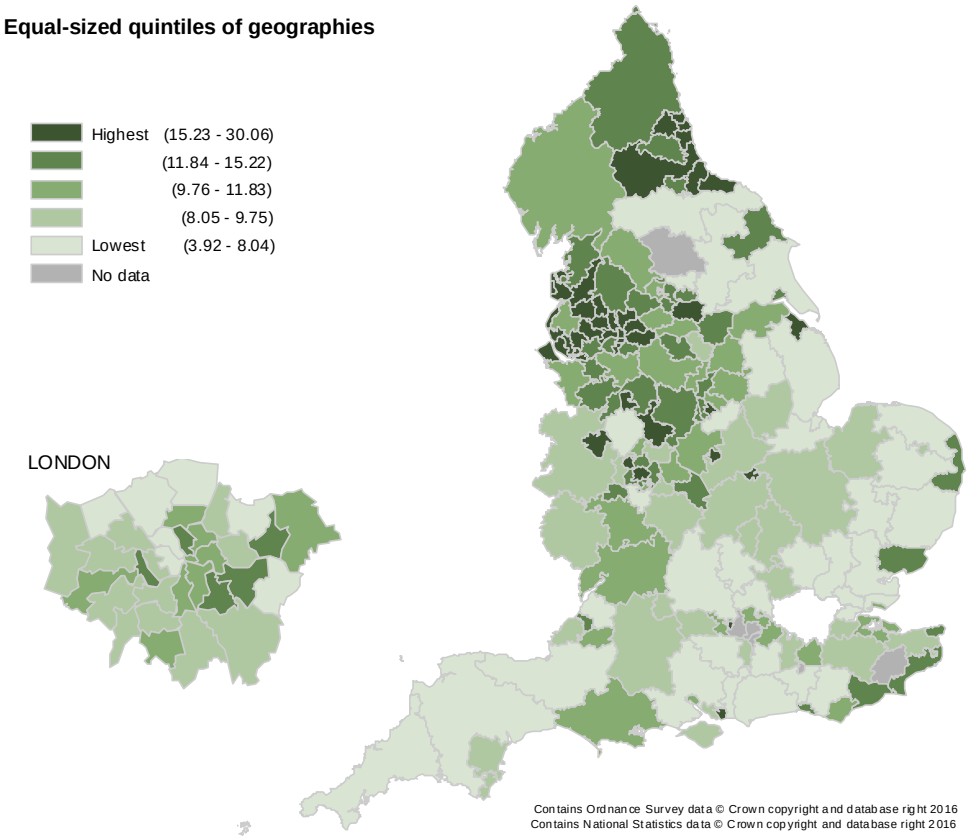
CHRONIC LIVER DISEASE

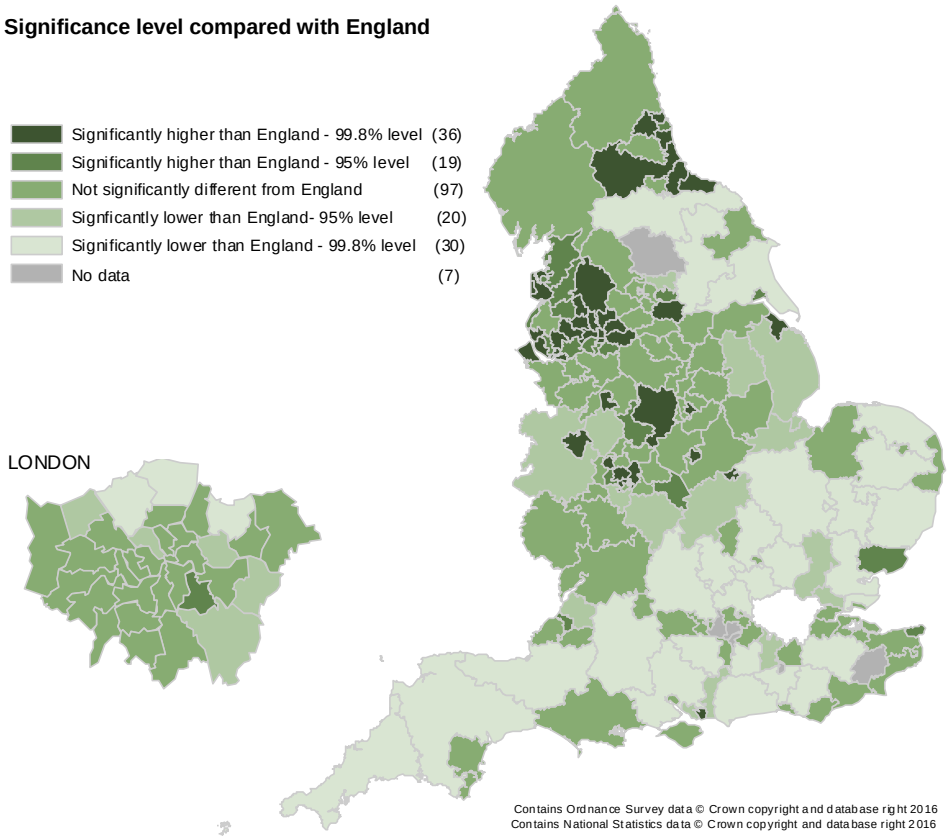
Map 1c: Variation in mortality rate in people aged under 75 years from chronic liver disease including cirrhosis per population by CCG (2013-15)

Directly standardised rate per 100,000

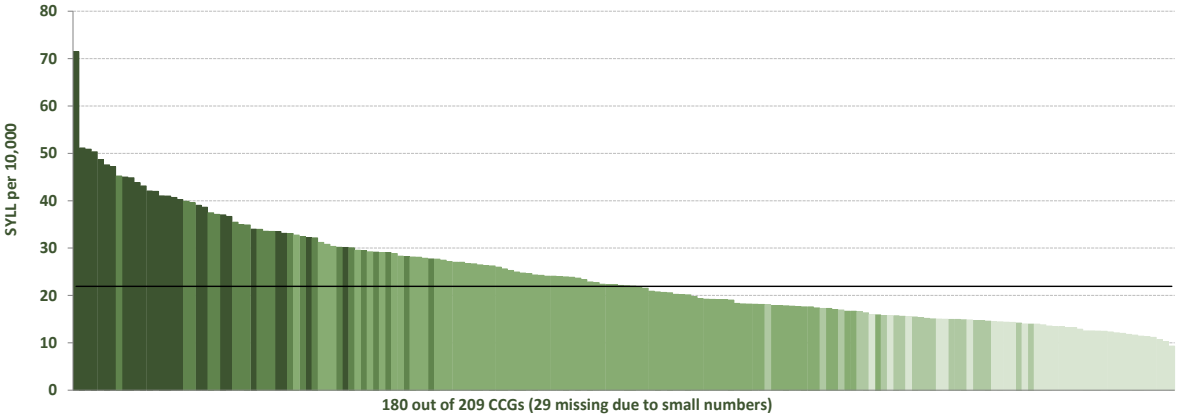
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long term conditions
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW

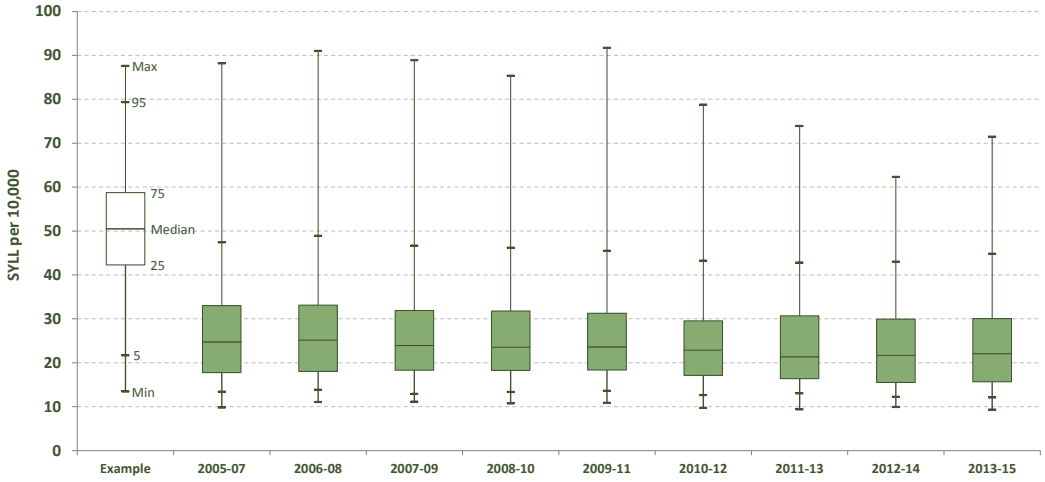




Variation in rate of years of life lost in people aged 1 to 64 years from chronic liver disease including cirrhosis per population by CCG (2013-15)



180 out of 209 CCGs (29 missing due to small numbers)



Max-Min (Range)		78.4	79.9	77.8	74.6	80.8	69.1	64.5	52.4	62.1	NARROWING Significant
95th-5th percentile		34.0	35.1	33.8	32.9	31.9	30.6	29.8	30.8	32.7	NARROWING Significant
75th-25th percentile		15.3	15.1	13.6	13.5	12.9	12.4	14.3	14.4	14.4	No significant change
Median		24.8	25.1	23.9	23.5	23.6	22.9	21.4	21.7	22.1	DECREASING Significant

Context

Death from chronic liver disease has been rising in recent decades, and between 1995 and 2014 the all-age directly standardised mortality rate in England increased by 49%.[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 to 55 years.[2] Liver disease is responsible for almost 12% of deaths in men aged 40 to 49 years.[3]

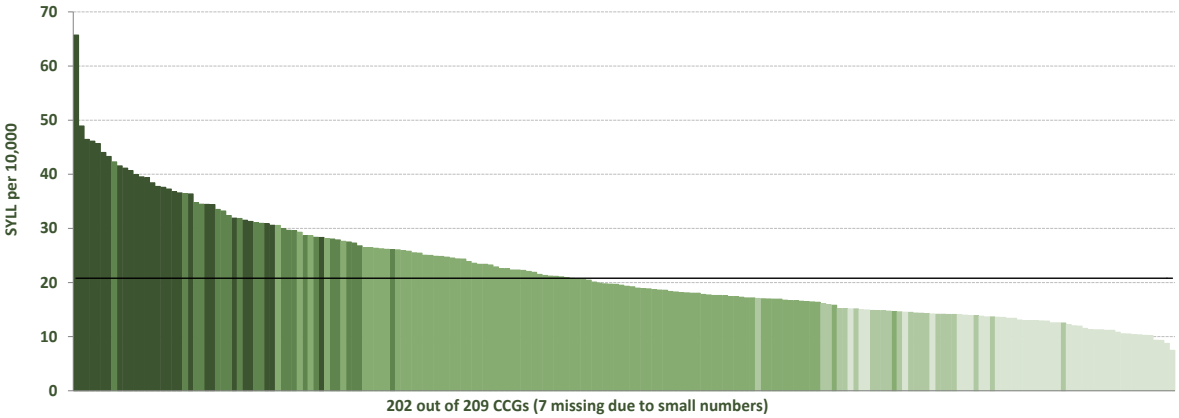
Chronic liver disease is one of the main causes of premature death for men and women aged under 75 years. In 2015, the rate of years of life lost (YLLs) from chronic liver disease was the fourth highest cause in both sexes, ahead of stroke, land transport accidents and colorectal cancer (Figure 1.1). However the burden from chronic liver disease does not seem to have become as prominent in the awareness and understanding of the general public and healthcare professionals as that for other causes of premature mortality.

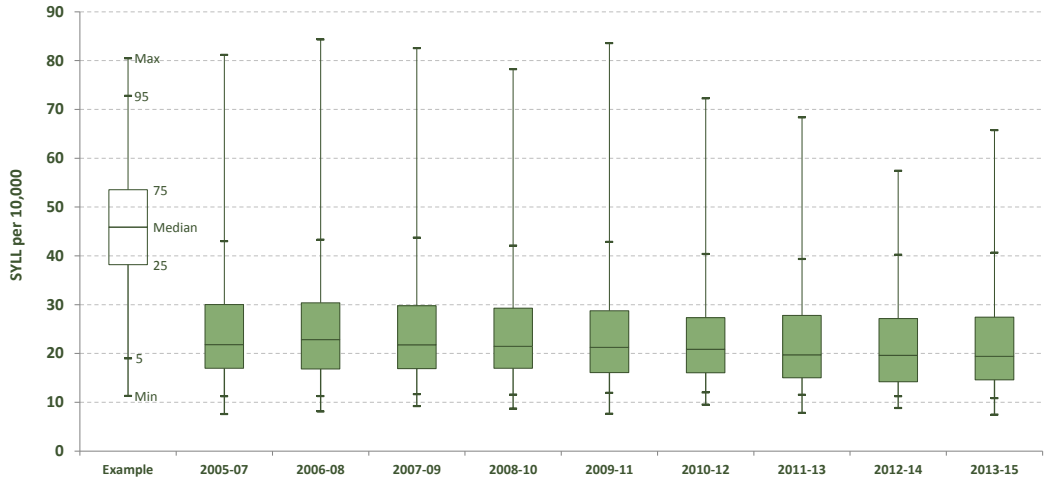
Chronic liver disease is largely preventable but many people are not diagnosed until a late stage of disease progression when interventions may be limited and costly. The major contributing causes of liver disease are:

- alcohol; with the increasing consumption and the decreasing cost of alcohol, more people are being diagnosed with alcohol-related liver disease – peak age for admission and death is 35 to 55 years,

[1] NHS Digital. NHS Digital Indicator Portal. Menu pathway: NHS Digital 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, all persons, annual trend 1995–2014. https://indicators.ic.nhs.uk/webview/
[2] North West Public Health Observatory. Indications of Public Health in the English Regions 8: Alcohol. Association of Public Health Observatories; 2007. www.nwph.net/Publications/Alcohol_Indications.pdf
[3] Analysis conducted in 2010 by Tom Kennel, North West Public Health Observatory.

Variation in rate of years of life lost in people aged 1 to 74 years from chronic liver disease including cirrhosis per population by CCG (2013-15)



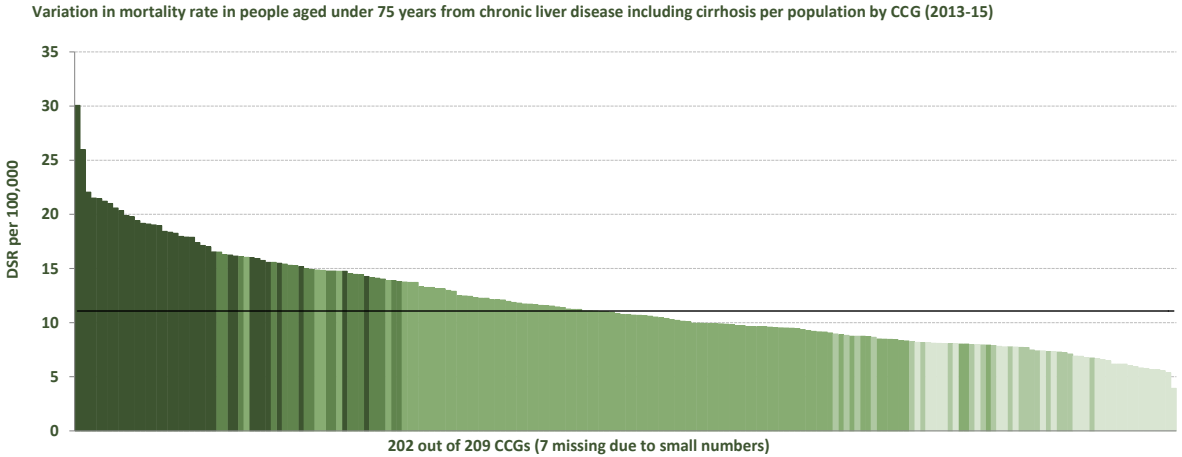


Max-Min (Range)		73.6	76.2	73.3	69.5	75.9	62.7	60.5	48.6	58.3	NARROWING Significant
95th-5th percentile		31.8	32.1	32.1	30.5	30.9	28.4	27.8	29.0	29.8	NARROWING Significant
75th-25th percentile		13.1	13.6	12.9	12.3	12.7	11.3	12.8	12.9	12.8	No significant change
Median		21.8	22.9	21.8	21.5	21.3	20.8	19.7	19.6	19.4	DECREASING Significant

but numbers of admissions and deaths are increasing at all ages

- obesity and diabetes type 2, both of which are increasing – England has high rates of obesity and diabetes when compared with many other countries with developed economies; people with diabetes or who are obese are susceptible to many health problems, but a high proportion have non-alcoholic fatty liver disease (NAFLD) and non-alcoholic steatohepatitis (NASH); 5% to 10% of cases can progress to cirrhosis; as the prevalence of diabetes and of obesity increase, the number of people with cirrhosis will increase
- chronic viral 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; a considerable number of people with hepatitis C remain undiagnosed; among those known to have hepatitis C, treatment rates are improving with more effective treatment
- 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

Several other causes of acute or chronic liver disease contribute to years of life lost and premature mortality, many of which have effective treatments. Although these other causes of liver disease are not increasing in



Max-Min (Range)		32.8	34.1	32.6	29.2	30.6	27.2	27.0	22.6	26.1	NARROWING Significant
95th-5th percentile		13.0	14.2	15.1	14.7	14.2	13.0	12.3	13.1	13.6	No significant change
75th-25th percentile		6.3	6.4	5.9	6.1	5.7	5.4	5.8	6.1	6.2	No significant change
Median		11.5	11.8	11.4	11.4	11.2	11.3	10.5	10.6	10.8	DECREASING Significant

prevalence, a greater awareness can lead to more effective prevention of the consequences.

The years of life lost indicators reflect the fact that the majority of people with chronic liver disease die at a younger age (below 75 years).[2]

Magnitude of variation

Map 1a: Years of Life Lost in people aged 1 to 64 years from chronic liver disease including cirrhosis

The maps and column chart display the Age Standardised Years of Life Lost (SYLL) for 2013-15, during which CCG values ranged from 9.3 to 71.5 per 10,000 population, which is a 7.7-fold difference between CCGs. The England value for 2013-15 was 21.9 per 10,000 population. The boxplot shows the distribution of CCG values for the period 2005-07 to 2013-15. Both the maximum to minimum range and the 95th to 5th percentile gap narrowed significantly. The median decreased significantly from 24.8 per 10,000 population in 2005-07 to 22.1 per 10,000 population in 2013-15.

Map 1b: Years of Life Lost in people aged 1 to 74 years from chronic liver disease including cirrhosis

The maps and column chart display the Age Standardised Years of Life Lost (SYLL) for 2013-15, during which CCG values ranged from 7.5 to 65.7 per 10,000 population, which is an 8.8-fold difference between CCGs. The England value for 2013-15 was 20.8 per 10,000 population. The boxplot shows the distribution of CCG values for the period 2005-07 to 2013-15. Both the maximum to minimum range and the 95th to 5th percentile gap narrowed significantly. The median decreased significantly from 21.8

per 10,000 population in 2005-07 to 19.4 per 10,000 population in 2013-15.

Map 1c: Mortality rate in people aged under 75 years from chronic liver disease including cirrhosis

The maps and column chart display the data for 2013-15, during which CCG values ranged from 3.9 to 30.1 per 100,000 population, which is a 7.7-fold difference between CCGs. The England value for 2013-15 was 11.1 per 100,000 population. The boxplot shows the distribution of CCG values for the period 2005-07 to 2013-15. The maximum to minimum range narrowed significantly. The median decreased significantly from 11.5 per 100,000 population in 2005-07 to 10.8 per 100,000 population in 2013-15.

Although the median for all three indicators has decreased significantly from 2005-07 to 2013-15, these decreases could reflect improved data collection; it may be too early to conclude the decreases reflect any improvement.

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

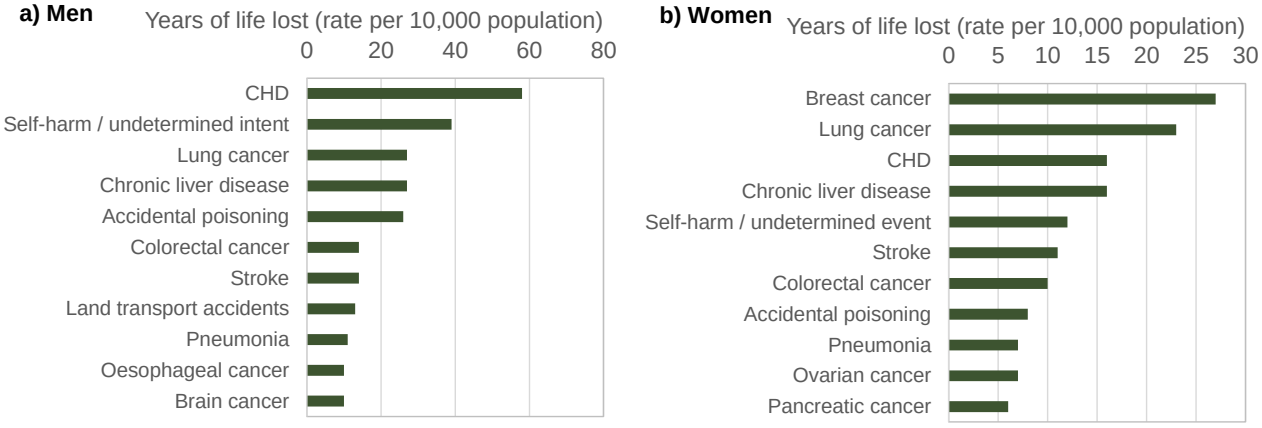
- the level of alcohol consumption
- the prevalence of diabetes, obesity, hepatitis B and hepatitis C
- the level of investment in preventative measures
- the configuration of services
- the timing of diagnosis
- degree of adherence to clinical guidance
- level of patient compliance with prevention or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

Options for action

To reduce the years of life lost from chronic liver disease, commissioners, clinicians and service providers need:

- to review the rates of years of life lost in people aged under 65 years and under 75 years in the local population
- to review mortality rates in people under 75 years in the local population
- to assess strategies for preventing and treating chronic liver disease, and identify actions to reduce mortality from chronic liver disease (see Box 1.1), including risk assessment in particular population subgroups and diagnosis of liver disease at an earlier stage
- to review service configuration and care pathway integration, including end-of-life care, to reduce unplanned admissions
- 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

Figure 1.1: Rate of years of life lost in people aged under 75 years for major causes of death per 10,000 population in England 2015 (source: Deaths Registered in England and Wales, 2015, ONS)



Box 1.1: Actions to prevent liver disease

1. Raise the profile of risk factors for liver disease in the general population
2. Conveying information to people about the health of their liver and the causes of damage
3. Early identification of liver disease and early intervention in primary care
4. 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
5. Effective collaboration among primary and secondary care providers to ensure patients gain access to appropriate expertise and services that can manage their disease
6. Raising awareness of the scale of the problem of liver disease among professional groups
7. Skills development in the identification and management of liver disease for healthcare professionals
8. Using digital and multimedia resources to enable people to become more involved in self-management
9. Liaising with private and third sector organisations in the local community to enlist their support in promoting healthy lifestyles

RESOURCES

- NHS Digital. NHS Digital Information Portal. Menu pathway: NHS Digital Indicators; Compendium of Population Health Indicators; Illness or Condition; Digestive Diseases & Disorders; Chronic Liver Disease. https://indicators.ic.nhs.uk/webview
- Public Health England. Local Alcohol Profiles for England. https://fingertips.phe.org.uk/profile/local-alcohol-profiles
- North West Public Health Observatory. Indications of Public Health in the English Regions 8: Alcohol. Association of Public Health Observatories; 2007. www.nwph.net/Publications/Alcohol_Indications.pdf
- PHE data analysis and tools. Scroll down to ‘Obesity, diet and physical activity’. www.gov.uk/guidance/phe-data-and-analysis-tools#obesity-diet-and-physical-activity
- NHS England. NHS Diabetes Prevention Programme. www.england.nhs.uk/diabetes/diabetes-prevention
- NICE interactive flowchart. Preventing type 2 diabetes overview. https://pathways.nice.org.uk/pathways/preventing-type-2-diabetes
- NHS Digital. National Diabetes Audit. http://content.digital.nhs.uk/nda

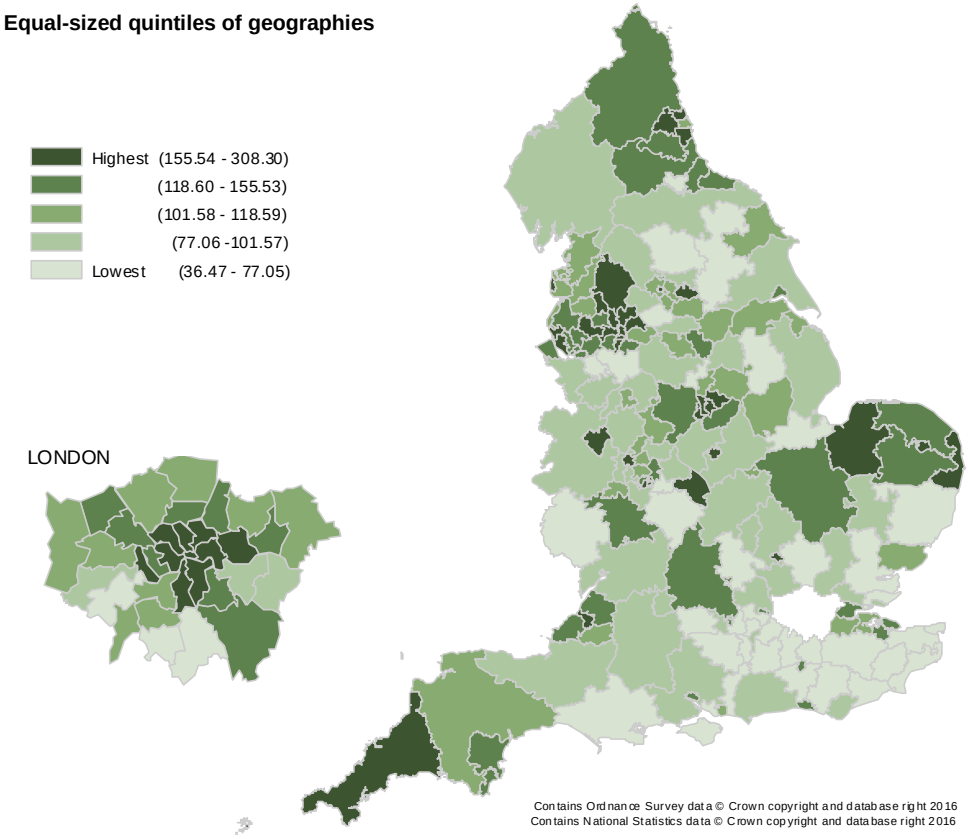
CHRONIC LIVER DISEASE

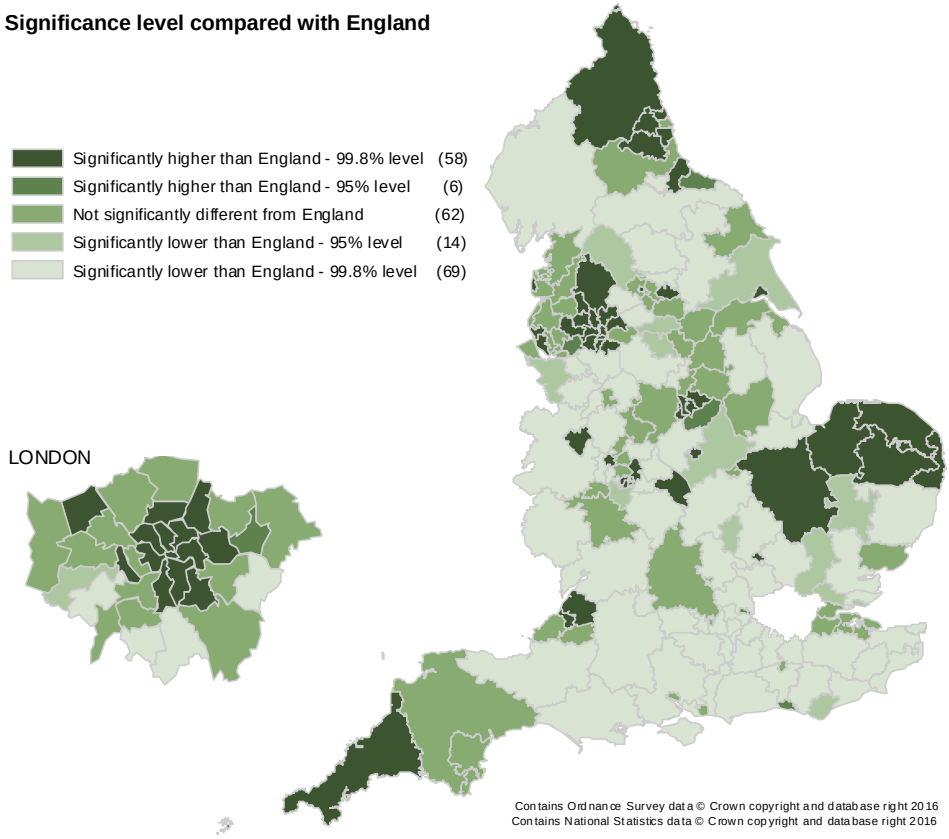
Map 2: Variation in rate of admissions to hospital at least once for cirrhosis in people aged 18 years and over per population by CCG (2014/15)

Directly standardised rate per 100,000

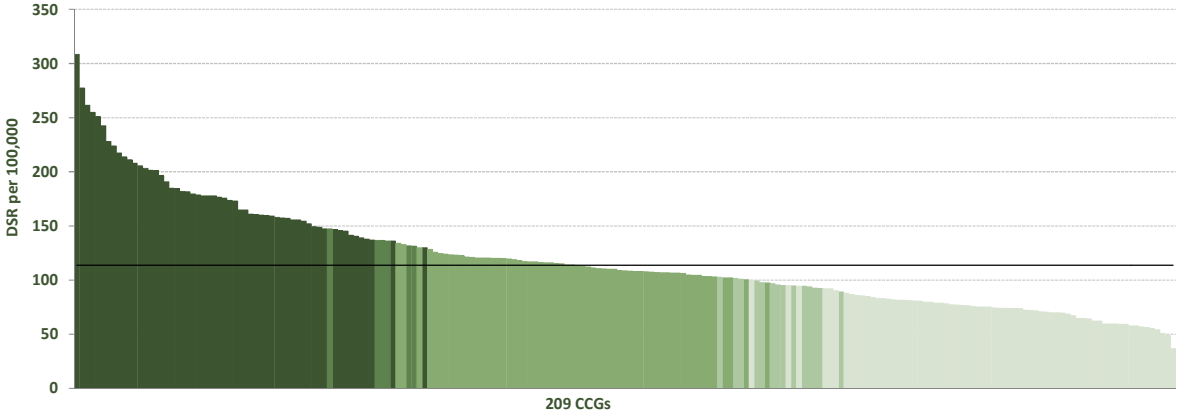
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long term condition
PHOF Domain 4: Healthcare public health and preventing premature mortality

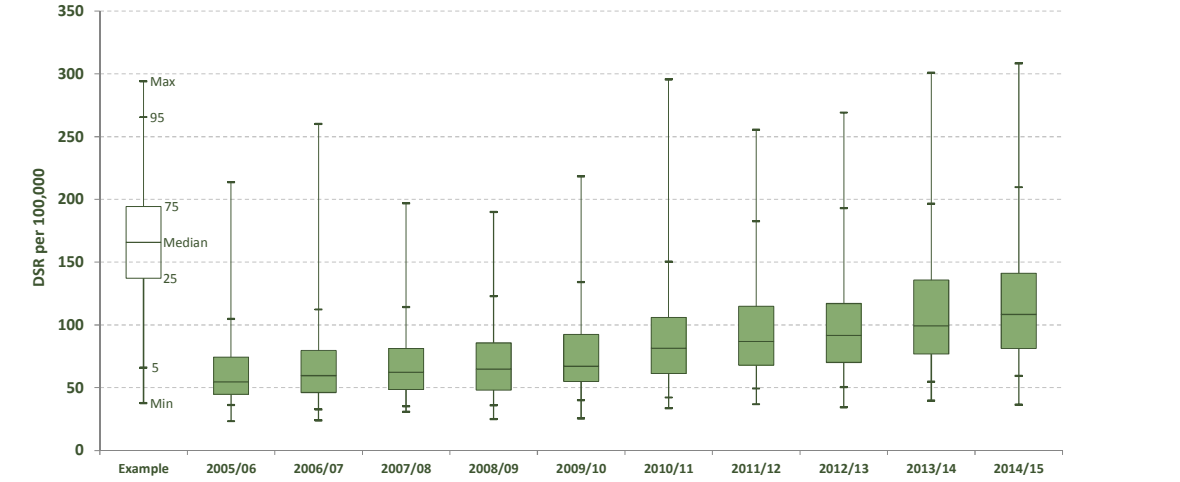
OPTIMUM VALUE: LOW





Variation in rate of admissions to hospital at least once for cirrhosis in people aged 18 years and over per population by CC G (2014/15)





Max-Min (Range)		190.2	236.3	166.0	164.9	192.8	261.7	218.6	234.8	261.1	271.8	WIDENING Significant
95th-5th percentile		68.5	79.9	79.1	87.0	94.0	108.2	133.2	142.6	141.8	150.5	WIDENING Significant
75th-25th percentile		29.8	33.4	32.6	37.6	37.3	44.6	46.9	46.9	58.9	60.0	WIDENING Significant
Median		54.8	59.6	62.4	64.7	67.1	81.6	86.9	91.7	99.4	108.4	INCREASING Significant

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 more people died from cirrhosis than died in transport incidents and more women died from cirrhosis than died from 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. However, since the mid-1970s the mortality rate in other EU countries, eg France and Italy, has fallen. Among people aged under 65 years, the chronic liver disease and cirrhosis mortality rate for the UK overtook those in France and Italy in the early 2000's (Figure 2.1).

Although there are many different causes of cirrhosis, it is often due to excess alcohol consumption. Other causes that are becoming increasingly important are chronic viral hepatitis, especially hepatitis C, and non-alcoholic steatohepatitis (NASH), that can develop from non-alcoholic fatty liver disease (NAFLD). Alcohol consumption

will increase the rate of progression of cirrhosis irrespective of the original cause.

The considerable increase in chronic liver disease and cirrhosis incidence is reflected in the hospital admissions data supporting this Atlas. There was a greater than two-fold increase in adult (aged 18 and over) admissions from 27,830 in 2005/06 to 57,147 in 2014/15

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 admissions for 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

The maps and column chart display the data for 2014/15, during which CCG values ranged from 36.5 to 308.3 per 100,000 population, which is an 8.5-fold difference between CCGs. The England value for 2014/15 was 113.7 per 100,000 population. The boxplot shows the distribution of CCG values for the period 2005/06 to 2014/15.There has been significant widening of all three measures of variation and the median increased significantly from 54.8 per 100,000 population in 2005/06 to 108.4 per 100,000 population in 2014/15.

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

To reduce the prevalence of cirrhosis, commissioners, clinicians and service providers need:

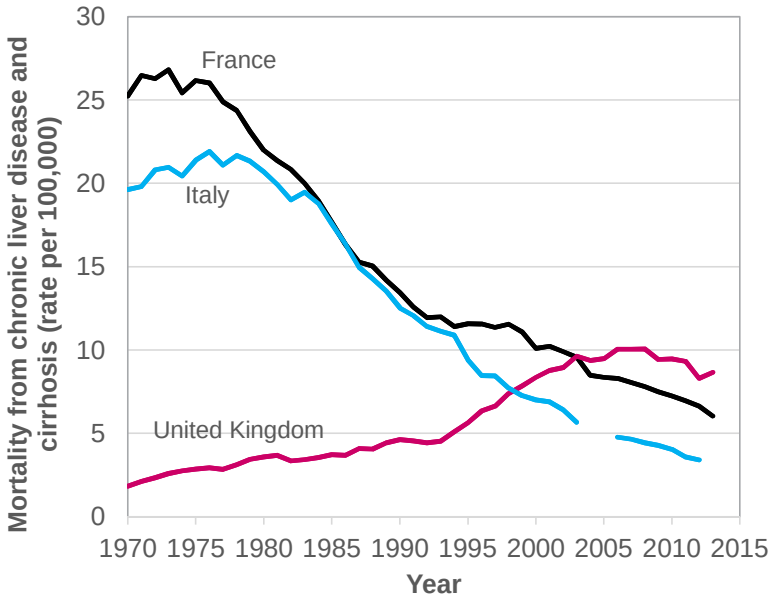
- to review hospital admission rates for cirrhosis in the locality
- to assess the current pathway of care for people presenting with cirrhosis, and identify improvements
- to focus on the causes of cirrhosis and opportunities for early detection to avoid future admissions and complications (see ‘Resources’)
- 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

- NICE. Cirrhosis in over 16s: assessment and management. NICE guideline [NG50]. Published date: July 2016. www.nice.org.uk/guidance/ng50
- NICE. Interactive flowcharts. Cirrhosis overview. https://pathways.nice.org.uk/pathways/cirrhosis
- NICE. Alcohol-use disorders – prevention. Public health guideline [PH24]. Published date: June 2010. http://guidance.nice.org.uk/PH24
- NICE. Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence. Clinical guideline [CG115]. Published date: February 2011. www.nice.org.uk/guidance/CG115
- NICE. Alcohol-use disorders: diagnosis and management of physical complications. Clinical guideline [CG100]. Published date: June 2010. http://guidance.nice.org.uk/CG100
- NICE. Interactive flowchart. Alcohol-use disorders overview. http://pathways.nice.org.uk/pathways/alcohol-use-disorders
- PHE. Alcohol Learning Resources. Improving Local Alcohol Interventions. www.alcohollearningcentre.org.uk/
- PHE. Alcohol Care in England’s Hospitals: An opportunity not to be wasted. November 2014.www.alcohollearningcentre.org.uk/_assets/Alcohol_Care_in_Englands_Hospitals_An_opportunity_not_to_be_wasted_PHE_Nov_14.pdf
- NICE. Non-alcoholic fatty liver disease (NAFLD): assessment and management. NICE guideline [NG49]. Published date: July 2016. www.nice.org.uk/guidance/ng49
- NICE. Interactive flowcharts. Non-alcoholic fatty liver disease overview. https://pathways.nice.org.uk/pathways/non-alcoholic-fatty-liver-disease
- Annual Report of the Chief Medical Officer: Surveillance Volume, 2012: On the State of the Public’s Health. First published (online only) March 2014. http://www.gov.uk/government/publications/chief-medical-officer-annual-report-surveillance-volume-2012
- British Society of Gastroenterology. www.bsg.org.uk

- European Association for the Study of the Liver. www.easl.eu
- American Association for the Study of Liver Diseases. www.aasld.org

Figure 2.1: Rate (directly standardised) of mortality from chronic liver disease and cirrhosis in people aged under 65 (source: World Health Organisation Health for All Database (HFA-DB), July 2016)[1]



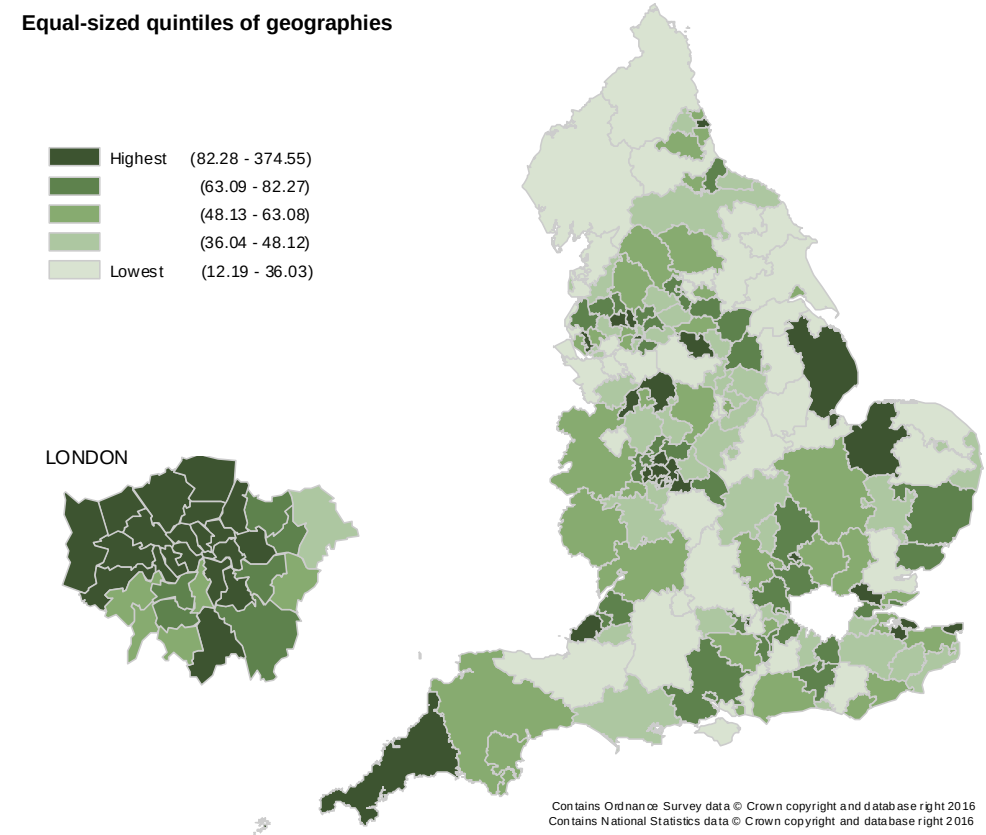
[1] WHO HFA-DB July 2016 data http://data.euro.who.int/hfadb/

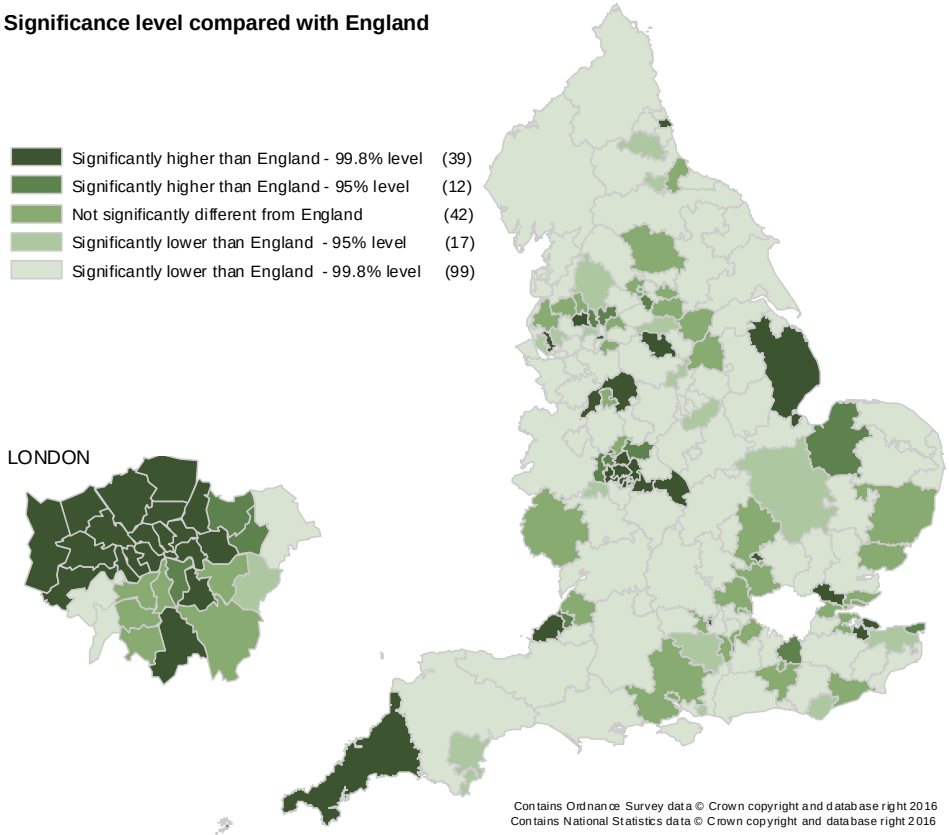
CHILDREN AND YOUNG PEOPLE

Map 3: Experimental Statistic: Variation in rate of hospital admissions for liver disease in children and young people aged 18 years and under per population by CCG (2010/11- 2014/15)

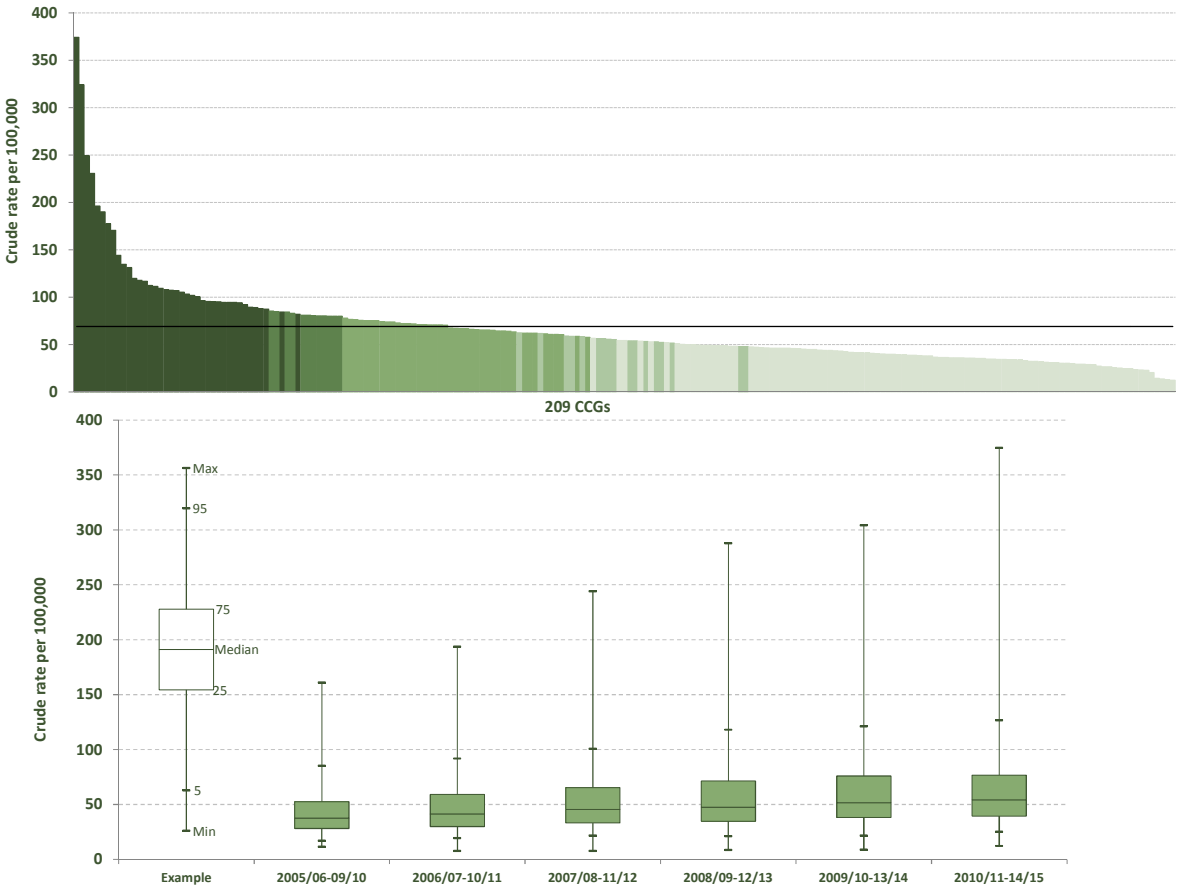
Crude rate per 100,000

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long term conditions
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
PHOF Domain 4: Healthcare public health and preventing premature mortality
OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION





Variation in rate of hospital admissions for liver disease in children and young people aged 18 years and under per populatio n by CCG (2010/11- 2014/15)



Max-Min (Range)		149.5	186.0	236.5	279.0	295.4	362.4	WIDENING Significant
95th-5th percentile		68.0	72.4	78.9	97.1	99.5	101.4	WIDENING Significant
75th-25th percentile		24.3	29.3	32.3	36.7	37.7	37.3	WIDENING Significant
Median		37.6	41.2	45.4	47.6	51.5	54.1	INCREASING Significant

Context

Although liver disease in children is rare, with only 1,000 children a year diagnosed in the UK,[1] prevalence is increasing,[2] and childhood liver disease is a growing problem.[3] There are two key reasons for the increase in the prevalence of children and young people living with liver disease:

- children are surviving longer from congenital liver diseases
- the increasing incidence of lifestyle related liver disease in children.

The increase in the prevalence of non-alcoholic fatty liver disease (NAFLD) is of particular concern.[1] Children's liver disease includes a range of disorders (see Table 3.1).

Table 3.1: Liver diseases in childhood

Neonates	Older children
Alagille syndrome Alpha-1 antitrypsin deficiency Biliary atresia Choledochal cyst Progressive familial intrahepatic cholestasis	Autoimmune disease Congenital hepatic fibrosis Cystic fibrosis and liver disease Hepatitis A, B and C Non-alcoholic fatty liver disease (NAFLD) Wilson's disease

[1] Dhawan A, Samyn M, Joshi D. Young adults with paediatric liver disease: future challenges. Archives of Diseases in Childhood. DOI: http://dx.doi.org/10.1136/archdischild-2015-309580

[2] Kelly DA. Paediatric liver disease: lessons for adult practice. The Lancet Gastroenterology and Hepatology Volume 2, No. 6, p390-392, June 2017. DOI: http://dx.doi.org/10.1016/S2468-1253(17)30108-5

[3] Hadzic N, Baumann U, McKiernan P, McLin V, Nobili V. Long-term challenges and perspectives of pre-adolescent liver disease. The Lancet Gastroenterology and Hepatology Volume 2, No. 6, p435-445, June 2017. DOI: http://dx.doi.org/10.1016/S2466-1253(16)30160-1

Many of the childhood liver diseases are precursors of adult chronic liver disease, cirrhosis and hepatocellular carcinoma and thus require long-term management. [2,3]

The signs of liver disease in children are shown in Table 3.2.

Table 3.2: Signs of liver disease in children

Need for identification and assessment	Need for referral	Need for A&E
➢ Jaundice ➢ Pale stools ➢ Itchy skin ➢ Loss of appetite ➢ Bleeding and/or bruising easily ➢ Poor growth ➢ Bone fractures	➢ Jaundice ➢ Abdominal pain ➢ Fever ➢ Swelling of the abdomen	➢ Changes in mental state ➢ Vomiting blood ➢ Blood in the stools

Many babies have 'newborn jaundice' lasting 3 to 5 days after birth because their liver is not yet fully developed. Newborn jaundice that persists after 2 weeks of age (prolonged jaundice) may be a sign of liver disease and should be investigated (NICE clinical guideline CG98; see 'Resources'). Neonatal jaundice is common and early recognition and referral for investigation of the symptoms and signs of neonatal liver disease are important to improve outcomes.

In the UK the management of children's liver disease, including hepatobiliary surgery and transplantation, is centralised to three national centres in Birmingham, London and Leeds. There is a national consensus about the liver conditions that are managed at the national centres, and the services are funded centrally as a Highly Specialised Service. All three national centres provide access and support to referring hospitals 24 hours a day and 7 days a week through agreed referral pathways. There is also a shared care network with regional paediatric gastroenterology centres or district general hospitals providing outreach and care near to where children with liver disease live.[4]

The improved survival of children with childhood onset of liver disease means there is a need to develop effective transition services to support young adults with liver disease with physical and/or mental health issues and the adult hepatologists who will care for them.[4]

Public Health England (PHE) has designated this indicator an 'experimental statistic' with the intention of developing and refining it; PHE welcomes discussion about the best way of monitoring variation in service provision for liver disease in children and young people.

Magnitude of variation

The maps and column chart display the data for 2010/11-14/15, during which CCG values ranged from 12.2 to 374.5 per 100,000 population, which is a 30.7-fold difference between CCGs. The England value for 2010/11-14/15 was 69.2 per 100,000 population.

The boxplot shows the distribution of CCG values for the period 2005/06-09/10 to 2010/11-14/15. There has been significant widening of all three measures of variation. The median increased significantly from 37.6 per 100,000 in 2005/06-09/10 to 54.1 per 100,000 in 2010/11-14/15.

Possible reasons for this variation may include:

- the prevalence of liver disease in children and young people, including neonatal jaundice, in local populations
- data management, eg coding for neonatal jaundice, particularly in maternity hospitals with large numbers

[4] Williams R, Aspinall R, Bellis M, Camps-Walsh G, Cramp M, Dhawan A et al. Addressing liver disease in the UK: a blueprint for attaining excellence in health care and reducing premature mortality from lifestyle issues of excess consumption of alcohol, obesity and viral hepatitis. Lancet 2014; 384 (9958):1953-1997. DOI: http://dx.doi.org/10.1016/s0140-6736%2814%2961838-9

of pre-term infants with physiological (or newborn) jaundice
- the level of awareness of the symptoms and signs of children's liver disease, especially in primary care
- the timing and timeliness of referral to specialist services
- compliance with treatment
- access to specialist centres

It is possible that there may be higher rates of admission in some areas surrounding one or more of the national centres for the management of liver disease in children and young people.

Options for action

To improve outcomes for children's liver disease, commissioners, clinicians and service providers need to review hospital admissions for children's liver disease in the local area and ascertain the underlying reasons for admission. Timely admission for early diagnosis and management may improve outcomes and reduce costs in the long term.

Primary and community healthcare professionals need to be trained to recognise the key symptoms and signs of a liver condition in newborn babies and children (see 'Resources' for information for professionals about the Yellow Alert campaign to increase recognition of the signs of prolonged jaundice in newborn babies). This needs to be accompanied by public awareness campaigns of the symptoms and signs of liver disease in newborn babies and children.

Commissioners need to specify that service providers follow NICE guidance on the diagnosis and treatment of neonatal jaundice in newborn babies caused by increased levels of bilirubin in the blood (CG98 and QS57; see 'Resources').

There is a need for action in several areas relating to the main risk factors for the development of liver disease in children and young people. At a population level it is important to reduce:

- childhood obesity and non-alcoholic fatty liver disease
- levels of alcohol consumption in children and young people

Commissioners need to specify that public health agencies and service providers, particularly in primary care and school settings, follow NICE guidance on:

- the identification, assessment and management of obesity (CG189; see 'Resources') and lifestyle services for weight management in children and young people (PH47; see 'Resources')
- the prevention of alcohol-related problems (see PH24; see 'Resources'), and the diagnosis, assessment and management of harmful drinking and alcohol dependence in children and young people aged 10 to 17 years (CG115 and QS11; see 'Resources')

To prevent vertical transmission of hepatitis B, commissioners need to specify that service providers follow NICE guidance (CG165, see 'Resources') and the public health functions agreement (Section 7A) service specification No.1 (see 'Resources') regarding the care of pregnant and breastfeeding women with hepatitis B and the immunisation of newborn babies at risk from the mother's hepatitis B infection.

Commissioners need to ensure that referral pathways, for children and young people diagnosed with liver disease, to one of the three designated national centres are in place and that local paediatricians have adequate support for appropriate local management of children and young people with liver disease.

RESOURCES

- NICE. Jaundice in newborn babies under 28 days. Clinical guideline [CG98]. Published date: May 2010. Last updated: October 2016. www.nice.org.uk/cg98
- NICE. Interactive flowchart. Neonatal jaundice overview. https://pathways.nice.org.uk/pathways/neonatal-jaundice
- NICE. Jaundice in newborn babies under 28 days. Quality standard [QS57]. Published date: March 2014. www.nice.org.uk/guidance/qs57
- NICE. Non-alcoholic fatty liver disease (NAFLD): assessment and management. NICE guideline [NG49]. Published date: July 2016. www.nice.org.uk/guidance/ng49
- NICE. Interactive flowchart. Non-alcoholic fatty liver disease overview. https://pathways.nice.org.uk/pathways/non-alcoholic-fatty-liver-disease
- NICE. Obesity: identification, assessment and management. Clinical guideline [CG189]. Published date: November 2014. www.nice.org.uk/guidance/cg189
- NICE. Weight management: lifestyle services for overweight or obese children and young people. Public health guideline [PH47]. Published date: October 2013. www.nice.org.uk/guidance/ph47
- NICE. Alcohol-use disorders: prevention. Public health guideline [PH24]. Published date: June 2010. www.nice.org.uk/guidance/ph24
- NICE. Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence. Clinical guideline [CG115]. Published date: February 2011. www.nice.org.uk/guidance/cg115
- NICE. Alcohol-use disorders: diagnosis and management. Quality standard [QS11]. Published date: August 2011. www.nice.org.uk/guidance/cg115
- NICE. Liver disease. Quality standard [QS152]. Published date: June 2017. www.nice.org.uk/guidance/qs152
- NICE. Hepatitis B (chronic): diagnosis and management. Clinical guideline [CG165]. Published date: June 2013. www.nice.org.uk/guidance/cg165
- NICE. Interactive flowchart. Hepatitis B (chronic) overview. https://pathways.nice.org.uk/pathways/hepatitis-b-chronic
- NICE. Hepatitis B. Quality standard [QS65]. Published date: July 2014. www.nice.org.uk/guidance/qs65
- NICE. Hepatitis B and C testing: people at risk of infection. Public health guideline [PH43]. Published date: December 2012. Last updated: March 2013. www.nice.org.uk/guidance/ph43
- NICE. Interactive flowchart. Hepatitis B and C testing overview. https://pathways.nice.org.uk/pathways/hepatitis-b-and-c-testing
- PHE, NHS England. NHS public health functions agreement 2017-18. Service specification No. 1 Neonatal hepatitis B immunisation programme. Version number: 1.0. First published: April 2017. www.england.nhs.uk/wp-content/uploads/2017/04/service-spec-01.pdf
- Children's Liver Disease Foundation. Yellow Alert. For professionals. www.yellowalert.org/For-Professionals

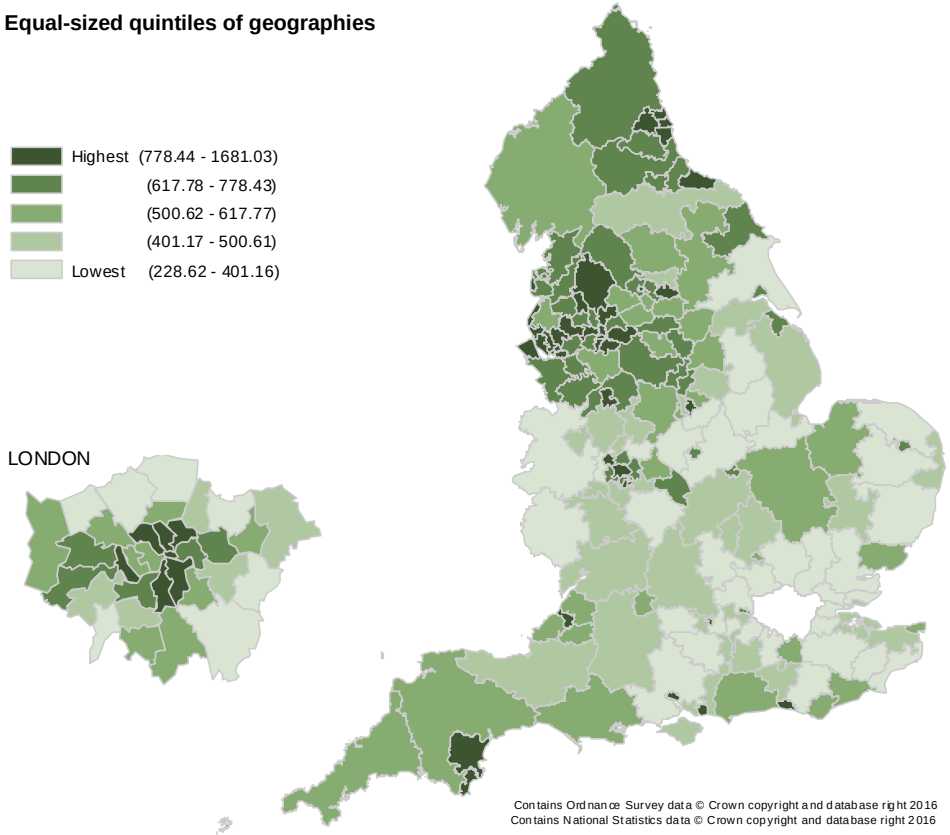
ALCOHOL USE

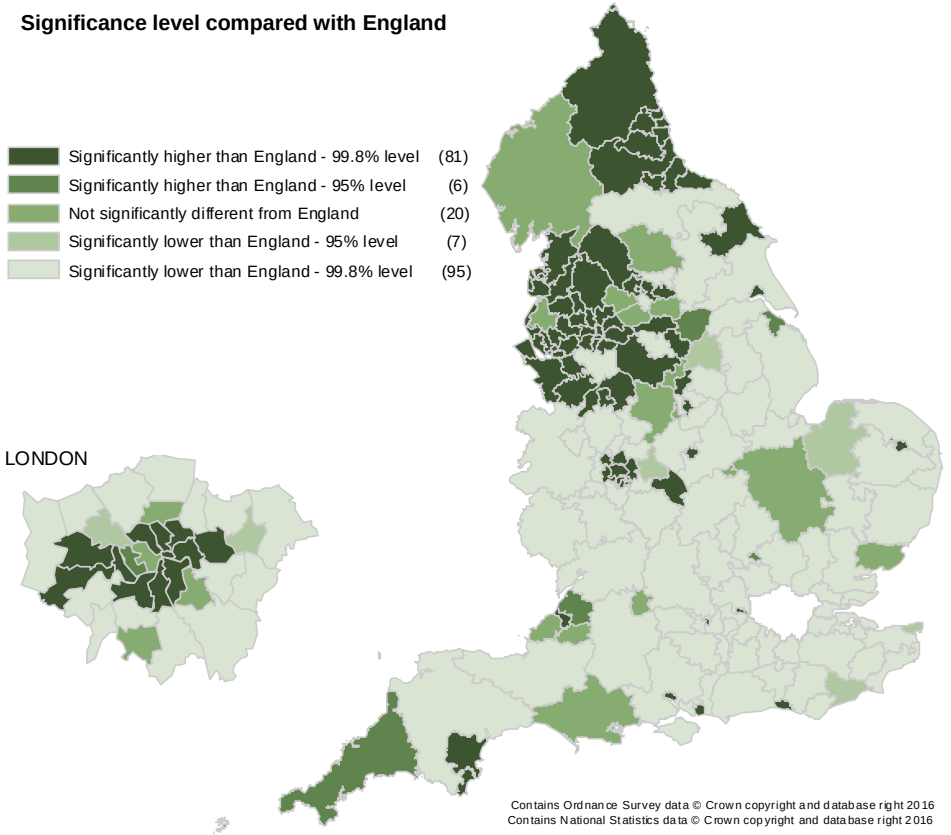
Map 4a: Variation in rate of alcohol-specific admissions in people of all ages per population by CCG (2015/16)

Directly standardised rate per 100,000

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 3: Helping people to recover from episodes of ill health following injury
NHS Domain 5: Treating and caring for people in a safe environment & protecting them from avoidable harm
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW





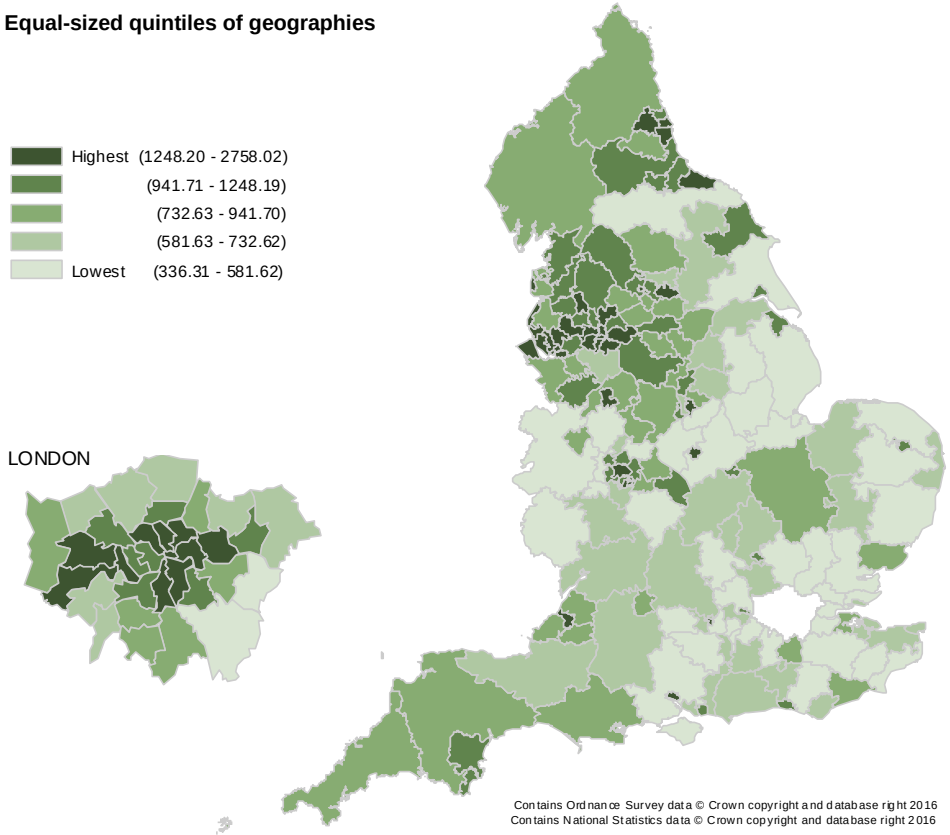
ALCOHOL USE

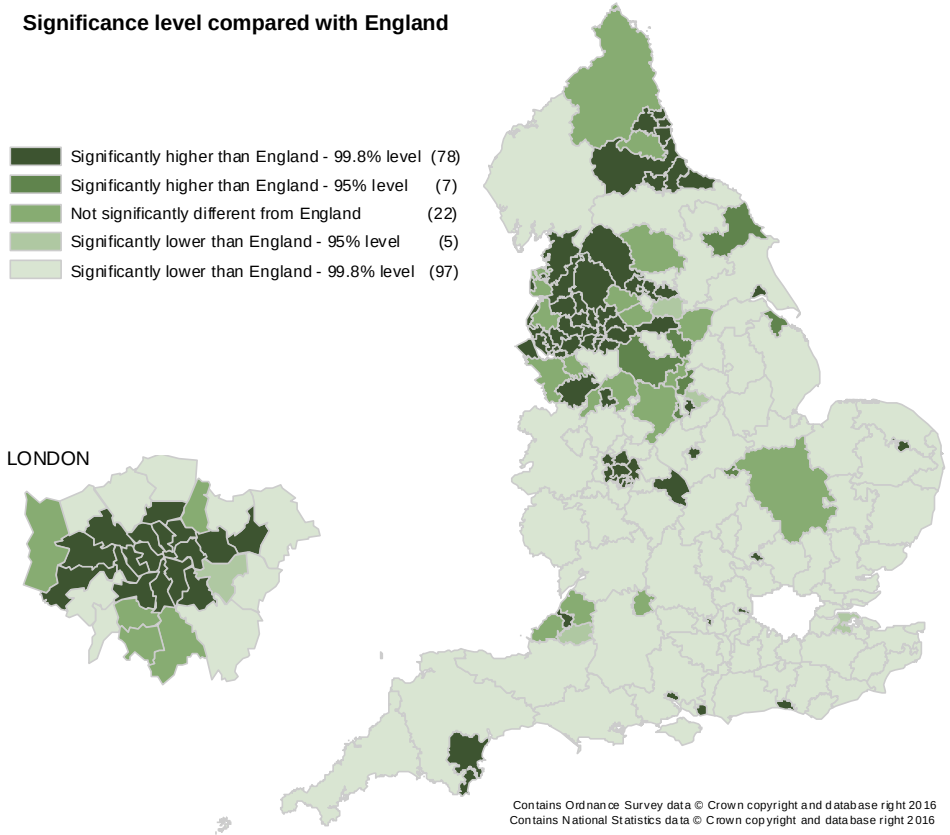
Map 4b: Variation in rate of alcohol-specific admissions in men of all ages per population by CCG (2015/16)

Directly standardised rate per 100,000

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 3: Helping people to recover from episodes of ill health following injury
NHS Domain 5: Treating and caring for people in a safe environment & protecting them from avoidable harm
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW





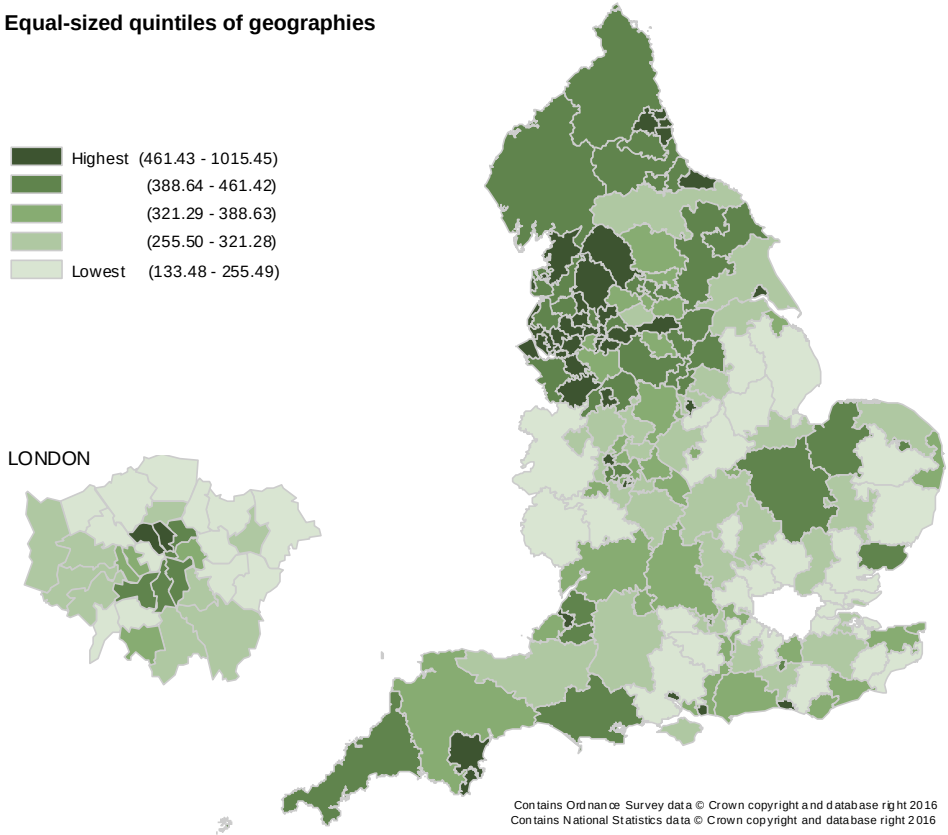
ALCOHOL USE

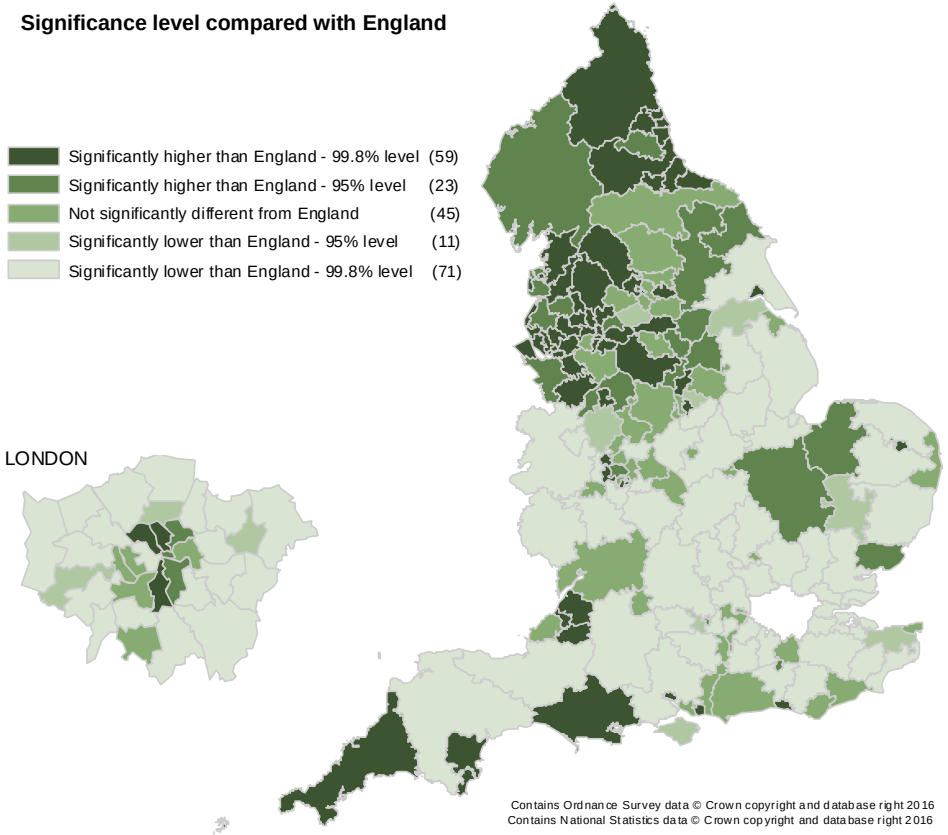
Map 4c: Variation in rate of alcohol-specific admissions in women of all ages per population by CCG (2015/16)

Directly standardised rate per 100,000

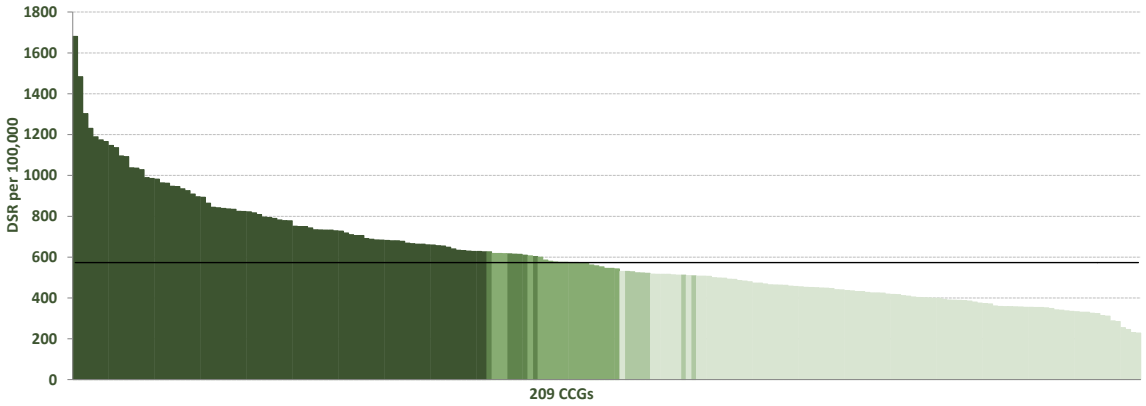
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 3: Helping people to recover from episodes of ill health following injury
NHS Domain 5: Treating and caring for people in a safe environment & protecting them from avoidable harm
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW





Variation in rate of alcohol-specific admissions in people of all ages per population by CCG (2015/16)



Max-Min (Range)		987.0	1101.7	1046.8	1095.7	1199.5	1421.7	1658.4	1639.0	1553.0	1571.1	1452.4	WIDENING Significant
95th-5th percentile		573.9	604.3	626.3	676.0	764.2	816.8	810.9	744.8	748.4	729.3	740.2	WIDENING Significant
75th-25th percentile		225.2	239.1	249.3	267.4	269.2	316.8	313.8	300.9	280.9	296.3	302.1	WIDENING Significant
Median		358.4	373.3	396.5	433.2	475.4	519.9	540.4	528.1	559.8	548.8	545.0	INCREASING Significant

Context

In England for people aged 15 to 49 years alcohol misuse is the leading risk factor for early mortality, ill health and disability; for people of all ages it is the fifth leading risk factor.[1] In 2015 more working years of life were lost in England as a result of alcohol-related deaths than from the 10 leading causes of cancer combined.[2]

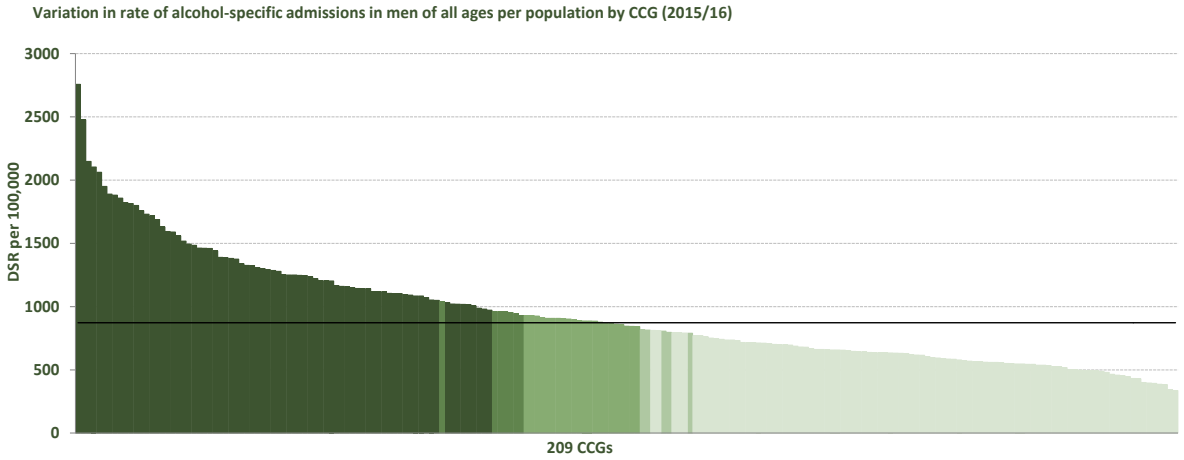
Beyond health consequences for the individual, alcohol use also contributes to considerable economic and human costs to government, society at large and individual drinkers and their associates. Economic estimates have placed the annual cost in high-income countries between 1.4% and 2.7% of gross domestic product,[3] equivalent to a cost of between £27 billion and £52 billion in England during 2016.[2]

Since 2003/04 alcohol-related hospital admissions have been increasing steadily, accounting for more than 1 million admissions in 2014/15, in about 333,000 of which the main reason for admission was attributed to alcohol.[2] Hospital admissions tend to be concentrated in the lowest three socioeconomic deciles with almost half (47%) of all admissions occurring in the three lowest socioeconomic groups.

[1] GBD 2013 Risk Factors Collaborators, Forouzanfar MH, Alexander L, Anderson HR, Bachman VF, Biryukov S, Brauer M et al. Global, regional, and national comparative risk assessment of 79 behavioural, environmental and occupational, and metabolic risks or clusters of risks in 188 countries, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. The Lancet 2015; 386(10010): 2287-2323. doi: 10.1016/S0140-6736(15)00128-2. Epub 2015 Sep 11.

[2] Burton R, Henn C, Lavoie D, O'Connor R, Perkins C, Sweeney K et al. A rapid evidence review of the effectiveness and cost-effectiveness of alcohol control policies: an English perspective. The Lancet 2016; 389(10078): 1558-1580. DOI: http://dx.doi.org/10.1016/S0140-6736(16)32420-5

[3] Rehm J, Mathers C, Popova S, Thavorncharoensap M, Teerawattananon Y, Patra J. Global burden of disease and injury and economic cost attributable to alcohol use and alcohol-use disorders. The Lancet 2009; 373(9682): 2223-2233. DOI: http://dx.doi.org/10.1016/S0140-6736(09)60746-7



		2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	
Max-Min (Range)		1591.9	1844.3	1833.2	1754.5	2200.7	2512.2	2559.6	2674.3	2451.9	2556.5	2421.7	WIDENING Significant
95th-5th percentile		1010.4	1143.1	1135.8	1141.4	1199.9	1259.7	1261.0	1298.7	1301.2	1351.4	1353.6	WIDENING Significant
75th-25th percentile		398.5	426.1	457.8	454.0	495.4	551.4	571.7	559.1	504.5	514.1	518.0	WIDENING Significant
Median		551.5	570.6	606.4	641.9	707.5	774.3	814.1	791.5	818.9	829.2	845.5	INCREASING Significant

The focus of this indicator is alcohol-specific admissions, that is, 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]

In 2014 there were an estimated 23,000 deaths related to alcohol use in England,[2] about 6,000 of which were due to alcohol-specific causes. The rate of alcohol-related mortality for men is more than double that for women (65.4 versus 28.8 per 100,000 population). There is also considerable regional variation with the highest rates in the North East (58.6 per 100,000 population) and the lowest in London (39.0 per 100,000 population).

Magnitude of variation

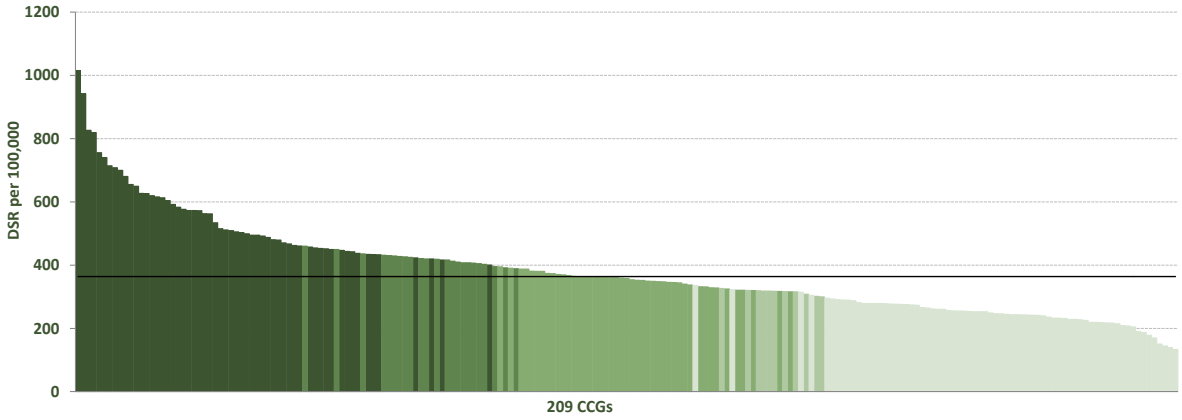
Map 4a: Alcohol-specific admissions in people

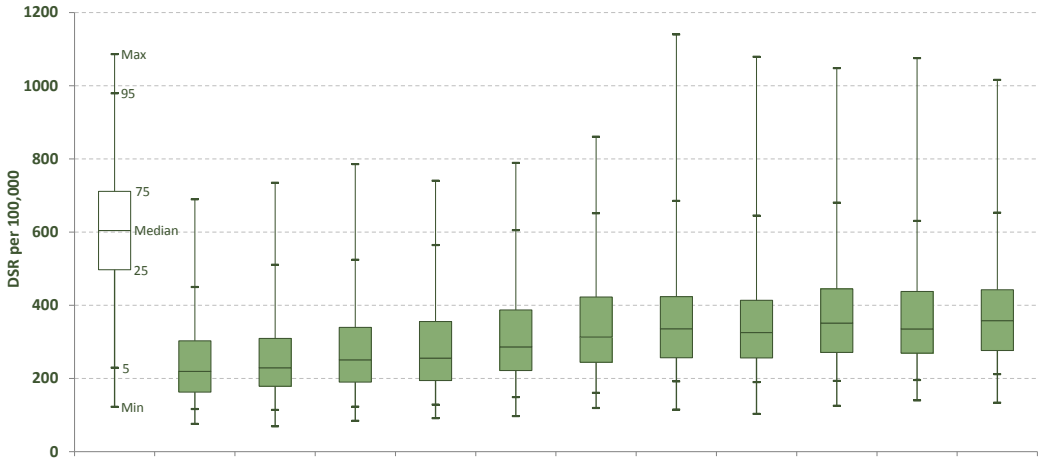
The maps and column chart display the data for 2015/16, during which CCG values ranged from 228.6 to 1,681.0 per 100,000 population, which is a 7.4-fold difference between CCGs. The England value for 2015/16 was 573.2 per 100,000 population.

The boxplot shows the distribution of CCG values for the period 2005/06 to 2015/16. There has been significant widening of all three measures of variation. The median increased significantly from 358.4 per 100,000 in 2005/06 to 545.0 per 100,000 in 2015/16.

[4] Jones L et al. Alcohol-attributable fractions for England. Alcohol-attributable mortality and hospital admissions. Liverpool John Moores University & North West Public Health Observatory; 2008. https://www.alcohollearningcentre.org.uk/_assets/AlcoholAttributableFractions.pdf

Variation in rate of alcohol-specific admissions in women of all ages per population by CCG (2015/16)





Max-Min (Range)		613.8	665.6	701.6	649.2	691.8	741.5	1024.9	975.8	922.7	935.6	882.0	WIDENING Significant
95th-5th percentile		333.5	396.6	401.7	436.0	456.4	490.6	493.5	455.0	487.2	434.9	441.7	WIDENING Significant
75th-25th percentile		140.1	130.8	149.6	161.5	165.6	178.6	167.1	157.9	173.7	168.6	166.0	WIDENING Significant
Median		219.0	228.8	250.6	255.5	286.3	313.0	335.8	325.5	351.2	335.4	357.8	INCREASING Significant

Map 4b: Alcohol-specific admissions in men

The maps and column chart display the data for 2015/16, during which CCG values ranged from 336.3 to 2,758.0 per 100,000 population, which is a 8.2-fold difference between CCGs. The England value for 2015/16 was 872.4 per 100,000 population.

The boxplot shows the distribution of CCG values for the period 2005/06 to 2015/16. There has been significant widening of all three measures of variation. The median increased significantly from 551.5 per 100,000 in 2005/06 to 845.5 per 100,000 in 2015/16.

Map 4c: Alcohol-specific admissions in women

The maps and column chart display the data for 2015/16, during which CCG values ranged from 133.5 to 1,015.5 per 100,000 population, which is a 7.6-fold difference between CCGs. The England value for 2015/16 was 364.1 per 100,000 population.

The boxplot shows the distribution of CCG values for the period 2005/06 to 2015/16. There has been significant widening of all three measures of variation. The median increased significantly from 219.0 per 100,000 population in 2005/06 to 357.8 per 100,000 population in 2015/16.

Much of the variation in alcohol-specific admission rates is likely to be due to differences in the volume and patterns 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 some of the variation.

Options for action

To reduce the hospital admission rate due to alcohol-specific conditions, commissioners, clinicians and primary and secondary care service providers need:

- to bring together all stakeholders in the local area working to reduce alcohol-related harm to identify what is working well and the opportunities for further improvement using the Alcohol CLeaR self-assessment tool (see 'Resources')
- to develop plans for an integrated system for alcohol harm prevention, treatment and recovery in adults using Public Health England's (PHE's) document 'Adults – alcohol JSNA support pack 2017-18: commissioning prompts' (see 'Resources')
- to review current patterns of acute service provision to ascertain whether alternatives to hospital admission are available when appropriate
- to learn from initiatives in other hospital services, for instance, those described in PHE's document 'Alcohol Care in England's Hospitals: An opportunity not to be wasted' (see 'Resources')
- to establish appropriately resourced alcohol care teams in district general hospitals and consider the need for services that engage assertively high-need, high-cost alcohol-dependent patients
- to explore opportunities for early detection in the health service
- to develop a local alcohol treatment pathway (see 'Resources')
- to conduct rigorous monitoring and evaluation to assess the impact of interventions (Box 4.1)

Box 4.1: High Impact Changes[5]

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

[5] Local Alcohol Profiles for England (LAPE) www.lape.org.uk/

RESOURCES

- PHE Alcohol Learning Resources. Alcohol CLeaR self-assessment tool. www.alcohollearningcentre.org.uk/Topics/Browse/CLeaR/
- Public Health England. Adults – alcohol JSNA support pack 2017- 18: commissioning prompts. Planning for alcohol harm prevention, treatment and recovery in adults. September 2016. www.nta.nhs.uk/uploads/jsna-support-pack-prompts-adult-alcohol-2017-final.pdf
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- NICE. Alcohol-use disorders: diagnosis and management of physical complications. Clinical guideline [CG100]. Published date: June 2010. http://guidance.nice.org.uk/CG100
- NICE interactive flowchart. Alcohol-use disorders overview. http://pathways.nice.org.uk/pathways/alcohol-use-disorders

- PHE Alcohol Learning Resources. Improving Local Alcohol Interventions. www.alcohollearningcentre.org.uk/
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- Department of Health. Local Routes: Guidance for developing alcohol treatment pathways. 2009. http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110423

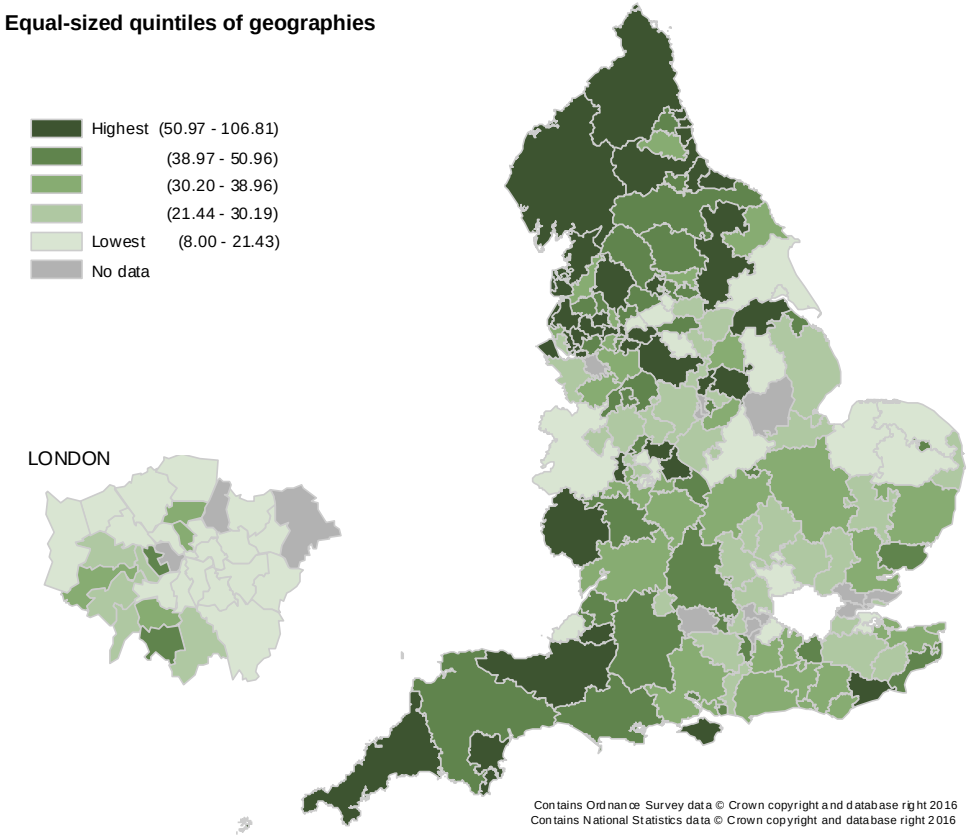
ALCOHOL USE

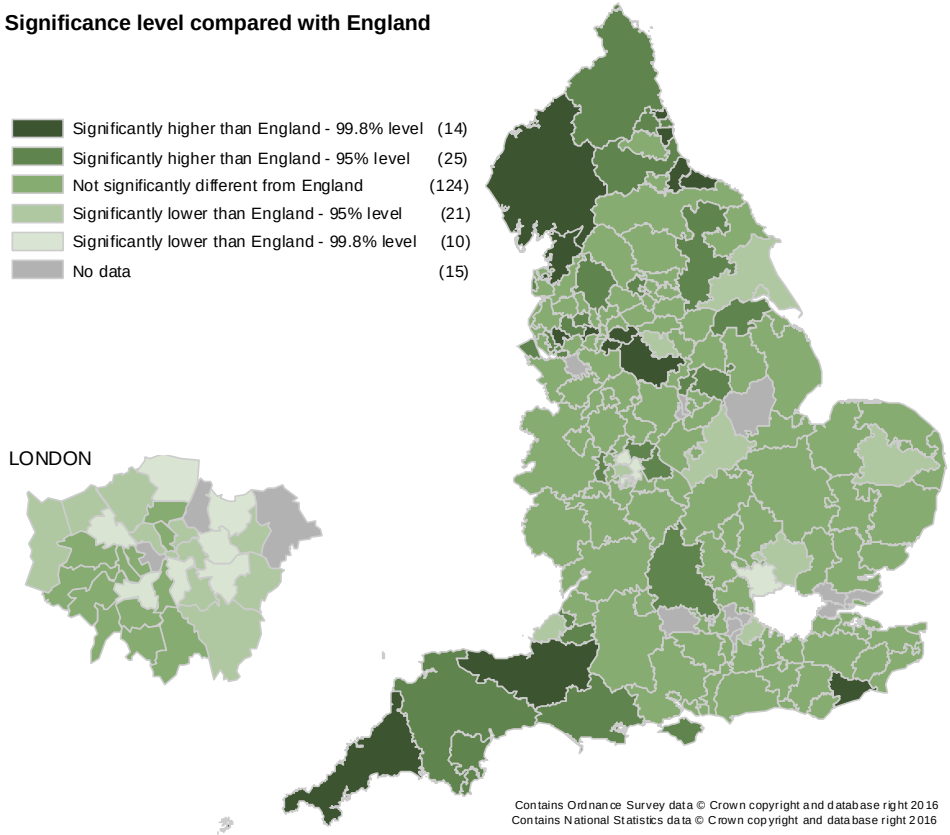
Map 5: Variation in rate of alcohol-specific admissions in people aged under 18 years per population by CCG (2015/16)

Crude rate per 100,000

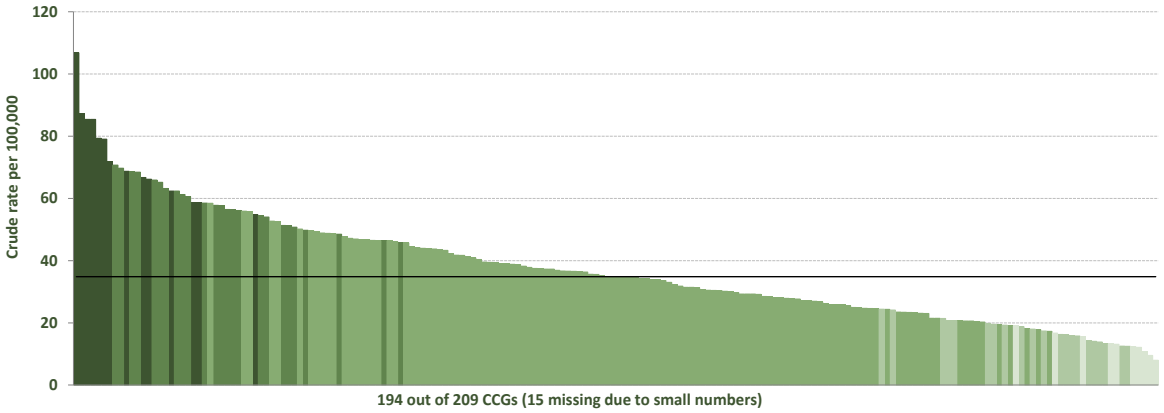
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
NHS Domain 5: Treating and caring for people in a safe environment & protecting them from avoidable harm
PHOF Domain 4: Healthcare public health and preventing premature mortality

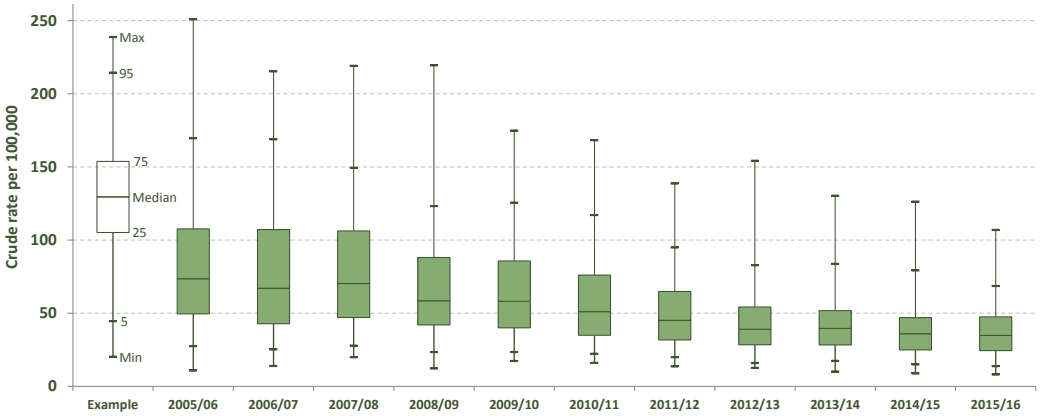
OPTIMUM VALUE: LOW





Variation in rate of alcohol-specific admissions in people aged under 18 years per population by CCG (2015/16)





		2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	
Max-Min (Range)		240.1	201.3	199.2	207.2	157.6	152.3	125.0	141.6	120.1	117.5	98.8	NARROWING Significant
95th-5th percentile		142.2	143.6	121.6	99.7	102.2	94.8	75.0	66.8	66.3	64.2	54.9	NARROWING Significant
75th-25th percentile		58.2	64.4	59.2	46.0	45.7	41.1	33.1	25.8	23.4	22.1	23.1	NARROWING Significant
Median		73.6	67.1	70.3	58.4	58.1	51.0	45.2	39.0	39.5	35.9	34.7	DECREASING Significant

Context

Young people are particularly susceptible to the harms of alcohol consumption and are more likely to drink and drive or sustain an alcohol-related injury.[1] Alcohol consumption in young people is associated with future alcohol misuse, educational problems and violent behaviour.[2,3,4,5] Particular concern has centred on the volume and pattern of drinking among children and young people (Box 5.1), because starting to drink at an early age is associated with higher trends of alcohol dependence in adulthood and a wide range of other adverse consequences.[6]

Alcohol consumption among children aged 11 to 15 years has been steadily decreasing, and at the time of writing is at its lowest ever recorded levels.[7] In 2014, 38% of pupils had drunk alcohol, but regular drinking in children is uncommon, with 4% of children aged 11 to 15 years reporting they drank alcohol at least once a week (regular) and a further 5% reporting they drank alcohol once a fortnight. Nearly half (49%) of pupils that drank alcohol in the previous 4 weeks, however, had been drunk; of these 63% had deliberately tried to get drunk.[7] Self-reported drinking prevalence increases with age: from about 8% of children aged 11 years to almost 70% of young people aged 15 years who report drinking.[7] There is also wide geographical variability in alcohol consumption among children aged 11 to 15 years

[1] Newbury-Birch D, Walker J, Avery L et al. Impact of alcohol consumption on young people: A systematic review of published reviews. Research Report DCSF-RR067. Department for children, schools and families. 2009. http://dera.ioe.ac.uk/11355/1/DCSF-RR067.pdf
[2] Healey C Rahman A, Faizal M, Kinderman P.. Underage drinking in the UK: changing trends, impact and interventions. A rapid evidence synthesis. International Journal of Drug Policy 2014; 25(1): 124-132.
[3] Bellis MA et al. Teenage drinking, alcohol availability and pricing: a cross-sectional study of risk and protective factors for alcohol-related harms in school children. BMC Public Health 2009; 9(1): 380.
[4] Best D, Manning V, Gossop M, Gross S, Strang J. Excessive drinking and other problem behaviours among 14–16 year old schoolchildren. Addictive behaviors 2006; 31(8):1424-1435.
[5] Liang W, Chikritzhs T. Age at first use of alcohol predicts the risk of heavy alcohol use in early adulthood: A longitudinal study in the United States. International Journal of Drug Policy 2015; 26(2):131-134.
[6] Department of Health. Guidance on the Consumption of Alcohol by Children and Young People. A report by the Chief Medical Officer. December 2009. http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_110256.pdf
[7] NHS Digital. Statistics on Alcohol England, 2017. Publication date: May 03, 2017. www.content.digital.nhs.uk/catalogue/PUB23940

ranging from 14.6% to 77.6% in local authorities across England.[7]

Professionals from a range of disciplines including health, education, social care and criminal justice agencies need to identify, assess and appropriately refer young people with alcohol-related problems.[6]

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.[8] NICE also recommends cognitive behavioural therapy (CBT) as an effective intervention for treating young people's substance misuse.[8] Specialist substance misuse treatment interventions are effective in young people: evidence-based techniques appear to reduce drop-out rates from treatment and confer benefit to aspects of a young person's life beyond their substance misuse.

Magnitude of variation

The maps and column chart display the data for 2015/16, during which CCG values ranged from 8.0 to 106.8 per 100,000 population, which is a 13.4-fold difference between CCGs. The England value for 2015/16 was 34.9 per 100,000 population.

The boxplot shows the distribution of CCG values for the period 2005/06 to 2015/16. There has been significant narrowing of all three measures of variation. The median decreased significantly from 73.6 per 100,000 in 2005/06 to 34.7 per 100,000 in 2015/16.

Much of the variation observed is likely to be due to differences in the rate of alcohol use. Other reasons for variation include differences in:

- the level of deprivation, which appears to have an adverse impact,
- the level of obesity, which can worsen the impact of alcohol,[9]
- demography
- coding for association with alcohol

Box 5.1: Patterns of drinking in children and young people

- 11 million units of alcohol are consumed in a week by 11–17-year-olds[10,11]
- 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%[12]
- 400,000 young people aged 11–15 years were drunk in the previous four weeks[10]
- The majority of 15- and 16-year-olds associate alcohol consumption with positive consequences (75%) and having a lot of fun (68%)[10]
- Starting drinking at an early age is associated with higher trends of alcohol dependence in adulthood and a wide range of other adverse consequences[6]

Options for action

To reduce hospital admissions due to alcohol-specific conditions in young people, commissioners, clinicians and service providers need:

- to bring together all of the stakeholders in the local area working to reduce alcohol-related harm in young people and using the Alcohol CLeaR self-assessment tool (see 'Resources')

[8] NICE. Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence. Clinical guideline [CG115]. Published date: February 2011. www.nice.org.uk/guidance/CG115
[9] 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
[10] NHS Information Centre (2012) Smoking, Drinking and Drug Use Among Young People in England 2011. www.ic.nhs.uk/pubs/sdd11fullreport
[11] Office for National Statistics (2010) General Lifestyle Survey
[12] HibbelB, 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. www.espad.org/sites/espad.org/files/The_2011_ESPAD_Report_FULL_2012_10_29.pdf

identify what is working well and the opportunities for further improvement
- to develop universal and targeted prevention interventions, and specialised interventions for young people already experiencing harm, using PHE's document 'Young people substance misuse JSNA support pack 2017-18: commissioning prompts' (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 adhere to the Royal College of Psychiatrists' practice standards for young people with substance misuse problems (see 'Resources')
- to follow NICE guidance (CG115; see 'Resources') and provide psychosocial interventions, such as CBT, as part of the service
- to conduct rigorous monitoring and evaluation to assess the impact of interventions

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

- NHS Digital. Statistics on Alcohol, England, 2017. Publication date: May 03, 2017. www.content.digital.nhs.uk/catalogue/PUB23940
- PHE Alcohol Learning Resources. Alcohol CLeaR self-assessment tool. www.alcohollearningcentre.org.uk/Topics/Browse/CLeaR/
- Public Health England. Young people substance misuse JSNA support pack 2017-18: commissioning prompts. Good practice prompts for planning comprehensive interventions. September 2016. www.nta.nhs.uk/uploads/jsna-support-pack-prompts-young-people-2017-final.pdf
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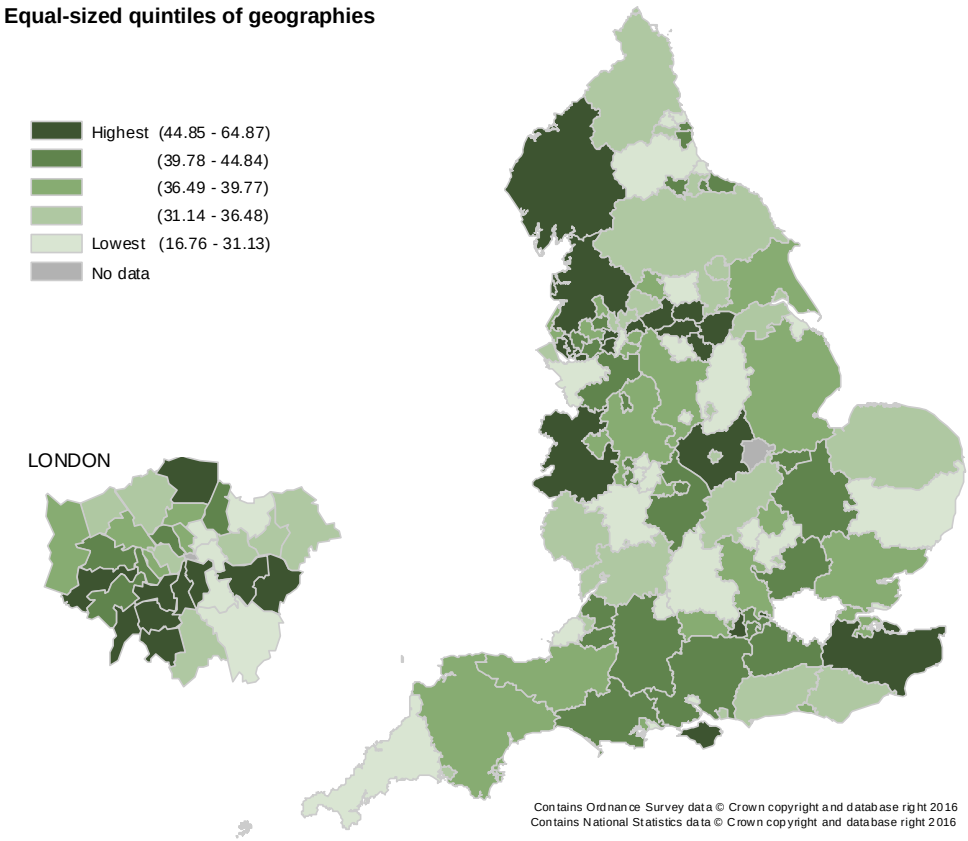
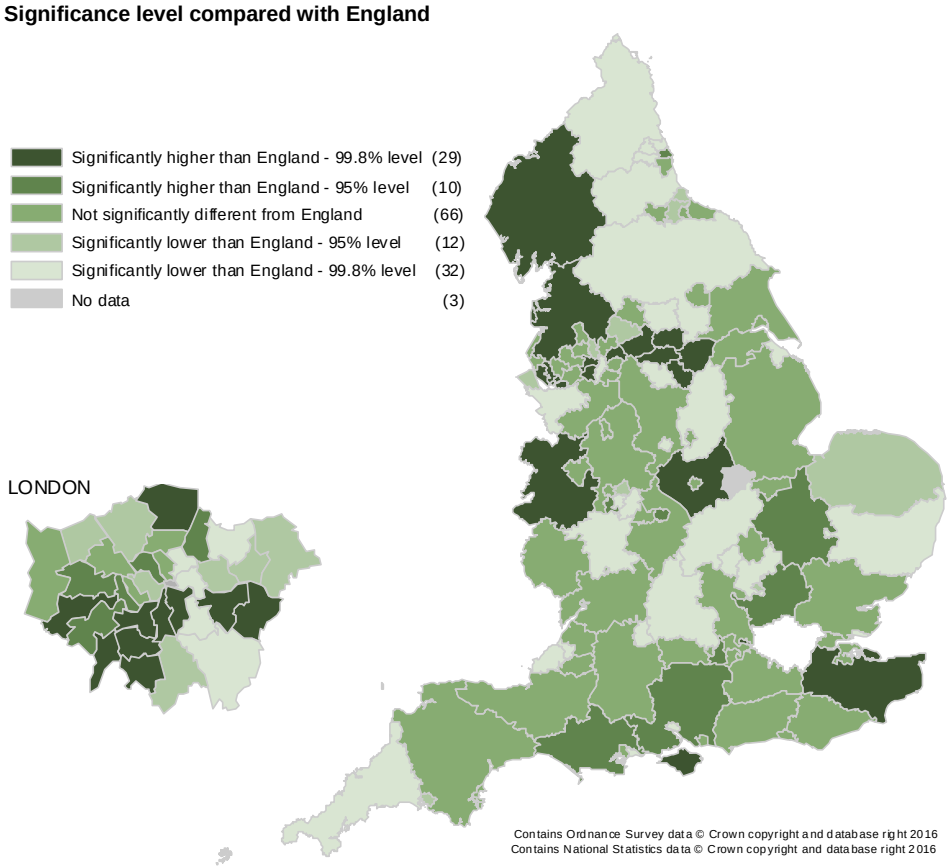
ALCOHOL USE

Map 6: Variation in percentage of people aged 18 to 75 with alcohol use who completed structured treatment successfully and did not re-present to treatment within 6 months by upper-tier local authority (2015)

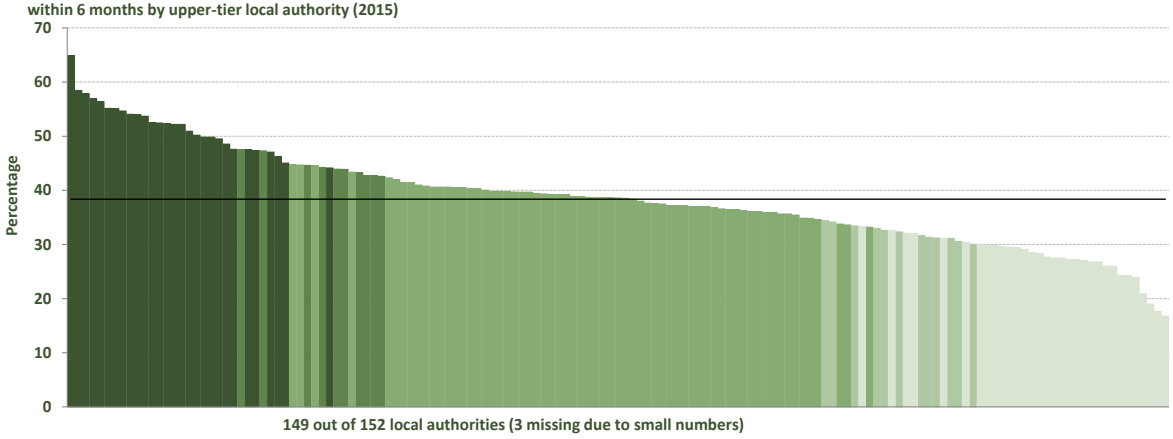
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long term conditions
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
PHOF Domain 2: Health improvement

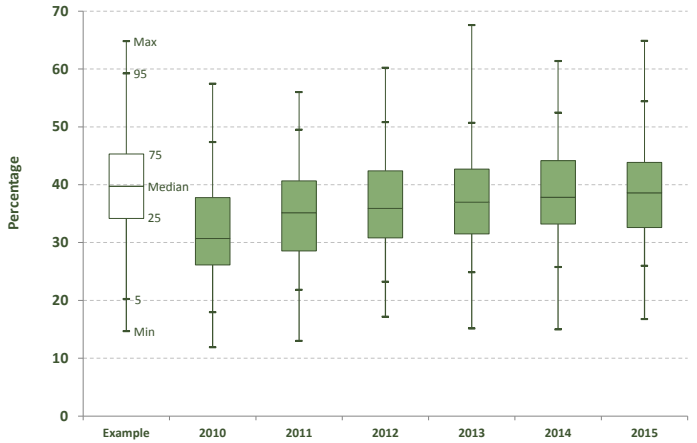
OPTIMUM VALUE: HIGH





Variation in percentage of people aged 18 to 75 with alcohol use who completed structured treatment successfully and did not re-present to treatment within 6 months by upper-tier local authority (2015)





		2010	2011	2012	2013	2014	2015	
Max-Min (Range)		45.6	43.0	43.0	52.5	46.4	48.1	No significant change
95th-5th percentile		29.4	27.7	27.6	25.8	26.7	28.4	No significant change
75th-25th percentile		11.6	12.1	11.6	11.2	11.0	11.3	No significant change
Median		30.7	35.2	35.9	37.0	37.8	38.6	INCREASING Significant

Context

In England alcohol use is the leading risk factor for early mortality, ill health and disability for people aged 15 to 49 years; for people of all ages it is the fifth leading risk factor.[1] Alcohol use can lead to cirrhosis of the liver and liver cancer.

In 2015 more working years of life were lost in England as a result of alcohol-related deaths than from the 10 leading causes of cancer combined.[2]

Alcohol use has considerable economic and human costs for government, society at large and individual drinkers and their associates. Economic estimates have placed the annual cost in high-income countries at between 1.4% and 2.7% of gross domestic product,[3] equivalent to between £27 billion and £52 billion in England during 2016.[2]

Alcohol dependence is characterised by craving, tolerance, a preoccupation with alcohol and continued drinking despite harmful consequences. People with harmful or dependent levels of alcohol use can benefit from structured treatment, involving psychological and pharmacological interventions, which can increase people's motivation to change behaviour patterns and reduce alcohol consumption. In addition, to facilitate and sustain recovery, it is important for people with harmful or dependent levels of alcohol use to receive recovery support interventions and services, such as peer support, mutual aid and other positive social networks,

[1] GBD 2013 Risk Factors Collaborators, Forouzanfar MH, Alexander L, Anderson HR, Bachman VF, Biryukov S, Brauer M et al. Global, regional, and national comparative risk assessment of 79 behavioural, environmental and occupational, and metabolic risks or clusters of risks in 188 countries, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. The Lancet 2015; 386(10010): 2287-2323. DOI: https://doi.org/10.1016/S0140-6736(15)00128-2. Epub 2015 Sep 11.

[2] Burton R, Henn C, Lavoie D, O'Connor R, Perkins C, Sweeney K et al. A rapid evidence review of the effectiveness and cost-effectiveness of alcohol control policies: an English perspective. The Lancet 2016; 389(10078): 1558-1580. DOI: http://dx.doi.org/10.1016/S0140-6736(16)32420-5

[3] Rehm J, Mathers C, Popova S, Thavorncharoensap M, Teerawattananon Y, Patra J. Global burden of disease and injury and economic cost attributable to alcohol use and alcohol-use disorders. The Lancet 2009; 373(9682): 2223-2233. DOI: http://dx.doi.org/10.1016/S0140-6736(09)60746-7

family/parenting support, education, training, employment and housing.

When young people present to specialist substance misuse services, the second most common substance about which they need help is alcohol, although young people are rarely dependent. In general the needs of young people with alcohol use problems are different from those of adults. Young people require psychosocial, harm reduction and family interventions rather than treatment for dependence, which only a minority of young people need.

Structured treatment for alcohol use is delivered according to a care plan which contains clear goals that are regularly reviewed with the client, and may involve several concurrent or sequential treatment interventions. In particular NICE judges the following interventions to be effective:

- cognitive behavioural therapy
- motivational enhancement therapy
- social behaviour and networks therapy
- behavioural therapies that apply principles of positive reinforcement
- behavioural couples therapy

Pharmacological therapies endorsed by NICE and licensed for use in the UK are benzodiazepines, usually chlordiazepoxide, for medically assisted withdrawal, nalmefene for consumption reduction in dependent drinkers and acamprosate, naltrexone and disulfiram for relapse prevention.

The point estimate of prevalence of people with alcohol dependence potentially in need of specialist assessment and treatment in England in 2014/15 was 595,131, which represents 1.39% of the population aged 18 years and over.[4] This includes 313,753 with mild dependence (0.73%), 173,399 with moderate dependence (0.41%) and 107,979 with severe dependence (0.25%).[4] This estimate of prevalence suggests there is considerable unmet need for treatment of alcohol dependence.

In 2015/16, 144,908 people with problematic or dependent levels of alcohol consumption were in contact with alcohol treatment services, 85,035 (58.7%) of whom were treated for alcohol use only and 59,873 (41.3%) for use of alcohol and other substances.[5]

Of people receiving treatment for alcohol use only:

- 61% were men
- 86% were White British, 2% White Irish and 4% 'Other White' (3% not stated)
- the median age was 45 years
- 51% referred themselves into treatment and 28% were referred into treatment through health and social care services
- the average waiting time to first intervention was 3.9 days[4]

Of the people who were given a prescribed intervention, 94% received them for less than 12 months. The majority of prescriptions were to enable safe withdrawal from alcohol dependence.[4]

Of the people who exited treatment:

- 62% completed treatment successfully, based on a clinical judgement that the person no longer had a need for structured treatment having achieved all care plan goals and overcome the dependent use of alcohol which brought them into treatment, after an average of 197.5 days
- 27% did not complete treatment[4]

[4] Pryce R, Buykx P, Gray L, Stone T, Drummond C, Brennan A. Estimates of Alcohol Dependence in England based on APMS 2014, including Estimates of Children Living in a Household with an Adult with Alcohol Dependence. Prevalence, Trends and Amenability to Treatment. Prepared for Public Health England. March 2017. www.nta.nhs.uk/uploads/estimates-of-alchohol-dependency-in-england[0].pdf
[5] Public Health England, University of Manchester National Drug Evidence Centre, Department of Health. Adult substance misuse statistics from the National Drug Treatment Monitoring System (NDTMS) 1st April 2015 to 31st March 2016. Published November 2016. www.ndtms.net/Publications/downloads/Adult%20Substance%20Misuse/adult-statistics-from-the-national-drug-treatment-monitoring-system-2015-2016.pdf

- During treatment 1% of people died, 68% of whom were men[4]

Magnitude of variation

The maps and column chart display the data for 2015, during which local authority values ranged from 16.8% to 64.9%, which is a 3.9-fold difference between local authorities. The England value for 2015 was 38.4%.

The boxplot shows the distribution of local authority values for the period 2010 to 2015. There was no significant change in any of the three variation measures between 2010 and 2015. The median increased significantly from 30.7% in 2010 to 38.6% in 2015.

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

- levels of social and health inequalities among people with alcohol use in local populations
- the timing of identification and referral of people with dependent alcohol use
- the availability of alcohol treatment and recovery services
- access to alcohol treatment and recovery services
- the level of service coverage
- the severity of dependence among people with alcohol use in local populations
- the co-use of other harmful substances such as opiate or non-opiate drugs
- physical and/or psychological co-occurring conditions
- social factors such as the level of support from family and social networks, involvement in the criminal justice system and homelessness
- compliance with treatment and treatment goals

Options for action

In light of unmet need commissioners, clinicians, service providers and other stakeholders need to undertake a comprehensive needs assessment locally in order to ascertain the level of alcohol-related harm and the need for structured treatment services and interventions.

To optimise structured treatment for alcohol use and meet the needs of clients, commissioners, clinicians and primary and secondary care service providers need:

- to enhance the understanding of all local partner agencies working to reduce alcohol-related harm about what is working well and the opportunities for further improvement using the Alcohol CLeaR self-assessment tool (see ‘Resources’)
- to develop plans for an integrated system for alcohol harm prevention, treatment and recovery in adults using Public Health England’s document ‘Adults – alcohol JSNA support pack 2017-18: commissioning prompts’ (see ‘Resources’) and NICE guidance (PH24, CG115, CG100 and QS11; see ‘Resources’)
- to develop local alcohol treatment pathways that can be clearly understood (e.g. Department of Health guidance entitled ‘Local Routes’, see ‘Resources’)
- to conduct rigorous monitoring and evaluation to assess the impact of interventions on dependent drinking of all severities
- To improve outcomes for people receiving treatment for alcohol use, commissioners need to specify that service providers comply with NICE guidance (CG115, CG100 and QS11; see ‘Resources’).

Commissioners, clinicians and primary and secondary care providers also need:

- to explore opportunities for prevention and early detection in the health service, such as hospital alcohol liaison services, brief interventions in primary care and other settings and evidence-based screening in the NHS Health Check
- to review and develop local evidence-based awareness and behaviour change campaigns on alcohol with the aims of delaying the age of first use in young people and making lower risk drinking the

social norm (eg mentor-ADEPIS website, see 'Resources')

For guidance on planning and commissioning effective services for young people, see 'Resources'.

RESOURCES

- Public Health England, University of Manchester National Drug Evidence Centre, Department of Health. Adult substance misuse statistics from the National Drug Treatment Monitoring System (NDTMS) 1st April 2015 to 31st March 2016. Published November 2016. www.ndtms.net/Publications/downloads/Adult%20Substance%20Misuse/adult-statistics-from-the-national-drug-treatment-monitoring-system-2015-2016.pdf
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- Department of Health. Guidance on the consumption of alcohol in children and

[6] The PHE Alcohol Learning Centre is scheduled to be moved to the GOV.UK website in November 2017.

young people. A report by the Chief Medical Officer. Published date: 17 December 2009. http://webarchive.nationalarchives.gov.uk/20130103185806/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110258

- PHE Alcohol Learning Resources.[7] e-Learning/training. www.alcohollearningcentre.org.uk/eLearning
- Public Health England. Healthier Lives. Alcohol & Drugs. http://healthierlives.phe.org.uk/topic/drugs-and-alcohol
- Public Health England. Public Health Outcomes Framework. Overarching indicators. www.phoutcomes.info

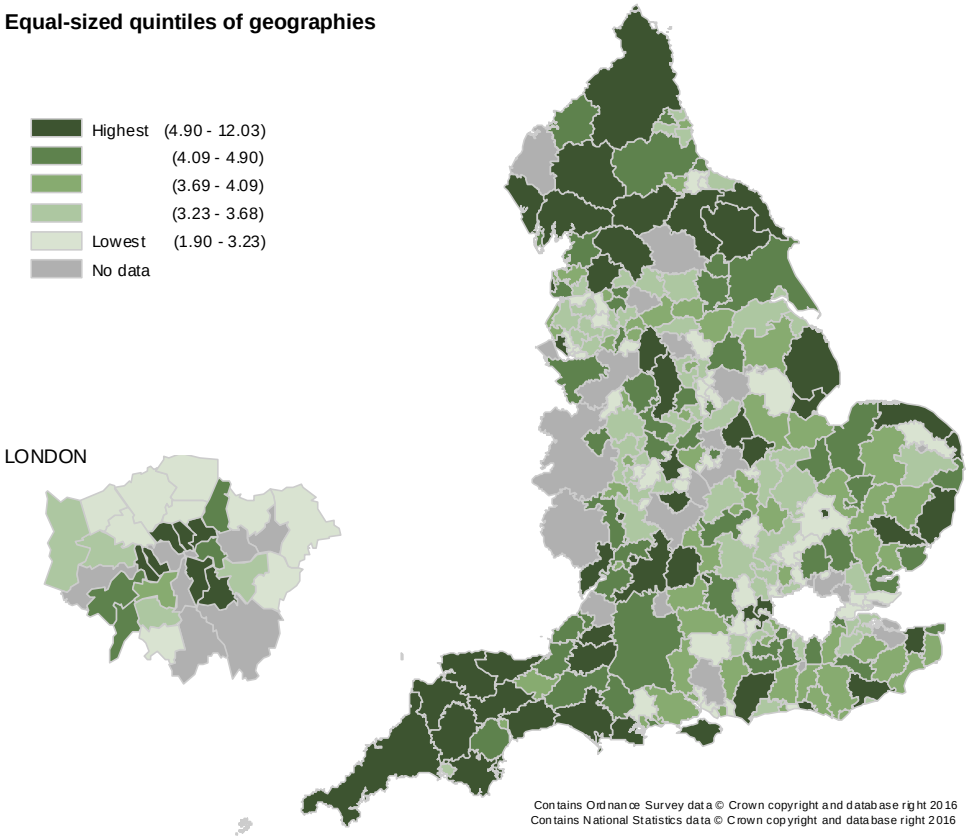
ALCOHOL USE

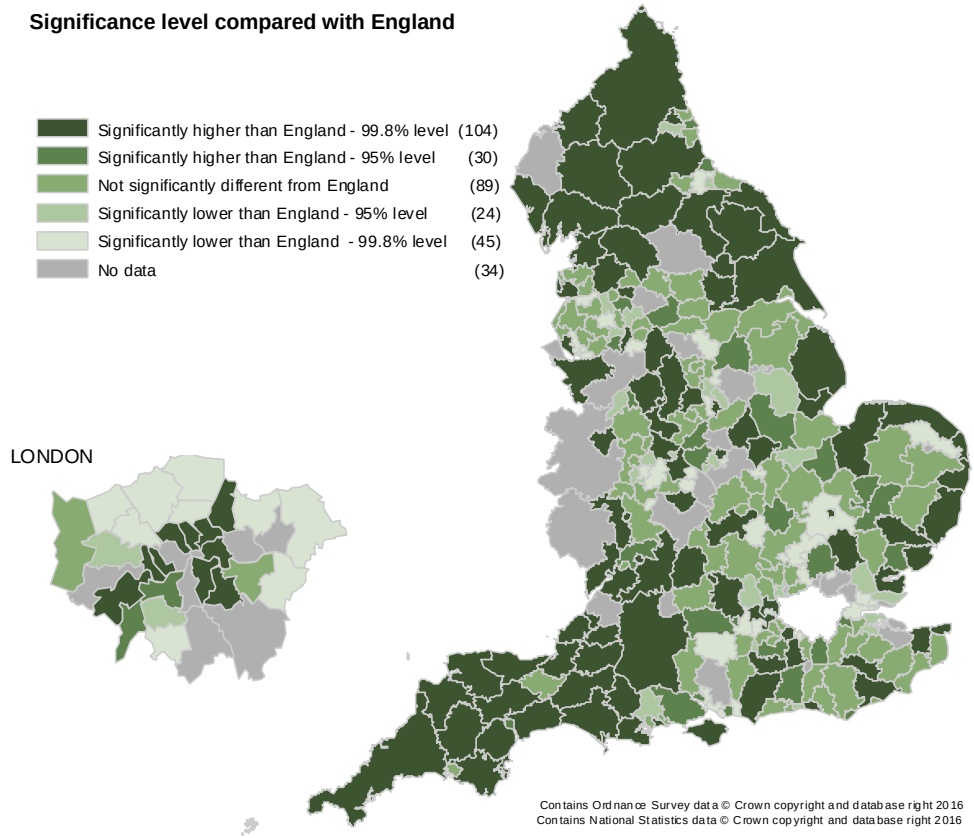
Map 7: Variation in rate of premises licensed to sell or supply alcohol per population aged 18 years and over by lower-tier local authority per population (2016)

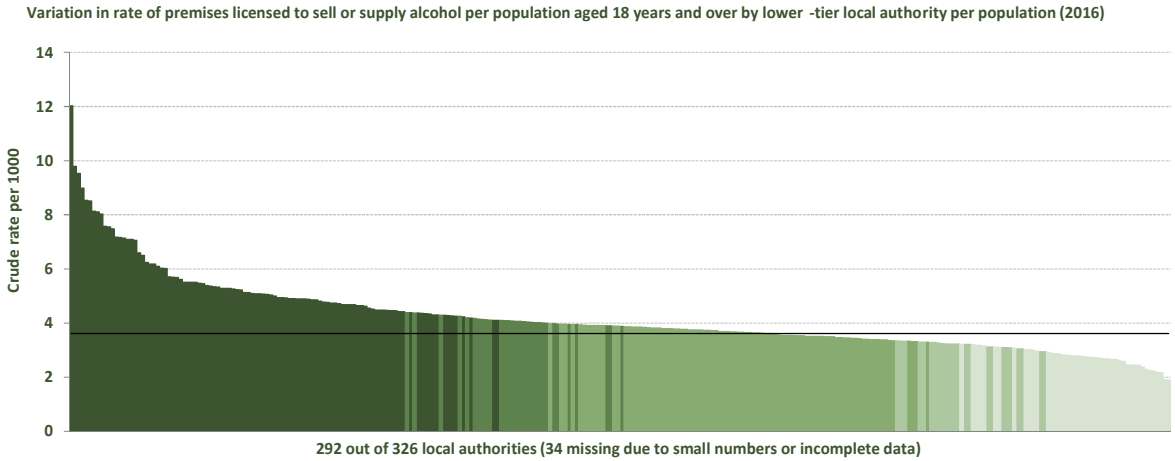
Crude rate per 1,000

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long term conditions
PHOF Domain 1: Improving the wider determinants of health

OPTIMUM VALUE: LOW







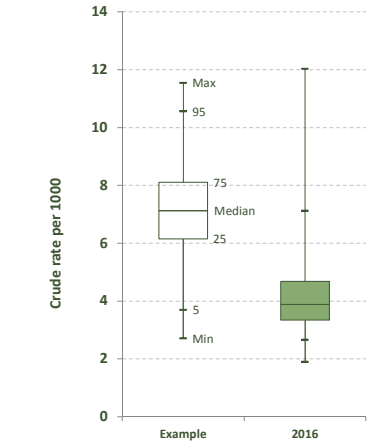
Context

Excessive alcohol consumption damages the liver and can lead to alcoholic liver disease, including fatty liver disease, alcoholic hepatitis and cirrhosis.[1] Liver disease is responsible for 86% of directly attributable mortality from alcohol in the UK.

Levels of alcohol consumption, for individuals or populations, are influenced by the accessibility of alcohol, which depends on three factors or drivers:

- availability
- affordability
- acceptability[1]

The availability of alcohol is governed by the Licensing Act 2003 and the Licensing Act 2003 (Mandatory Conditions) order 2014 (see 'Resources'). In addition the sale of alcohol below the cost of duty plus VAT was banned under the Licensing Act 2003 (Mandatory Conditions) order 2014.



Max-Min (Range)		10.1
95th-5th percentile		4.5
75th-25th percentile		1.3
Median		3.9

The Licensing Act 2003, administered by local authorities, covers the sale, by retail, or supply of alcohol, the provision of regulated entertainment and the provision of late-night refreshment. The types of businesses and organisation that need a licence under the Licensing Act 2003 are pubs and bars, cinemas, theatres, nightclubs, late-opening cafes, takeaways and supermarkets and 'qualifying' clubs.

In 2016 there were 210,000 licensed premises in England and Wales, an increase of 4% on 2010.[1]

Under the Licensing Act 2003 local authorities need to prepare and publish a statement of licensing policy (SLP), which includes a vision for the area and a statement of intent that guides practice when carrying out licensing functions. The SLP must be kept under review and the licensing authority may make any revisions to the SLP as it considers appropriate.

There are four statutory objectives of equal importance to be addressed when any licensing functions are undertaken:

- the prevention of crime and disorder
- public safety
- the prevention of public nuisance
- the protection of children from harm

The legislation also supports a number of other key aims and purposes. These are important and should be principal

[1] Public Health England. The Public Health Burden of Alcohol and the Effectiveness and Cost-effectiveness of Alcohol Control Practices. An evidence review. Published: December 2016. www.gov.uk/government/uploads/system/uploads/attachment_data/file/583047/alcohol_public_health_burden_evidence_review.pdf

aims for all organisations and individuals involved in licensing work (see Box 7.1)

Under the Licensing Act 2003 health bodies and Directors of Public Health in England are responsible authorities who must be notified of applications and are entitled to make representations to the licensing authority if they determine there are appropriate grounds to do so.

The SLP could be used to highlight relevant local public health concerns in relation to alcohol harm and ways to address them. Before determining policy the licensing authority must consult with responsible authorities including public health. Public health should engage with the licensing authority early to establish when the SLP is to be reviewed and how public health can be involved.

Policies that sufficiently reduce the hours during which alcohol is available for sale, particularly late-night on-trade sales, can substantially reduce alcohol-related harm in the night-time economy.[1] There is also a clear relationship between the density of alcohol outlets and social disorder, however, research findings are more mixed for other outcomes.[1]

In the Secretary of State's guidance issued under section 182 of the Licensing Act 2003 (see 'Resources') the phrase 'cumulative impact' of licensed premises is defined as:

> '… the potential impact on the promotion of the licensing objectives of a significant number of licensed premises concentrated in one area. The number, type and density of licensed premises selling alcohol within an area may be such as to give rise to serious problems of crime, disorder and/or public nuisance.'

These can be referred to as cumulative impact zones or stress areas. The Home Office defines it as a cumulative impact policy (CIP).

For this indicator the denominator is per head of population aged 18 years and over; however in the Local Alcohol Profiles for England (LAPE; see 'Resources') there is an alternative formulation in which density of licensed premises is presented per square kilometre, indicating the spatial density of licensed premises in contrast to the population density, as shown here.[2]

Box 7.1: Key aims and purposes under section 182 of the Licensing Act 2003 (paragraph 1.5)

- Protecting the public and local residents from crime, antisocial behaviour and noise nuisance caused by irresponsible premises
- Giving the police and licensing authorities the powers they need to effectively manage and police the night-time economy and take action against premises that are causing problems
- Recognising the important role which pubs and other licensed premises play in our local communities by minimising the regulatory burden on businesses, encouraging innovation and supporting responsible premises
- Providing a regulatory framework for alcohol which reflects the needs of local communities and empowers local authorities to make and enforce decisions about the most appropriate licensing decisions in their local area
- Encouraging greater community involvement in licensing decisions and giving local residents the opportunity to have their say regarding licensing decisions that may affect them

Magnitude of variation

The maps and column chart display the data for 2016, during which local authority values ranged from 1.9 to 12.0 per 1,000 population, which is a 6.3-fold difference between local authorities. The England value for 2016 was 3.6 per 1,000 population. The boxplot shows the distribution of local authority values for 2016.

[2] Public Health England. Local Alcohol Profiles for England. Consumption and Availability. Indicator 18.01 Number of premises licensed to sell alcohol per square kilometre. NB: this indicator is available only at the geography of a lower-tier local authority.

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

- historical and existing levels of demand in different local populations
- sociocultural norms around alcohol consumption and abstinence in different local populations
- licensing policy, including CIPs
- planning policy
- the nature and proportion of various sectors in different local economies, such as the leisure and entertainment industry, tourism, retail, business services, manufacturing or agriculture

Options for action

To reduce alcohol-related harm in relation to the availability of alcohol from licensed premises, the Director of Public Health and public health team can:

- identify the level of alcohol-related harm in the local population and the people most at risk using, for instance, the Local Alcohol Profiles for England (LAPE; see 'Resources')
- harvest local knowledge to identify hotspots of alcohol harm and/or high levels of consumption in the local area
- identify the types of applications that are likely to have a negative impact on the promotion of the statutory licensing objectives locally (eg a 24-hour vertical drinking establishment) and make those a priority for public health responses
- for each application about which it is deemed a priority to respond, the Director of Public Health/public health team can consider whether it would be appropriate to suggest the imposition of one or more licensing conditions (see 'Resources') to address relevant concerns
- engage with the regular (5-yearly or more frequently at the instigation of the licensing authority) review of the SLP and ensure that such involvement is relevant and appropriate to the promotion of the four statutory objectives for licensing
- involve the local health and wellbeing board and the wider public health community in the SLP review process
- engage the community and ascertain their views
- share data and evidence with other responsible authorities

The SLP can be reviewed for a specific reason such as to include a CIP; the Director of Public Health/Public Health Team can also submit alcohol harm-related information to such a review, including, for instance:

- the number of people in the area in structured treatment for alcohol use
- levels of deprivation in the area
- alcohol consumption levels in the area
- other statistics from LAPE

The Director of Public Health and other responsible authorities (police, fire service, child protection services, environmental health, trading standards, health and safety, planning and the licensing authority) can work together to discuss and address the impact of licensed premises on the local population, for instance, in a joint local licensing group or forum.

The Director of Public Health can also consider engaging with schemes such as Pubwatch, Best Bar None and community alcohol partnerships.

RESOURCES

- Home Office. Revised guidance issued under section 182 of Licensing Act 2003. Published: 13 October 2014. Last revised: 13 July 2017 https://www.gov.uk/government/publications/explanatory-memorandum-revised-guidance-issued-under-s-182-of-licensing-act-2003
- Public Health England. Alcohol licensing: a guide for public health teams. Published: 8 March 2017. Last updated: 21 March 2017 www.gov.uk/guidance/alcohol-licensing-a-guide-for-public-health-teams
- Public Health England, Local Government Association. Public health and the Licensing Act 2003 – guidance note

on effective participation by public health teams. Published: October 2014. www.nta.nhs.uk/uploads/phe-licensing-guidance-2014.pdf

- Home Office. Alcohol licensing. Published: 26 March 2013. Last updated: 1 April 2017 www.gov.uk/guidance/alcohol-licensing
- Home Office. Guidance on mandatory licensing conditions: For suppliers of alcohol and enforcement authorities in England and Wales. Published date: 3 September 2014 www.gov.uk/government/publications/guidance-on-mandatory-licensing-conditions
- Public Health England. The Public Health Burden of Alcohol and the Effectiveness and Cost-effectiveness of Alcohol Control Practices. An evidence review. Published: December 2016 www.gov.uk/government/uploads/system/uploads/attachment_data/file/583047/alcohol_public_health_burden_evidence_review.pdf
- Public Health England. Local Alcohol Profiles for England https://fingertips.phe.org.uk/local-alcohol-profiles
- PHE Alcohol Learning Resources[3] www.alcohollearningcentre.org.uk

[3] The PHE Alcohol Learning Centre is scheduled to be moved to the GOV.UK website in November 2017.

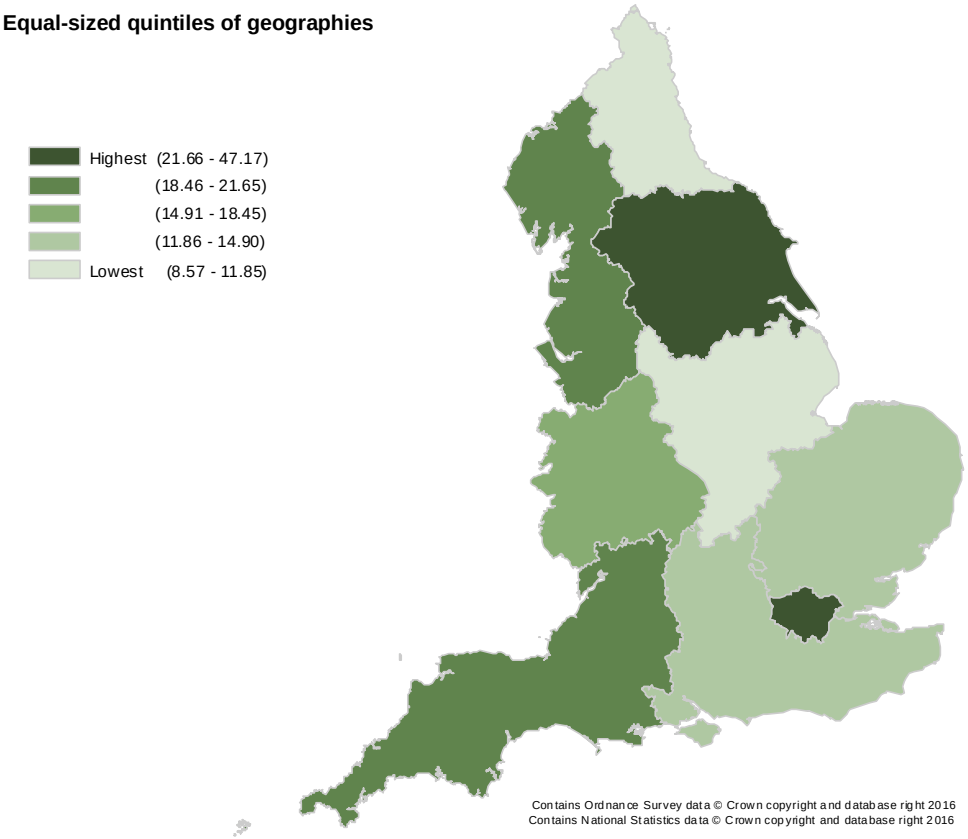
HEPATITIS C

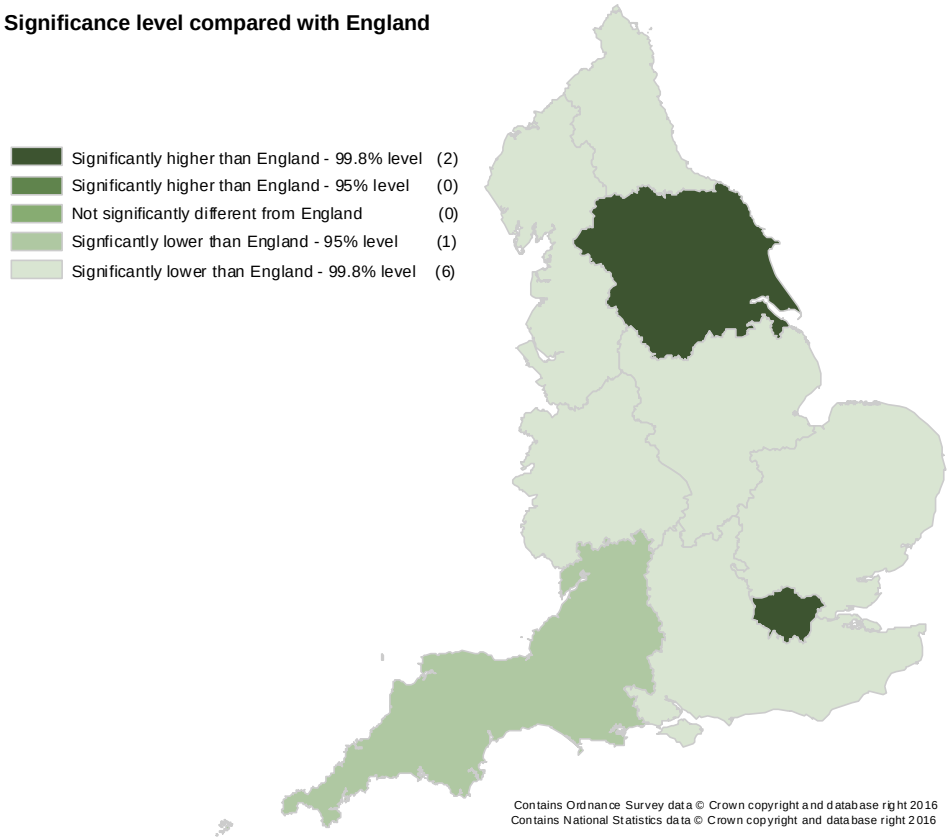
Map 8: Variation in rate of laboratory reports for confirmed hepatitis C per population by region (2015)

Crude rate per 100,000

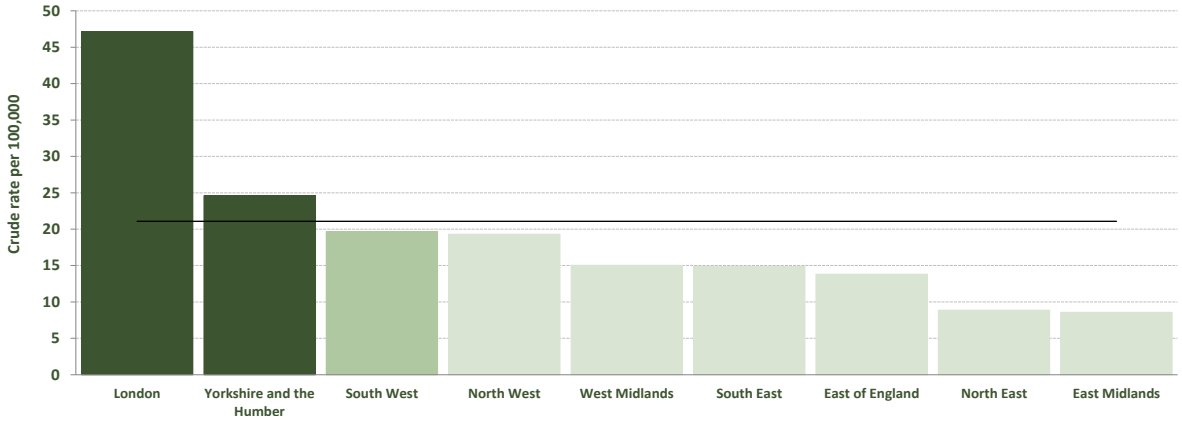
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long term conditions
PHOF Domain 3: Health protection

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION





Variation in rate of laboratory reports for confirmed hepatitis C per population by region (2015)



		2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
Max-Min (Range)		23.6	20.9	19.4	19.6	15.3	16.6	22.0	24.8	33.6	38.6	WIDENING Significant
95th-5th percentile		19.8	18.9	16.3	15.8	12.1	14.2	18.3	21.3	26.8	29.4	No significant change
75th-25th percentile		8.0	10.8	9.0	6.8	2.0	7.1	12.2	14.6	8.2	5.9	No significant change
Median		12.2	12.3	13.2	13.5	13.6	15.0	14.9	13.8	14.9	15.0	INCREASING Significant

Context

Hepatitis C is a bloodborne viral infection that is transmitted through contact with infected blood. In the UK the most important risk factor for hepatitis C infection is injecting drug use.[1] About 70 to 75% of people infected with acute hepatitis C develop a chronic condition which can result in liver failure and liver cancer. The most recent national estimates suggest that 214,000 people in the UK are chronically infected with hepatitis C,[1] 160,000 of whom are thought to live in England.[2]

Acute hepatitis C is a notifiable disease. Public Health England (PHE; formerly the Health Protection Agency) introduced national surveillance standards for hepatitis C in 2007. Statutory laboratory reporting was introduced in 2010. Prior to the introduction of statutory laboratory reporting there was considerable under-reporting of hepatitis C diagnoses.[3]

Surveillance of hepatitis C enables the targeting of preventive and control measures.

[1] Public Health England. Hepatitis C in the UK 2015 report.
www.gov.uk/government/uploads/system/uploads/attachment_data/file/448710/NEW_FINAL_HCV_2015_IN_THE_UK_REPORT_28072015_v2.pdf
[2] Harris RJ, Ramsay M, Hope V et al. Hepatitis C prevalence in England remains low and varies by ethnicity: an updated evidence synthesis. European Journal of Public Health 2012; 22 (2): 187–92.
[3] Health Protection Agency. Hepatitis C in the UK: 2012 Report.
www.hcvaction.org.uk/sites/default/files/resources/Hepatitis%20C%20in%20the%20UK%202012%20Report%20%28Health%20Protection%20Agency%29.pdf

During 2015 in England and Wales there were 11,626 confirmed laboratory reports of hepatitis C, a decrease of 3.1% in the number of reports when compared with that in 2014.[4] Where known, more than two-thirds of laboratory reports (69%) were in men.[4] Where known, more than half of laboratory reports (53%) were in people aged between 15 and 44 years, and almost half (45%) were in people aged 45 years and over.[4] Since 2006 the highest number of reports of hepatitis C has consistently been seen in people aged 15 to 44 years.[4]

Magnitude of variation

The maps and column chart display the data for 2015, during which region values ranged from 8.6 to 47.2 per 100,000 population, which is a 5.5-fold difference between regions. The England value for 2015 was 21.1 per 100,000 population.

The boxplot shows the distribution of region values for the period 2006 to 2015. The maximum to minimum range widened significantly. The median increased significantly from 12.2 per 100,000 population in 2006 to 15.0 per 100,000 population in 2015.

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

- the demography of local populations – some ethnic groups may have a higher prevalence of hepatitis C
- the level of injecting drug use in the local population
- prevalence of newly diagnosed cases of hepatitis C, people who may require treatment
- incidence of new cases of hepatitis C
- coverage of laboratory reporting
- the level of investment in laboratory services
- the organisation of local services
- access to services for testing and counselling
- effectiveness of local preventive measures, for example, needle exchange and opioid substitution programmes

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

To improve and increase laboratory reporting for hepatitis C, commissioners, local authorities (Directors of Public Health), health and wellbeing boards, clinicians and providers of primary care, secondary care and public health services need to work in partnership:

- to review the completeness of reporting by laboratories responsible for reporting hepatitis C in the locality
- to identify the level of increase in hepatitis C that has taken place in the local population over the last 5 to 10 years
- to review the local demographic profile of people at risk and use the data to help improve the identification and treatment of people with hepatitis C
- to introduce consistent methods of reporting, for example, polymerase chain reaction (PCR) results
- to ensure 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

In accordance with NICE guidance PH43 (see ‘Resources’) commissioners should commission integrated services for

[4] Public Health England. Health Protection Report weekly report. Infection Reports. Volume 10, Number 24. Published on 22 July 2016. Immunisation. Laboratory reports of hepatitis A infection, and hepatitis C: 2015.www.gov.uk/government/uploads/system/uploads/attachment_data/file/540334/hpr2416_hepAC.pdf

hepatitis C testing and treatment and laboratory services for testing, with testing perceived as part of a care pathway covering diagnosis, treatment and immunisation.

Laboratory services providing hepatitis C testing should:

- have Clinical Pathology Accreditation (UKAS; see 'Resources')
- be able to support the range of samples used for hepatitis C testing (or refer the sample to a laboratory that can perform the test)
- automatically test samples positive for hepatitis C antibody for the presence of hepatitis C virus, for example, PCR assay (or refer the sample to a laboratory that can perform the test)
- deliver results within 2 weeks of receipt of the sample together with an accurate interpretation of the laboratory results and guidance of the future management of confirmed cases
- provide accurate data according to the items listed in Box 8.1

Box 8.1: Data on hepatitis C testing required from laboratory services (NICE PH43; see 'Resources')

- Number of people tested and the type of test performed
- Referral source of samples
- Exposure category (if provided)
- Number of people testing positive, which should include PCR positive/current and PCR negative/resolved

Standards for local surveillance and follow-up of hepatitis C (see 'Resources') need to be followed, including laboratory reporting to PHE centres in line with national public health legislation.

Commissioners need to specify that primary care, secondary care and public health service providers follow NICE guidance PH43, including as relevant:

- increasing awareness of hepatitis C infection among healthcare professionals and people at risk of hepatitis infection to increase the number of people who are tested and the level of undiagnosed infection reduced
- raising awareness and understanding of hepatitis C in primary care, for instance, through e-learning (see 'Resources') or training
- exploring ways of sustaining the level of testing among people attending drug services
- expanding the use of newer technologies, such as dried blood testing, to facilitate testing in non-clinical settings
- where relevant identifying ways of enhancing testing across the prison estate

RESOURCES

- Public Health England. Hepatitis C in the UK 2015 report. www.gov.uk/government/uploads/system/uploads/attachment_data/file/448710/NEW_FINAL_HCV_2015_IN_THE_UK_REPORT_28072015_v2.pdf
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- Health Protection Agency. Standards for local surveillance and follow-up of hepatitis B and C. 2011. www.gov.uk/government/uploads/system/uploads/attachment_data/file/324052/Standards_surveillance_follow_up_hep_B_and_C__final_.pdf
- NICE. Hepatitis B and C testing: people at risk of infection. Public health guideline [PH43]. Published date: December 2012. Last updated: March 2013. www.nice.org.uk/guidance/ph43

- NICE interactive flowchart. Hepatitis B and C testing overview. https://pathways.nice.org.uk/pathways/hepatitis-b-and-c-testing
- RCGP Learning. RCGP Clinical Courses and Certifications. 'Hepatitis B & C', and 'Hepatitis C: Enhancing Prevention, Testing and Care'. http://elearning.rcgp.org.uk/course/index.php?categoryid=8
- United Kingdom Accreditation Service (UKAS). Clinical Pathology Accreditation. www.ukas.com/services/accreditation-services/clinical-pathology-accreditation/

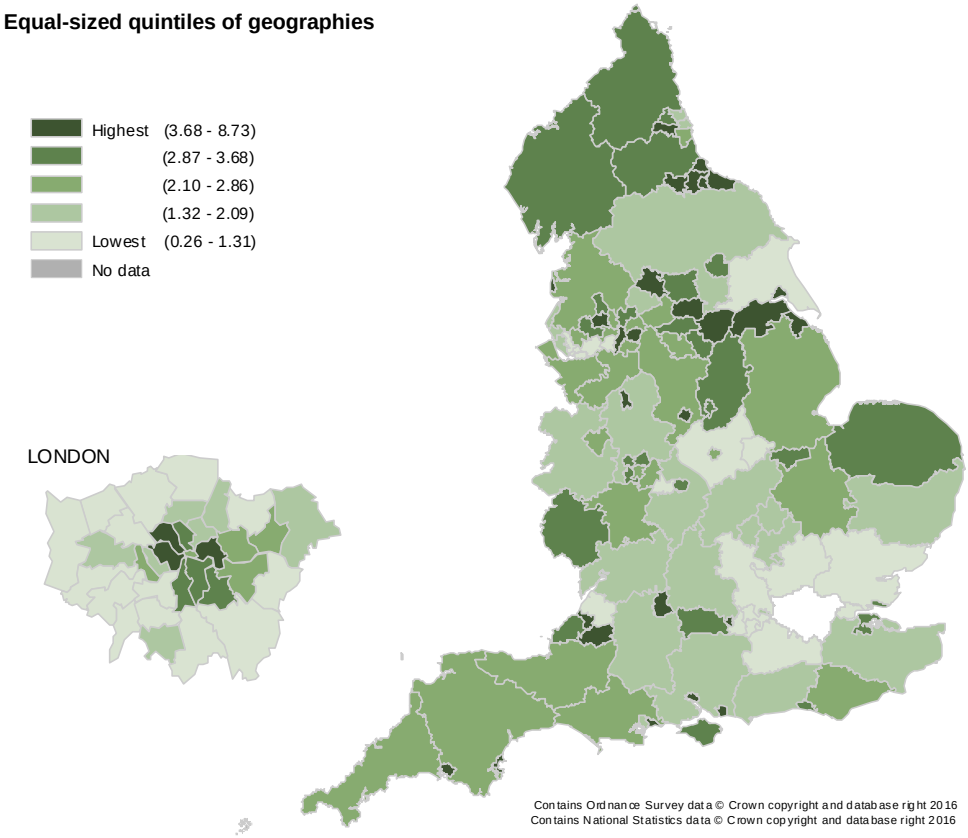
HEPATITIS C

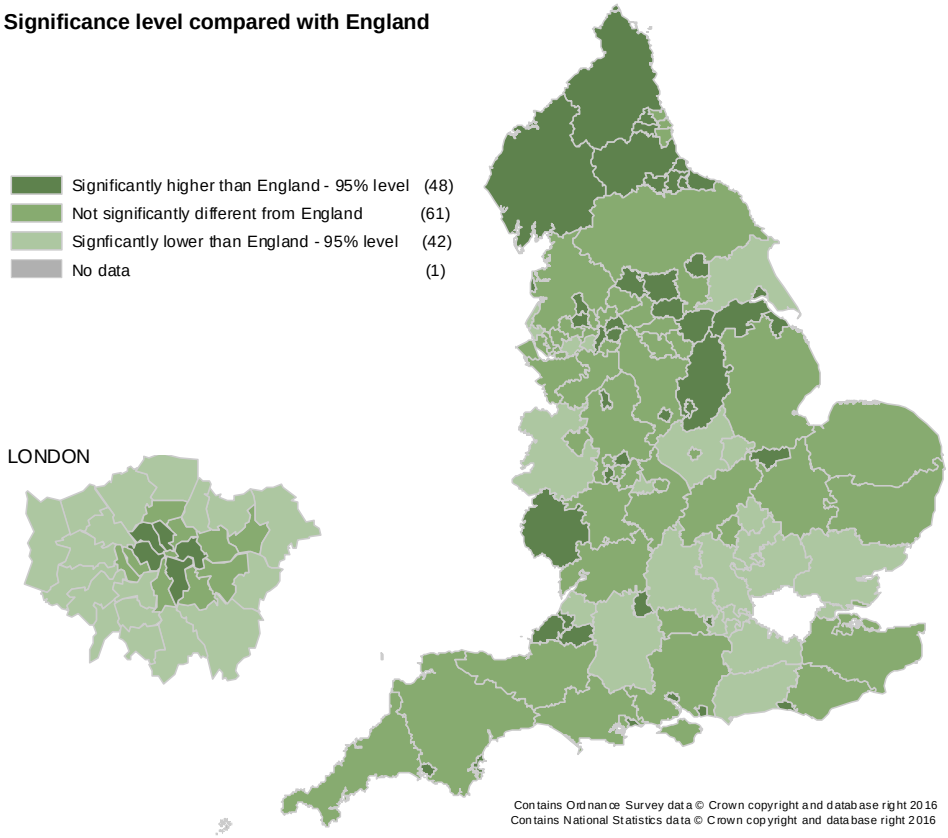
Map 9: Variation in estimated prevalence of injecting of opiate and/or crack cocaine in people aged 15 to 64 years per population by upper-tier local authority (2011/12)

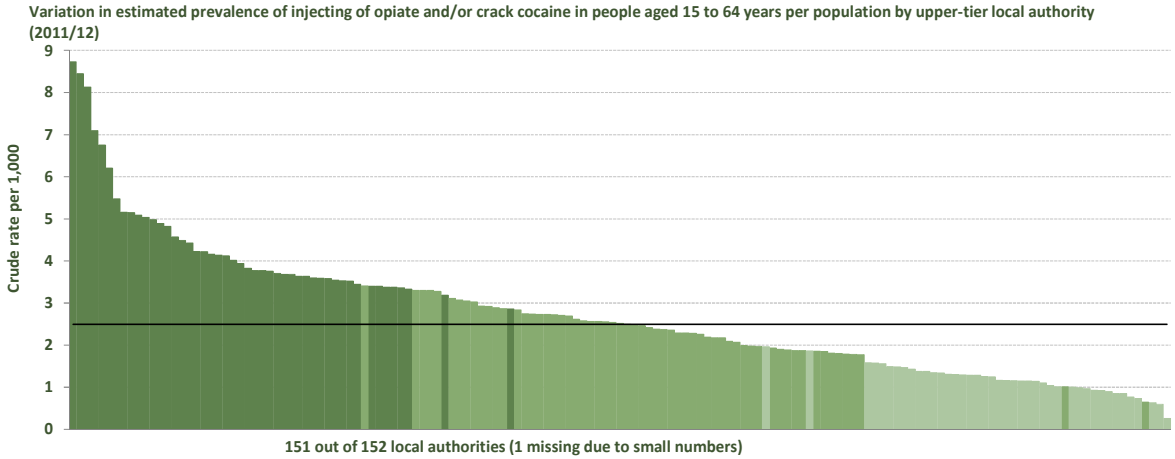
Crude rate per 1,000

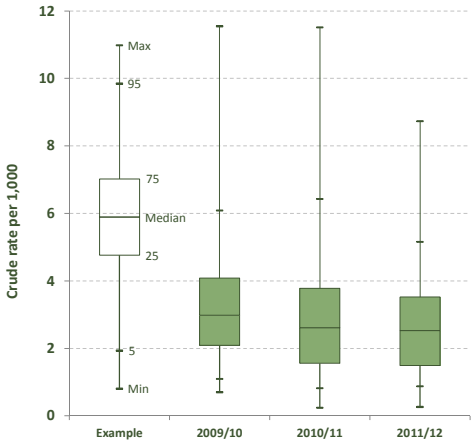
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long-term conditions
NHS Domain 5: Treating and caring for people in safe environment and protecting them from avoidable harm
PHOF Domain 2: Health improvement

OPTIMUM VALUE: LOW









Max-Min (Range)		10.8	11.3	8.5	No significant change
95th-5th percentile		5.0	5.6	4.3	No significant change
75th-25th percentile		2.0	2.2	2.0	No significant change
Median		3.0	2.6	2.5	No significant change

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 from hepatitis C 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 in particular injecting drug use, is difficult. Indirect techniques that use various data sources tend to offer more reliability, although such prevalence estimates need to be treated with caution because they are difficult to validate.

The prevalence estimates for this indicator include people aged 15 to 64 years, resident in each local authority area, and known to be injecting opiate drugs and/or crack cocaine. The data is 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’).

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]

[1] Further results and a detailed explanation of the methodology can be found in the report of the study: Hay G, Dos Santos AR, Worsley J, Millar T. Estimates of the Prevalence of Opiate Use and/or Crack Cocaine Use, 2011/12. Liverpool John Moores University. www.nta.nhs.uk/uploads/estimates-of-the-prevalence-of-opiate-use-and-or-crack-cocaine-use-2011-12-summary-report-v2.pdf

Other drugs that can be taken by injection include:

- other psychoactive drugs, such as cocaine and amphetamines
- image and performance-enhancing drugs

Magnitude of variation

The maps and column chart display the data for 2011/12, during which local authority values ranged from 0.3 to 8.7 per 1,000 population, which is a 33.7-fold difference between local authorities. The England value for 2011/12 was 2.5 per 1,000 population.

The boxplot shows the distribution of local authority values for 2009/10 to 2011/12.
There was no significant change in any of the three variation measures between 2009/10 and 2011/12.

Options for action

When planning service improvement and development for people who inject drugs, local areas, commissioners, clinicians and service providers could review:

- prevalence estimates for the locality
- the degree of contact with this underserved, 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 diagnosed with hepatitis C
- ways to address barriers to treatment to reduce hepatitis C and liver disease in this underserved, high-risk group
- access to vaccination against hepatitis B

RESOURCES

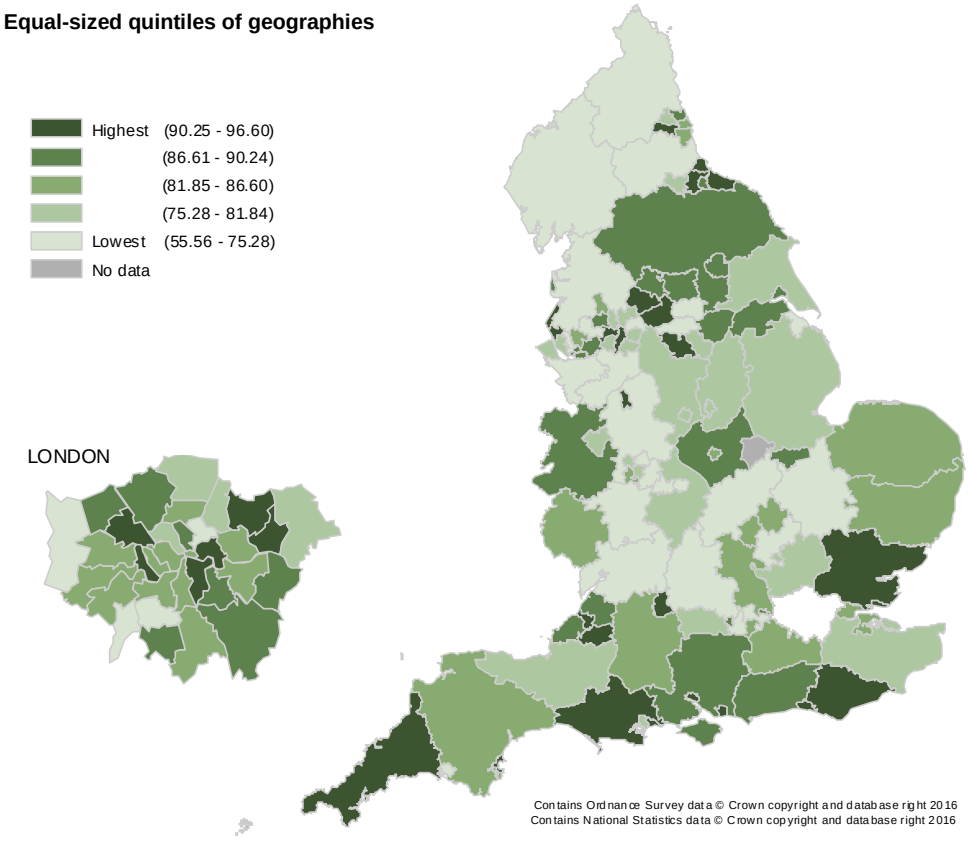
- Hay G, Dos Santos AR, Worsley J, Millar T. Estimates of the Prevalence of Opiate Use and/or Crack Cocaine Use, 2011/12. Liverpool John Moores University. www.nta.nhs.uk/uploads/estimates-of-the-prevalence-of-opiate-use-and-or-crack-cocaine-use-2011-12-summary-report-v2.pdf

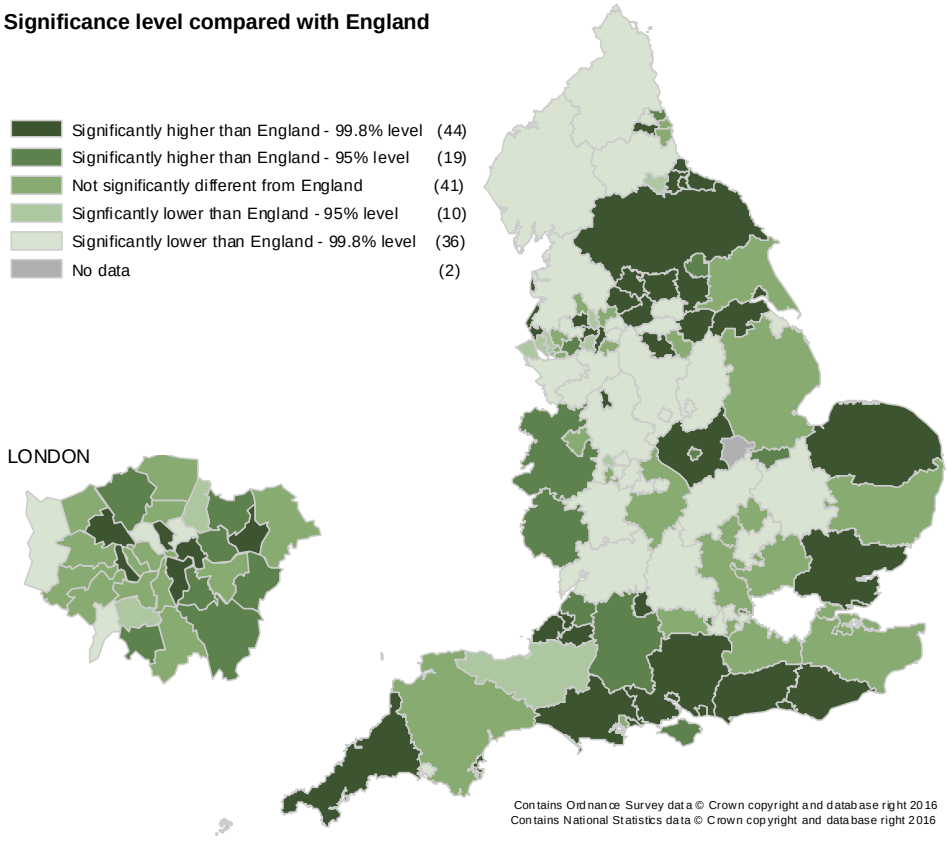
HEPATITIS C

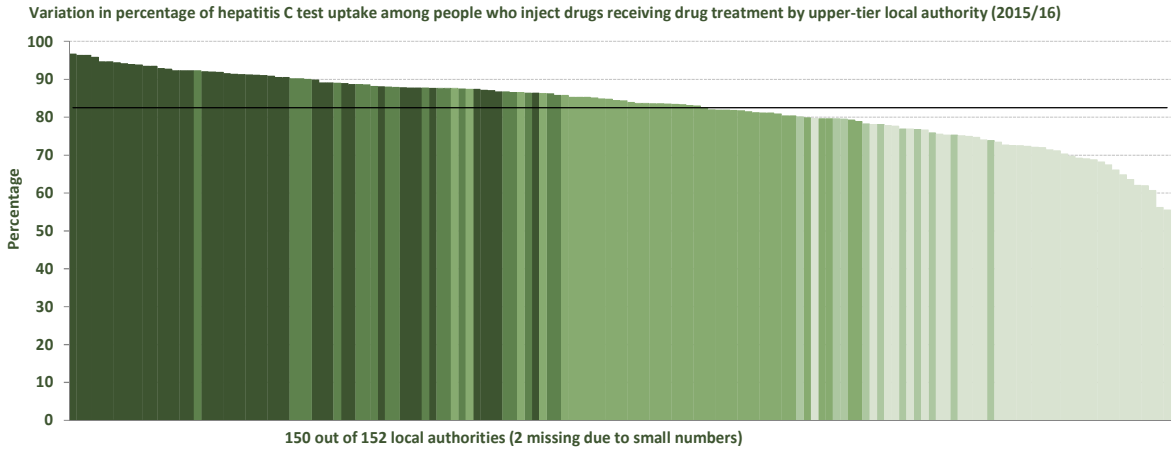
Map 10: Variation in percentage of hepatitis C test uptake among people who inject drugs receiving drug treatment by upper-tier local authority (2015/16)

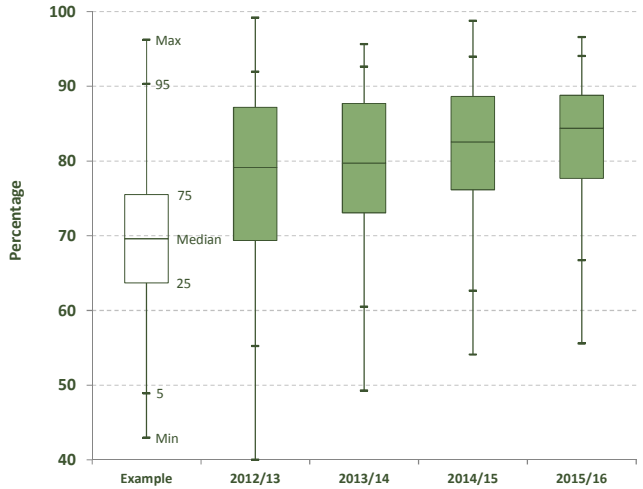
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long-term conditions
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
NHS Domain 5: Treating and caring for people in safe environment and protecting them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

OPTIMUM VALUE: HIGH









Max-Min (Range)		59.2	46.4	44.7	41.0	No significant change
95th-5th percentile		36.7	32.1	31.3	27.3	NARROWING Significant
75th-25th percentile		17.8	14.7	12.5	11.1	NARROWING Significant
Median		79.1	79.7	82.5	84.4	INCREASING Significant

Context

In the UK people who inject drugs are at greatest risk of hepatitis C infection. Infection is acquired when people share contaminated injecting equipment that has been used by people with hepatitis C.

Preventing the spread of hepatitis C is an important public health issue, which can have wide-reaching benefits, reducing health harms for individuals and the subsequent cost to society.

People at risk of hepatitis C infection should be offered access to screening tests and tests to confirm hepatitis C infection. Testing can be an important step:

- to help people with hepatitis C 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

Magnitude of variation

The maps and column chart display the data for 2015/16, during which local authority values ranged from 55.6% to 96.6%, which is a 1.7-fold difference between local authorities. The England value for 2015/16 was 82.5%.

The boxplot shows the distribution of local authority values for the period 2012/13 to 2015/16. Both the 95th to 5th percentile gap and the 75th to 25th percentile gap narrowed significantly. The median increased significantly from 79.1% in 2012/13 to 84.4% in 2015/16.

Options for action

When planning services for people at increased risk of hepatitis C, local authorities should assess local need and work with their commissioned services:

- to review the percentage of people receiving drug treatment who are offered and accept hepatitis C testing
- to ascertain the reasons for low rates of testing
- to ensure that professionals 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

- Public Health England. Hepatitis C in England 2017 report. www.gov.uk/government/uploads/system/uploads/attachment_data/file/599738/hepatitis_c_in_england_2017_report.pdf
- Public Health England. Hepatitis C in England 2016 report. www.gov.uk/government/uploads/system/uploads/attachment_data/file/565459/Hepatitis_C_in_the_UK_2016_report.pdf
- NICE. Hepatitis B and C testing: people at risk of infection. Public health guideline [PH43]. Published date: December 2012. Last updated: March 2013. www.nice.org.uk/guidance/ph43
- NICE interactive flowchart. Hepatitis B and C testing overview. https://pathways.nice.org.uk/pathways/hepatitis-b-and-c-testing
- Public Health England. Turning evidence into practice: Improving access to, and completion of, hepatitis C treatment. July 2015. www.hcvaction.org.uk/resource/turning-evidence-practice-improving-access-and-completion-hepatitis-c-treatment
- Public Health England. Turning evidence into practice: Preventing blood-borne virus transmission among people who inject drugs. September 2015. www.nta.nhs.uk/uploads/teip-bbv-2015.pdf
- Department of Health (England) and the devolved administrations. Drug Misuse and Dependence: UK guidelines on clinical management. London: 2007. www.nta.nhs.uk/uploads/clinical_guidelines_2007.pdf
- Harm Reduction Works – campaign materials. www.harmreductionworks.org.uk/

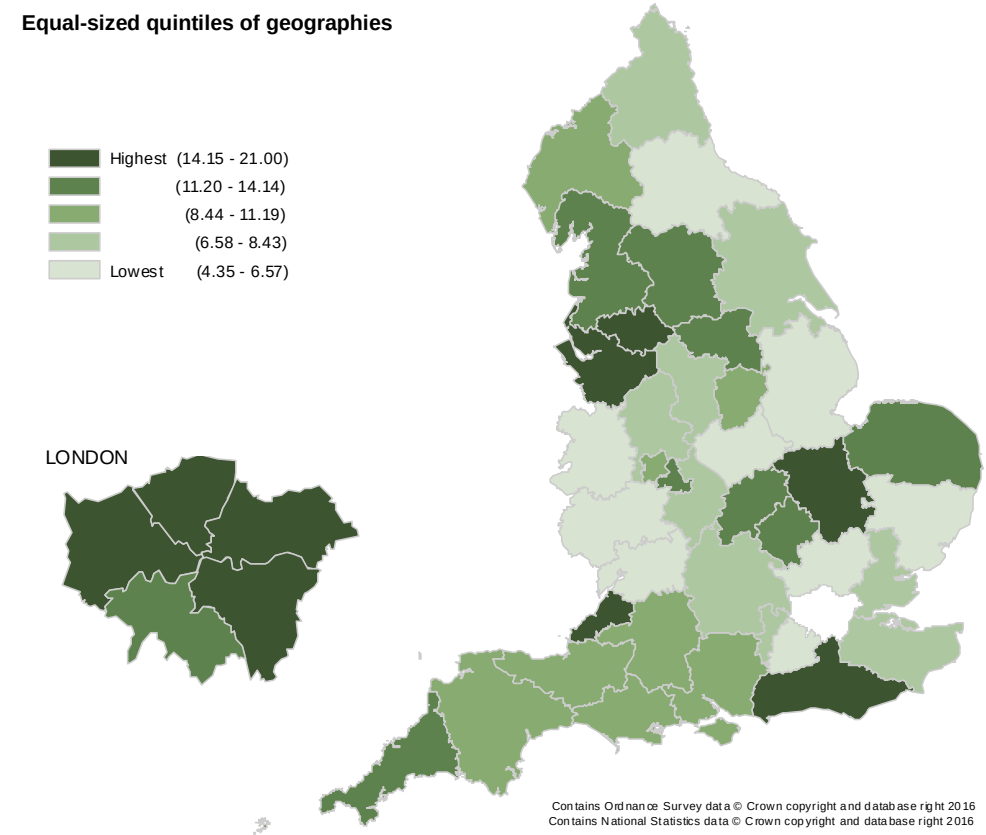
HEPATITIS C

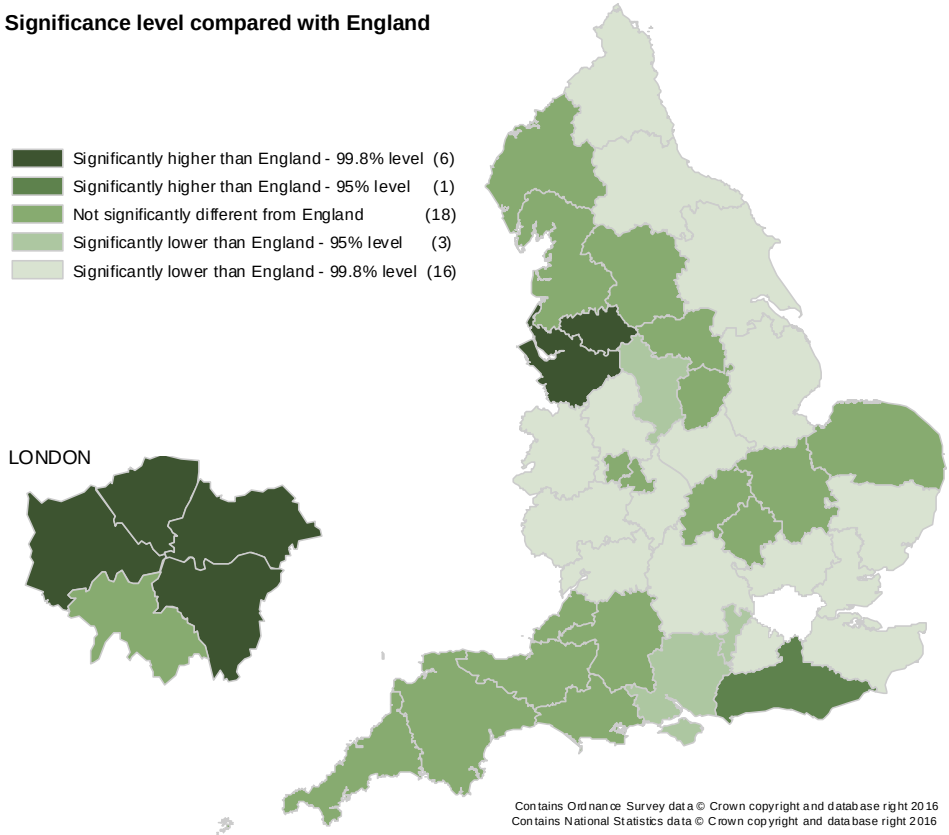
Map 11a: Variation in rate of hospital admissions for hepatitis C-related end-stage liver disease or hepatocellular carcinoma per population by Sustainability Transformation Partnerships (STP) (2012/13 - 2014/15)

Crude rate per 1,000,000

NHS Domain 4: Ensuring that people have a positive experience of care
NHS Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW





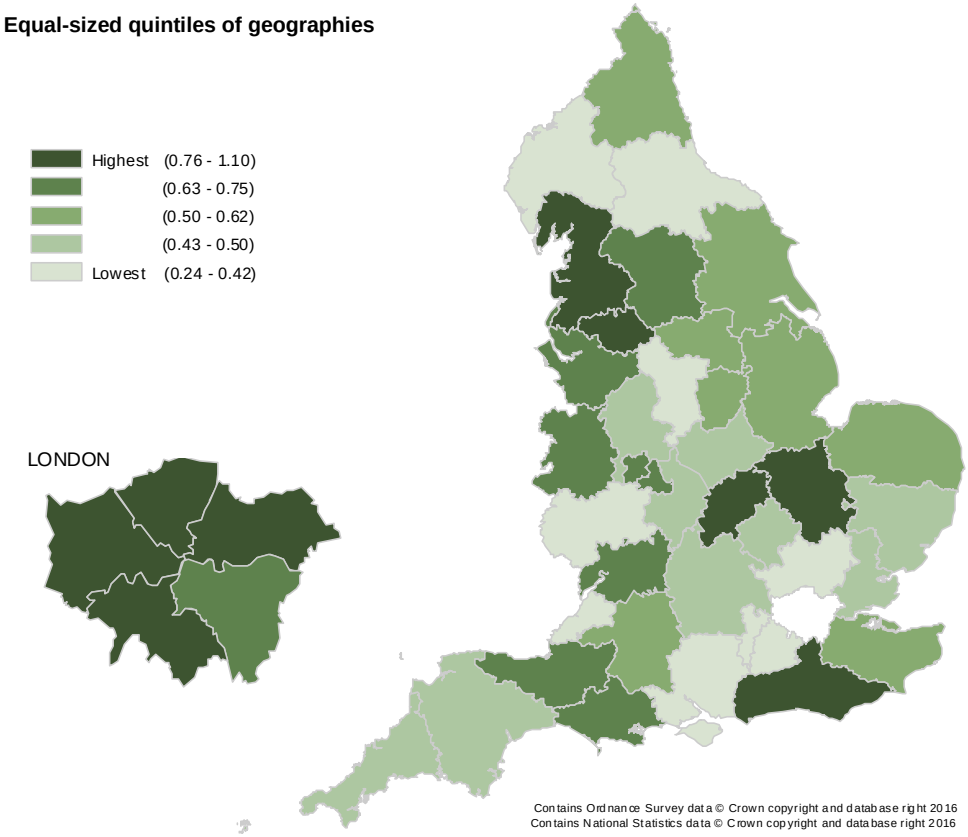
HEPATITIS C

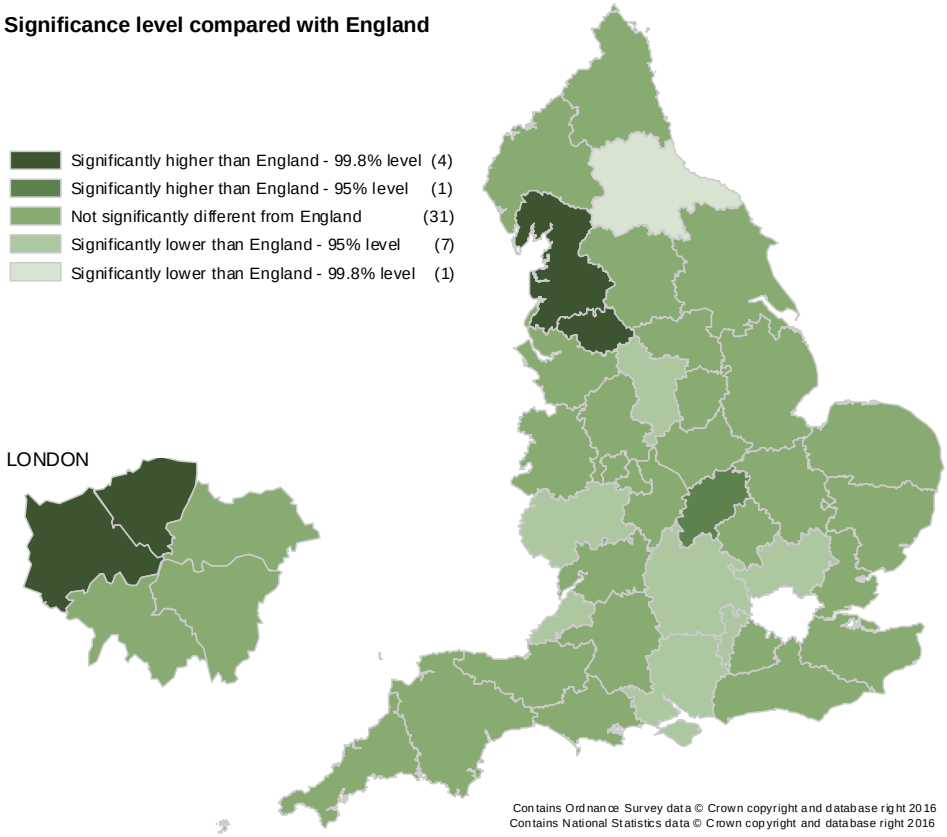
Map 11b: Variation in rate of mortality from hepatitis C-related end-stage liver disease or hepatocellular carcinoma per population by Sustainability Transformation Partnerships (STP) (2011-2015)

Crude rate per 100,000

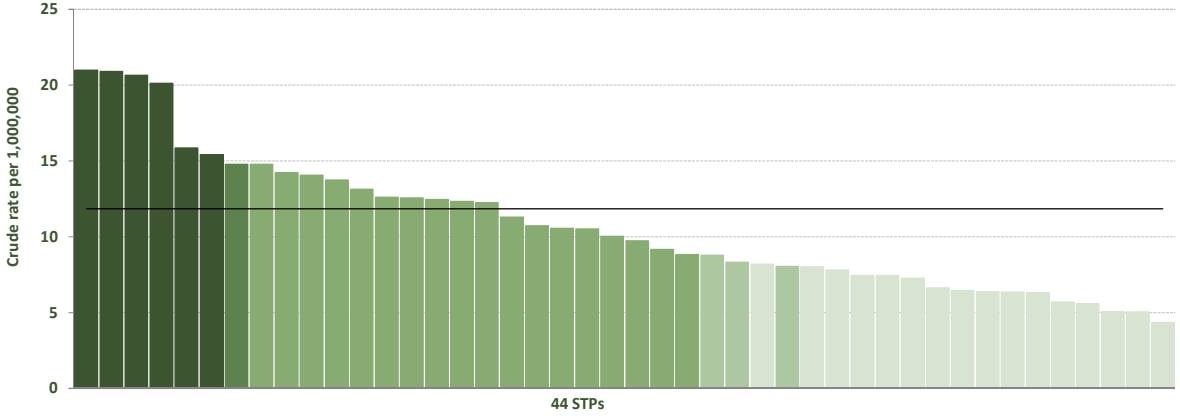
NHS Domain 1: Preventing people from dying prematurely
PHOF Domain 4: Healthcare public health and preventing premature mortality

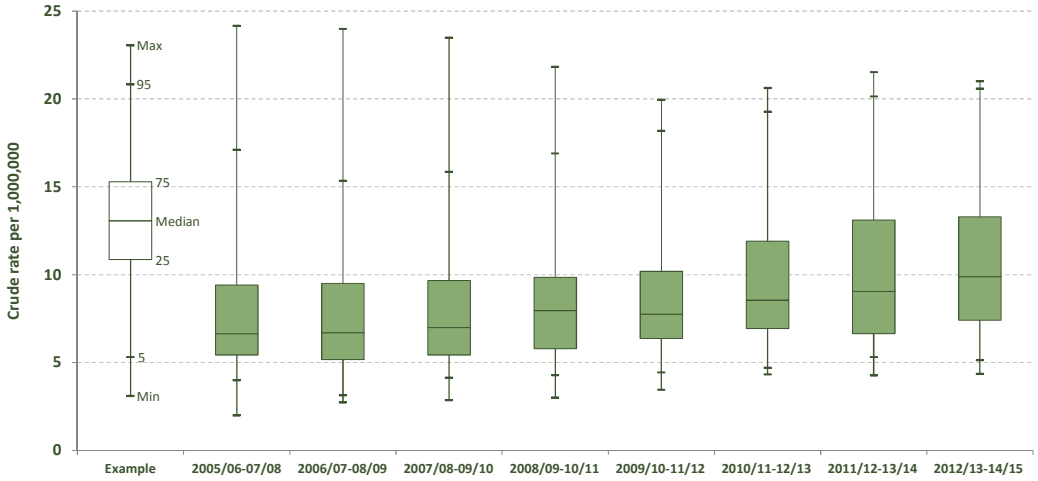
OPTIMUM VALUE: LOW





Variation in rate of hospital admissions for hepatitis C -related end-stage liver disease or hepatocellular carcinoma per populat ion by Sustainability Transformation Partnerships (STP) (2012/13 - 2014/15)





Max-Min (Range)		22.2	21.3	20.6	18.8	16.5	16.3	17.3	16.7	NARROWING Significant
95th-5th percentile		13.1	12.2	11.7	12.6	13.7	14.6	14.8	15.5	WIDENING Significant
75th-25th percentile		4.0	4.3	4.2	4.1	3.8	5.0	6.5	5.9	WIDENING Significant
Median		6.6	6.7	7.0	8.0	7.8	8.5	9.0	9.9	INCREASING Significant

Context

Although exposure to hepatitis C virus often leads to a chronic infection, antiviral treatments are available that will successfully clear the virus in the vast majority of patients. Unless there is a considerable increase in people receiving effective treatment, however, the future burden of hepatitis C-related disease will be substantial.

In England between 2005 and 2014 deaths from hepatitis C-related end-stage liver disease and hepatocellular carcinoma more than doubled,[1] although an 8% fall in the number of deaths from these indications in 2015 would suggest that increased treatment with new direct-acting antiviral drugs, particularly in people with more advanced disease, may be beginning to have an effect.[1]

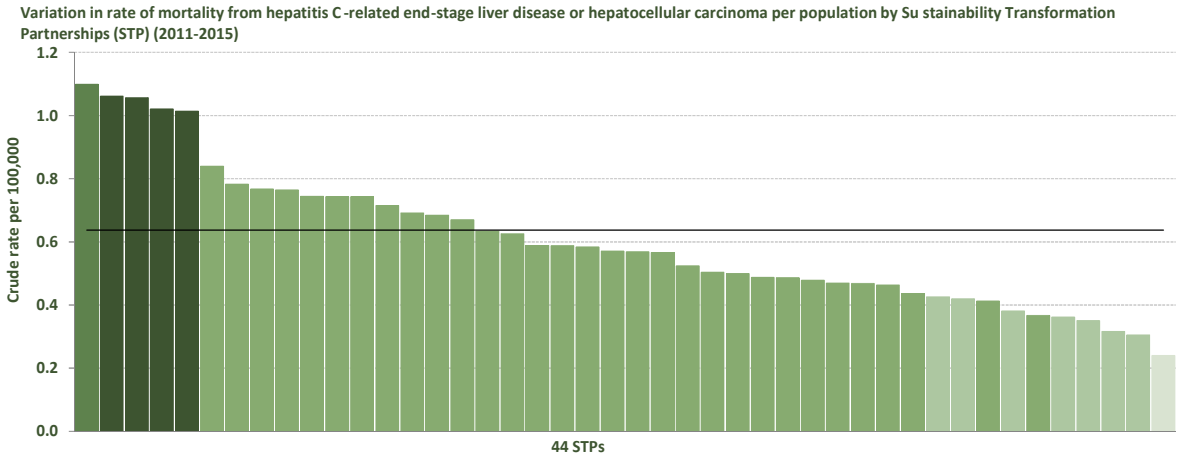
The NHS targets are:

- to have treated about 10,000 patients in 2016
- to increase the number of people treated to 15,000 per year by 2020

On the assumptions that these targets can be achieved and a rate of treating 15,000 people per year can be maintained, statistical modelling[2] has been used to predict that the number of people who would be living with hepatitis C-related cirrhosis or hepatocellular carcinoma in England:

- by 2020 would be about 5,480
- by 2030 would be about 2,620

[1] Public Health England. Hepatitis C in England: 2017 report. www.gov.uk/government/uploads/system/uploads/attachment_data/file/599738/hepatitis_c_in_england_2017_report.pdf
[2] Harris RJ, Martin NK, Rand E, Mandal S, Mutimer D, Vickerman P et al. New treatments for hepatitis C virus (HCV): scope for preventing liver disease and HCV transmission in England. J Viral Hepat. 2016;(8):631-643.



Max-Min (Range)		0.88	0.93	0.93	0.87	0.93	0.85	0.86	No significant change
95th-5th percentile		0.60	0.62	0.60	0.60	0.67	0.71	0.73	WIDENING Significant
75th-25th percentile		0.27	0.32	0.29	0.31	0.32	0.27	0.29	No significant change
Median		0.33	0.36	0.39	0.45	0.47	0.52	0.57	INCREASING Significant

These predictions represent a fall in hepatitis C-related of cirrhosis or hepatocellular carcinoma of 56% by 2020 and of 81% by 2030.[1]

Admission to hospital for hepatitis C-related end-stage liver disease and hepatocellular carcinoma is an outcome indicator of how successful the identification and care of people with hepatitis C have been.

Death certificate data from the Office for National Statistics shows the number of hepatitis C-related deaths from end-stage liver disease and hepatocellular carcinoma has increased from 187 in 2005 to 387 in 2014, and decreased to 357 in 2015.[1]

Mortality from hepatitis C and end-stage liver disease or hepatocellular carcinoma is an outcome indicator of how successful the identification and care of people with hepatitis C have been.

Magnitude of variation

Map 11a: Hospital admissions for hepatitis C-related end-stage liver disease or hepatocellular carcinoma

The maps and column chart display the data for 2012/13 to 2014/15, during which STP values ranged from 4.4 to 21.0 per million population, which is a 4.8-fold difference between STPs. The England value for 2012/13 to 2014/15 was 11.8 per million population. The boxplot shows the distribution of STP values for the period 2005/06-2007/08 to 2012/13-2014/15. The maximum to minimum range narrowed significantly, whereas both the 95th to 5th and the 75th to 25th percentile gaps widened significantly. The median increased significantly from 6.6 per million population in 2005/06-2007/08 to 9.9 per million population in 2012/13-2014/15.

Reasons for the degree of variation observed include differences in:

- the prevalence of hepatitis C
- the historical and changing patterns of risks and risk behaviours, such as injecting drug use, in local populations
- the prevalence of comorbidities, such as the level of alcohol use

In addition many patients who present with hepatitis C-related end-stage liver disease or hepatocellular carcinoma present with advanced disease and are not previously known to hepatology or gastroenterology 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

Map 11b: Mortality from hepatitis C-related end-stage liver disease or hepatocellular carcinoma

The maps and column chart display the data for 2011-15, during which STP values ranged from 0.2 to 1.1 per 100,000 population, which is a 4.6-fold difference between STPs. The England value for 2011-15 was 0.6 per 100,000 population. The boxplot shows the distribution of STP values for the period 2005-09 to 2011-15. The 95th to 5th percentile gap widened significantly. The median increased significantly from 0.3 per 100,000 population in 2005-09 to 0.6 per 100,000 population in 2011-15.

Reasons for warranted variation are differences in:

- the prevalence of hepatitis C
- the historical and changing patterns of risks and risk behaviours, such as injecting drug use, in local populations
- the prevalence of comorbidities, such as the level of alcohol use

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

- the degree of compliance with treatment
- the configuration of treatment services
- the level of access to treatment services
- the timing of diagnosis

Options for action

For people with hepatitis C to receive the best possible care, it is essential that the aim of testing and treatment services is to prevent progression to end-stage liver disease and cancer. It is important for commissioners, clinicians and service providers to make available specialised services for:

- local hepatitis C populations, to identify people at risk and offer testing with a view to treatment
- people with end-stage liver disease and cancer, to ensure there is access to expert care to optimise outcomes

Commissioners need to work with all clinicians and service providers to ensure that:

- the local operational delivery network for hepatitis C treatment is effective, including improving people's access to accredited laboratory and other services (map A.5)
- people with hepatitis C receive appropriate and early intervention with effective therapy, which should reduce progression to end-stage liver disease and cancer (secondary prevention); treating end-stage liver disease and cancer will help to reduce mortality (supportive care and transplant)

Commissioners should also review:

- trends in mortality in the local area
- local interventions 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 local area (intention-to-treat outcomes of people testing positive) to identify not only the barriers to a successful treatment outcome but also the ways in which those barriers can be addressed
- collaboration between specialist services and other agencies to ascertain whether the best possible outcomes for this group of people are being obtained

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

- care and treatment 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

To increase the number and proportion of people with hepatitis C being diagnosed,[1] commissioners need to specify that service providers:

- raise awareness of hepatitis C among professionals in primary care and other settings, such as drug services, through encouraging participation in e-learning (see 'Resources')
- follow NICE guidance on testing people at risk of hepatitis C infection (PH43; see 'Resources')
- sustain and enhance testing[3] among people attending drug services
- expand the use of newer technologies, such as dried blood spot testing, in non-clinical settings
- promote and offer testing to groups of people not in regular contact with health services who may have acquired hepatitis C many years previously, such as people who acquired hepatitis C infection through past injecting drug use, medical or dental treatment in countries where poor blood screening and/or infection control practices exist or transfusion in the UK prior to September 1991 – some people in these groups may have advanced asymptomatic disease
- where relevant locally, monitor bloodborne virus opt-out testing for new receptions to prisons to inform strategies to improve the offer and uptake of testing
- produce appropriate communications to mark World Hepatitis Day

Commissioners could consider commissioning bloodborne virus opt-out testing in drug services.[1]

Commissioners need to specify that laboratory service providers[1]:

- perform ribonucleic acid amplification on the same sample as the original antibody assay to reduce the turnaround time for referral, benefitting patient care and increasing cost-effectiveness
- include patient referral instructions on the laboratory report

To increase the number of people with hepatitis C accessing treatment,[1] commissioners need to work with public health agencies, clinicians and other stakeholders:

- to simplify referral pathways
- to improve the availability, access and uptake of approved hepatitis C treatments in primary and secondary care, drug treatment services, prisons and other settings not only for people newly diagnosed or already engaged with treatment services but also for people who have been diagnosed but subsequently lost to follow-up

[3] Department of Health (England), The Scottish Government, Welsh Assembly, Northern Ireland Executive. Drug Misuse and Dependence: UK Guidelines on Clinical Management. 2007. www.nta.nhs.uk/publications/documents/clinical_guidelines_2007.pdf

- where relevant, to monitor Health and Justice Indicators of Performance to ensure equity of access to hepatitis C care and treatment pathways for all prisoners and immigration detainees
- to explore innovative approaches to outreach and patient support

Service providers need to be aware that after treatment people with a sustained viral response should be given appropriate information and support to help guard against re-infection.[1]

At a national level Public Health England needs to analyse the agreed national treatment monitoring dataset to assess equity, access, uptake and effect of treatment on the future burden of hepatitis C-related disease in England.[1] This analysis will not only inform future healthcare planning but also enable progress to be monitored against World Health Organization goals to eliminate hepatitis C as a serious public health threat by the year 2030.

RESOURCES

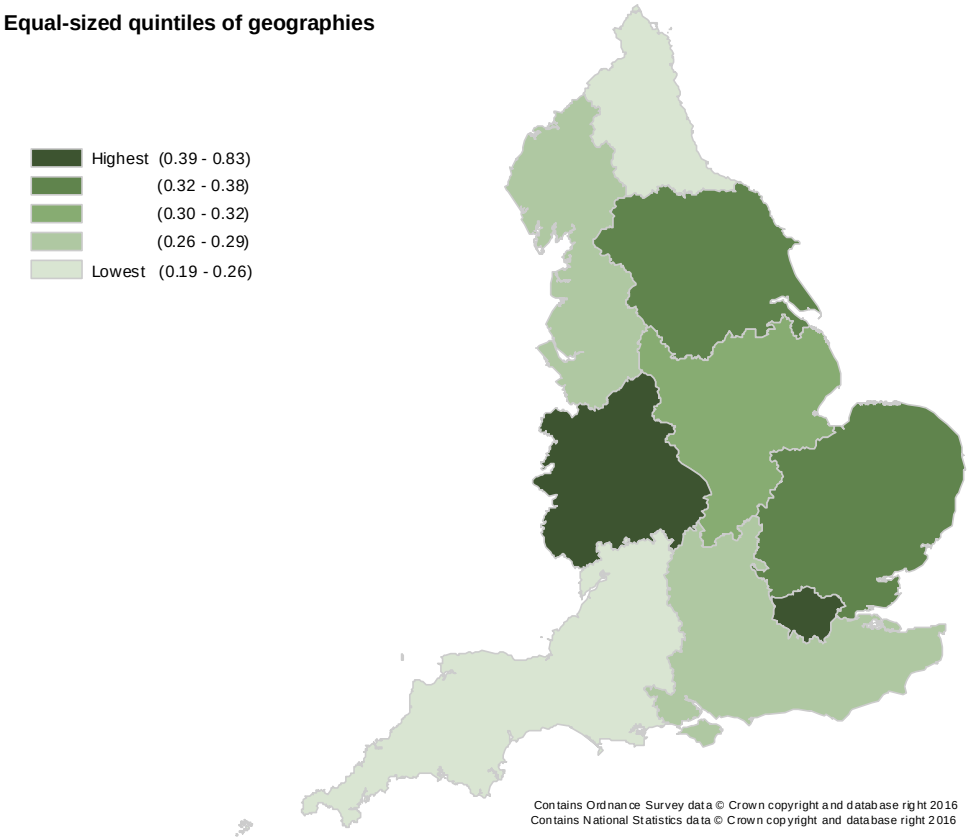
- PHE. Hepatitis C in England 2017 report. http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/599738/hepatitis_c_in_england_2017_report.pdf
- PHE. Hepatitis C in the UK: 2016 report. www.gov.uk/government/uploads/system/uploads/attachment_data/file/565459/Hepatitis_C_in_the_UK_2016_report.pdf
- NICE. Hepatitis B and C testing: people at risk of infection. Public health guideline [PH43]. Published date: December 2012. Last updated: March 2013. www.nice.org.uk/guidance/ph43
- NICE. Interactive flowchart. Hepatitis B and C testing overview. https://pathways.nice.org.uk/pathways/hepatitis-b-and-c-testing
- RCGP Learning. RCGP Clinical Courses and Certifications. ‘Hepatitis B & C’, and ‘Hepatitis C: Enhancing Prevention, Testing and Care’. http://elearning.rcgp.org.uk/course/index.php?categoryid=8

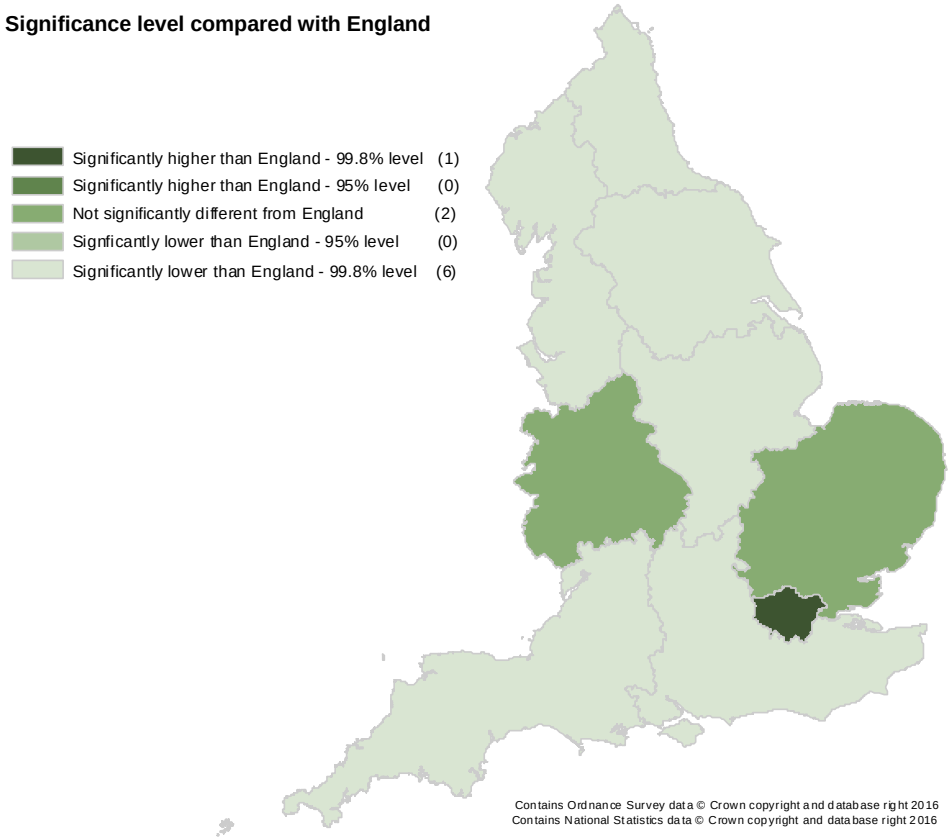
HEPATITIS B

Map 12: Variation in percentage of women who tested positive for hepatitis B in the NHS Infectious Diseases in Pregnancy Screening Programme by region (2015)

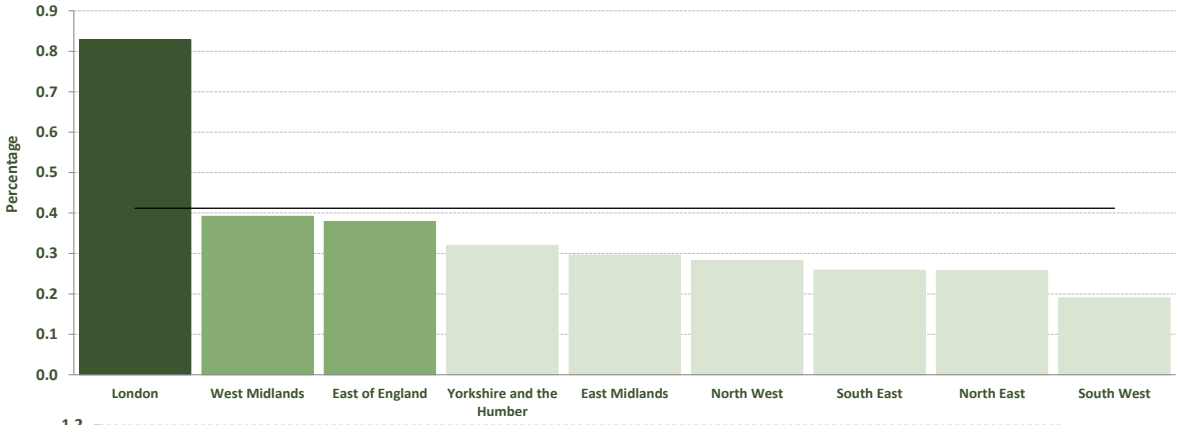
NHS Domain 2: Enhancing quality of life for people with long term conditions
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
NHS Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm
PHOF Domain 3: Health protection

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION





Variation in percentage of women who tested positive for hepatitis B in the NHS Infectious Diseases in Pregnancy Screening Programme by region (2015)



		2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
Max-Min (Range)		0.90	0.99	1.04	0.88	0.87	0.82	0.88	0.90	0.77	0.74	0.64	NARROWING Significant
95th-5th percentile		0.60	0.69	0.71	0.63	0.59	0.55	0.59	0.61	0.58	0.51	0.44	NARROWING Significant
75th-25th percentile		0.12	0.12	0.13	0.20	0.08	0.05	0.08	0.05	0.16	0.10	0.12	No significant change
Median		0.23	0.27	0.25	0.30	0.29	0.28	0.27	0.33	0.26	0.29	0.30	No significant change

Context

The UK National Screening Committee (UK NSC) recommends that systematic population screening in pregnancy for HIV, hepatitis B and syphilis is offered and recommended to all eligible women.[1] Screening for susceptibility to rubella ceased on 1 April 2016.

The NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme, part of Public Health England (PHE), has responsibility for implementing this policy and managing the programme in England.[2] The programme works collaboratively with the Screening Quality Assurance Services to support service improvements.[3] The objectives for the programme are as follows:

- to reduce the risk of mother-to-child transmission
- to ensure that women are identified early in pregnancy
- to facilitate appropriate assessment and management for the women's own health
- to facilitate appropriate neonatal referral and management[4]

[1] UK National Screening Committee. www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc
[2] Public Health England. Population Screening Programmes. NHS Infectious Diseases in Pregnancy Screening (IDPS) programme. www.gov.uk/topic/population-screening-programmes/infectious-diseases-in-pregnancy
[3] Public Health England. NHS Population Screening: quality assurance. www.gov.uk/guidance/nhs-population-screening-quality-assurance
[4] Public Health England and NHS England. NHS public health functions agreement 2017-18. Service Specification No. 15. Infectious Diseases in Pregnancy Screening Programme. First published: April 2017. www.england.nhs.uk/wp-content/uploads/2017/06/service-specification-15.pdf

National coverage of antenatal hepatitis B screening increased from 93% in 2005 to 98% in 2015.[5] In 2015, 0.4% of pregnant women screened for hepatitis B were positive for hepatitis B surface antigen, which is a marker of current infection.[5] There has been no significant change in hepatitis B-positive rates since 2005.[5] In 2015, for diagnoses where all information was available, 25% of pregnant women who were diagnosed as hepatitis B-positive were identified through antenatal screening in the current pregnancy.[5] As this group of women may not have been diagnosed in the absence of routine screening, the babies would have been at increased risk of infection through mother-to-child transmission.

The data for this indicator in 2015 was collected from maternity units by regions, with the help of Field Epidemiology Services, and collated into national data by PHE, National Infections Service (NIS), Colindale. The IDPS Programme introduced new screening standards in April 2016.[6] The standards include clear metrics that assess the screening pathway and help service providers and commissioners to identify where improvements are needed. To measure performance against these standards the IDPS programme introduced a new annual fiscal year data collection process, which replaced the NIS process from April 2016.[7] The programme also commissions the Centre of Epidemiology for Child Health at University College London Hospitals (UCLH) Institute of Child Health to collect data on screening programme outcomes.

Magnitude of variation

The maps and column chart display the data for 2015, during which region values ranged from 0.2% to 0.8%, which is a 4.4-fold difference between regions. The England value for 2015 was 0.4 %.

The boxplot shows the distribution of region values for the period 2005 to 2015.
Both the maximum to minimum range and the 95th to 5th percentile gap narrowed significantly, with the higher levels reducing. The median for England did not change significantly.

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

- 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 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. Variability in the data is likely to be resolved with the introduction of screening programme key performance indicators for coverage for all three infections, and implementation of the new national Maternity Services Data Set which will provide more accurate data on the number of women:

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

Options for action

To ensure Hepatitis B-positive mothers are known about to prevent vertical transmission to their child, commissioners, clinicians and service providers should refer to the NHS IDPS Programme Service Specification No.15 (see ‘Resources’) and supporting documents to ensure a programme is set up correctly and meets the standards set

[5] Public Health England. National Antenatal Infections Screening Monitoring: annual data tables. Last updated: 13 January 2017. www.gov.uk/government/publications/national-antenatal-infections-screening-monitoring-annual-data-tables
[6] Public Health England. Infectious diseases in pregnancy screening: programme standards. Last updated: 30 March 2016. www.gov.uk/government/publications/infectious-diseases-in-pregnancy-screening-programme-standards
[7] Public Health England. Antenatal screening programmes: annual standards data collection. Last updated: 27 April 2017. www.gov.uk/government/publications/infectious-diseases-in-pregnancy-screening-annual-data-collection

by the national screening team (see ‘Resources’ for programme standards and laboratory handbook).

RESOURCES

- Public Health England. Infectious diseases in pregnancy screening (IDPS): programme overview. www.gov.uk/guidance/infectious-diseases-in-pregnancy-screening-programme-overview
- Public Health England. National Antenatal Infections Screening Monitoring (NAISM). www.gov.uk/guidance/infectious-diseases-during-pregnancy-screening-vaccination-and-treatment
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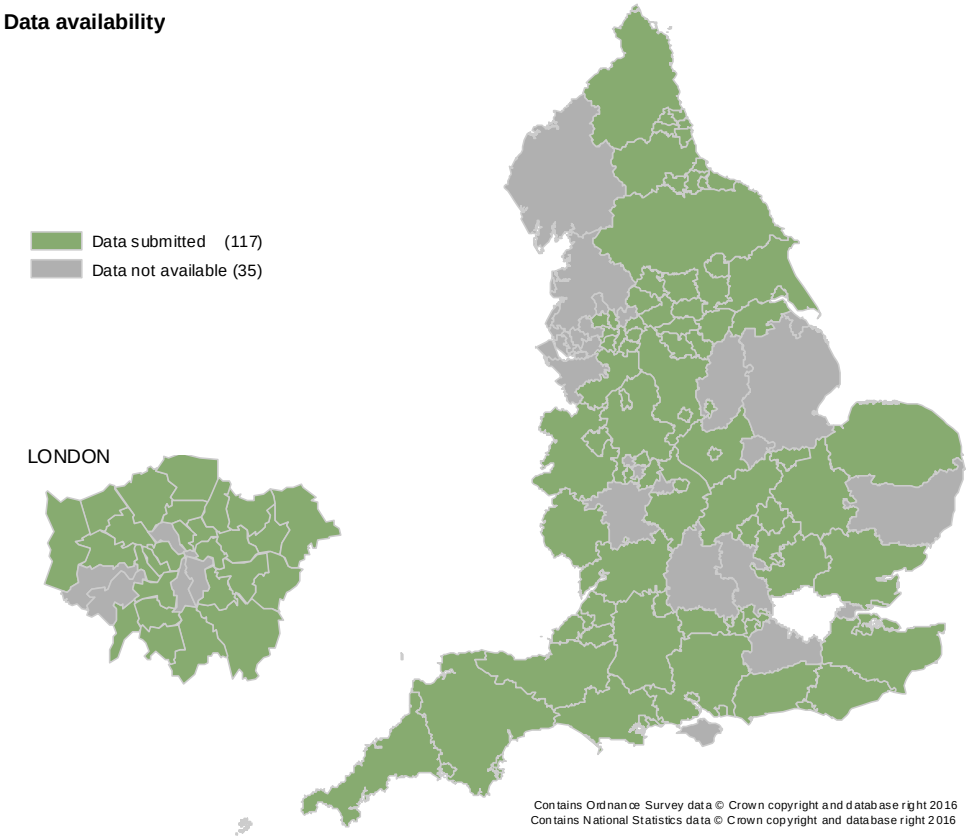
- Public Health England and NHS England. NHS public health functions agreement 2017-18. Service Specification No. 15. Infectious Diseases in Pregnancy Screening Programme. First published: April 2017. www.england.nhs.uk/wp-content/uploads/2017/06/service-specification-15.pdf
- Public Health England. NHS Infectious Diseases in Pregnancy Screening Programme: Standards 2016 to 2017. Published March 2016. www.gov.uk/government/uploads/system/uploads/attachment_data/file/529070/IDPS_Programme_Standards_2016_to_2017.pdf
- Public Health England. NHS Infectious Diseases in Pregnancy Screening Programme: Laboratory Handbook 2016 to 2017. Published July 2016. www.gov.uk/government/uploads/system/uploads/attachment_data/file/539828/NHS_Infectious_Diseases_in_Pregnancy_Screening_Programme_Laboratory_Handbook_2016_2017_with_gateway_number.pdf

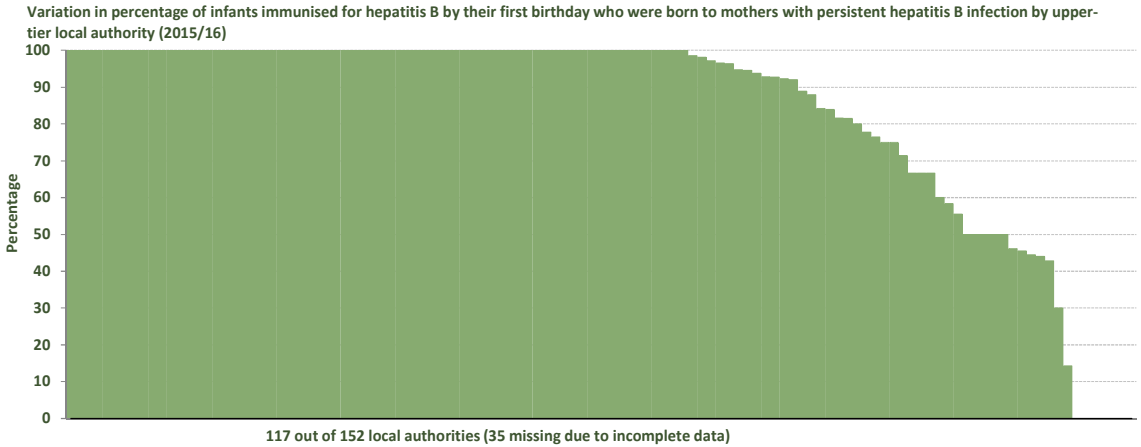
HEPATITIS B

Map 13: Variation in percentage of infants immunised for hepatitis B by their first birthday who were born to mothers with persistent hepatitis B infection by upper-tier local authority (2015/16)

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm
PHOF Domain 3: Health protection

OPTIMUM VALUE: HIGH





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.[1]

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 babies 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’).

Local authority data is sent to Public Health England through the COVER programme. Valid data on the denominator of children at risk and/or the numerator of children vaccinated with three doses by 12 months of age are not available for some local authorities. Local authorities providing zero returns for 2015/16 were asked to confirm that there were no infants born to persistently infected pregnant women in the population. Local authorities unable to provide confirmation were coded as missing data.

Magnitude of variation

The map and column chart display the data for 2015/16, during which local authority values ranged from 0.0% to 100.0%. The England value is not calculated for this indicator due to incompleteness of the data.

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

Options for action

When planning service improvement or development for vaccination of the newborn against hepatitis B, commissioners, clinicians and service providers need to ensure that local arrangements follow national guidance (see ‘Resources’) and meet quality statements 3 and 4 in the NICE quality standard (QS65; see ‘Resources’).

Commissioners also need to monitor valid coverage data quarterly to improve the vaccination rates achieved in 2015/16.

- 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

[1] NHS Executive. Screening of pregnant women for hepatitis B and immunisation of babies at risk. Health Service Circular 1998/127. Issue date: 22 July 1998.
http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4011840.pdf

infants at risk in order to improve reporting and/or achieve higher rates of coverage

RESOURCES

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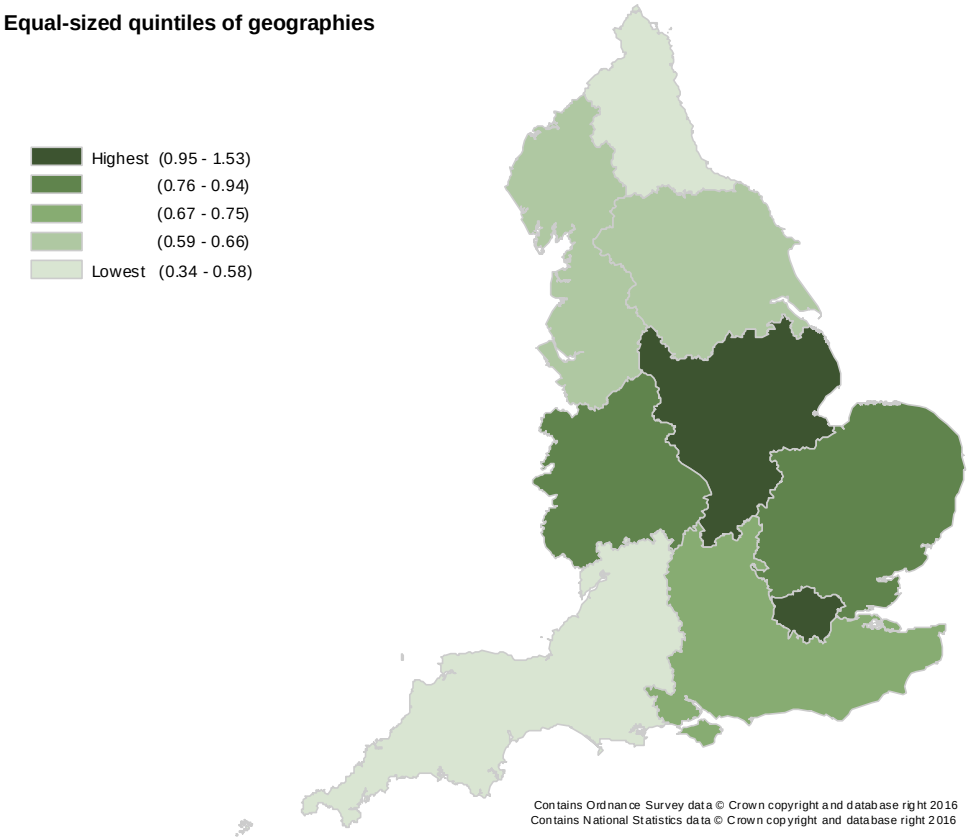
HEPATITIS B

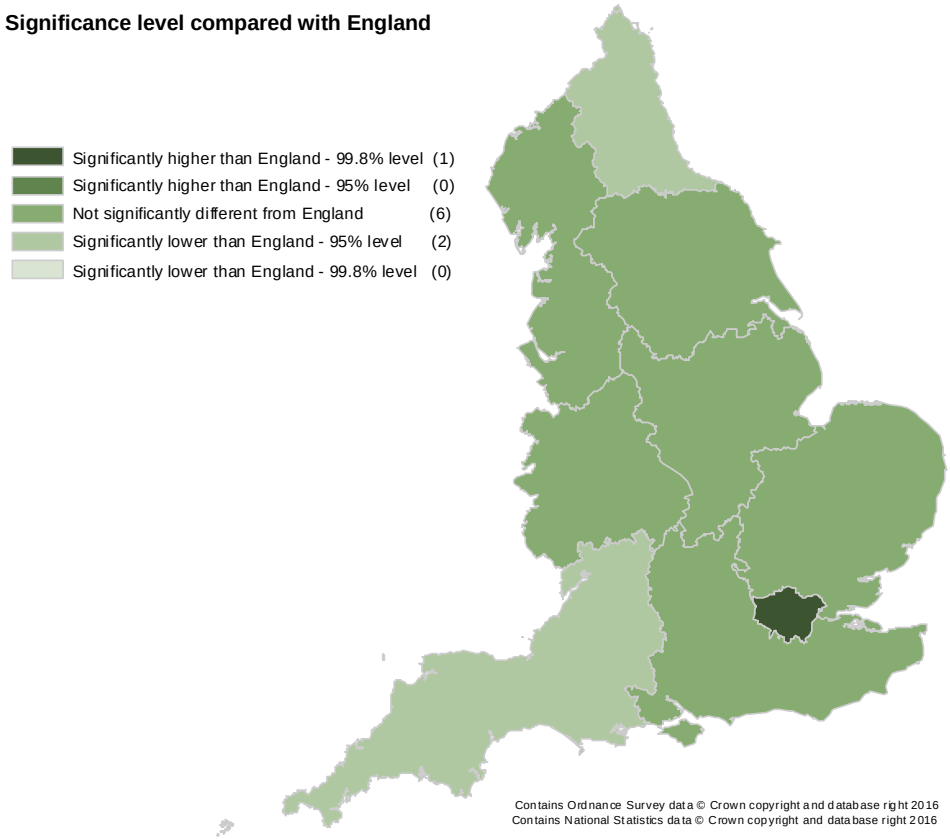
Map 14: Variation in rate of laboratory reports for acute or probable acute hepatitis B per population by region (2015)

Crude rate per 100,000

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long term conditions
PHOF Domain 3: Health protection

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION





Variation in rate of laboratory reports for acute or probable acute hepatitis B per population by region (2015)

Max-Min (Range)		1.13	1.06	1.28	1.52	1.56	0.87	1.11	1.19	No significant change
95th-5th percentile		1.09	0.98	0.92	1.07	1.25	0.65	0.81	0.95	No significant change
75th-25th percentile		0.45	0.43	0.23	0.18	0.21	0.19	0.11	0.21	NARROWING Significant
Median		1.00	1.03	0.84	0.99	0.84	0.67	0.82	0.69	DECREASING Significant

Context

Hepatitis B is a bloodborne infection of the liver caused by the hepatitis B virus, which can provoke an acute illness characterised by nausea, malaise, abdominal pain and jaundice.[1] It can also lead to a chronic persistent infection associated with an increased risk of chronic liver disease and hepatocellular carcinoma.[1]

Acute hepatitis B is a notifiable disease. Public Health England (PHE; formerly the Health Protection Agency) introduced national surveillance standards for hepatitis B in 2007 and published the first annual report in 2008. Statutory laboratory reporting was introduced in 2010. Surveillance of hepatitis B enables the targeting of preventive and control measures such as the implementation of a selective immunisation programme.

The incidence of acute hepatitis B is low in England (0.83 per 100,000 population in 2015),[1] and there has been a gradual decline in incidence since 2008. Incidence is higher in men than in women: 1.17 versus 0.49 per 100,000 population.[1] In 2015 men aged 45-54 years had the highest incidence at 2.0 per 100,000 population.[1]

In 2015 only 22.3% of the total cases of acute hepatitis B had ethnicity recorded: 66.0% of cases were White, 20.6% Black or Black British and 11.8% Asian or Asian British.[1]

For 56% of acute cases associated exposure information was recorded: for more than half the cases (56.6%), the probable route of exposure was heterosexual exposure.[1] Other routes of exposure included sex between men

[1] Public Health England. Acute Hepatitis B (England): annual report for 2015. Health Protection Report weekly report. Infection reports/Immunisation. Volume 10, Number 28, Published on: 26 August 2016. www.gov.uk/government/uploads/system/uploads/attachment_data/file/549028/hpr2816_hepB.pdf

(15.6%), healthcare-related exposure (8.2%), unspecified risk relating to travel abroad (8.2%), skin-piercing, tattooing and acupuncture (4.7%), and injecting drug use (3.5%).[1]

Magnitude of Variation

The maps and column chart display the data for 2015, during which region values ranged from 0.3 to 1.5 per 100,000 population, which is a 4.5-fold difference between regions. The England value for 2015 was 0.8 per 100,000 population.

The boxplot shows the distribution of region values for the period 2008 to 2015.
The 75th to 25th percentile gap narrowed significantly. The median decreased significantly from 1.0 per 100,000 population in 2008 to 0.7 per 100,000 population in 2015.

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

- the demography of local populations including patterns of ethnicity and migration
- the historical and changing patterns of risk and risk behaviours in local populations
- prevalence of newly diagnosed cases of hepatitis B
- incidence of new cases of hepatitis B
- coverage of laboratory reporting
- the level of investment in laboratory services
- the organisation of local services
- access to services for testing and counselling
- the effectiveness of local preventive and control measures

Options for action

Commissioners, local authorities, particularly Directors of Public Health, health and wellbeing boards, clinicians and providers of primary care, secondary care and public health services need to work in partnership:

- to review the completeness of laboratory reporting of hepatitis B in the locality
- to identify trends in incidence of acute hepatitis B in the local population and population subgroups over the last 5 to 10 years and review the profile of people at risk of infection locally
- to use these local data to improve the identification and treatment of people with hepatitis B and the implementation of targeted preventive and control measures

In accordance with NICE guidance (PH43; see ‘Resources’) commissioners should commission locally appropriate integrated services for hepatitis B testing and treatment, with testing seen as part of a care pathway covering diagnosis, treatment and immunisation.

In accordance with NICE guidance (PH43; see ‘Resources’) laboratory services providing hepatitis B testing should:

- have Clinical Pathology Accreditation (UKAS; see ‘Resources’)
- be able to support the range of samples used for hepatitis B testing (or refer the sample to a laboratory that can perform the test)
- deliver results within 2 weeks of receipt of the sample together with an accurate interpretation of the laboratory results and guidance on the future management of confirmed cases
- provide accurate data according to the items listed in Box 14.1

Box 14.1 Hepatitis B testing data required from laboratory services

- Number of people tested and the type of test performed
- Referral source of samples
- Exposure category (if provided)
- Number of people testing positive, which should include acute, chronic and past exposure

Standards for local surveillance and follow-up of hepatitis B (see ‘Resources’) need to be followed, including laboratory reporting to PHE centres in line with national public health legislation.

Commissioners need to specify that primary care, secondary care and public health service providers follow NICE guidance (PH43; see 'Resources') including, as relevant:

- raising awareness about hepatitis B in the local population and among people at increased risk of infection
- organising education and training for healthcare professionals who provide services for people at increased risk of infection (for example, see 'Resources' for RCGP Learning)
- tracing close contacts of people with hepatitis B infection
- providing neonatal hepatitis B infection vaccination services (see Map 13) to prevent vertical transmission

To facilitate early diagnosis, prompt treatment and the prevention of infection with hepatitis B, commissioners need to specify that service providers adhere to the NICE quality standard (QS65, particularly quality statement 1; see 'Resources') which states that children, young people and adults at increased risk of hepatitis B should be offered testing in a range of settings, such as GP practices, prisons or immigration removal centres, drugs services, and sexual health and genitourinary medicine clinics, alongside appropriate vaccination.

Testing and vaccination strategies need to be in line with PHE's guidance on immunisation against infectious disease (the green book, chapter 18; see 'Resources').

RESOURCES

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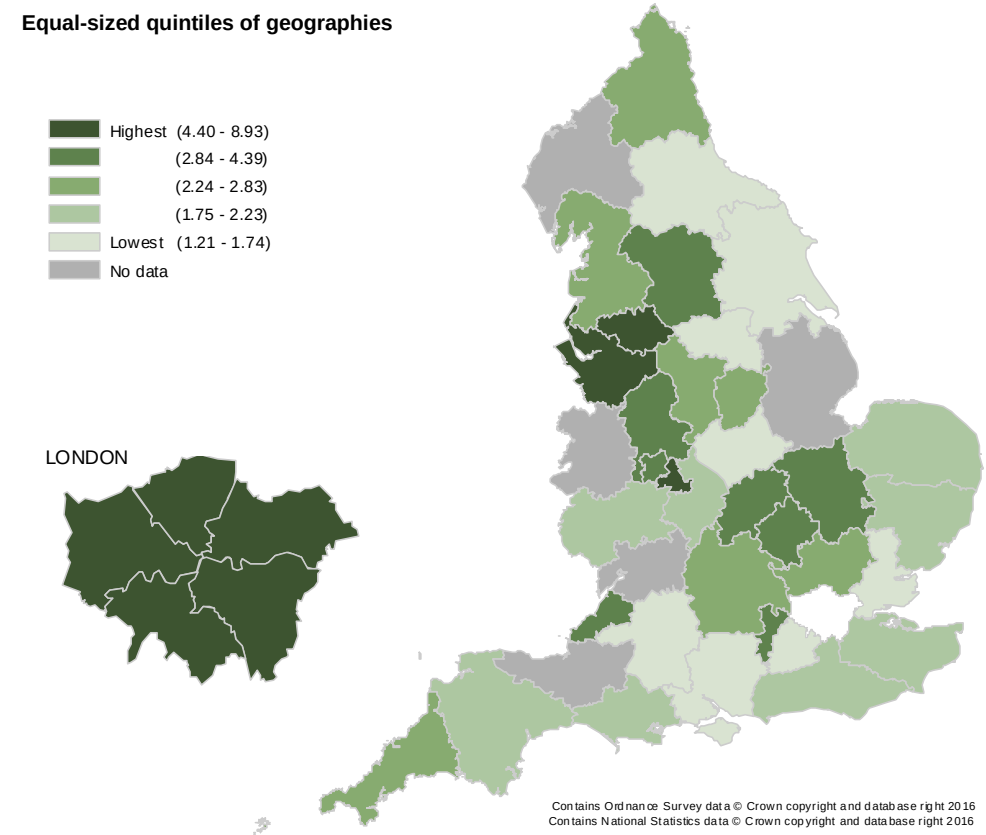
HEPATITIS B

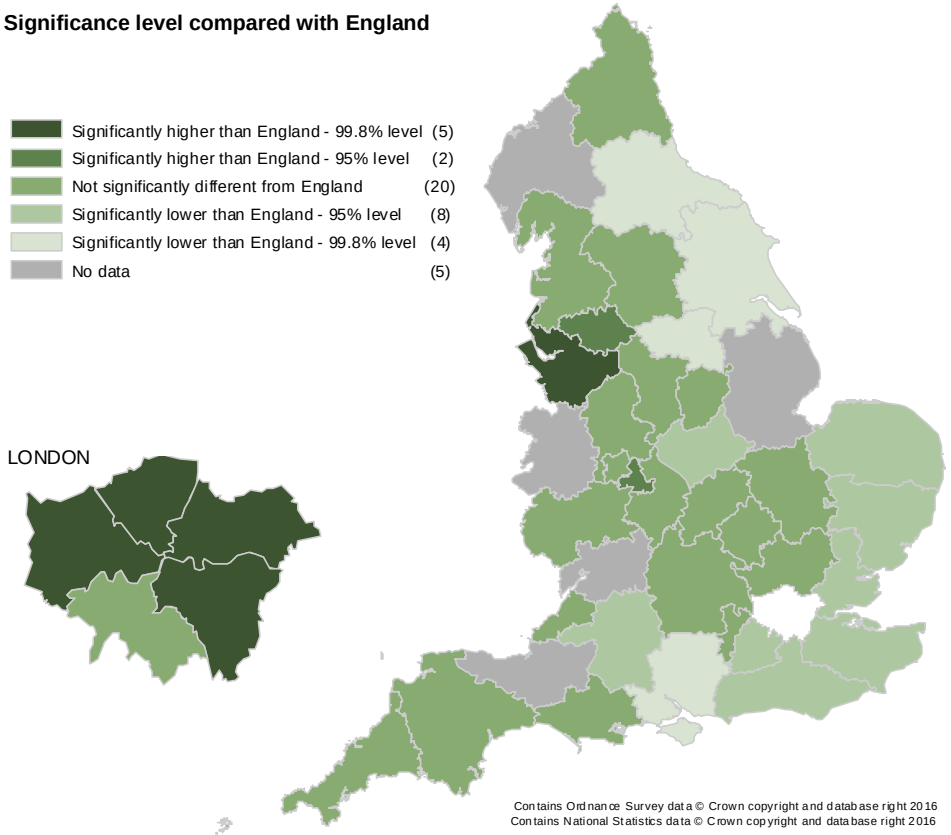
Map 15a: Variation in rate of hospital admissions for hepatitis B-related end-stage liver disease or hepatocellular carcinoma per population by Sustainability Transformation Partnerships (STP) (2012/13 - 2014/15)

Crude rate per 1,000,000

NHS Domain 4: Ensuring that people have a positive experience of care
NHS Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW





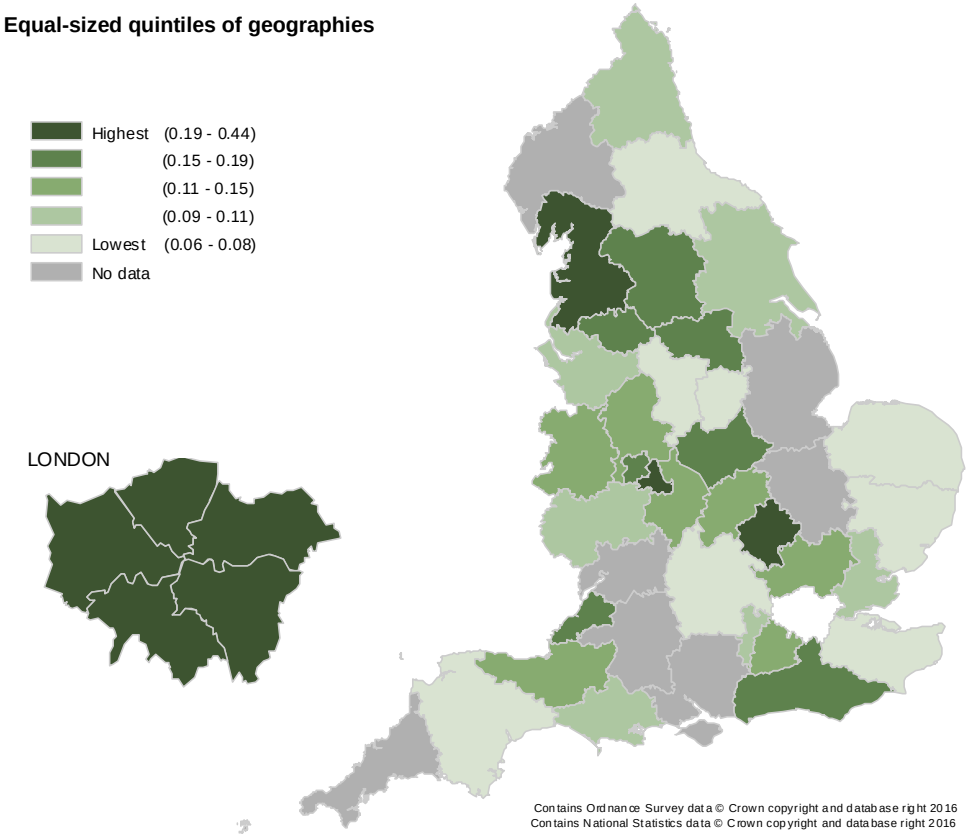
HEPATITIS B

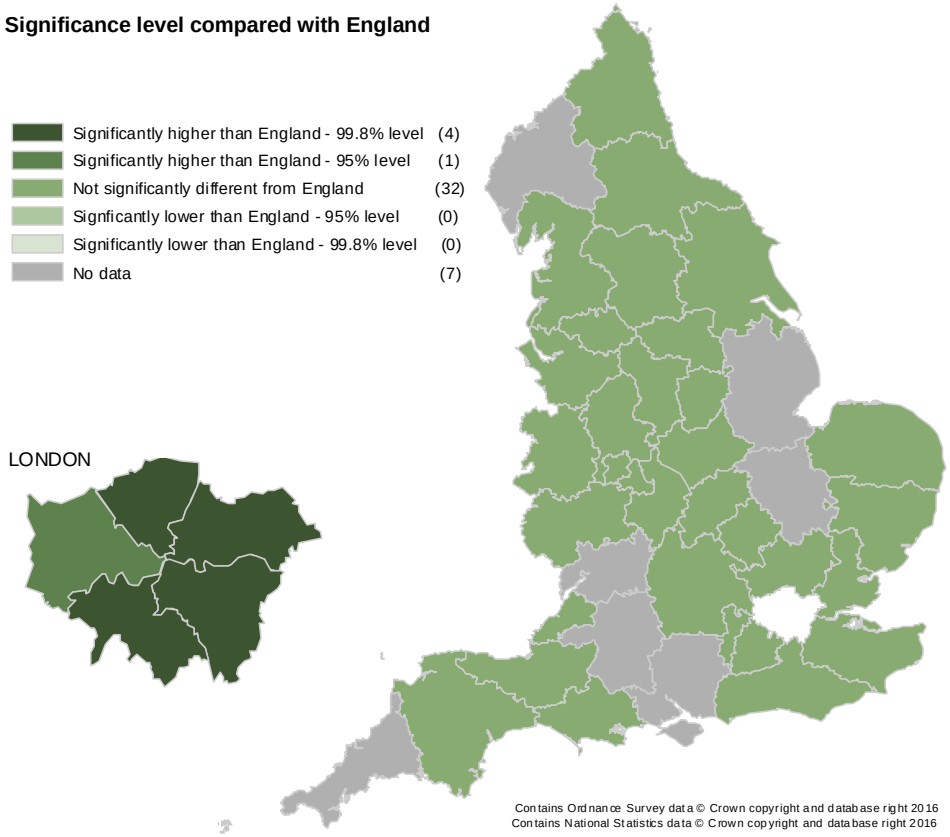
Map 15b: Variation in mortality rate from hepatitis B-related end-stage liver disease or hepatocellular carcinoma per population by Sustainability Transformation Partnerships (STP) (2011-2015)

Crude rate per 100,000

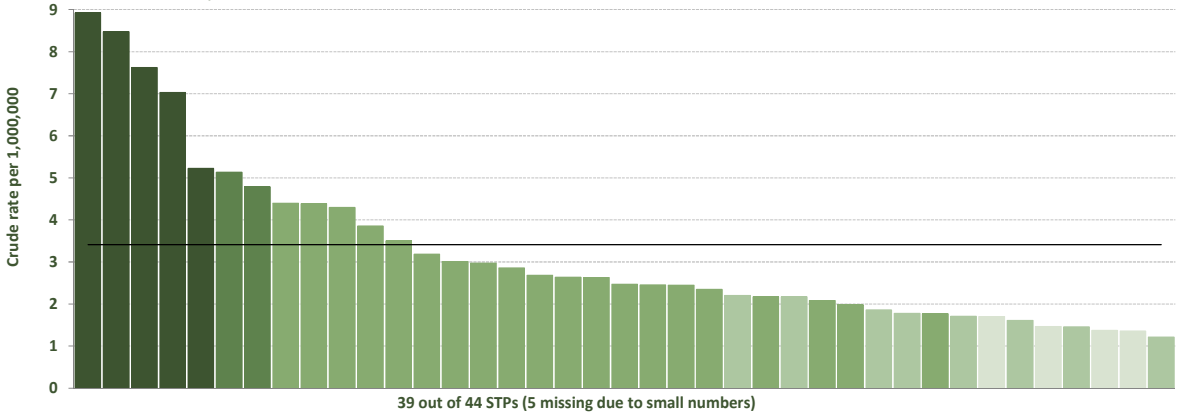
NHS Domain 1: Preventing people from dying prematurely
PHOF Domain 4: Healthcare public health and preventing premature mortality

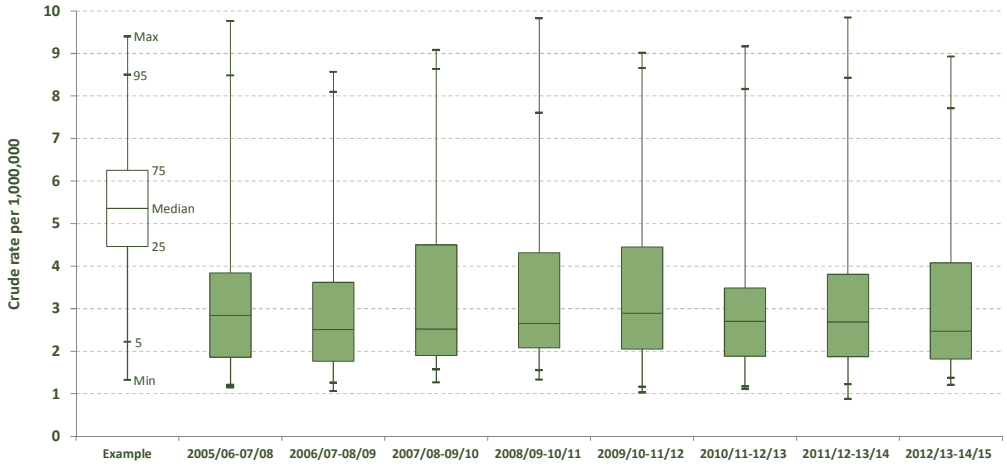
OPTIMUM VALUE: LOW





Variation in rate of hospital admissions for hepatitis B -related end-stage liver disease or hepatocellular carcinoma per populat ion by Sustainability Transformation Partnerships (STP) (2012/13 - 2014/15)





Max-Min (Range)		8.61	7.50	7.81	8.50	7.98	8.05	8.97	7.71	No significant change
95th-5th percentile		7.28	6.83	7.06	6.05	7.49	6.99	7.20	6.34	No significant change
75th-25th percentile		1.98	1.85	2.60	2.23	2.40	1.60	1.93	2.26	No significant change
Median		2.84	2.51	2.52	2.65	2.89	2.71	2.69	2.47	No significant change

Context

Chronic infection with hepatitis B is a risk factor for increased hospital admissions and mortality from chronic liver disease and hepatocellular carcinoma. Exposure to the hepatitis B virus can cause an acute infection, which is symptomatic in up to one-third of adults whereas symptoms are rare in children.[1] Although the illness is self-limiting, if the virus persists in the blood for longer than 6 months, the person will have developed a chronic (or persistent) hepatitis B infection.[1]

Rates of progression from acute to chronic hepatitis B vary according to age at time of exposure. Chronic hepatitis B infection is more likely to develop if the infection is acquired in childhood: 85% of hepatitis B infections in newborns become chronic,[2] whereas up to 10% of adults will develop chronic hepatitis B infection if the infection is acquired in adulthood.[1]

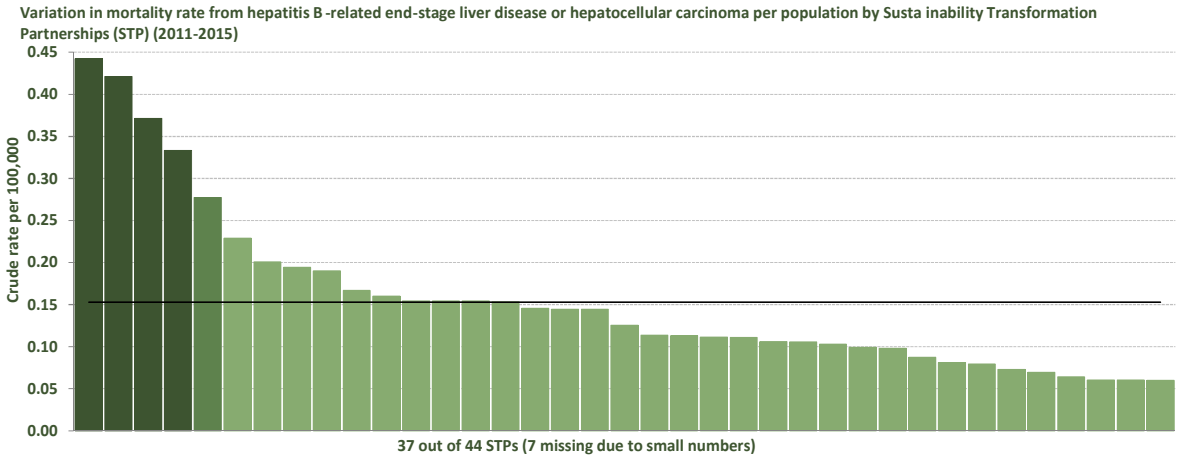
In some people chronic hepatitis B is inactive[1] but some people will develop a chronic active hepatitis which involves progressive damage to the liver leading to:

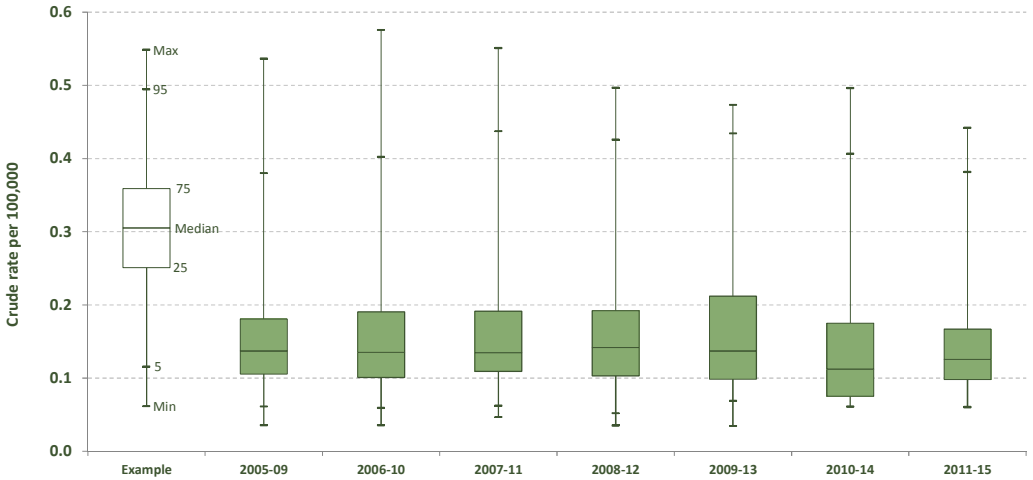
- fibrosis
- cirrhosis, which develops in about 15-20% of people who became infected as healthy adults – it may take up to 20 years after initial infection for the condition to become manifest[3]
- hepatocellular carcinoma, which develops in about 10% of people whose condition has progressed to cirrhosis and is detected on average 30 years after the initial infection[3]

[1] Public Health England. Hepatitis B: clinical and public health management. www.gov.uk/guidance/hepatitis-b-clinical-and-public-health-management

[2] NICE. Hepatitis B and C testing: people at risk of infection. Public health guideline [PH43]. Published date: December 2012. Last updated: March 2013. www.nice.org.uk/guidance/ph43

[3] NICE Clinical Knowledge Summaries. Hepatitis B. Last revised in March 2014. https://cks.nice.org.uk/hepatitis-b





Max-Min (Range)		0.50	0.54	0.50	0.46	0.44	0.44	0.38	NARROWING Significant
95th-5th percentile		0.32	0.34	0.38	0.37	0.37	0.35	0.32	No significant change
75th-25th percentile		0.08	0.09	0.08	0.09	0.11	0.10	0.07	No significant change
Median		0.14	0.13	0.13	0.14	0.14	0.11	0.13	No significant change

The goal of treatment for chronic hepatitis B is to prevent cirrhosis, hepatocellular carcinoma and liver failure. Without antiviral treatment the 5-year cumulative incidence of cirrhosis is 8-20% and people with cirrhosis are at significant risk of decompensated liver disease if they remain untreated.[4] Five-year survival rates for people with untreated decompensated cirrhosis can be as low as 15%.[4]

Antiviral treatment suppresses replication of the hepatitis B virus, decreases hepatic inflammation and fibrosis, and reduces the likelihood of disease progression and serious clinical outcomes.[4] There are many efficacious and safe treatment options for hepatitis B. Clinicians need to decide which individuals need immediate treatment, with which sequence and combination of drugs, and which individuals have low levels of hepatitis B virus in the blood with little sign of liver damage such that they can be monitored and given treatment only if there are signs of disease progression.[4]

As the mutation rate of hepatitis B virus DNA is high, there is a risk of drug resistance or decreased susceptibility to the drugs developing which should be taken into account when considering treatment with nucleoside or nucleotide analogues.[4]

Admission to hospital for a person with hepatitis B infection usually occurs if the person is severely unwell,[3] and admission for hepatitis B-related end-stage liver disease and hepatocellular carcinoma is an outcome indicator of how successful the identification and care of people with hepatitis B have been.

[4] NICE. Hepatitis B (chronic) diagnosis and management. Clinical guideline [CG165]. Published date: June 2013. www.nice.org.uk/guidance/cg165

The rate of mortality for hepatitis B-related end-stage liver disease and hepatocellular carcinoma is a stronger outcome indicator of how successful the identification and care of people with hepatitis B have been.

Magnitude of variation

Map 15a: Hospital admissions for hepatitis B-related end-stage liver disease or hepatocellular carcinoma

The maps and column chart display the data for 2012/13-2014/15, during which STP values ranged from 1.2 to 8.9 per million population, which is a 7.4-fold difference between STPs. The England value for 2012/13-2014/15 was 3.4 per million population.

The boxplot shows the distribution of STP values for the period 2005/06-2007/08 to 2012/13-2014/15.There was no significant change in any of the three variation measures between 2005/06-2007/08 and 2012/13-2014/15.

Map 15b: Mortality from hepatitis B-related end-stage liver disease or hepatocellular carcinoma

The maps and column chart display the data for 2011-15, during which STP values ranged from 0.1 to 0.4 per 100,000 population, which is a 7.4-fold difference between STPs. The England value for 2011-15 was 0.2 per 100,000 population.

The boxplot shows the distribution of STP values for the period 2005-09 to 2011-15. The maximum to minimum range narrowed significantly.

Possible reasons for the degree of variation observed in admissions or mortality include differences in:

- the prevalence of hepatitis B in local populations influenced by patterns of ethnicity and migration
- the historical and changing patterns of risks and risk behaviours in local populations
- opportunities for testing and engagement with hepatitis B treatment services
- access to drug treatment services where relevant
- the prevalence of comorbidities, such as the level of alcohol use
- the timeliness and timing of referral
- access to treatment services
- the timing of diagnosis
- the degree of compliance with treatment
- the configuration of treatment services
- management of treatment failure and drug resistance

Options for action

To reduce admissions and mortality from hepatitis B-related end-stage liver disease and hepatocellular carcinoma, commissioners, clinicians and service providers need to review:

- local interventions to prevent infection, detect infection and prevent the development of advanced liver disease

To increase the number and proportion of people with hepatitis B being diagnosed and treated, commissioners need to specify that service providers:

- raise awareness of hepatitis B among professionals in primary and secondary care and other settings, for example, through encouraging participation in e-learning (see ‘Resources’)

For people with hepatitis B to receive the best possible care, it is essential that the aim of testing and treatment services is to prevent progression to end-stage liver disease and hepatocellular carcinoma. It is important for commissioners, clinicians and service providers to make available specialised services for:

- local hepatitis B populations, to identify people at risk and offer testing with a view to treatment
- people with end-stage liver disease and hepatocellular carcinoma, to ensure there is access to expert care to optimise outcomes

Commissioners need to work with clinicians and service providers to ensure that:

- the local operational delivery network for hepatitis B treatment is effective, including improving people's access to accredited laboratory and other services
- people with hepatitis B receive appropriate and timely intervention with effective therapy, which should reduce progression to end-stage liver disease and hepatocellular carcinoma (secondary prevention) – treating end-stage liver disease and hepatocellular carcinoma will help to reduce mortality (supportive care and transplant)

To provide appropriate and timely intervention with effective therapy, local protocols need to be developed between primary and secondary care to ensure that:

- care and treatment pathways for medical and social care are in place
- NHS staff receive appropriate skills development to enable them to deliver service improvements for people with hepatitis B infection
- follow NICE guidance on testing people at risk of hepatitis B infection and ensure that all high-risk groups are immunised against hepatitis B (PH43; see 'Resources')
- promote and offer testing to groups of people not in regular contact with health services who may have acquired hepatitis B many years previously, for example, through medical or dental treatment in countries where poor blood screening and/or infection control practices exist, transfusion in the UK prior to September 1991 or past injecting drug use – some people who have acquired hepatitis B previously may have advanced asymptomatic disease
- follow NICE guidance on the diagnosis and management of chronic hepatitis B (CG165; see 'Resources') and ensure that testing, diagnostic and treatment services adhere to the NICE quality standard for hepatitis B (QS65; see 'Resources') especially to help reduce mortality

Commissioners should review:

- trends in mortality in the local area
- treatment outcomes against the number of people testing positive for hepatitis B in the local area (intention-to-treat outcomes of people testing positive) to identify not only the barriers to a successful treatment outcome but also the ways in which those barriers can be addressed
- the depth of collaboration between specialist services and other agencies to ascertain whether the best possible outcomes for people with hepatitis B are being obtained

Commissioners could consider specifying that laboratory service providers include patient referral instructions on the laboratory report.

To increase the number of people with hepatitis B accessing treatment, commissioners need to work with public health agencies, clinicians and other stakeholders:

- to simplify referral pathways
- to improve the availability, access and uptake of approved hepatitis B treatments in primary and secondary care and other settings not only for people newly diagnosed or already engaged with treatment services but also for people who have been diagnosed but subsequently lost to follow-up

To prevent vertical transmission of hepatitis B, commissioners need to specify that service providers follow NICE guidance (CG165, see 'Resources') and Public health functions agreement (Section 7A) service specification No. 1 (see 'Resources') regarding the care of pregnant and breastfeeding women with hepatitis B and the immunisation of new-born babies at risk from the mother's hepatitis B infection.

RESOURCES

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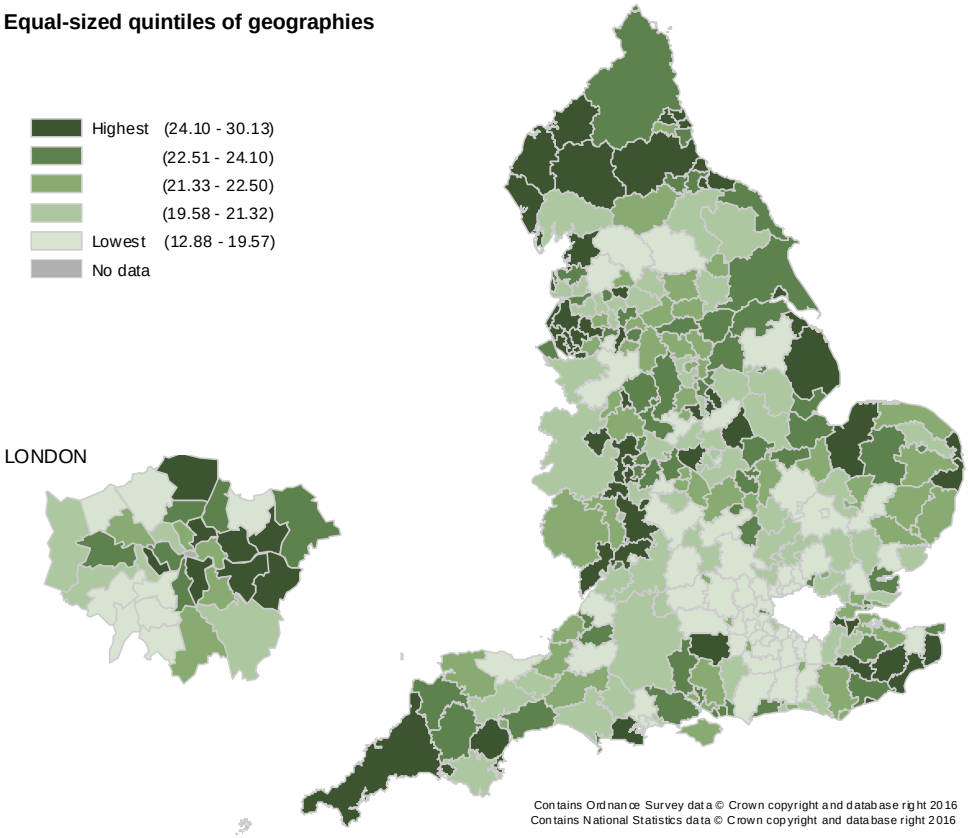
- NICE interactive flowchart. Hepatitis B and C testing overview. https://pathways.nice.org.uk/pathways/hepatitis-b-and-c-testing
- Public Health England, NHS England. NHS public health functions agreement 2017-18. Service specification No. 1 Neonatal hepatitis B immunisation programme. Version number: 1.0. First published: April 2017. www.england.nhs.uk/wp-content/uploads/2017/04/service-spec-01.pdf
- Health Protection Agency. Standards for local surveillance and follow-up of hepatitis B and C. 2011. www.gov.uk/government/uploads/system/uploads/attachment_data/file/324052/Standards_surveillance_follow_up_hep_B_and_C__final_.pdf
- Public Health England. Immunisation against infectious disease: the green book. Chapter 18: Hepatitis B. February 2016. www.gov.uk/government/publications/hepatitis-b-the-green-book-chapter-18
- United Kingdom Accreditation Service (UKAS). Clinical Pathology Accreditation. www.ukas.com/services/accreditation-services/clinical-pathology-accreditation/
- RCGP Learning. RCGP Clinical Courses and Certifications. ‘Hepatitis B & C’. http://elearning.rcgp.org.uk/course/index.php?categoryid=8

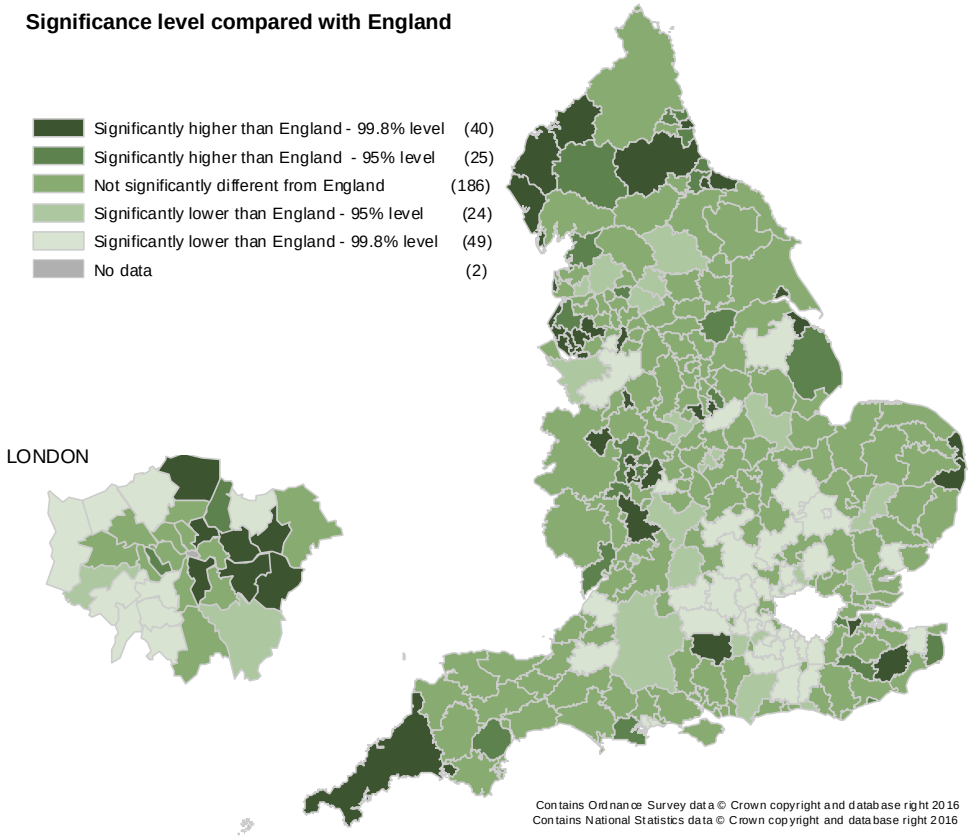
OBESITY

Map 16a: Variation in percentage of children in school reception year classified as overweight or obese by lower-tier local authority (school year 2015/16)

NHS Domain 1: Preventing people from dying prematurely
PHOF Domain 2: Health Improvement

OPTIMUM VALUE: LOW





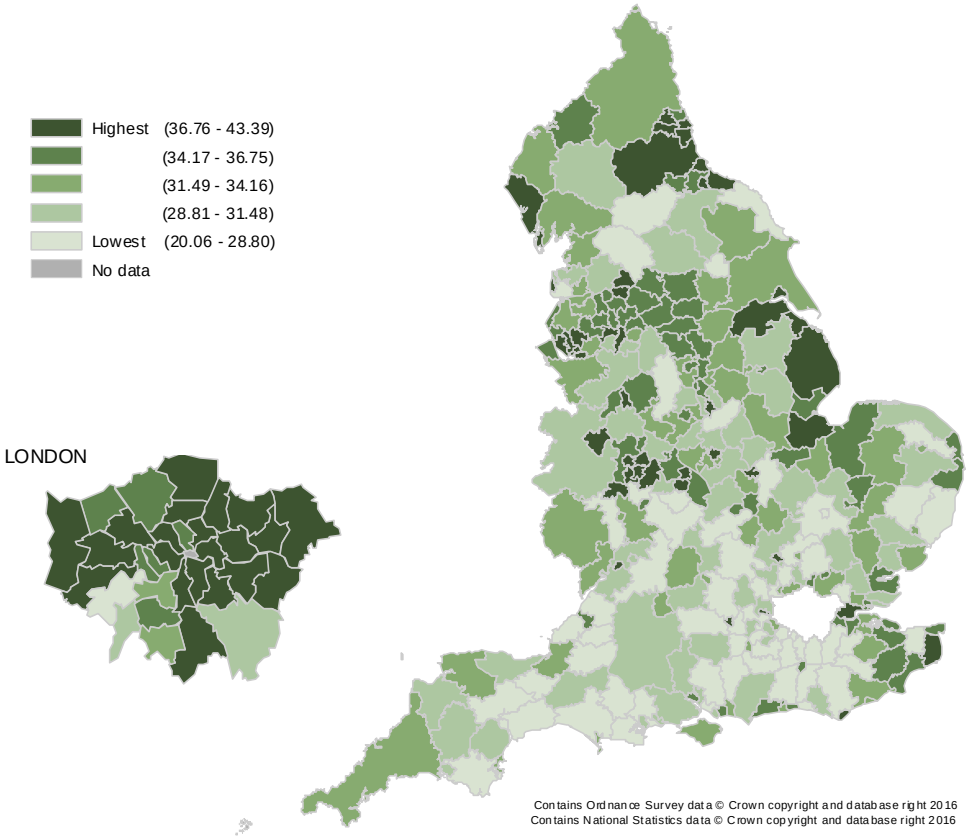
OBESITY

Map 16b: Variation in percentage of children in school year 6 classified as overweight or obese by lower-tier local authority (school year 2015/16)

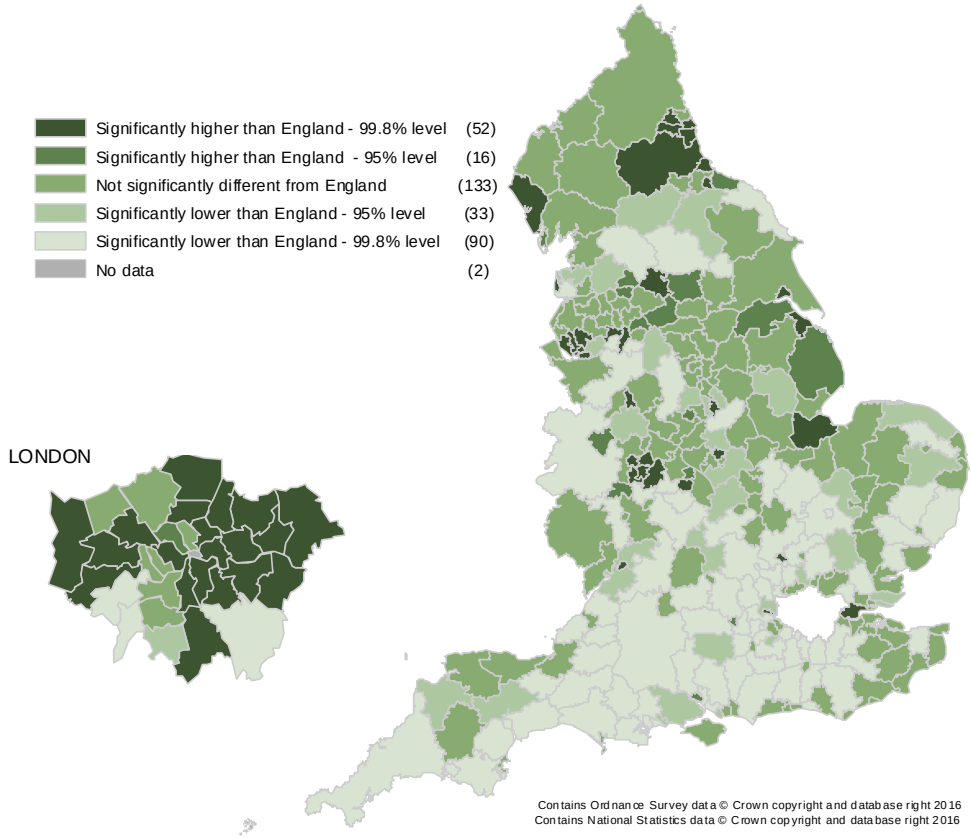
NHS Domain 1: Preventing people from dying prematurely
PHOF Domain 2: Health Improvement

OPTIMUM VALUE: LOW

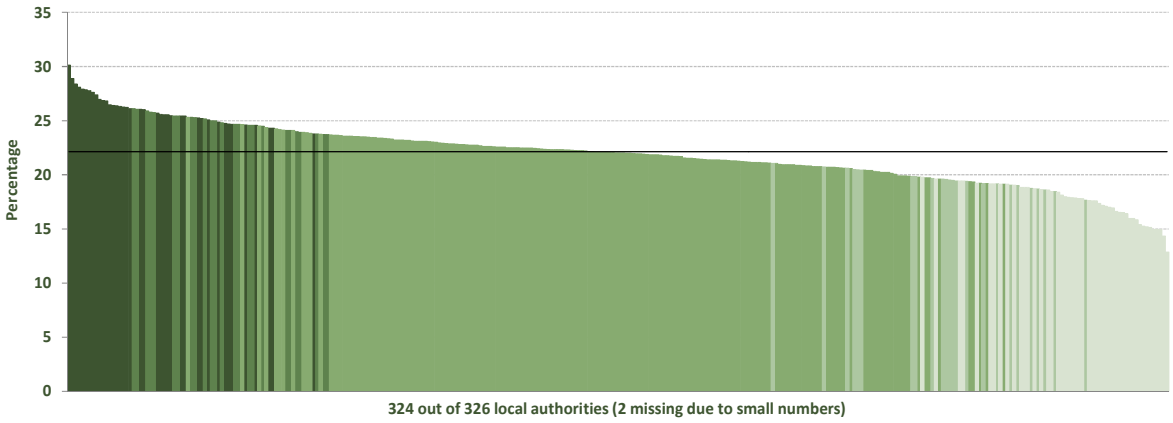
Equal-sized quintiles of geographies



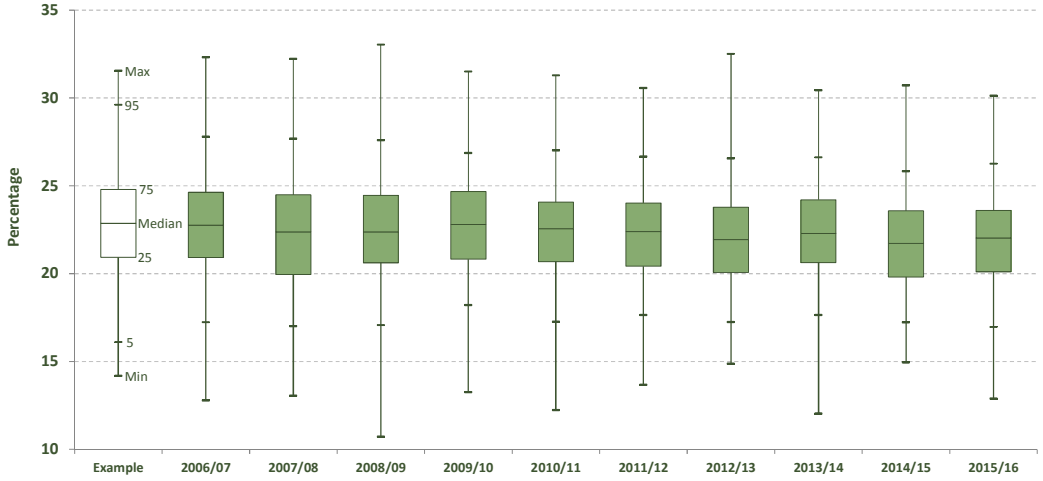
Significance level compared with England



Variation in percentage of children in school reception year classified as overweight or obese by lower -tier local authority (school year 2015/16)



324 out of 326 local authorities (2 missing due to small numbers)



	Example	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	
Max-Min (Range)		19.5	19.2	22.3	18.2	19.1	16.9	17.6	18.4	15.8	17.3	NARROWING Significant
95th-5th percentile		10.6	10.7	10.5	8.7	9.8	9.0	9.3	9.0	8.6	9.3	NARROWING Significant
75th-25th percentile		3.7	4.5	3.8	3.9	3.4	3.6	3.7	3.6	3.8	3.5	No significant change
Median		22.8	22.4	22.4	22.8	22.6	22.4	21.9	22.3	21.7	22.0	DECREASING Significant

Context

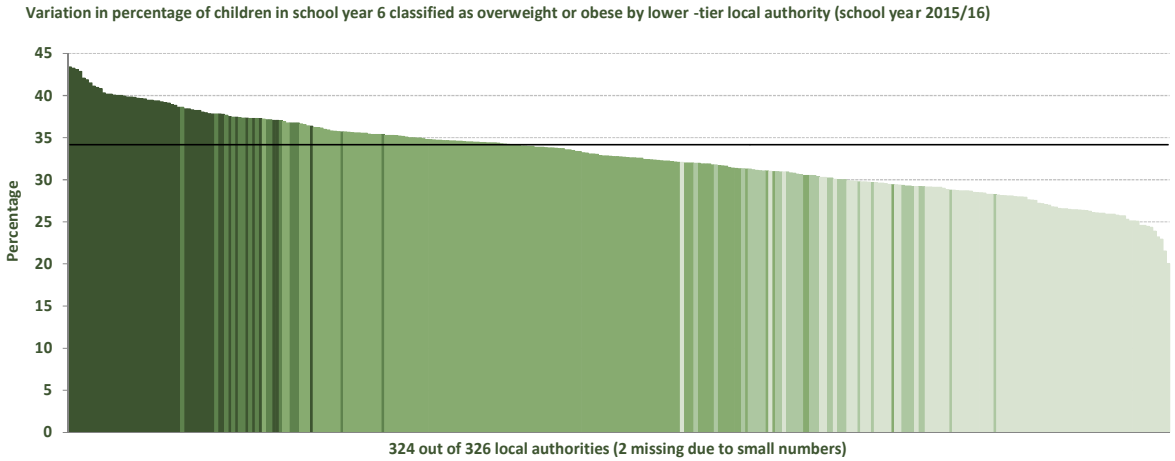
Non-alcoholic fatty liver disease (NAFLD) is the term for a for a range of conditions caused by a build-up of fat in the liver and can lead onto much more severe liver disorders in later life.

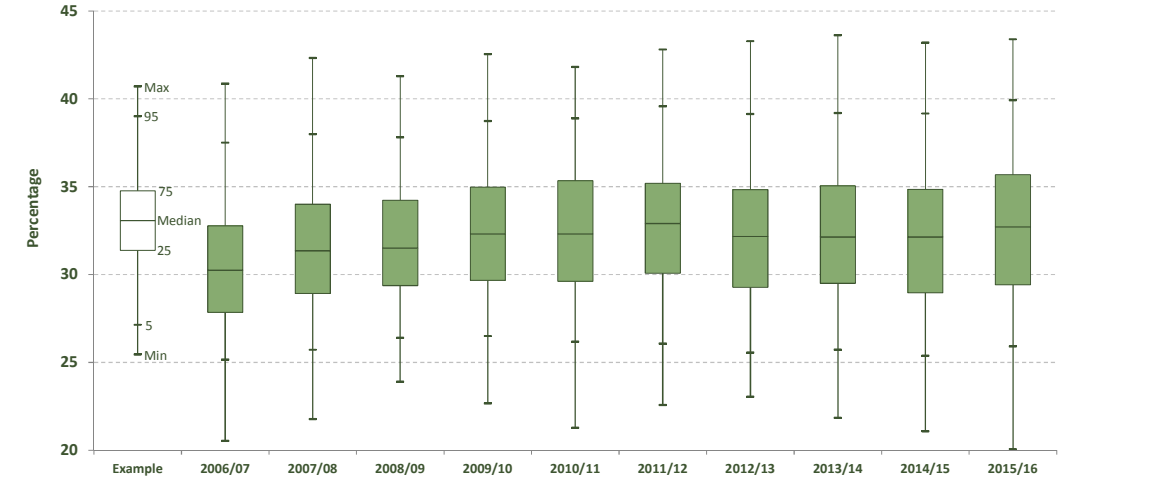
Childhood obesity is a major public health concern around the world and recent statistics from the World Health Organization[1] suggest that 41 million children aged under 5 are overweight or obese. Obesity in childhood is a known risk factor for being overweight or obese in adulthood.

Recent guidelines from NICE state that the emergence of childhood obesity means that there are increasing numbers younger people who have NAFLD, with some prevalence studies suggesting that up to 38% of obese children have evidence of NAFLD.[2] The Lancet Commission has also reported that NAFLD is the most prevalent liver condition in children and young people in high income countries[3]. Although, this condition does not appear to have functional effects, studies in adults suggest that 2-3% may progress to steatohepatitis, a serious condition which is potentially life limiting.

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 largest source of recorded data on childhood obesity data in England (see Table 16.1).

[1] World Health Organization. Report of the commission on ending childhood obesity. World Health Organization, 2016.
[2] NICE Guideline (NG49), July 2016. Non-alcoholic fatty liver disease (NAFLD): assessment and management
[3] Williams et al. (2014) Addressing liver disease in the UK: a blueprint for attaining excellence in health care and reducing premature mortality from lifestyle issues of excess consumption of alcohol, obesity, and viral hepatitis. Lancet; 384: 1953–97





Max-Min (Range)		20.3	20.6	17.4	19.9	20.5	20.2	20.2	21.8	22.1	23.3	WIDENING Significant
95th-5th percentile		12.4	12.3	11.4	12.2	12.7	13.5	13.6	13.5	13.8	14.0	WIDENING Significant
75th-25th percentile		4.9	5.1	4.9	5.3	5.7	5.1	5.6	5.6	5.9	6.3	WIDENING Significant
Median		30.2	31.4	31.5	32.3	32.3	32.9	32.2	32.1	32.1	32.7	INCREASING Significant

In the school year 2015/16:

- in reception, more than one in five children were overweight or obese; in year 6 this figure increased to one in three children
- 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

Table 16.1: Proportion of children according to weight categories[4] (school year 2015/16)[5]

Weight category	Reception year	Year 6
Overweight and obese – all children	22.1%	34.2%
Obese	9.3%	19.8%
-Boys	9.6%	21.7%
-Girls	9.0%	17.9%
Healthy weight – all children	76.9%	64.5%
-Boys	76.1%	62.9%
-Girls	77.8%	66.2%
Underweight – all children	1.0%	1.3%
-Boys	1.2%	1.2%
-Girls	0.7%	1.5%

[4] 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

[5] NHS Digital. National Child Measurement Programme England, 2015/16 school year. 3 November 2016. http://content.digital.nhs.uk/article/2021/Website-Search?productid=23381&q=NCMP+England+2015-2016&sort=Relevance&size=10&page=1&area=both#top

Magnitude of variation

Map 16a: Children in school reception year classified as overweight or obese

The maps and column chart display the data for school year 2015/16, during which local authority values ranged from 12.9% to 30.1 %, which is a 2.3-fold difference between local authorities. The England value for 2015/16 was 22.1%.

The boxplot shows the distribution of local authority values for the period school years 2006/07 to 2015/16. Both the maximum to minimum range and the 95th to 5th percentile gap narrowed significantly. The median decreased significantly from 22.8% in 2006/07 to 22.0% in 2015/16.

Map 16b: Children in school year 6 classified as overweight or obese

The maps and column chart display the data for school year 2015/16, during which local authority values ranged from 20.1% to 43.4 %, which is a 2.2-fold difference between local authorities. The England value for school year 2015/16 was 34.2 %.

The boxplot shows the distribution of local authority values for the school years 2006/07 to 2015/16. There has been significant widening of all three measures of variation. The median increased significantly from 30.2% in 2006/07 to 32.7% in 2015/16.

The degree of variation observed is closely related to differences in the level of deprivation, which is associated with certain aspects of a child's diet and level of physical activity. It is important to note that the prevalence of childhood obesity is high in all local authorities, with excessive levels across the country; obesity is a major problem even in the local authorities which have the lowest prevalence.

For both school years measured in the NCMP, there is a trend of widening inequalities. Potential reasons for differences seen in the degree of variation between areas are complex but are likely to be influenced by factors that affect diet such as lack of food choices relating to the density of fast food outlets in the local area. Other potential reasons may include:

- lower levels of physical activity due to demographic, social, individual and environmental factors
- lack of access to lifestyle management services such as exercise referral or weight management schemes

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 and sustainability and transformation plan footprints:

- to review local prevalence and trends for obesity
- to refine and develop local strategies for reducing obesity in children, supported by guidance from NICE (see 'Resources') and other organisations. This needs to be conducted as part of a whole-system response in conjunction with national, regional and health service responses

RESOURCES

- NICE. Obesity in children and young people: prevention and lifestyle weight management programmes. Quality standard [QS94]. July 2015. www.nice.org.uk/guidance/qs94
- NICE interactive flowcharts. Lifestyle weight management services for overweight or obese children and young people overview. https://pathways.nice.org.uk/pathways/lifestyle-weight-management-services-for-overweight-or-obese-children-and-young-people
- NICE interactive flowcharts. Obesity prevention: pre-school and school-based interventions. https://pathways.nice.org.uk/pathways/obesity#path=view%3A/pathways/obesity/obesity-prevention-pre-school-and-school-based-interventions.xml&content=view-index
- NICE interactive flowcharts. Managing children and young people who are overweight or obese. https://pathways.nice.org.uk/pathways/obesity#path=view%3A/pathways/obesity/managing-children-and-young-people-who-are-overweight-or-obese.xml&content=view-index

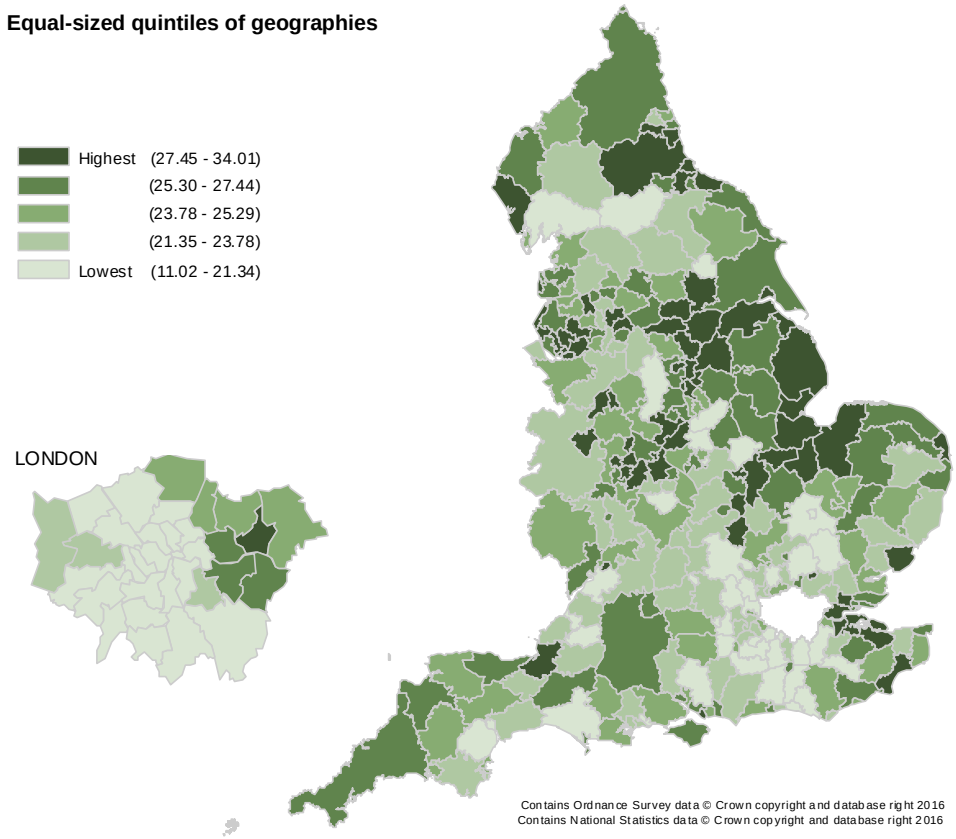
- NICE interactive flowcharts. Obesity overview. https://pathways.nice.org.uk/pathways/obesity
- Health Survey for England 2015. Physical activity in children. Published 14th December 2016. www.content.digital.nhs.uk/catalogue/PUB22610/HSE2015-Child-phy-act.pdf
- Public Health England. National Child Measurement Programme (NCMP) www.noo.org.uk/NCMP
- NHS Digital. National Child Measurement Programme England, 2015/16 school year. 3 November 2016. http://content.digital.nhs.uk/article/2021/Website-Search?productid=23381&q=NCMP+England+2015-2016&sort=Relevance&size=10&page=1&area=both#top
- National Obesity Observatory (2015) National Child Measurement Programme. Changes in children's body mass index between 2006/07 and 2013/14. https://khub.net/c/document_library/get_file?uuid=9b1a42df-741d-4089-bd33-49124839eb7e&groupId=31798783
- Public Health England. Local Health and Care Planning: Menu of preventative interventions. November 2016. www.gov.uk/government/uploads/system/uploads/attachment_data/file/565944/Local_health_and_care_planning_menu_of_preventative_interventions.pdf
- Public Health England, Chartered institute of Environmental Health, London Metropolitan University, Children's Food Trust and Local Government Association. Strategies for Encouraging Healthier 'Out of Home' Food Provision. A toolkit for local councils working with small food businesses. March 2017. www.gov.uk/government/uploads/system/uploads/attachment_data/file/604912/Encouraging_healthier_out_of_home_food_provision_toolkit_for_local_councils.pdf

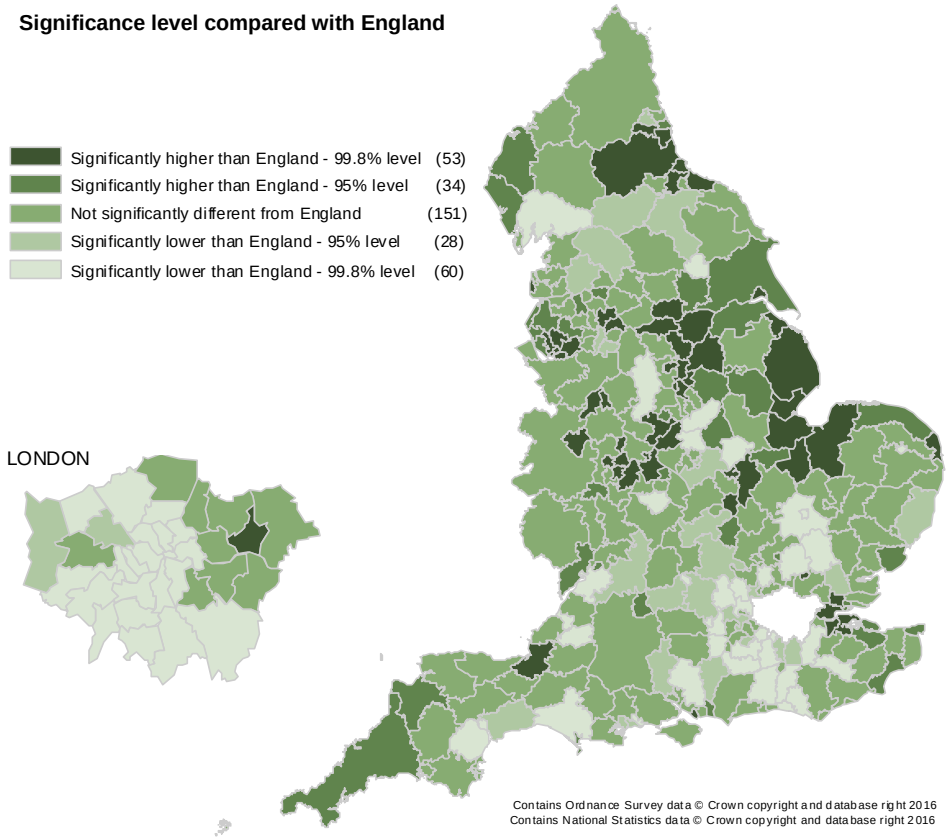
OBESITY

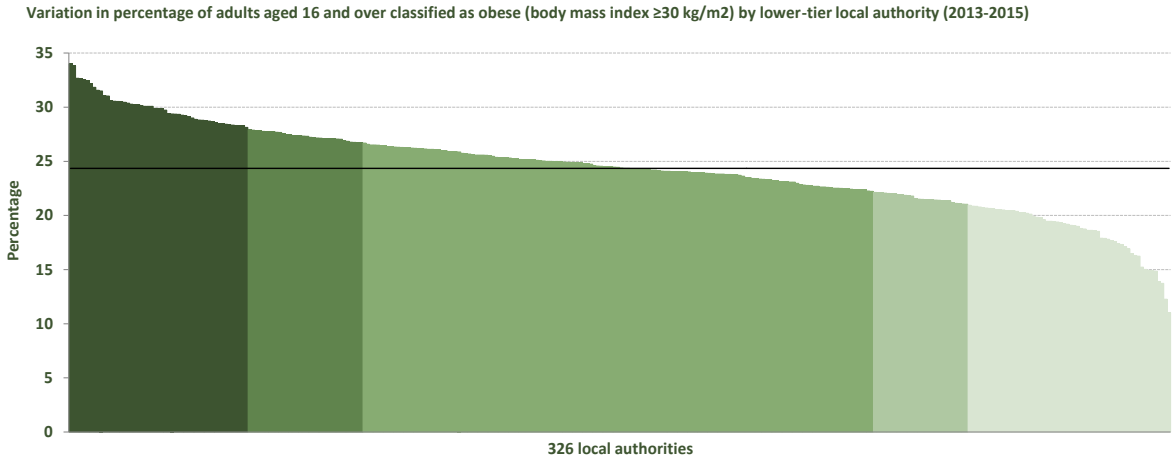
Map 17: Variation in percentage of adults aged 16 and over classified as obese (body mass index ≥30 kg/m^2) by lower-tier local authority (2013-15)

NHS Domain 1: Preventing people from dying prematurely
PHOF Domain 2: Health Improvement

OPTIMUM VALUE: LOW



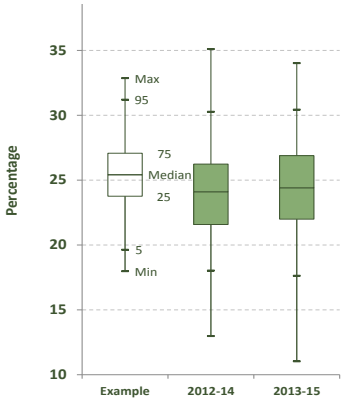




Context

In recent years, it has been recognised that obesity contributes to the increasing burden of liver disease. In England, 27% of the adult population, around 12 million adults, is thought to be obese.[1]

Non-alcoholic fatty liver disease (NAFLD) is the term for a range of conditions caused by a build-up of fat in the liver. An early stage of NAFLD is called fatty liver or steatosis. This is where fat accumulates in the liver cells without any inflammation or scarring. For many people, the condition will not advance and a serious liver condition will not develop, but for some, NAFLD can progress to non-alcohol related steatohepatitis (NASH)[2] which is a much more serious liver condition.



		2012-14	2013-15
Max-Min (Range)		22.1	23.0
95th-5th percentile		12.2	12.8
75th-25th percentile		4.7	4.9
Median		24.1	24.4

NAFLD is becoming increasingly common in parallel with the increasing prevalence of obesity and other components of the metabolic syndrome.[3,4]

Recent NICE guidelines suggest that the prevalence of NAFLD in the general population is estimated at 20-30%, and that 2-3% have NASH. Disease progression is variable, being more common in those that are overweight or with diabetes. [5]

The prevalence of obesity among adults has increased sharply during the 1990s and early 2000s (see Table 17.1).

Table 17.1: Proportion of adults categorised as obese (BMI 30 kg/m²) over time[6,7]

Population subgroup	Proportion categorised as obese		Proportion predicted to be obese in 2034 (steady progress scenario)[8]
	1993	2015	
Men	13%	27%	36%
Women	16%	27%	36%

Obesity is an accumulation of excess body fat when energy intake from food and beverage consumption exceeds the

[1] NHS Digital. Health Survey for England, 2015 [NS]. Publication date: December 14, 2016. www.content.digital.nhs.uk/catalogue/PUB22610

[2] British Liver Trust. Non-alcoholic fatty liver disease. www.britishlivertrust.org.uk/wp-content/uploads/44951-NAFLD-A5-Booklet-Web-compressed.pdf

[3] Rinella ME. Nonalcoholic Fatty Liver Disease. A Systematic Review. JAMA. 2015;313(22):2263–2273

[4] Neuschwander-Tetri, B. A. (2017). Non-alcoholic fatty liver disease. BMC Medicine, 15:45.

[5] NICE Guideline (NG49), July 2016. Non-alcoholic fatty liver disease (NAFLD): assessment and management. www.nice.org.uk/guidance/ng49

[6] Public Health England. UK and Ireland prevalence and trends.
http://webarchive.nationalarchives.gov.uk/20170110171021/https://www.noo.org.uk/NOO_about_obesity/adult_obesity/UK_prevalence_and_trends

[7] NHS Digital. Health Survey for England 2015 Adult overweight and obesity. Published 14th December 2016. http://content.digital.nhs.uk/catalogue/PUB22610/HSE2015-Adult-obe.pdf

[8] UK Health Forum. Risk factor based health modelling for Public Health England. July 2014. www.ukhealthforum.org.uk/prevention/pie/?entryid43=38207

energy expended through metabolism and physical activity. The causes of obesity are complex, and relate to a variety of societal and behavioural factors.[9]

Obesity is associated with multiple health risks including:

- type 2 diabetes
- cardiovascular disease
- some cancers
- increased risk of skeletal and joint problems

Obesity is also associated with psychological conditions and reduced wellbeing.

The current costs to the NHS attributable to overweight and obesity are £6.1 billion.[10,11] The wider costs to society and the economy have been estimated to rise to £49.9 billion per year by 2050.[5] The treatment and prevention of obesity are major public health challenges.

Magnitude of variation

The maps and column chart display the period 2013-15, during which local authority values ranged from 11.0% to 34.0%, which is a 3.1-fold difference between local authorities. The England value for 2013-15 was 24.4%.

The boxplot shows the distribution of local authority values for the period 2012-14 to 2013-15.

When interpreting this data, it is important to note that the statistics presented are modelled estimates rather than actual prevalence. These estimates, however, give the best indication of relative rates of obesity prevalence currently available. It should also be borne in mind that the prevalence of obesity is high in all local authorities, with excessive levels across the country; obesity is a major problem even in the local authorities with the lowest prevalence.

Prevalence of obesity in adults varies by age, sex, ethnic group and disability.[12] When compared with men, a higher proportion of women have a BMI >40 kg/m^2.[6] 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. Although data are limited, people with disabilities are more likely to be obese and have lower levels of physical activity.

Obesity prevalence can vary with socioeconomic status, where the effect is seen in women but not in men: 39% of women in the second lowest household income quintile were obese compared with 17% of women in the highest income quintile.[13]

Potential reasons for differences seen in the degree of variation between areas are complex but are likely to be influenced by factors that affect diet and those that effect food including the density of fast food outlets in the local area. Other potential reasons may include:

[9] Government Office for Science. Foresight - Tackling Obesities: Future Choices Project Report. 2nd edition. First published: October 2007. www.gov.uk/government/collections/tackling-obesities-future-choices

[10] Scarborough P, Bhatnagar P, Wickramasinghe KK et al. The economic burden of ill health due to diet, physical inactivity, smoking, alcohol and obesity in the UK: an update to 2006-07 NHS costs. J Public Health (Oxf). 2011 Dec;33(4):527-35. doi: 10.1093/pubmed/fdr033. Epub 2011 May 11. www.ncbi.nlm.nih.gov/m/pubmed/21562029

[11] Public Health England. Making the case for tackling obesity – why invest? Including Slide 10: The annual costs of obesity. http://webarchive.nationalarchives.gov.uk/20170210161227/http://www.noo.org.uk/slide_sets

[12] Public Health England. Health Inequalities. http://webarchive.nationalarchives.gov.uk/20170110170207/http://www.noo.org.uk/NOO_about_obesity/inequalities

[13] NHS Digital. Health Survey for England 2015 Adult overweight and obesity. Published 14th December 2016. www.content.digital.nhs.uk/catalogue/PUB22610/HSE2015-Adult-obe.pdf

- lower levels of physical activity due to demographic, social, individual and environmental factors
- lace of access to lifestyle management services such as exercise referral or weight management schemes

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, service providers and public health departments should consider working with their local health and wellbeing boards and sustainability and transformation footprints:

- to review local prevalence and trends for obesity
- to refine and develop local strategies for reducing obesity, supported by guidance from NICE (see 'Resources') and other organisations. This needs to be conducted as part of a whole-system response in conjunction with national, regional and health service responses

RESOURCES

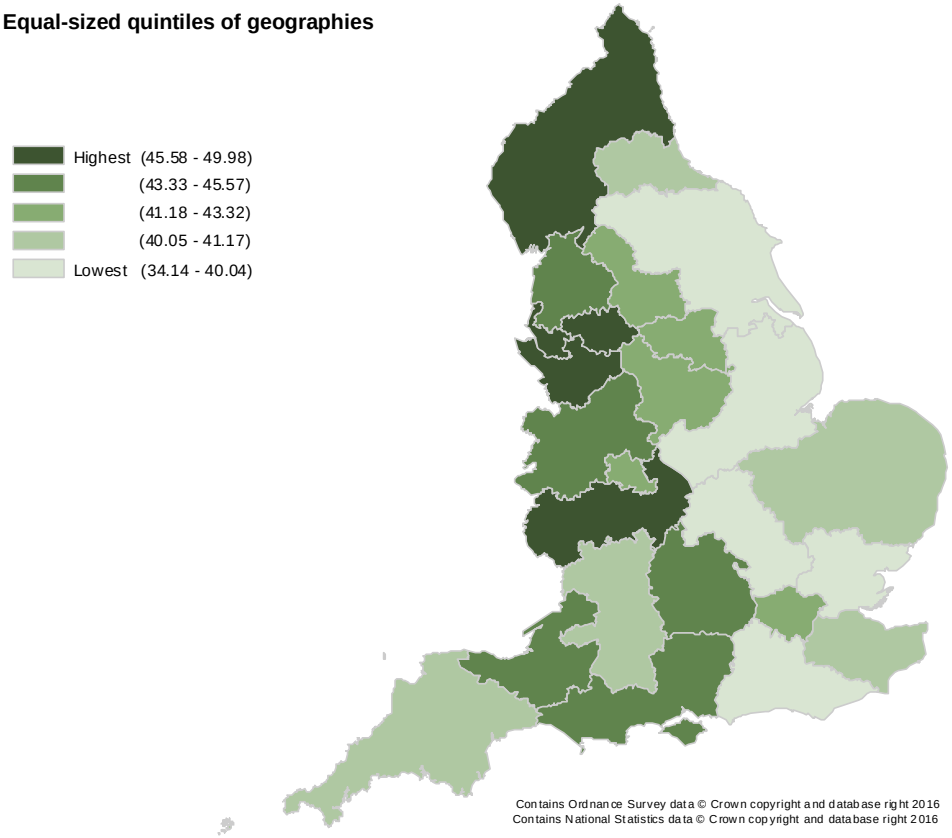
- Public Health England Obesity website. Wide-ranging authoritative information on data, evaluation and evidence related to weight status and its determinants. http://webarchive.nationalarchives.gov.uk/20160805121933/http://www.noo.org.uk
- Public Health England. Adult obesity international comparisons data factsheet. https://khub.net/c/document_library/get_file?uuid=5ac29533-d3f0-4805-b78b-58456d062e0d&groupId=31798783
- Public Health England. Adult diet data factsheet. https://khub.net/c/document_library/get_file?uuid=74906681-d783-4f61-bad2-3094e1c4302a&groupId=31798783
- Public Health England. Adult obesity and socioeconomic status data factsheet. https://khub.net/c/document_library/get_file?uuid=66f4f8fd-468e-4280-af13-dae5d1436fe1&groupId=31798783
- Public Health England. Adult physical activity data factsheet. https://khub.net/c/document_library/get_file?uuid=b5155254-f0c6-4f6b-a06d-3c5847d84c1e&groupId=31798783
- NICE. Preventing excess weight gain. NICE guideline [NG7]. March 2015. www.nice.org.uk/guidance/ng7
- NICE. Obesity in adults: prevention and lifestyle weight management programmes. Quality standard [QS111]. January 2016. www.nice.org.uk/guidance/qs111
- NICE. Interactive flowcharts. Lifestyle weight management services for overweight or obese adults overview. https://pathways.nice.org.uk/pathways/lifestyle-weight-management-services-for-overweight-or-obese-adults
- NICE interactive flowcharts. Obesity overview. https://pathways.nice.org.uk/pathways/obesity
- NICE interactive flowcharts. Obesity: working with local communities overview. https://pathways.nice.org.uk/pathways/obesity-working-with-local-communities
- NICE interactive flowcharts. Physical activity overview. https://pathways.nice.org.uk/pathways/physical-activity
- NICE interactive flowcharts. Diet overview. https://pathways.nice.org.uk/pathways/diet
- NHS Digital. Health Survey for England – 2012 [NS]. Chapter 2: Physical activity in adults. http://content.digital.nhs.uk/catalogue/PUB13218/HSE2012-Ch2-Phys-act-adults.pdf
- Public Health England. Local Health and Care Planning: Menu of preventative interventions. November 2016. www.gov.uk/government/uploads/system/uploads/attachment_data/file/565944/Local_health_and_care_planning_menu_of_preventative_interventions.pdf
- Public Health England. Strategies for Encouraging Healthier 'Out of Home' Food Provision. A toolkit for local councils working with small food businesses. March 2017. www.gov.uk/government/uploads/system/uploads/attachment_data/file/604912/Encouraging_healthier_out_of_home_food_provision_toolkit_for_local_councils.pdf

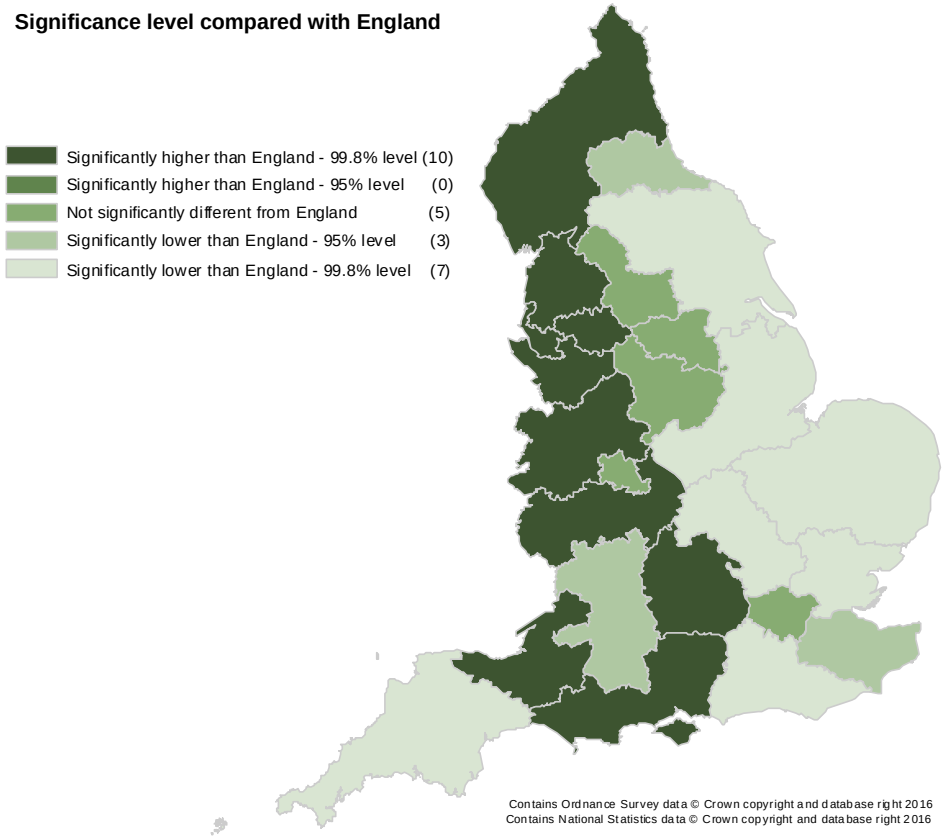
INFLUENZA VACCINE

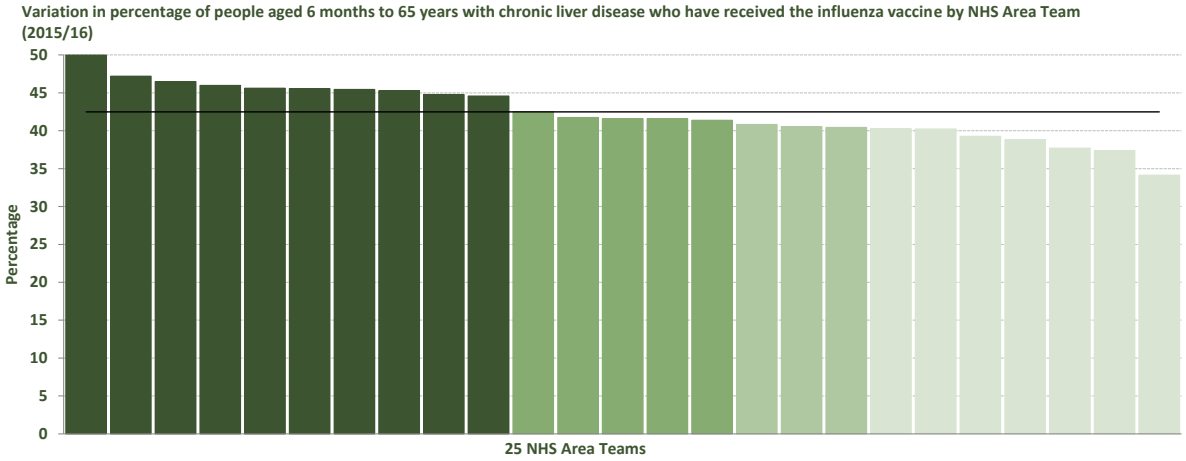
Map 18: Variation in percentage of people aged 6 months to 65 years with chronic liver disease who have received the influenza vaccine by NHS Area Team (2015/16)

NHS Domain 2: Enhancing quality of life for people with long-term conditions
NHS Domain 5: Treating and caring for people in a safe environment & protecting them from avoidable harm
PHOF Domain 3: Health protection

OPTIMUM VALUE: HIGH





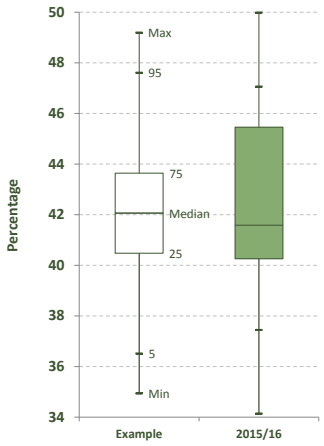


Context

The common symptoms of influenza are chills, fever, nasal and sinus congestion, sore throat and extreme fatigue, however, people with chronic liver disease are at increased risk from the complications of influenza, such as bronchitis or pneumonia. Some of these complications can be life-threatening: every year several thousand people in England die from the complications of influenza.

In people with liver disease the immune system is weakened, increasing their susceptibility to the influenza virus. In addition underlying liver disease can limit the type of medications it is possible for people to take to control influenza symptoms and to treat any potential complications.

People who have had a liver transplant or who are on the waiting list for a transplant are particularly at risk from influenza:



Max-Min (Range)		15.8
95th-5th percentile		9.6
75th-25th percentile		5.2
Median		41.6

- it can increase the rate of rejection and drug resistance in people who have had a liver transplant
- for people with cirrhosis waiting for a transplant it can worsen their condition

Vaccination every year can protect against the influenza virus, and in 2016 Public Health England recommended that everyone with a chronic liver condition should have a free influenza vaccination.

The influenza vaccination season is from October to February, but most people get influenza in December or January. To protect people with chronic liver disease from the influenza virus and its complications it is best to offer vaccination as early as possible in the campaign before influenza circulation starts.

Magnitude of variation

The maps and column chart display the data for 2015/16, during which NHS Area Team values ranged from 34.1% to 50.0%, which is a 1.5-fold difference between NHS Area Teams. The England value for 2015/16 was 42.5%.

The boxplot shows the distribution of NHS Area Team values for 2015/16.

The data shows that at best only one person in every two people under the age of 65 years with chronic liver disease received an influenza vaccination in 2015/16.

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

- level of awareness among people with chronic liver disease of the need for influenza vaccination
- effectiveness of the promotion and offer of influenza vaccination to people with chronic liver disease, particularly in primary care
- access to free influenza vaccination services

Options for action

To increase the number of people with chronic liver disease receiving influenza vaccination, commissioners need to ensure that service providers, particularly general practitioners and community pharmacies, promote and offer the service to people with chronic liver disease.

General practitioners need to invite people with chronic liver disease for influenza vaccination using a variety of methods, such as letter, telephone call, text message or email, either for a specific appointment or to an influenza vaccination clinic. Influenza vaccination clinics need to be promoted on practice websites.

Commissioners can encourage community pharmacies to participate in free influenza vaccination programmes. Being able to access vaccination at a community pharmacy may be more convenient for some people with chronic liver disease than attending the general practice.

Commissioners could consider specifying that primary care service providers responsible for delivering the national flu vaccination programme undergo education and training in promoting the uptake of influenza vaccination (see ‘Resources’ for e-learning package).

All healthcare professionals responsible for the care and treatment of people with chronic liver disease need to take the opportunity of Making Every Contact Count (MECC; see ‘Resources’) to highlight the importance of annual influenza vaccination especially as the season approaches.

RESOURCES

- Public Health England. Annual flu programme. 17 October 2013. Last updated: 15 June 2017. www.gov.uk/government/collections/annual-flu-programme
- Public Health England. Influenza, the green book, chapter 19. Published: 20 March 2013. Last updated: 28 August 2015. www.gov.uk/government/publications/influenza-the-green-book-chapter-19
- Public Health England. The flu vaccination winter 2017 to 2018: who should have it and why. Published: 6 August 2015. Last updated: 12 June 2017. www.gov.uk/government/uploads/system/uploads/attachment_data/file/618591/Flu_vaccination__A5_booklet.pdf
- NHS Health Education England in partnership with Public Health England. e-Learning for Healthcare. Flu Immunisation. www.e-lfh.org.uk/programmes/flu-immunisation
- Public Health England. Making Every Contact Count (MECC): practical resources. Published: 26 January 2016. Last updated: 12 April 2016. www.gov.uk/government/publications/making-every-contact-count-mecc-practical-resources
- NHS Choices. The flu jab. Page last reviewed: 12/07/2016. www.nhs.uk/conditions/vaccinations/pages/flu-influenza-vaccine.aspx

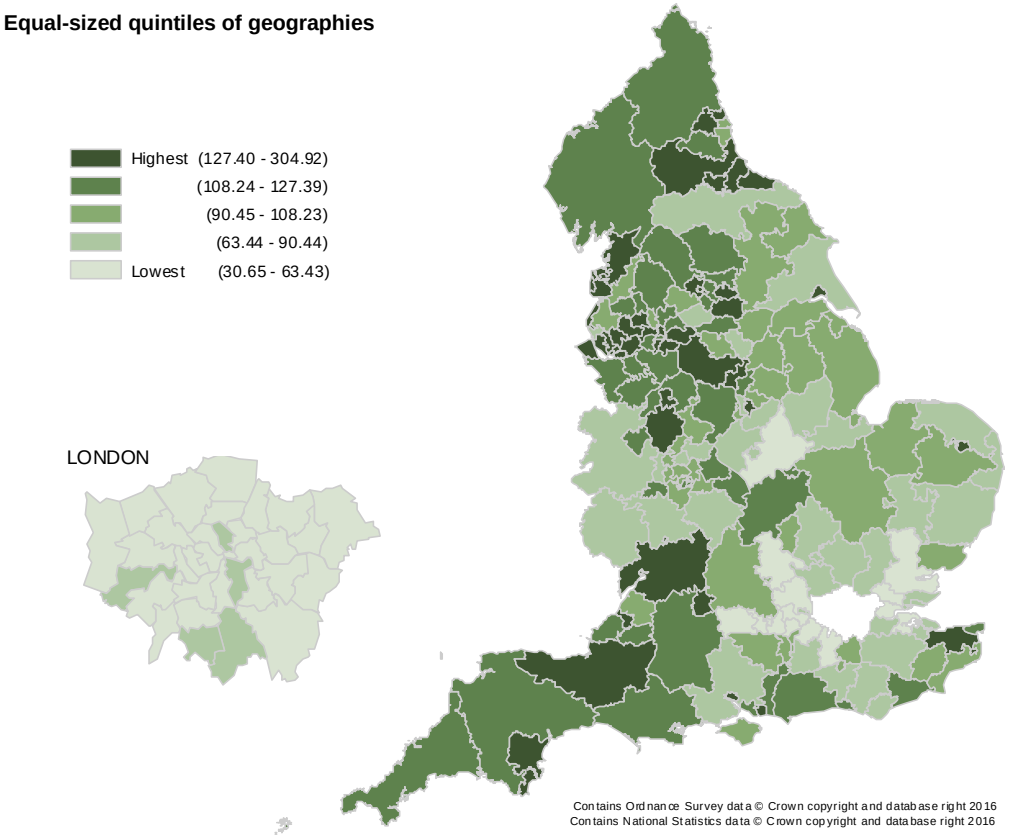
PARACETAMOL OVERDOSE AND POISONING

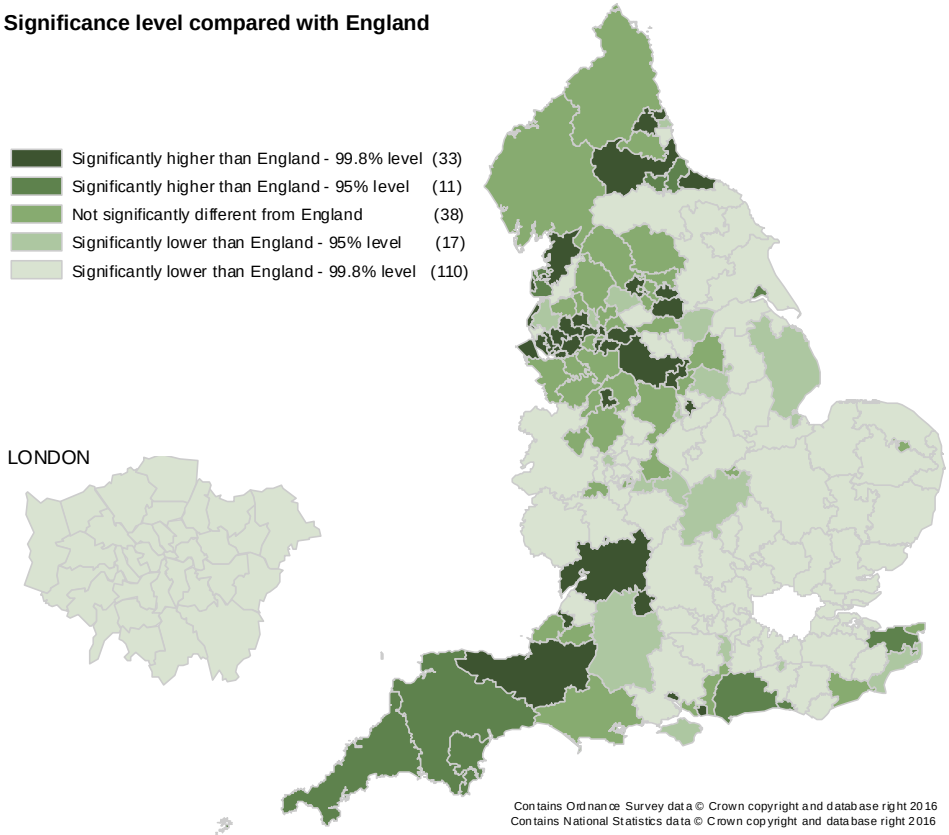
Map 19a: Variation in rate of hospital admissions where the primary diagnosis is paracetamol overdose per population by CCG (2013/14 – 2014/15)

Directly standardised rate per 100,000

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW



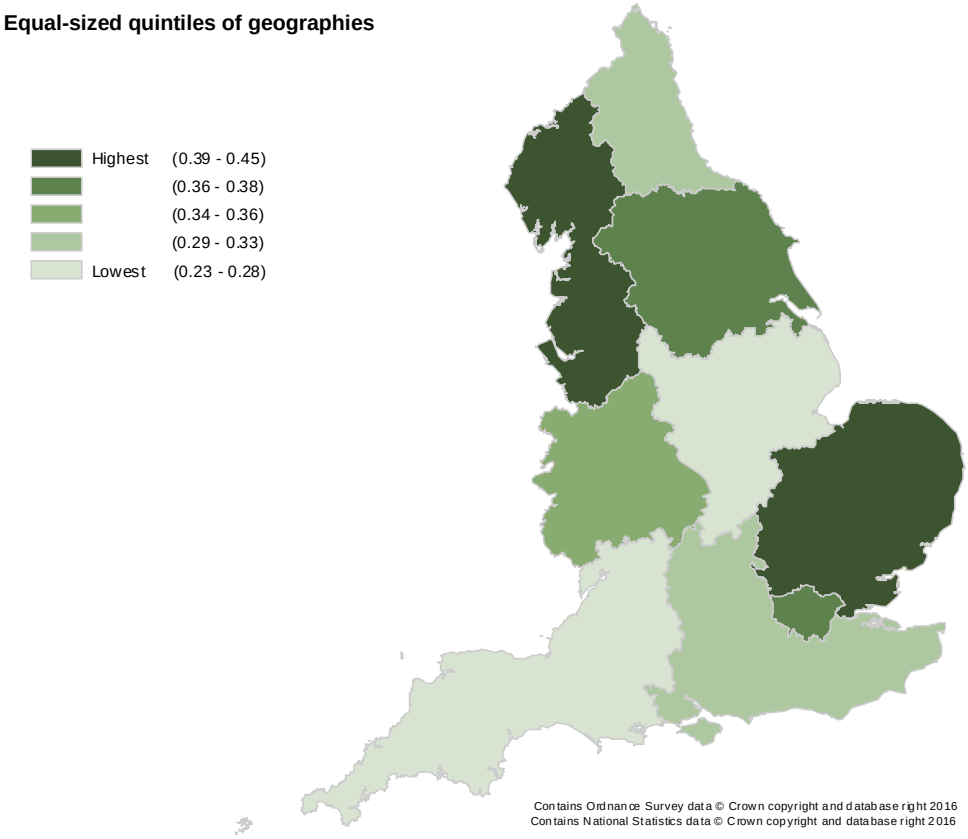


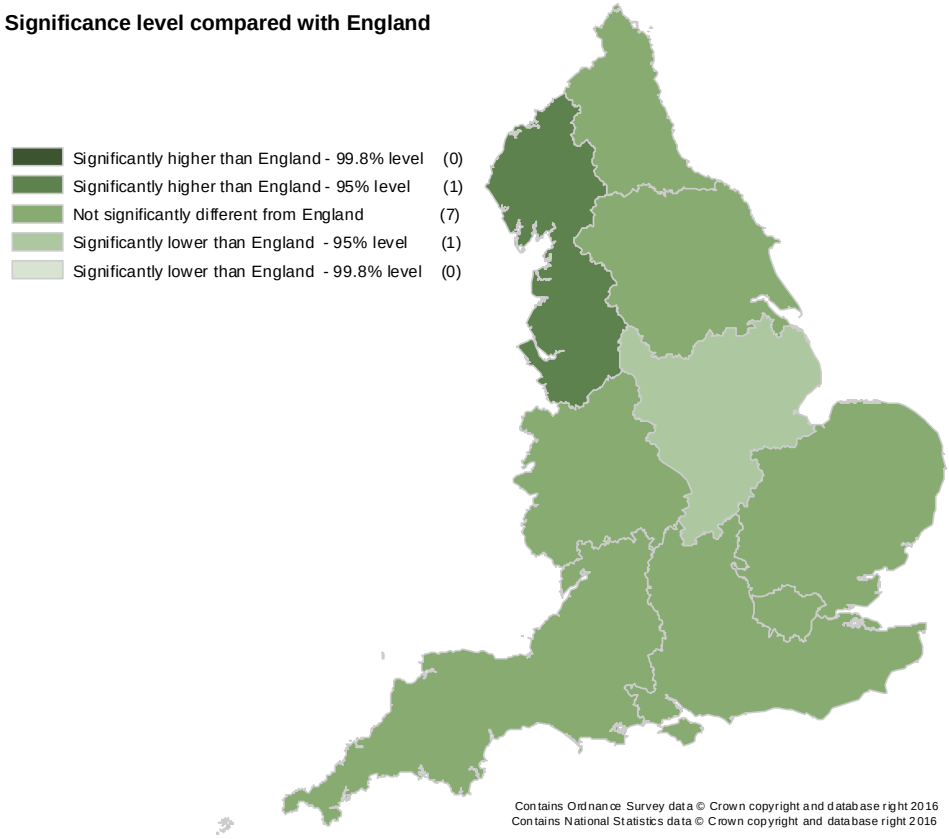
PARACETAMOL OVERDOSE AND POISONING

Map 19b: Variation in percentage of deaths from paracetamol poisoning per hospital admissions for paracetamol overdose by region (2012-2014)

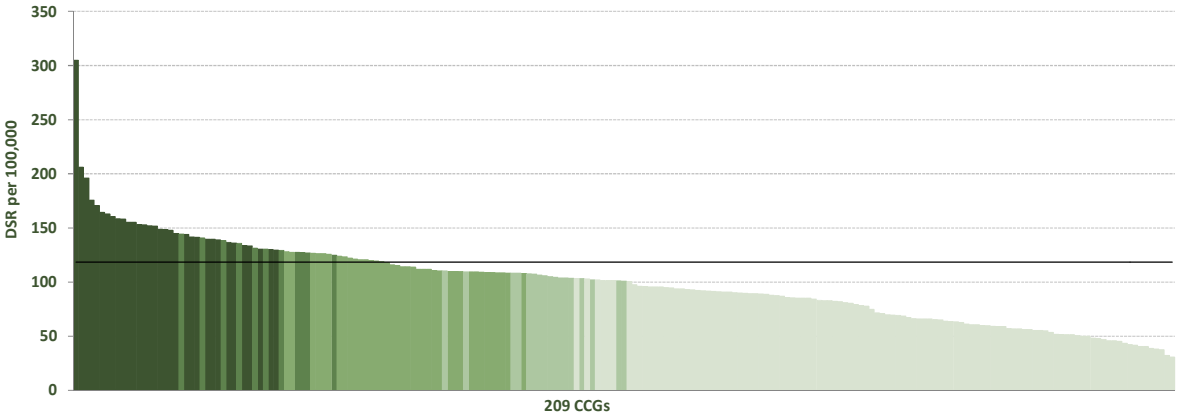
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm
PHOF Domain 4: Healthcare public health and preventing premature mortality

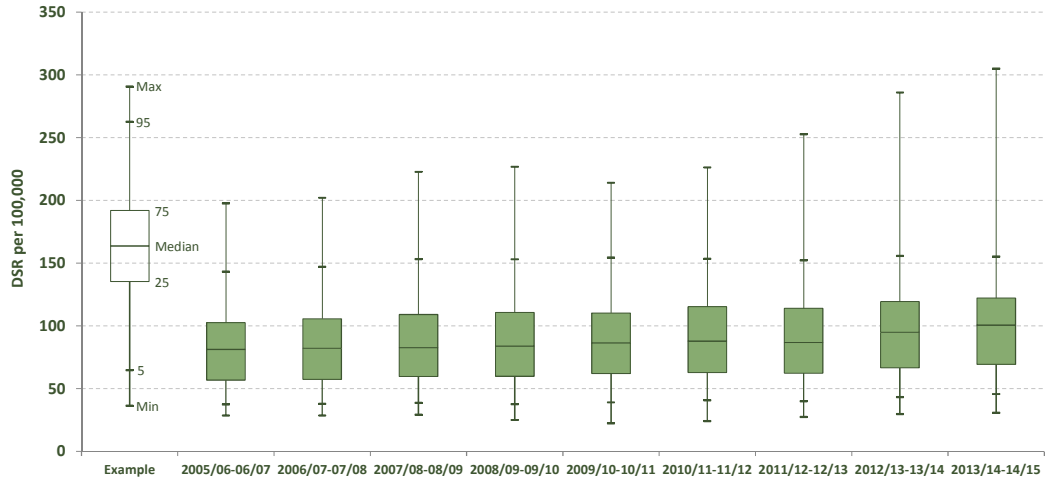
OPTIMUM VALUE: LOW





Variation in rate of hospital admissions where the primary diagnosis is paracetamol overdose per population by CCG (2013/14 - 2014/15)





Max-Min (Range)		169.0	173.5	193.5	201.8	191.8	202.1	225.1	256.2	274.3	WIDENING Significant
95th-5th percentile		105.8	109.3	114.6	115.6	115.5	112.7	112.4	112.6	109.8	No significant change
75th-25th percentile		45.8	48.3	49.4	50.9	48.3	52.4	51.7	52.8	52.8	WIDENING Significant
Median		81.3	82.1	82.7	83.9	86.5	87.8	86.8	94.8	100.7	INCREASING Significant

Context

Paracetamol is the most common drug taken in overdose in the UK. Each year about 100,000 people present to emergency departments in the UK with paracetamol poisoning and about half are admitted for antidote therapy with acetylcysteine.[1] Analysis for this atlas shows 53,731 admissions for paracetamol overdose in England in 2014. The trend in deaths involving paracetamol and its compounds has remained relatively stable in recent years (2011-15).[2] Analysis for this atlas shows 172 deaths mentioning paracetamol in England in 2015.

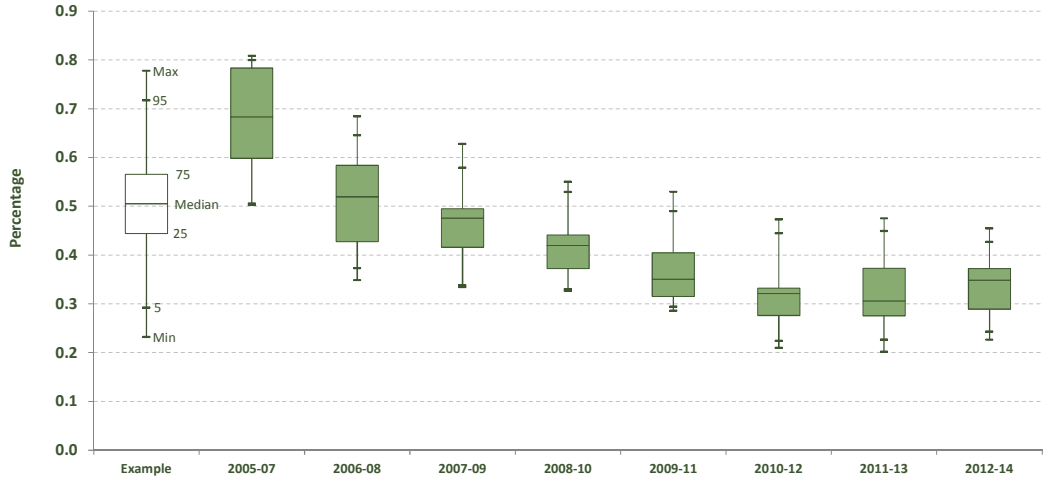
When taken in its normal dosage paracetamol is a safe and effective painkiller. It can also reduce the temperature of children and adults with fever, and is commonly used for this purpose. Taken in too high a dose, however, paracetamol can be dangerous and can cause fatal liver disease. Metabolites of paracetamol have a toxic effect on the cells of the liver (hepatocytes), which may be caused by as few as 12 tablets of paracetamol. It may take several days, however, before symptoms develop. Although the management of early paracetamol poisoning should be straightforward, the management of late-presenting cases, cases presenting after a staggered overdose and people with risk factors for enhanced toxicity from paracetamol poisoning can be much more complex.

Owing to the widespread availability of paracetamol it is a commonly used means of attempting suicide or deliberate self-harm. In addition, a lack of awareness of

[1] Park KB, Dear JW, Antoine DJ. Paracetamol (acetaminophen) poisoning. Systematic review 2101. BMJ Clinical Evidence. 2015 October. http://clinicalevidence.bmj.com/x/systematic-review/2101/overview.html

[2] Office for National Statistics. Deaths related to drug poisoning in England and Wales: 2015 registrations. Release date: 9 September 2016. www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsrelatedtodrugpoisoninginenglandandwales/2015registrations

Variation in percentage of deaths from paracetamol poisoning per hospital admissions for paracetamol overdose by region (2012-2014)



Max-Min (Range)		0.31	0.34	0.29	0.22	0.24	0.26	0.27	0.23	No significant change
95th-5th percentile		0.29	0.27	0.24	0.20	0.20	0.22	0.22	0.18	NARROWING Significant
75th-25th percentile		0.19	0.16	0.08	0.07	0.09	0.06	0.10	0.08	No significant change
Median		0.68	0.52	0.48	0.42	0.35	0.32	0.31	0.35	DECREASING Significant

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.[3] 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. The preferred antidote is acetylcysteine; this protects the liver if infused up to, and possibly beyond, 24 hours of ingesting paracetamol.[4] It is most effective if given within 8 hours of ingestion, after which effectiveness declines.[2]

The management of paracetamol overdose requires good and timely referral pathways from primary to secondary care, within secondary care itself from Accident and Emergency to Acute Medical Teams 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.

[3] BMJ Best Practice: Paracetamol Overdose (Updated March 2017). http://bestpractice.bmj.com/best-practice/monograph/337/diagnosis/step-by-step.html
[4] NICE Evidence Services BNF. Emergency treatment of poisoning. Paracetamol. https://bnf.nice.org.uk/treatment-summary/emergency-treatment-of-poisoning.html

Evidence-based treatment pathways can improve the chances of early and effective therapy and successful recovery from overdose. These are available to guide clinicians through the investigation and treatment of all patients presenting to hospital after a paracetamol overdose, which although common is sometimes difficult to manage.

To limit the number of people who take an overdose of paracetamol as a means of attempting suicide or deliberate self-harm, in 1998 the Medicines Control Agency restricted the quantity of paracetamol that could be bought in one purchase. Hawton et al found that, when compared with the pre-legislation data, following the introduction of the legislation there was an estimated average reduction of 17 deaths per quarter involving paracetamol alone (with or without alcohol) that received suicide or undetermined verdicts in England and Wales.[5] This decrease represents a 43% reduction or an estimated 765 fewer deaths over 11 years from October 1998 to end 2009, and 990 fewer deaths when accidental poisoning verdicts were included.[5] This decrease was largely unaltered when the analysis was adjusted for underlying trends in poisoning deaths.[5]

Magnitude of variation

Map 19a: Hospital admissions where the primary diagnosis is paracetamol overdose

The maps and column chart display the data for the period 2013/14 to 2014/15, during which CCG values ranged from 30.7 to 304.9 admissions for paracetamol poisoning per 100,000 population, which is a 9.9-fold difference between CCGs. The England value for 2013/14 to 2014/15 was 118.4 per 100,000 population. The boxplot shows the distribution of CCG values for the period 2005/06-2006/07 to 2013/14-2014/15. Both the maximum to minimum range and the 75th to 25th percentile gap widened significantly. The median increased significantly from 81.3 per 100,000 population in 2005/06-2006/07 to 100.7 per 100,000 population in 2013/14-2014/15**.**

The statistically significant increase in numbers of admissions over this time period contrasts with the reported stable number of deaths over a similar time period. However, it mirrors reported increases in the numbers of young people who self-harm.[6]

Map 19b: Deaths from paracetamol poisoning per hospital admissions for paracetamol overdose

In these maps and charts the numerator for this indicator is death registrations from paracetamol overdose from ONS by region and the denominator is the number of hospital admissions for paracetamol overdose by region derived from HES data.

The maps and column chart display the data for 2012-14, during which region values ranged from 0.23% to 0.45%, which is a 2.0-fold difference between regions. The England value for 2012-14 was 0.34%.

Although there are geographical differences in age-standardised admission rates for paracetamol poisoning, 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.

The boxplot shows the distribution of region values for the period 2005-07 to 2012-14. The 95th to 5th percentile gap narrowed significantly. The median of the region values decreased significantly from 0.68% in 2005-07 to 0.35% in 2012-14. Which means fewer people admitted for paracetamol poisoning died, despite the number of admissions rising significantly over this time period.

[5] Hawton K, Bergen H, Simkin SS et al. Long term effect of reduced pack sizes of paracetamol on poisoning deaths and liver transplant activity in England and Wales: interrupted time series analyses. BMJ 2013;346:f1403 doi: 10.1136/bmj.1403 (Published 7 February 2013) www.bmj.com/content/bmj/346/bmj.f403.full.pdf

[6] Morey, Y., Mellon, D., Dailami, N., Verne, J. and Tapp, A. (2016) Adolescent self-harm in the community: An update on prevalence using a self-report survey of adolescents aged 13 to 18 in England. Journal of Public Health, 39 (1). pp. 58-64. http://dx.doi.org/10.1093/pubmed/fdw010

Whether this is because health services are reacting in a more timely and effective way or whether the nature of paracetamol poisoning admissions has changed cannot be elucidated from this study. For example, this might have occurred through the changes introduced in 2012 of the thresholds for intervention with acetylcysteine, or perhaps because of the restrictions on pack size and number of packs which can be bought on one occasion.

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.

There is also an issue that there is very significant geographical variation in the use by Coroners of 'narrative' verdicts. This means that in some parts of the country there may be an under-reporting of paracetamol poisoning deaths as a result of suicide or self-harm[7]. This does not affect the number of reported paracetamol deaths but may affect the prevention strategies adopted in local areas.

Options for action

To appropriately reduce non-elective admissions to hospital where the diagnosis includes a paracetamol poisoning and to reduce deaths from paracetamol poisoning, commissioners, clinicians and various services need to work together to review:

- local rates of hospital admission for paracetamol overdose
- whether there are particular age-groups in whom, and areas where, the problem is greatest prevention measures within mental health services, schools and the community
- barriers to accessing therapies including crisis care services
- training, especially primary care professionals, to recognise and support people in or approaching suicidal crisis
- provision of population based education on the specific risk of paracetamol overdose
- use of evidence-based flowcharts in the treatment of paracetamol overdose (see 'Resources') are used by all service providers
- the speed of response and pathway of treatment and care in local services for people taking a paracetamol overdose
- audits of the management of incidents that are near fatal
- the consequences of paracetamol overdose on more specialised services and ensure that guidelines and treatment pathways are followed

RESOURCES

- Prescott K, Stratton R, Freyer A et al. Detailed analyses of self-poisoning episodes presenting to a large regional teaching hospital in the UK. Br J Clin Pharmacol 2009 Aug; 68(2): 260–268. doi: 10.1111/j.1365-2125.2009.03458.x
- Medicines and Healthcare products Regulatory Agency. Treating paracetamol overdose with acetylcysteine: new guidance. Published 25 September 2012. www.gov.uk/drug-safety-update/treating-paracetamol-overdose-with-intravenous-acetylcysteine-new-guidance
- National Poisons Information Service (NPIS). www.npis.org/
- TOXBASE, the primary clinical toxicology database of the National Poisons Information Service (for health professionals only). www.toxbase.org/
- Office for National Statistics. Deaths related to drug poisoning in England and Wales: 2015 registrations. Release date: 9 September 2016. www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsrelatedtodrugpoisoninginenglandandwales/2015registrations
- BMJ Best Practice: Paracetamol Overdose (Updated March 2017). http://bestpractice.bmj.com/best-practice/monograph/337/treatment/step-by-step.html

[7] Gunnell D, Bennewith O, Simkin S, Cooper J, Klineberg E, Rodway C, et al. Time trends in coroners' use of different verdicts for possible suicides and their impact on officially reported incidence of suicide in England: 1990–2005. Psychological Medicine. 2013; 43: 1415-1422. doi:10.1017/S0033291712002401

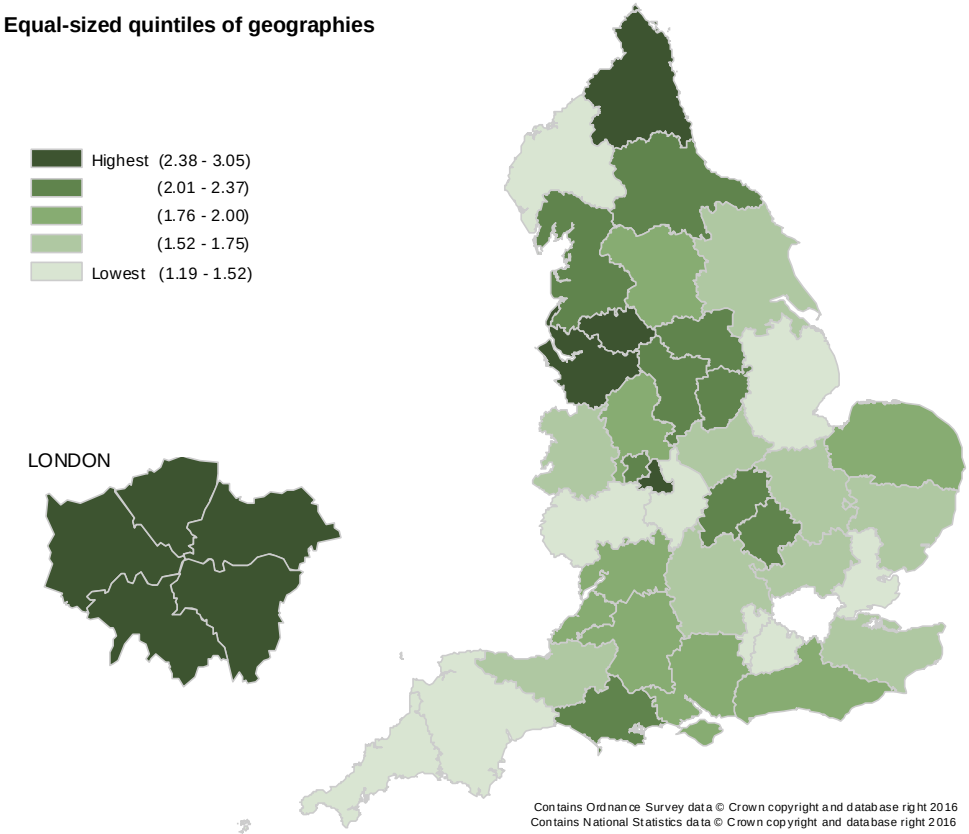
LIVER CANCER

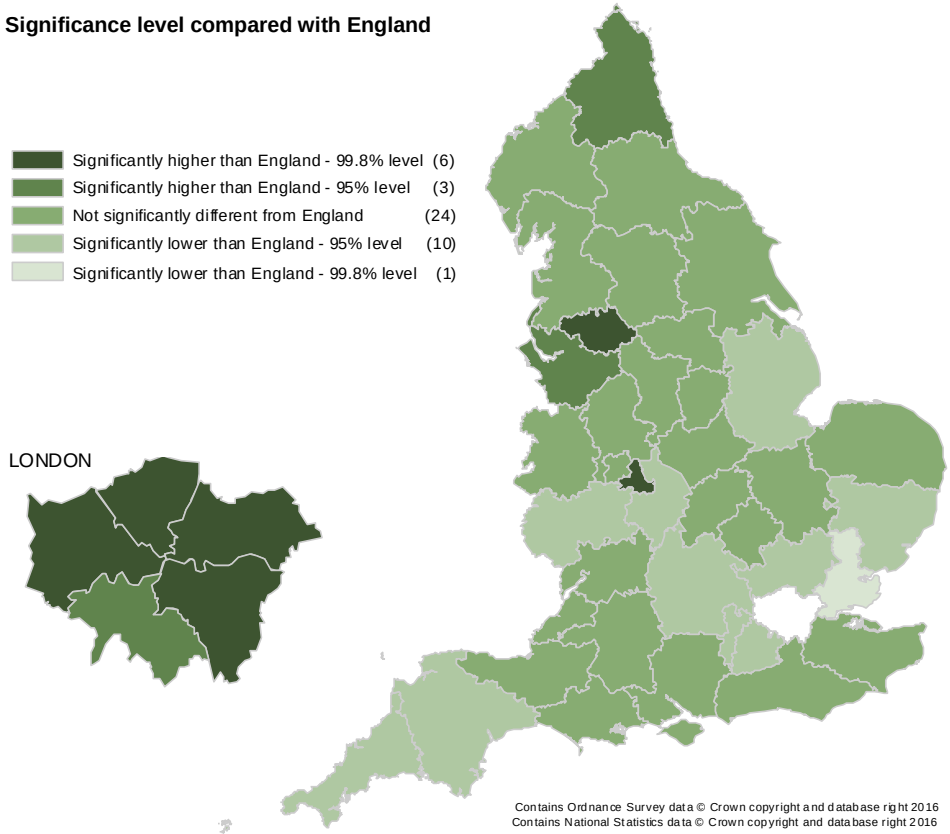
Map 20: Variation in mortality rate in people aged under 75 years due to hepatocellular carcinoma per population by Sustainability Transformation Partnerships (STP) (2011-2015)

Directly standardised rate per 100,000

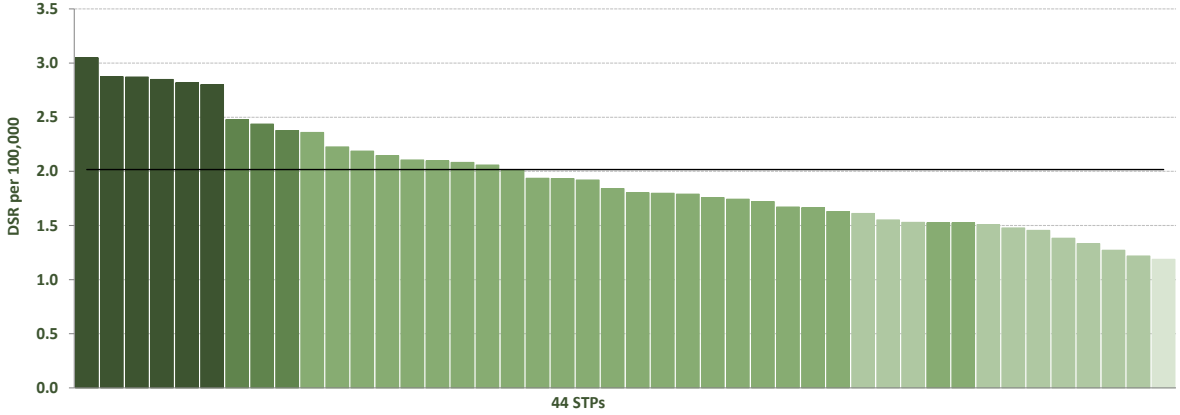
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 4: Ensuring that people have a positive experience of care
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW





Variation in mortality rate in people aged under 75 years due to hepatocellular carcinoma per population by Sustainability Transformation Partnerships (STP) (2011-2015)



Max-Min (Range)		2.19	2.61	1.96	2.18	2.20	1.91	1.86	No significant change
95th-5th percentile		1.61	1.76	1.74	1.65	1.69	1.70	1.59	No significant change
75th-25th percentile		0.54	0.64	0.61	0.66	0.67	0.69	0.65	No significant change
Median		1.37	1.39	1.50	1.68	1.76	1.75	1.82	INCREASING Significant

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 5,550 people are diagnosed with primary liver cancer each year in the UK, which accounts for about 2% 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 becoming more common at all ages. It is now the ninth commonest cause of cancer death and has the largest increase in mortality over the last 10 years compared to all other cancers.[1]

[1] Cancer Research UK: Cancer Statistics www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/liver-cancer

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 most commonly 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 1c).

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 a small proportion are diagnosed in the early stages of the disease,[3] and it is only in these early diagnosed cases that treatment can be curative.[1]

Surveillance scans can be offered to people with cirrhosis who are at risk of liver cancer and this has been shown to lead to earlier diagnosis. However, the provision of high quality surveillance is variable across England.[4]

Overall, after diagnosis, at least 36% of people live for one year and at least 12% live for five years.[5]

Magnitude of variation

The maps and column chart display the data for 2011-15, during which STP values ranged from 1.2 to 3.0 per 100,000 population, which is a 2.6-fold difference between STPs. The England value for 2011-15 was 2.0 per 100,000 population.

The boxplot shows the distribution of STP values for the period 2005-09 to 2011-15. There was no significant change in any of the three variation measures between 2005-09 and 2011-15. The median increased significantly from 1.4 per 100,000 population in 2005-09 to 1.8 per 100,000 population in 2011-15.

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
- availability of surveillance tests to people with cirrhosis
- access to rapid diagnostic and treatment pathways
- level of patient compliance with prevention or treatment

[2] British Liver Trust. Fighting Liver Disease. Liver Cancer. www.britishlivertrust.org.uk/wp-content/uploads/Liver-Cancer_lores1.pdf
[3] Tsuchiya N, Sawada Y, Endo I, Saito K, Uemura Y, Nakatsura T. Biomarkers for the early diagnosis of hepatocellular carcinoma. World Journal of Gastroenterology : WJG. 2015;21(37):10573-10583. www.ncbi.nlm.nih.gov/pmc/articles/PMC4588079
[4] Cross TJS, Villaneuva A, Shetty S on behalf of the Hepatocellular Carcinoma UK (UK HCC) Study Group, et al A national survey of the provision of ultrasound surveillance for the detection of hepatocellular carcinoma Frontline Gastroenterology Published Online First: 07 December 2015. http://dx.doi.org/10.1136/flgastro-2015-100675
[5] Office for National Statistics. Cancer Survival in England: adults diagnosed between 2011 and 2015 and followed up to 2016 www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancersurvivalratescancersurvivalinenglandadultsdiagnosed

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

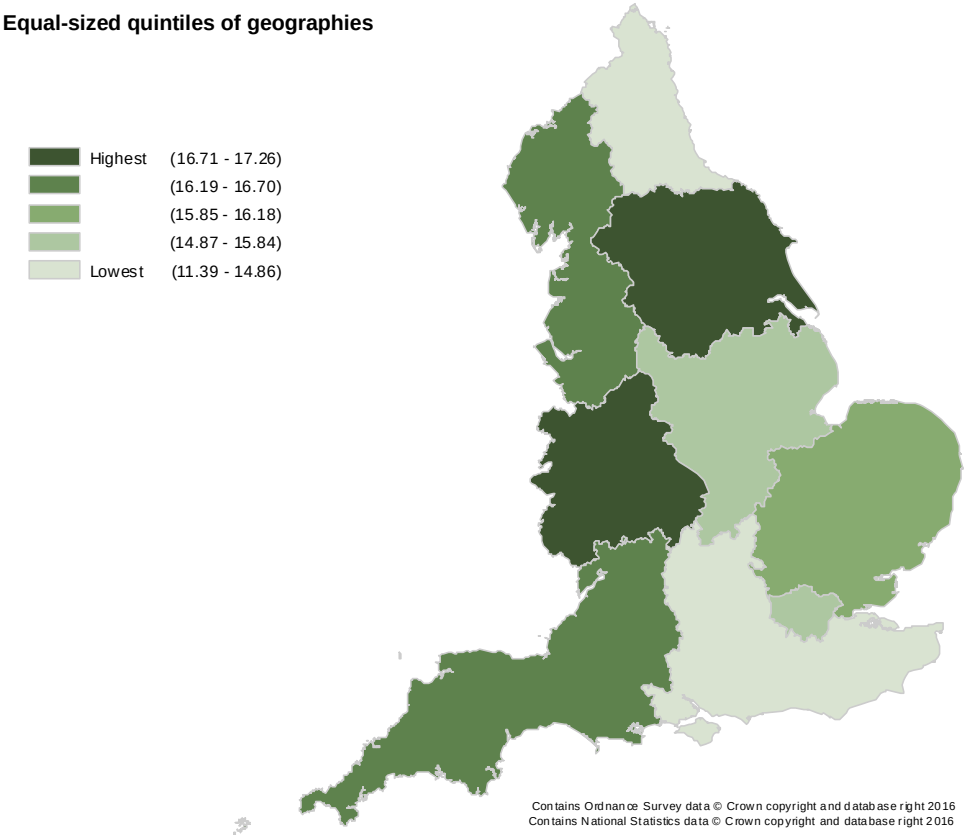
- National Cancer Registration and Analysis Service. www.ncin.org.uk/publications/data_briefings/trends_in_incidence_of_primary_liver_cancer_subtypes
- Cancer Research UK. Liver Cancer Mortality Statistics. www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/liver-cancer/mortality
- British Liver Trust. Fighting Liver Disease. Liver Cancer. www.britishlivertrust.org.uk/wp-content/uploads/Liver-Cancer_lores1.pdf
- NICE interactive flowchart. Liver cancers overview. https://pathways.nice.org.uk/pathways/liver-cancers
- NICE. Alcohol-use disorders – prevention. Public health guideline [PH24]. Published date: June 2010. http://guidance.nice.org.uk/PH24
- NICE. Alcohol-use disorders: diagnosis and management of physical complications. Clinical guideline [CG100]. Published date: June 2010. http://guidance.nice.org.uk/CG100
- NICE interactive flowchart. Alcohol-use disorders overview. http://pathways.nice.org.uk/pathways/alcohol-use-disorders
- PHE Alcohol Learning Resources. Improving Local Alcohol Interventions. www.alcohollearningcentre.org.uk/
- Public Health England. Alcohol Care in England's Hospitals: An opportunity not to be wasted. November 2014. www.alcohollearningcentre.org.uk/_assets/Alcohol_Care_in_Englands_Hospitals_An_opportunity_not_to_be_wasted_PHE_Nov_14.pdf

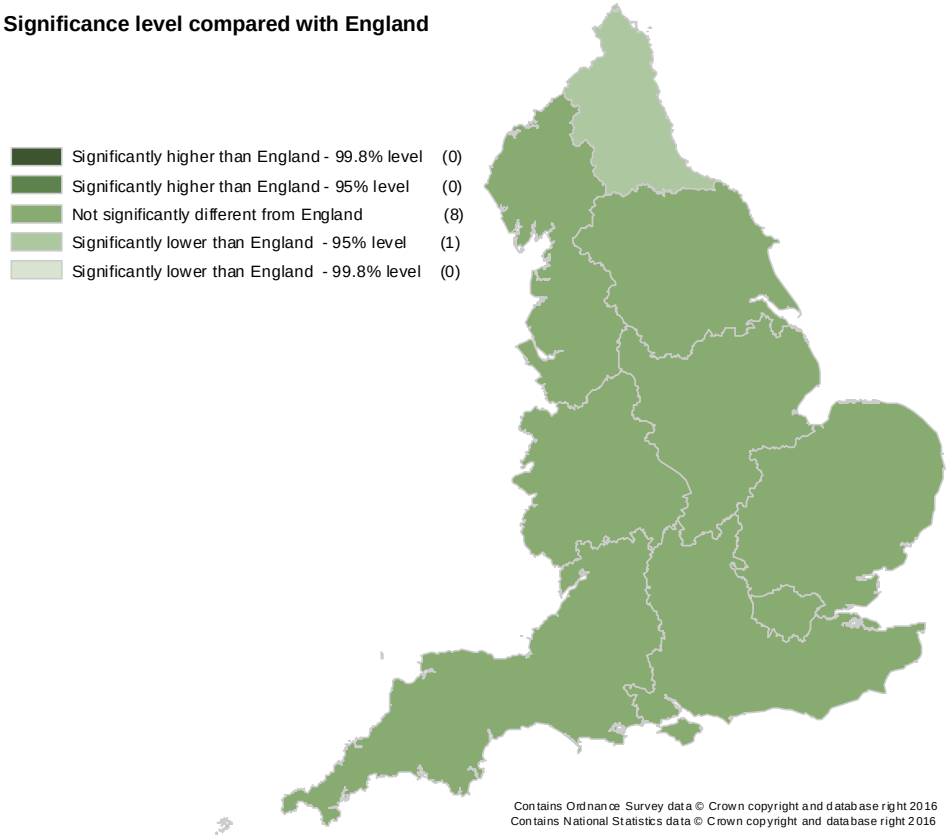
LIVER CANCER

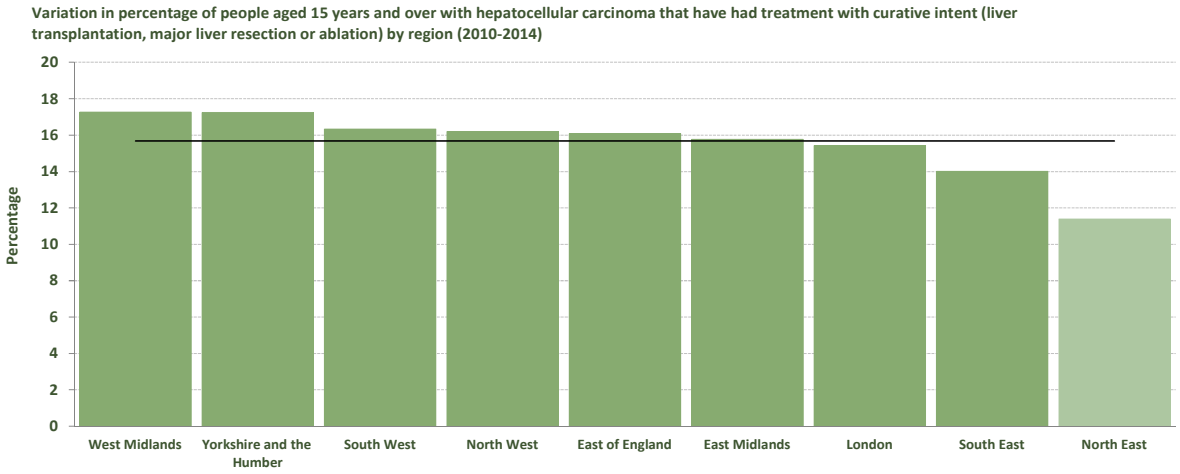
Map 21: Variation in percentage of people aged 15 years and over with hepatocellular carcinoma that have had treatment with curative intent (liver transplantation, major liver resection or ablation) by region (2010-2014)

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: HIGH



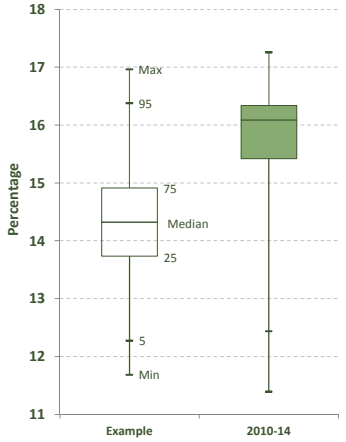




Context

In 2014, there were 5,550 new cases of liver cancer in the UK, which accounted for 2% of all cancers; two-thirds (66%) of new cases of liver cancer occurred in men.[1]
There are two main types of liver cancer:

- primary liver cancer, which is uncommon but serious and more likely to affect people who are aged over 60 years
- secondary liver cancer, where cancer has developed in another part of the body and spread to the liver, eg from the bowel, and which is far more common than primary liver cancer



Max-Min (Range)		5.9
95th-5th percentile		4.8
75th-25th percentile		0.9
Median		16.1

The most common form of primary liver cancer in men is hepatocellular carcinoma; it is the second most common in women.[2] Most cases of hepatocellular carcinoma are associated with cirrhosis of the liver, in which the liver is scarred as a result of damage over a long period of time. The causes of cirrhosis include:

- long-term hepatitis B and hepatitis C infection
- 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
- primary biliary cirrhosis, a long-term disease in which the bile ducts become damaged
- 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 – NAFLD is increasingly being associated with hepatocellular carcinoma

Treatment of liver cancer depends on the stage of the disease. Most clinicians use a combination staging system to categorise the stage of the disease encompassing:

- the features of the cancer
- the person's underlying liver function

In the Barcelona Clinic Liver Cancer (BCLC) staging system, there are five stages, starting at 0, through A, B and C to D.

[1] Cancer Research UK. Liver cancer statistics. www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/liver-cancer/incidence#heading-Zero
[2] National Cancer Intelligence Network (February 2012) Trends in incidence of primary liver cancer subtypes. NCIN Data Briefing. February 2012.
www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/upper_gi_cancers

At stage 0, the tumour is less than two centimetres in diameter and the person has normal liver function; in stage D, the liver has lost most of its function and the person has symptoms of end-stage liver disease, eg build-up of fluid in the abdomen. Only a small proportion of people are diagnosed in the early stages of the disease.[3]

If primary liver cancer is diagnosed at an early stage – stage 0 or stage A – it may be possible to treat the cancer using:

- resection, removing part of the liver surgically – the liver is the only organ in the body that has the capacity to regenerate (ie if part of a healthy liver is removed the remainder can increase in volume until it returns to the original volume)
- liver transplantation, replacing a person's original liver with a donor liver
- microwave or radiofrequency ablation to destroy the cancer cells
- There are two types of surgical resection:
- open surgical resection of the liver, which is the standard treatment for patients with hepatocellular carcinoma
- laparoscopic liver resection, a technique usually used to treat secondary liver cancer but which can be used to treat hepatocellular carcinoma

"Major" resection has been defined in National Cancer Registration and Analysis Service (NCRAS) documentation as an operation in which the surgeon "would attempt to remove the entire tumour". In liver resection this usually involves the removal of 3-4 or more liver segments. The decision whether to undertake surgical resection will be based not only on the size and extent of the tumour but also on the degree of associated cirrhosis because that affects liver function and the liver's regenerative capacity.

For the time-period 2010-14, 15.7% of hepatocellular carcinoma patients underwent treatment of curative intent, either liver transplant, major liver resection or ablation, within 6 months of their cancer diagnosis.

The correlation of the incidence of primary liver cancer with surgical resection could be viewed not only as an indicator of early detection but also of whether measures are in place to identify cases of primary liver cancer early. 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.

In 2017 a national collaboration has been established to develop a prospective detailed registry of all patients with HCC identified in England & Wales through liver cancer multidisciplinary team meetings and PHE. It is hoped that this will provide an accurate picture of the causes of any underlying liver disease in those with HCC, help identify changes in risk factors with time and the affected demographic data as well as a clear analysis of the treatments offered and the outcome.

In addition there will be a collaboration with Swansea University Health Economics Group to assess the costs of HCC and any interventions, data which will help future plans for therapy to be evaluated more readily.

Furthermore, clinical colleagues in both Scotland and Northern Ireland working with patients affected by HCC have agreed to collate data corresponding to that available in England & Wales to complete a UK wide picture.

Magnitude of variation

The maps and column chart display the data for 2010-14, during which region values ranged from 11.4 to 17.3%, which is a 1.5-fold difference between regions. The England value for 2010-14 was 15.7%. The boxplot shows the distribution of region values for the period 2010-14.

[3] Tsuchiya N, Sawada Y, Endo I, Saito K, Uemura Y, Nakatsura T. Biomarkers for the early diagnosis of hepatocellular carcinoma. World Journal of Gastroenterology : WJG. 2015;21(37):10573-10583. www.ncbi.nlm.nih.gov/pmc/articles/PMC4588079

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

- the age-sex structure of the local population
- the ethnic composition of the local population – the incidence is higher in Chinese, Black African, Bangladeshi and Pakistani men than in White men, and higher in Bangladeshi and Pakistani women than in White women[4]
- the incidence of hepatitis B and hepatitis C
- the incidence of cirrhosis
- levels of alcohol consumption in the local population
- the configuration of local services
- the provision of surveillance programmes for people at risk of developing primary liver cancer (eg people with cirrhosis)
- the timing of diagnosis
- criteria for the selection of people undergoing major resection
- degree of adherence to guidance
- level of patient compliance with prevention or treatment

Options for action

When planning service improvement or development to increase the early diagnosis rate for hepatocellular carcinoma, commissioners, clinicians and service providers need:

- to review the mortality rates and trends for primary liver cancer including hepatocellular carcinoma 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 prevention and improving outcomes for liver disease
- to consider developing and reviewing local registries and surveillance programmes (eg ultrasound scanning and blood testing every 6-12 months) 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 resection and transplantation.

RESOURCES

- National Cancer Intelligence Network. (2010) Geographic variation in primary liver and gallbladder cancer. NCIN Data Briefing. www.ncin.org.uk/publications/data_briefings/liver_and_gall_bladder
- National Cancer Intelligence Network. (February 2012) Trends in incidence of primary liver cancer subtypes. NCIN Data Briefing. www.ncin.org.uk/publications/data_briefings/trends_in_incidence_of_primary_liver_cancer_subtypes
- NICE. NICE interactive flowchart. Liver cancers overview. https://pathways.nice.org.uk/pathways/liver-cancers
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- British Liver Trust. Liver cancer. www.britishlivertrust.org.uk/liver-information/liver-conditions/liver-cancer

[4] National Cancer Intelligence Network (2012) Variation in incidence of primary liver cancer between ethnic groups, 2001-2007. NCIN Data Briefing. www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/upper_gi_cancers

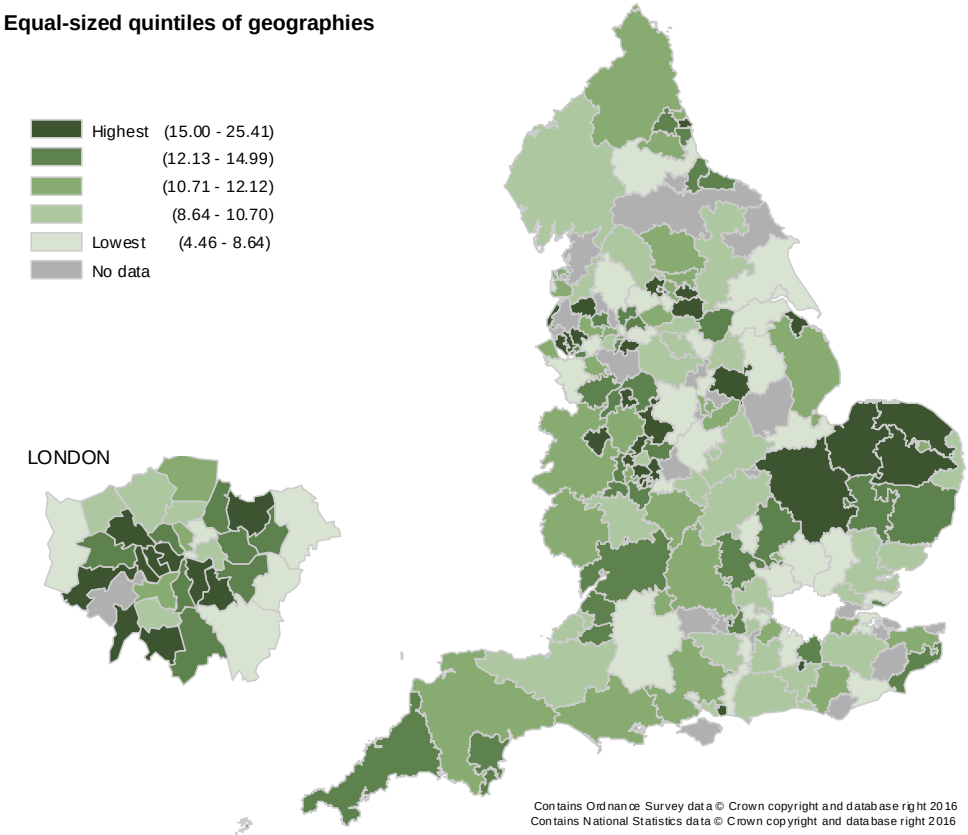
TRANSPLANTATION

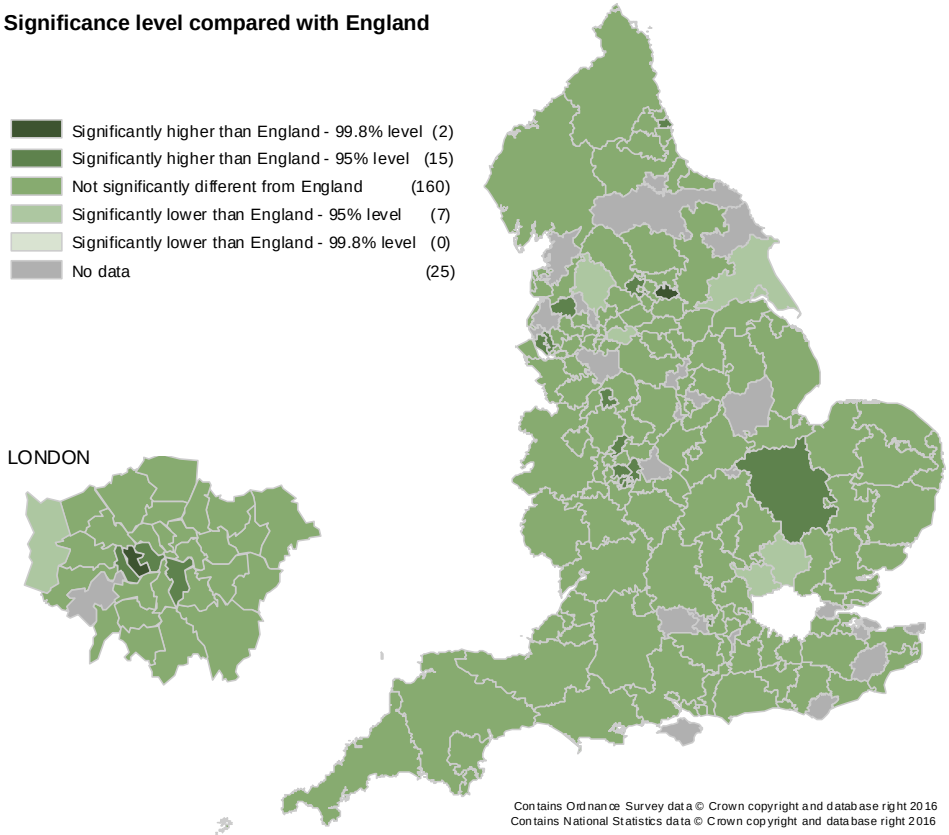
Map 22: Variation in rate of liver transplants from all donors per population by CCG (2010/11 - 2014/15)

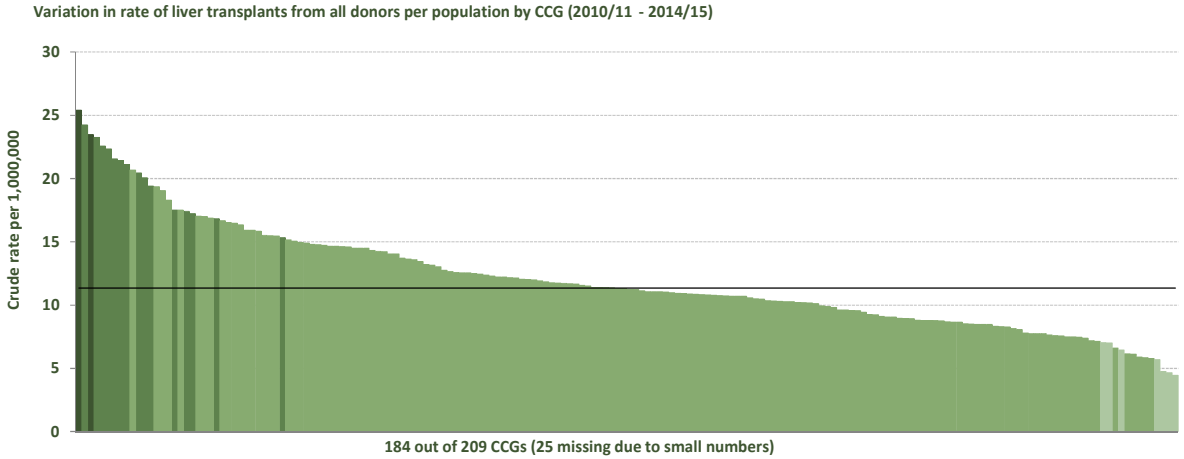
Crude rate per 1,000,000

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long term conditions
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION



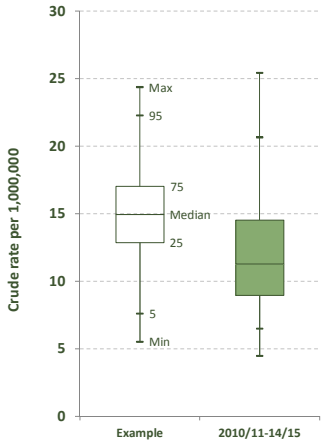




Context

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. Criteria for selection onto a transplant list have been defined (see 'Resources'), and are reviewed regularly by the Liver Advisory Group for the Directorate of Organ Donation and Transplantation at NHS Blood and Transplant (NHSBT). Criteria for referral for consideration of transplantation are different from those for transplantation.

Selection for a transplant list, once referred, is carefully monitored. There are British Association for the Study of the Liver and NHSBT guidelines for referral to a transplant centre (see 'Resources') to ensure that individuals across the country have equal access to a transplant centre for prompt assessment of their liver disease. NHS Blood and Transplant have developed a universal allocation process, identical in all transplant centres (see 'Resources').



Max-Min (Range)		21.0
95th-5th percentile		14.2
75th-25th percentile		5.6
Median		11.3

In the UK in 2014/15, 842 liver transplants were performed at six centres in England and one in Scotland as part of the deceased donor liver programme;[1] 38 living-lobe donor transplants and 2 domino donor transplants were also undertaken.[1] Of all liver transplants undertaken in adults in 2014/15, 12% were prioritised as 'super-urgent', where patients need a new liver as soon as possible due to rapid failure of the native organ;[1] the remainder of transplants are considered elective.

Survival following liver transplantation is good: for 2,081 of the 2,227 transplants from 1 April 2010 to 31 March 2014, the overall survival for adults at one year was 92.4%.[1]

Demand continues to exceed the supply of organs donated: in 2014/15 more patients were registered for a liver transplant than there were organs available for transplantation.[1] At 31 March 2015 there were 611 patients on the active transplant list;[1] since March 2008 the number of patients on the liver transplant list has doubled.[2]

At one year post-registration 11% of patients with liver disease had died while waiting for a liver transplant or had been removed from the transplant list due to their condition deteriorating.[1]

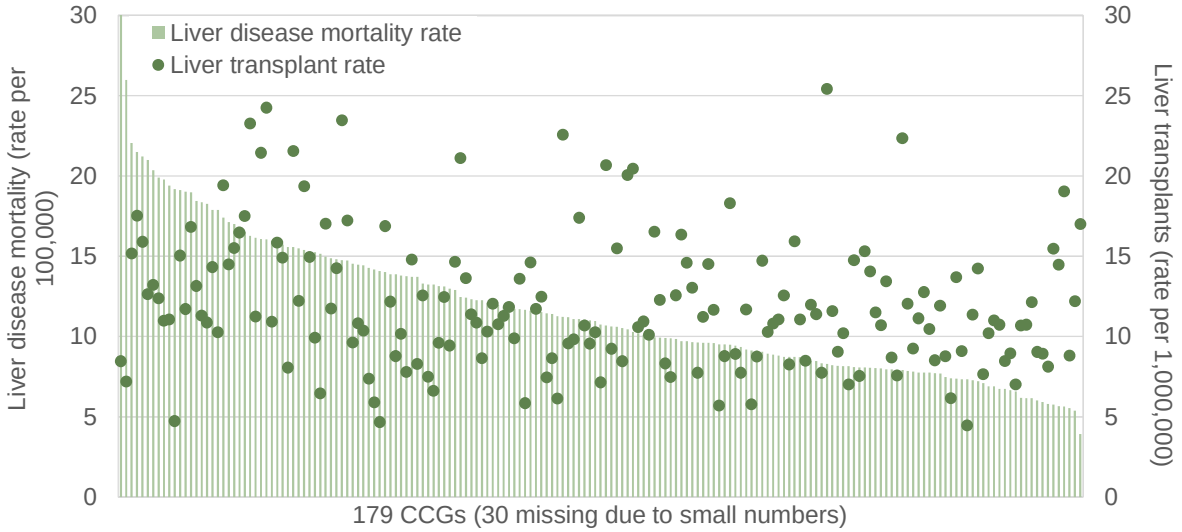
[1] NHS Blood and Transplant. Organ Donation and Transplantation Activity Report 2014/15. http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf
[2] NHS Blood and Transplant. Produced in collaboration with NHS England. Annual Report on Liver Transplantation. Report for 2014/2015 (1 April 2005 – 31 March 2015). Published September 2015. http://odt.nhs.uk/pdf/organ_specific_report_liver_2015.pdf

Magnitude of variation

The maps and column chart display the data for 2010/11 to 2014/15, during which CCG values ranged from 4.5 to 25.4 per million population, which is a 5.7-fold difference between CCGs. The England value for 2010/11 to 2014/15 was 11.4 per million population. The boxplot shows the distribution of CCG values for the period 2010/11 to 2014/15.

In Figure 22.1 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^2=0.0246).

Figure 22.1: Liver transplant rate per million population 2010/11 to 2014/15 (points) in relation to the rate of chronic liver disease mortality (directly standardised) per 100,000 population aged under 75 years 2013-15 (columns)



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

- the prevalence of liver disease
- access to expertise in liver disease locally
- local criteria for referral for assessment 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 service 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 care pathways for patients with liver disease
- 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

- NHS Blood and Transplant. Information concerning transplant activity by centre and nationally. www.organdonation.nhs.uk//statistics/
- NHS Blood and Transplant. Organ Donation and Transplantation Activity Report 2014/15. http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf
- British Association for the Study of the Liver and NHS Blood and Transplant. Guidelines for Referral for Liver Transplant Assessment. March 2012.

http://odt.nhs.uk/pdf/advisory_group_papers/LAG/referral_for_transplantation.pdf

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- Liver Advisory Group on behalf of NHS Blood and Transplant. Liver Transplantation: Selection Criteria and Recipient Registration. Policy POL195/6. Effective 02/05/17. http://odt.nhs.uk/pdf/liver_selection_policy.pdf
- Liver Advisory Group on behalf of NHS Blood and Transplant. Deceased Donor Liver Distribution and Allocation. Policy POL196/4.1. Effective 14/12/2015. http://odt.nhs.uk/pdf/liver_allocation_policy.pdf
- NHS England. Schedule 2 – The Services. A. Service Specifications. 170003/S. Liver Transplantation service (Adults). www.england.nhs.uk/wp-content/uploads/2017/04/liver-transplantation-service-adults.pdf
- NHS Blood and Transplant. Produced in collaboration with NHS England. Annual Report on Liver Transplantation. Report for 2014/2015 (1 April 2005 – 31 March 2015). Published September 2015. http://odt.nhs.uk/pdf/organ_specific_report_liver_2015.pdf
- NICE. Living-donor liver transplantation. Interventional procedures guidance [IPG535]. Published date: November 2015. www.nice.org.uk/guidance/ipg535

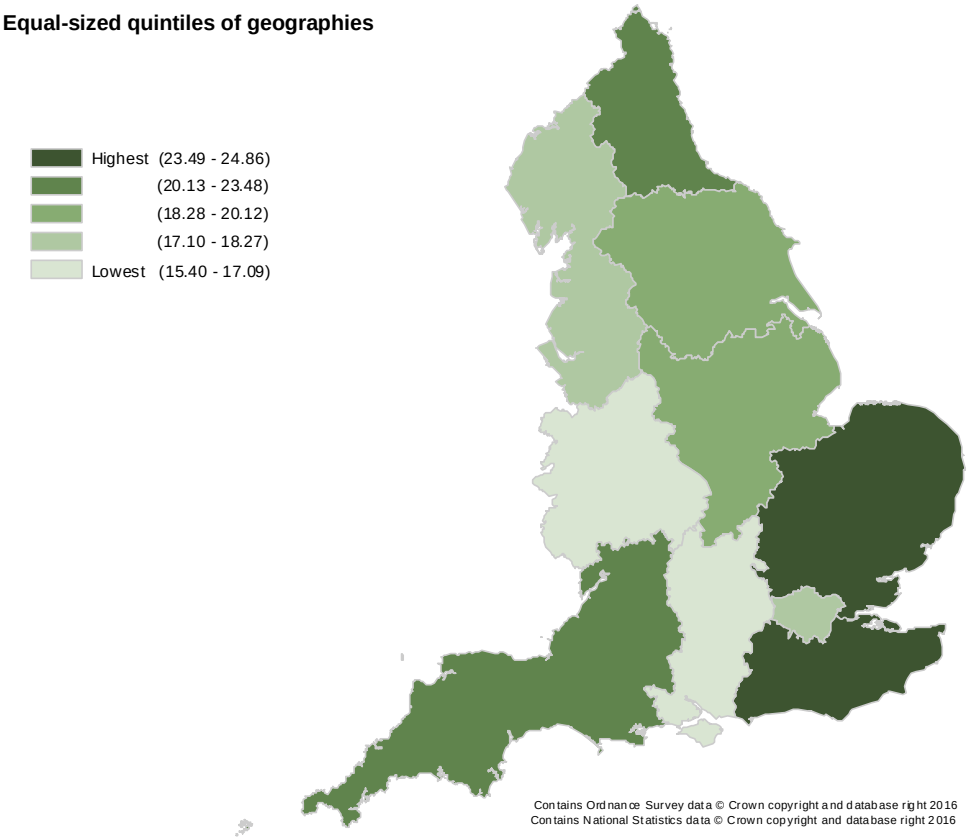
TRANSPLANTATION

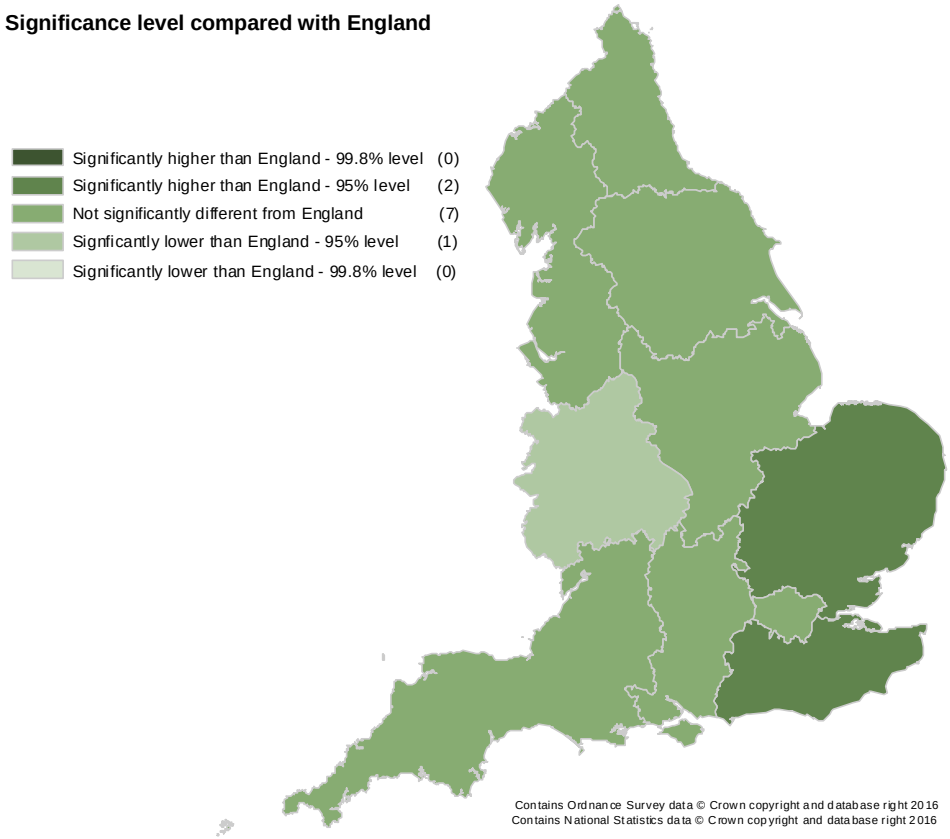
Map 23a: Variation in rate of organ donation from deceased donors per population by Strategic Health Authority (2014/15)

Crude rate per 1,000,000

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long-term conditions
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION





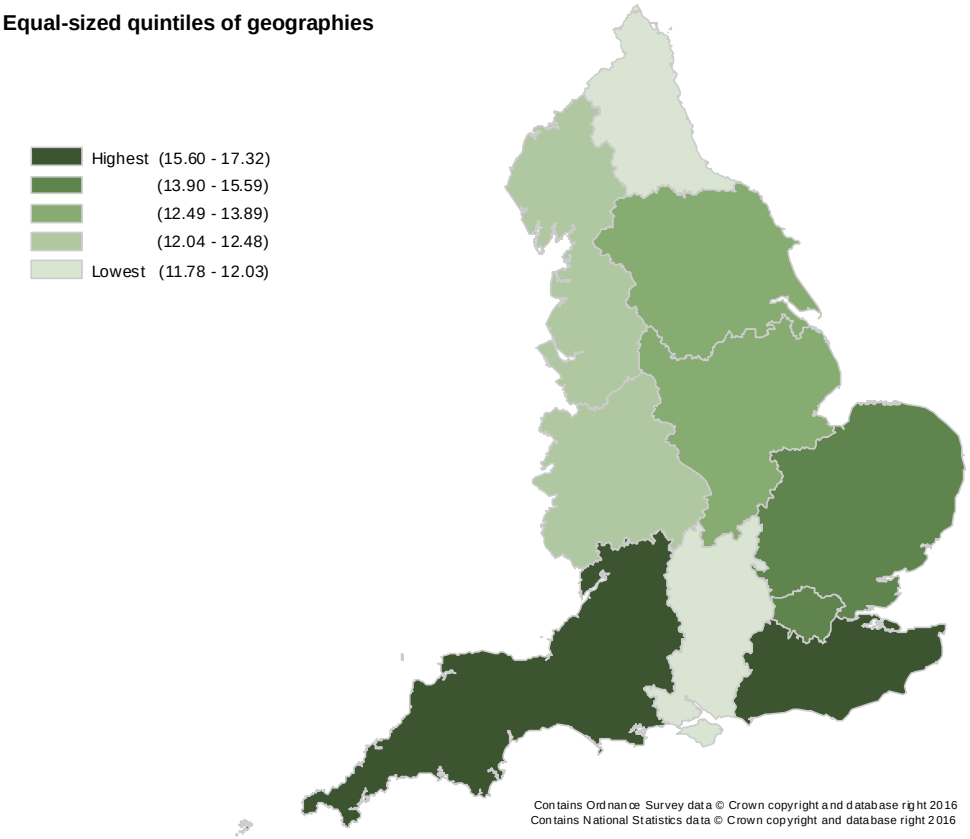
TRANSPLANTATION

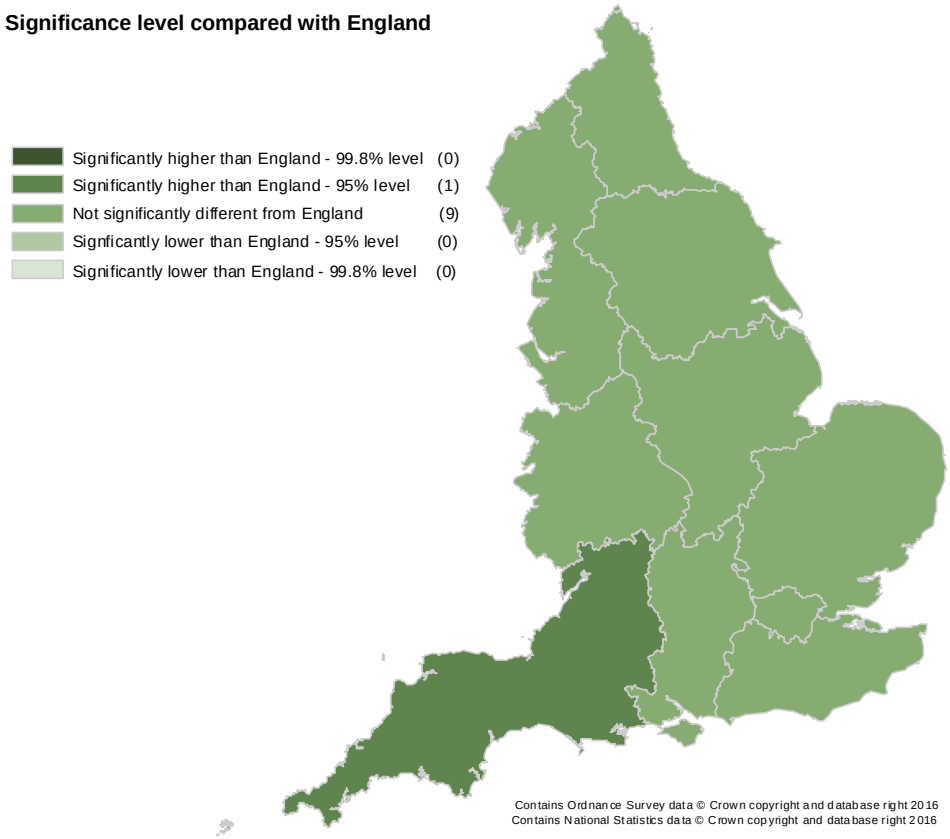
Map 23b: Variation in rate of liver donation from deceased donors per population by Strategic Health Authority (2014/15)

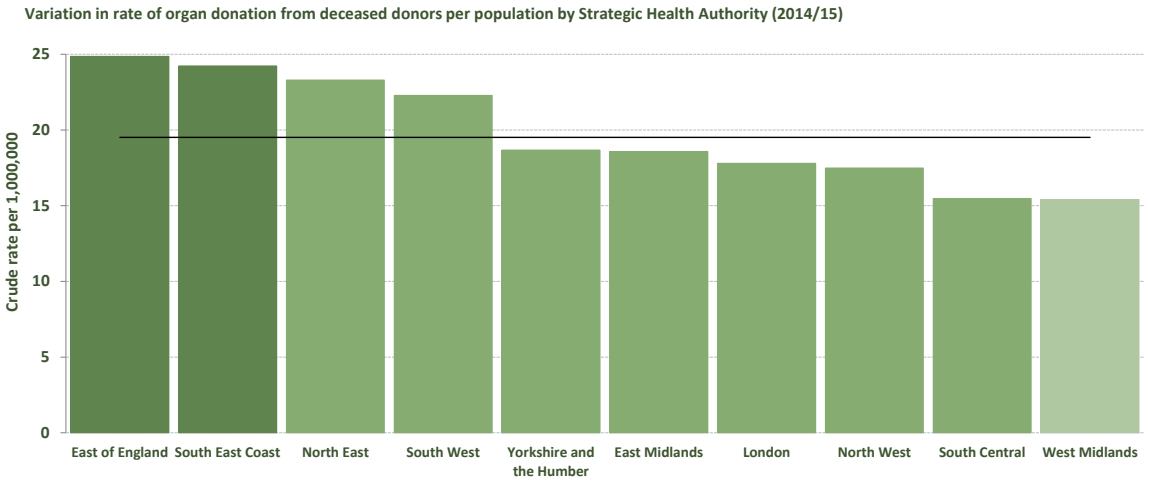
Crude rate per 1,000,000

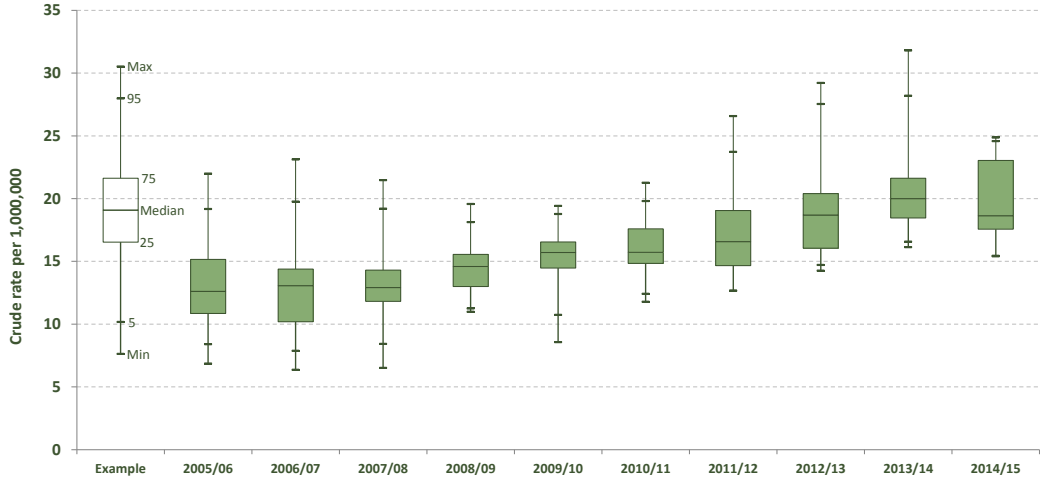
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long-term conditions
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION









Max-Min (Range)		15.1	16.8	15.0	8.6	10.9	9.5	13.9	15.0	15.7	9.5	No significant change
95th-5th percentile		10.8	11.9	10.8	6.9	8.0	7.4	11.1	12.8	11.6	9.1	No significant change
75th-25th percentile		4.3	4.2	2.5	2.6	2.1	2.7	4.4	4.3	3.2	5.5	No significant change
Median		12.6	13.1	12.9	14.6	15.7	15.7	16.6	18.7	20.0	18.6	INCREASING Significant

Context

In the Activity Report for 2015/16, NHS Blood and Transplant (NHSBT) highlight that organ donation is a relatively rare event.[1] Although about 500,000 people die in the UK each year, very few die in circumstances that enable their organs to be donated.[1] The collaborative UK strategy 'Taking Organ Donation to 2020' (see 'Resources') implemented in 2013, between the four UK health departments and NHSBT, was developed to increase the number of people who donate their organs after death.

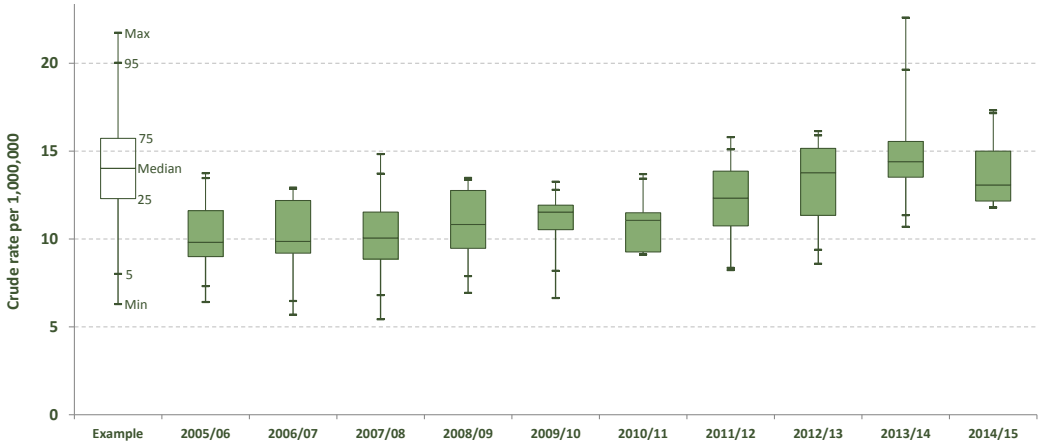
The aims of NICE guidance on organ donation for transplantation (CG135; see 'Resources') are:

- to promote discussion of organ donation as an integral part of end-of-life care
- to increase the number of organs available for people waiting for a transplant

In 2015/16 in England 1,134 people donated organs after their death, a rate of 20.9 per million population.[1] Although this represents an increase in the number of donors after death since 2008, the increase is mainly due to the expansion of programmes for donation after circulatory death and not to an increase in family consent rate. The UK has one of the lowest rates of family consent in countries with developed economies.[2] During 2015/16, 479 patients in the UK died while active/suspended on the transplant list or within one year of removal from the list.[1]

[1] NHS Blood and Transplant. Organ Donation and Transplantation. Activity Report 2015/16. https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1452/activity_report_2015_16.pdf
[2] The Scottish Government, Welsh Government, Department of Health, Department of Health, Social Services and Public Safety and NHS Blood and Transplant. Taking Organ Transplantation to 2020: A detailed strategy. [Not dated] www.nhsbt.nhs.uk/to2020/the-strategy

Variation in rate of liver donation from deceased donors per population by Strategic Health Authority (2014/15)



Max-Min (Range)		7.3	7.2	9.4	6.5	6.6	4.6	7.6	7.5	11.9	5.5	No significant change
95th-5th percentile		6.2	6.4	6.9	5.5	4.6	4.3	6.7	6.5	8.3	5.3	No significant change
75th-25th percentile		2.6	3.0	2.7	3.3	1.4	2.2	3.1	3.8	2.0	2.8	No significant change
Median		9.8	9.9	10.1	10.8	11.5	11.1	12.3	13.8	14.4	13.1	INCREASING Significant

The low consent rate is a challenge for all of society: improving the consent rate is the best opportunity to increase donor rates.[2] It is particularly important to increase donation rates in people from Black, Asian and minority ethnic (BAME) communities because the need for kidney transplants is high in these population groups: BAME groups in the UK represent 27% of people on the kidney transplant waiting list but only 5% of organ donors.[2]

There are two types of organ donation after death: donation after brain death (referred to as DBD) and donation after circulatory death (referred to as DCD). NHS Blood and Transplant defines eligible donors:

- after brain death as patients for whom death was confirmed following neurological tests and who had no absolute medical contraindications to solid organ donation[1]
- after circulatory death as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation[1]

Overall, on average, donors after circulatory death provide one less organ for transplantation than donors after brain death.[1] In England in 2015/16 the average number of organs donated per adult donor was 2.8 for circulatory death and 3.8 for brain death, partly because only 12% of donors after brain death were single-organ donors versus 47% of donors after circulatory death.[1]

Donor characteristics are changing: when compared with 2006/07, donors in 2015/16 tend to be older, more obese, less likely to have suffered a trauma-related death and more likely to have a more complex medical history, all of

which may have an adverse impact on the quality of organs and subsequent transplant outcomes.[1]

In 2015/16 for donors after brain death in the UK:

- the mean age was 51 years
- the mean body mass index (BMI) was 27[1]

In 2015/16 for donors after circulatory death in the UK:

- the mean age was 52 years
- the mean BMI was 27[1]

In 2015/16 in the UK only 6% of donors after brain death and only 3% of donors after circulatory death were from BAME groups, whereas these groups comprise 11% of the UK population.[1]

Focusing on liver donation from deceased donors in England in 2015/16, 845 donors donated their liver for transplant, a rate of 15.6 per million population: 597 were donors after brain death (11.0 per million population) and 248 were donors after circulatory death (4.6 per million population).[1] The mean age of deceased liver donors in the UK in 2015/16 was 50 years, and 5% of the deceased liver donors were from BAME groups.[1]

Magnitude of variation

Map 23a: Organ donation from deceased donors

The maps and column chart display the data for 2014/15, during which SHA values ranged from 15.4 to 24.9 per million population, which is a 1.6-fold difference between SHAs. The England value for 2014/15 was 19.5 per million population.

The boxplot shows the distribution of SHA values for the period 2005/06 to 2014/15. There was no significant change in any of the three variation measures between 2005/06 and 2014/15. The median increased significantly from 12.6 in 2005/06 to 18.6 per million population in 2014/15.

Map 23b: Liver donation from deceased donors

The maps and column chart display the data for 2014/15, during which SHA values ranged from 11.8 to 17.3 per million population, which is a 1.5-fold difference between SHAs. The England value for 2014/15 was 13.9 per million population.

The boxplot shows the distribution of SHA values for the period 2005/06 to 2014/15.
There was no significant change in any of the three variation measures between 2005/06 and 2014/15
The median increased significantly from 9.8 in 2005/06 to 13.1 per million population in 2014/15.

In a systematic review the following factors were found to affect views on organ donation after death:

- personal religious beliefs
- personal cultural beliefs
- family relationships
- knowledge of the organ donation process
- attitudes towards the healthcare system[3]

Options for action

NICE Guidance (CG135; see ‘Resources’) stipulates that every hospital should have a policy and protocol consistent with NICE recommendations for identifying patients who are potential donors and managing the consent process for deceased organ donation. In particular, service providers need:

[3] Irving MJ, Tong A, Jan S et al. Factors that influence the decision to be an organ donor: a systematic review of the qualitative literature. *Nephrology Dialysis Transplantation* 2012; 27: 2526-2533.

- to develop an approach where organ donation is viewed as a routine component of planning for end-of-life care
- using criteria laid out in NICE guidance CG135 to identify systematically patients who are potentially suitable donors as early as possible
- to ensure that healthcare teams caring for patients who are potentially suitable organ donors initiate discussions about potential organ donation with the specialist nurse for organ donation at the point in time when the criteria in NICE guidance CG135 have been met
- to ensure that multidisciplinary teams responsible for identification, referral and consent processes have the necessary skills and competencies, including knowledge of the basic principles and relative benefits of donation after brain death and donation after circulatory death, an understanding of the principles of the diagnosis of death using neurological or cardiorespiratory criteria and how they relate to the organ donation process, an ability to explain neurological death clearly to families, an understanding of the processes, policies and protocols relating to donor management and an ability to adhere to professional standards of practice about organ donation and end-of-life care
- to ensure consultant staff have the specific skills and knowledge needed, including knowledge of the law governing organ donation, knowledge of medical ethics relating to organ donation and skills in the diagnosis and confirmation of death using neurological or cardiorespiratory criteria

According to NICE guidance (CG135; see 'Resources') further research is needed to identify:

- why families refuse to give permission for organ donation
- the key components of an intervention aimed at improving rates of identification and the referral of potential donors
- the key components of an intervention aimed at improving consent rates
- whether a positive experience of approach and process of consent for families can increase the consent rate

RESOURCES

- The Scottish Government, Welsh Government, Department of Health, Department of Health, Social Services and Public Safety and NHS Blood and Transplant. Taking Organ Transplantation to 2020: A detailed strategy. www.nhsbt.nhs.uk/to2020/the-strategy
- NICE. Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation. Clinical guideline [CG135]. Published date: December 2011. Last updated: December 2016. www.nice.org.uk/guidance/cg135
- NICE interactive flowchart. Organ donation for transplantation overview. https://pathways.nice.org.uk/pathways/organ-donation-for-transplantation
- NHS Blood and Transplant. Organ Donation and Transplantation. Activity Report 2015/16. https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1452/activity_report_2015_16.pdf
- NHS Blood and Transplant. Organ Donation and Transplantation: Activity Report 2014/15. http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf
- NHS Blood and Transplant. Caring for Multi-Ethnic Communities: Religion, Culture and Organ Donation. http://odt.nhs.uk/pdf/caring_for_multi_ethnic_communities.pdf

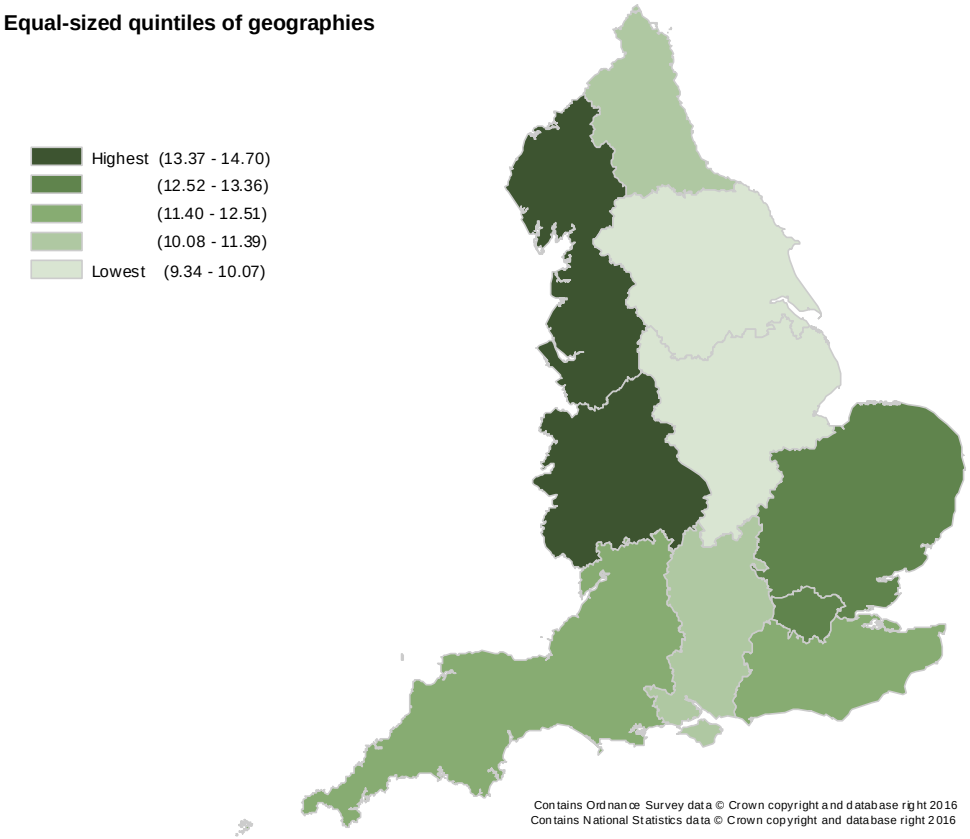
TRANSPLANTATION

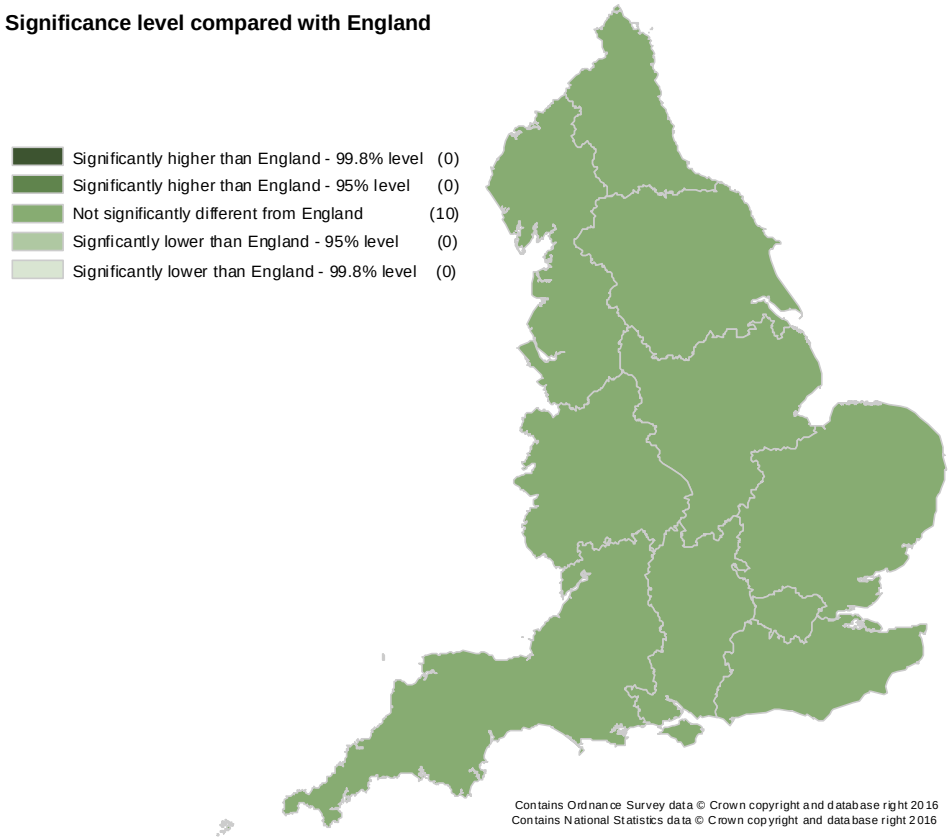
Map 24: Variation in rate of liver transplants from deceased donors per population by Strategic Health Authority (2014/15)

Crude rate per 1,000,000

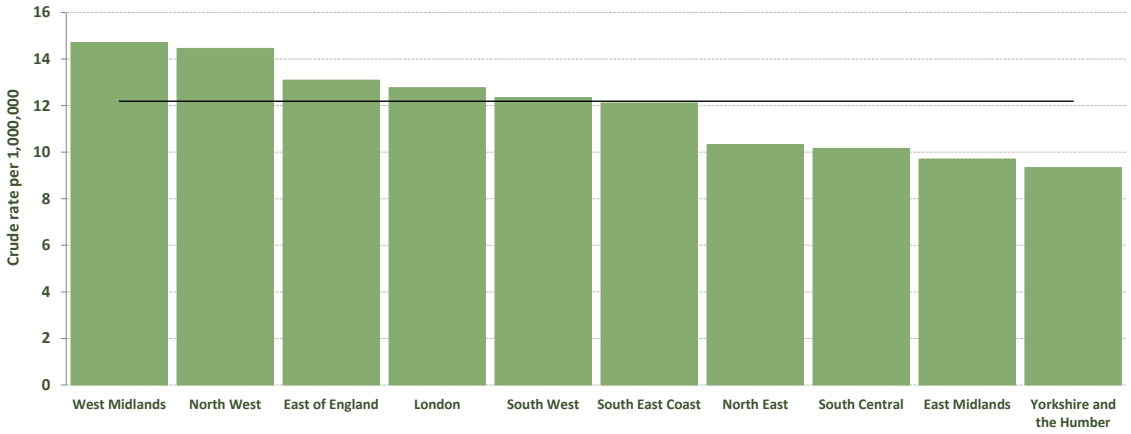
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 2: Enhancing quality of life for people with long term conditions
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
PHOF Domain 4: Healthcare public health and preventing mortality

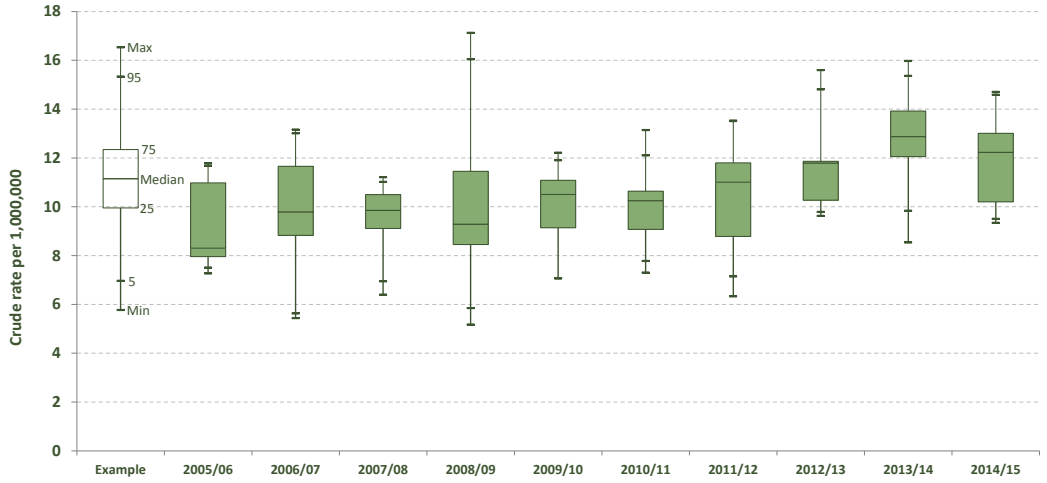
OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION





Variation in rate of liver transplants from deceased donors per population by Strategic Health Authority (2014/15)





Max-Min (Range)		4.5	7.7	4.8	12.0	5.2	5.8	7.2	6.0	7.4	5.4	No significant change
95th-5th percentile		4.2	7.4	4.1	10.2	4.8	4.3	6.4	5.0	5.5	5.1	No significant change
75th-25th percentile		3.0	2.8	1.4	3.0	1.9	1.6	3.0	1.6	1.9	2.8	No significant change
Median		8.3	9.8	9.9	9.3	10.5	10.3	11.0	11.8	12.9	12.2	INCREASING Significant

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 (see 'Resources'), and are reviewed regularly by the Liver Advisory Group for the Directorate of Organ Donation and Transplantation at NHS Blood and Transplant (NHSBT). Criteria for referral for consideration of transplantation are different from those for transplantation.

Selection for a transplant list, once referred, is carefully monitored. There are British Association for the Study of the Liver and NHSBT guidelines for referral to a transplant centre (see 'Resources') to ensure that individuals across the country have equal access to a transplant centre for prompt assessment of their liver disease. NHS Blood and Transplant have developed a universal allocation process, identical in all transplant centres (see 'Resources').

In the UK in 2014/15 the number of liver donors:

- after brain death was 684[1], which increased by 5% to 715 in 2015/16[2]
- after circulatory death was 240[1], which increased by 23% to 296 in 2015/16[2]

In the UK in 2014/15, 842 liver transplants were performed at six centres in England and one in Scotland as part of the

[1] NHS Blood and Transplant. Organ Donation and Transplantation Activity Report 2014/15. http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf
[2] NHS Blood and Transplant. Organ Donation and Transplantation. Activity Report 2015/16. https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1452/activity_report_2015_16.pdf

deceased donor liver programme[1] compared with 878 in 2015/16[2].

In 2014/15 the number of transplants from donors after brain death was 665[1] compared with 672 in 2015/16, an increase of 1%[2], whereas the number of transplants from donors after circulatory death was 177 in 2014/15[1] compared with 206 in 2015/16, an increase of 16%[2].

Of all liver transplants undertaken in adults in 2014/15 and in 2015/16, 12% were prioritised as 'super-urgent'[1,2], where patients need a new liver as soon as possible due to rapid failure of the native organ; the remainder of transplants are considered elective.

Survival following liver transplantation in the UK is good: for 2,141 transplants from 1 April 2011 to 31 March 2015, one-year survival for adult elective first transplants (unadjusted) was 93.4%.[3]

Demand continues to exceed the supply of organs donated: in 2014/15 more patients were registered for a liver transplant than there were organs available for transplantation.[1] At 31 March 2015 there were 611 patients on the active transplant list[1] compared with 584 at 31 March 2016, a decrease of 4%.[2] Since March 2008, however, the number of patients on the liver transplant list has doubled.[3]

In 2014/15 at one year post-registration 11% of patients with liver disease died while waiting for a liver transplant, or had been removed from the transplant list due to their condition deteriorating,[1] compared with 9% in 2015/16.[2]

Magnitude of variation

The maps and column chart display the data for 2014/15, during which SHA values ranged from 9.3 to 14.7 per million population, which is a 1.6-fold difference between SHAs. The England value for 2014/15 was 12.2 per million population.

The boxplot shows the distribution of SHA values for the period 2005/06 to 2014/15. There was no significant change in any of the three variation measures between 2005/06 and 2014/15. The median increased significantly from 8.3 in 2005/06 to 12.2 per million population in 2014/15.

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

- the prevalence of liver disease
- access to expertise in liver disease locally
- criteria for referral for assessment 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 service providers could:

- identify whether there are high mortality rates from liver disease 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 care pathways for patients with liver disease
- 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 patients to travel – this could be achieved via outreach networks from transplant and tertiary centres

RESOURCES

- NHS Blood and Transplant. Information concerning transplant activity by centre and nationally. www.organdonation.nhs.uk//statistics
- British Association for the Study of the Liver and NHS Blood and Transplant. Guidelines for Referral for Liver Transplant Assessment. March 2012.

[3] NHS Blood and Transplant. Produced in collaboration with NHS England. Annual Report on Liver Transplantation. Report for 2015/2016 (1 April 2006 – 31 March 2016). Published September 2016. https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1314/organ_specific_report_liver_2016.pdf

http://odt.nhs.uk/pdf/advisory_group_papers/LAG/referral_for_transplantation.pdf

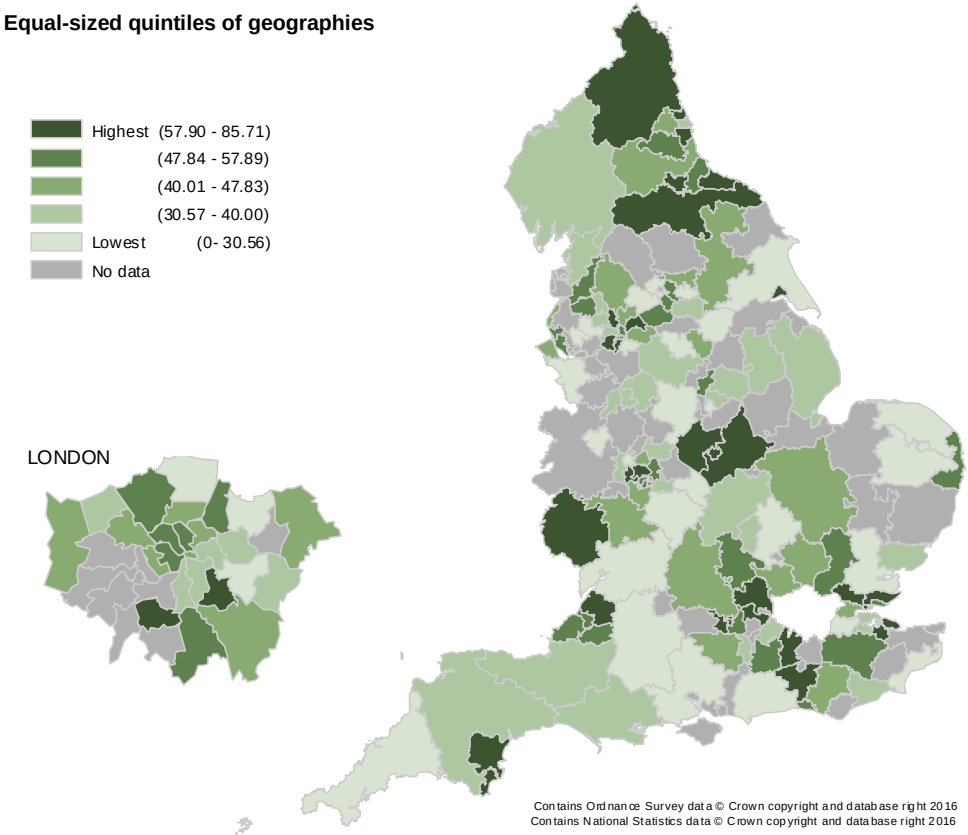
- NHS Blood and Transplant. Introduction to Patient Selection and Organ Allocation Policies. Policy POL200/3. Effective 08/12/2015. https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/4357/introduction_to_selection_and_allocation_policies.pdf
- Liver Advisory Group on behalf of NHS Blood and Transplant. Liver Transplantation: Selection Criteria and Recipient Registration. Policy POL195/6. Effective 02/05/17. http://odt.nhs.uk/pdf/liver_selection_policy.pdf
- Liver Advisory Group on behalf of NHS Blood and Transplant. Deceased Donor Liver Distribution and Allocation. Policy POL196/4.1. Effective 14/12/2015. http://odt.nhs.uk/pdf/liver_allocation_policy.pdf
- NHS England. Schedule 2 – The Services. A. Service Specifications. 170003/S. Liver Transplantation service (Adults). www.england.nhs.uk/wp-content/uploads/2017/04/liver-transplantation-service-adults.pdf
- NHS Blood and Transplant. Produced in collaboration with NHS England. Annual Report on Liver Transplantation. Report for 2014/2015 (1 April 2005 – 31 March 2015). Published September 2015. https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1314/organ_specific_report_liver_2016.pdf
- NHS Blood and Transplant. Organ Donation and Transplantation. Activity Report 2014/15. http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf
- NHS Blood and Transplant. Organ Donation and Transplantation. Activity Report 2015/16. https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1452/activity_report_2015_16.pdf

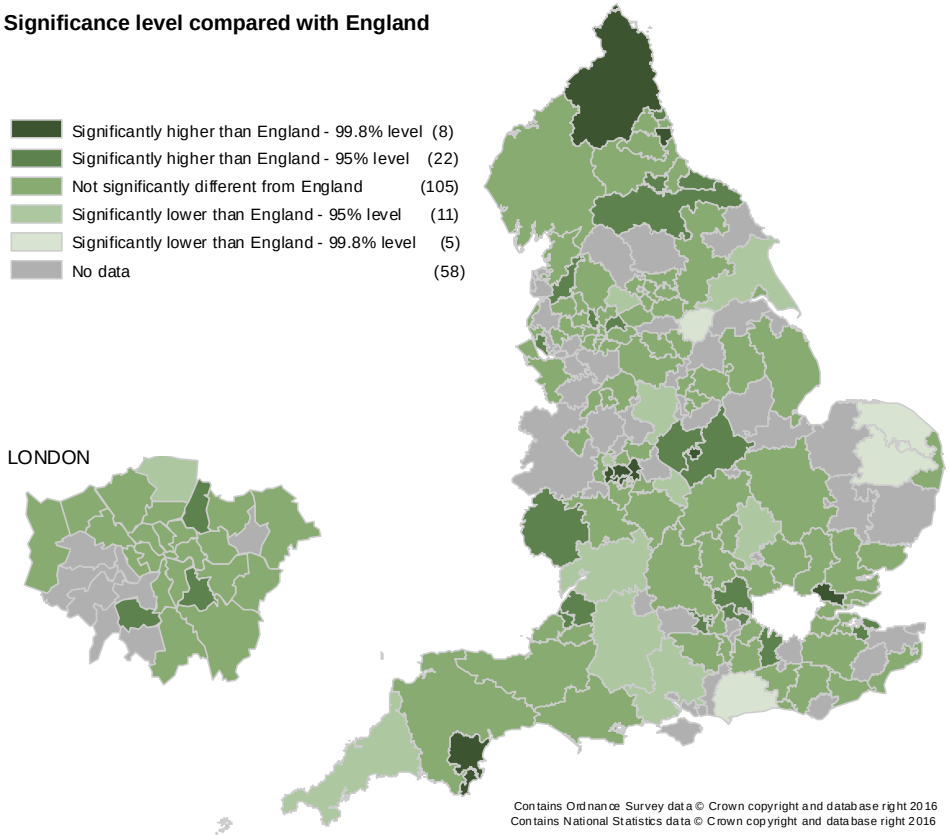
MANANGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

Map 25: Variation in percentage of admissions for oesophageal varices procedure that were emergency admissions by CCG (2014/15)

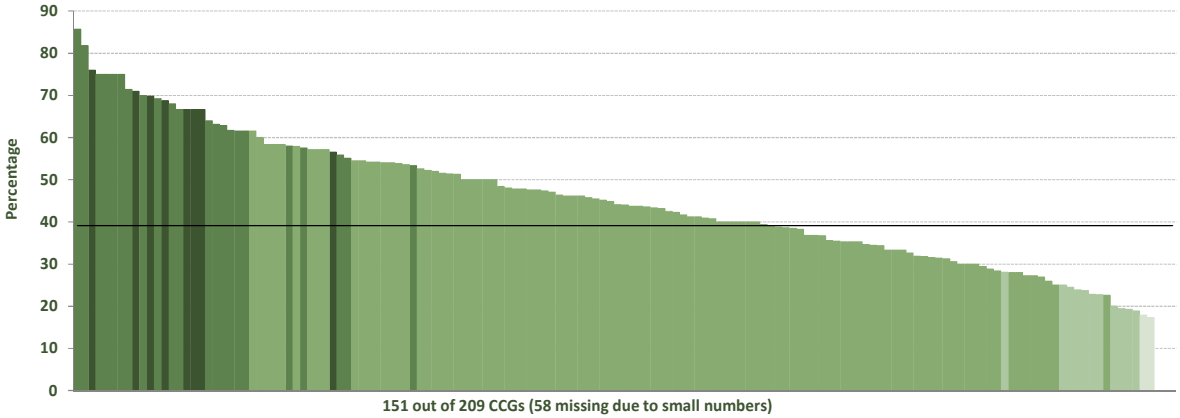
NHS Domain 1: Ensuring that people have a positive experience of care
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW





Variation in percentage of admissions for oesophageal varices procedure that were emergency admissions by CCG (2014/15)



Max-Min (Range)		100.0	100.0	100.0	100.0	100.0	93.3	100.0	85.7	100.0	85.7	No significant change
95th-5th percentile		40.0	59.8	67.2	73.3	54.3	61.7	58.4	62.0	55.0	51.4	No significant change
75th-25th percentile		18.3	27.7	26.3	23.1	20.6	26.4	25.1	24.2	22.3	21.5	No significant change
Median		81.8	57.5	55.8	50.0	47.1	46.9	42.2	40.6	40.8	44.0	DECREASING Significant

Context

Varices are blood vessels which form as a consequence of portal hypertension (high pressure in the portal vein - the main blood supply to the liver). This is most commonly caused by scarring from cirrhosis. Varices can occur throughout the GI tract however are most commonly found in the lower oesophagus. Varices are at risk of bleeding, which can vary in severity from a small ooze to a life threatening haemorrhage.[1]

The majority of patients with variceal bleeding have chronic liver disease, and oesophageal varices are a significant complication of cirrhosis. Although there are many causes of cirrhosis, alcohol consumption is the most common in the UK. NASH, viral hepatitis and autoimmune disorders are the next most common.

The size of the varices is directly related to the blood pressure in the portal vein, which in most cases is directly related to the severity of the underlying liver disease. Portal hypertension is seen in people with moderately advanced liver disease, which may be accompanied by other symptoms such as ascites (fluid in the abdomen; see Map 26) and encephalopathy (disturbance of brain function as a result of the impaired ability of the liver to detoxify proteins).

Vomiting blood secondary to varices is a sign of advanced cirrhosis of the liver. If bleeding occurs, it is characteristically severe, can be life-threatening and therefore requires urgent medical attention. Early intervention is usually effective and reduces the risk of further complications.

[1] British Liver Trust. Portal Hypertension. www.britishlivertrust.org.uk/liver-information/liver-conditions/portal-hypertension/. Accessed 5th June 2017.

Several procedures can be used to stop the bleeding and reduce the risk of recurrence:

- Drug treatment with terlipression by intravenous injection
- Banding – using endoscopy a small band is inserted around the base of the varix to control the bleeding
- Injection sclerotherapy – during endoscopy a sclerosant material is injected into the varices to induce blood-clotting and thereby stop the bleeding
- Transjugular intrahepatic portosystemic stent shunt (TIPSS), in which a stent is radiologically cited between hepatic and portal veins to reduce portal pressure and thereby reduce the risk of bleeding and/or the severity of a bleed

The use of the Sengstaken tube, where the tube is passed into the stomach and inflated putting pressure on the varices to stop the bleeding is now much rarer since the advent of the endoscopy.

Unless oesophageal varices bleed, they do not generate any other signs or symptoms. It is possibly to quantify size and location of varices using endoscopy.

It is possible to reduce the risk of variceal bleeding through the use of beta blockers, such as propranolol, which reduce portal pressure. Drug treatment can also be used to reduce the severity of a bleed should one occur.

Primary prophylaxis of variceal bleeding reduces risk of haemorrhage. This can be achieved using drug treatments (e.g. propranolol) to reduce pressure in the portal vein, or through an elective programme of variceal band ligation.

Magnitude of variation

The maps and column chart display the 2014/15 data, during which CCG values ranged from 0.0% to 85.7%. The England value for 2014/15 was 39.1%.

The boxplot shows the distribution of CCG values for the period 2005/06 to 2014/15.There was no significant change in any of the three variation measures between 2005/06 and 2014/15, however the median decreased significantly from 81.8% in 2005/06 to 44.0% in 2014/15.

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

- the organisation of services
- the availability of specialists

Options for action

When planning service improvement or development to reduce emergency admissions for oesophageal varices, commissioners, clinicians and service providers need:

- to review the emergency admission rate for oesophageal varices in the locality
- to identify opportunities for improving the early diagnosis of cirrhosis and other types of liver damage
- to improve the prevention and treatment of oesophageal varices
- to review the clinical management of and configuration of services for liver disease to ensure close collaboration among the different disciplines – hepatology, diagnostic pathology and radiology services, interventional radiology and liver surgery including resection and transplantation

RESOURCES

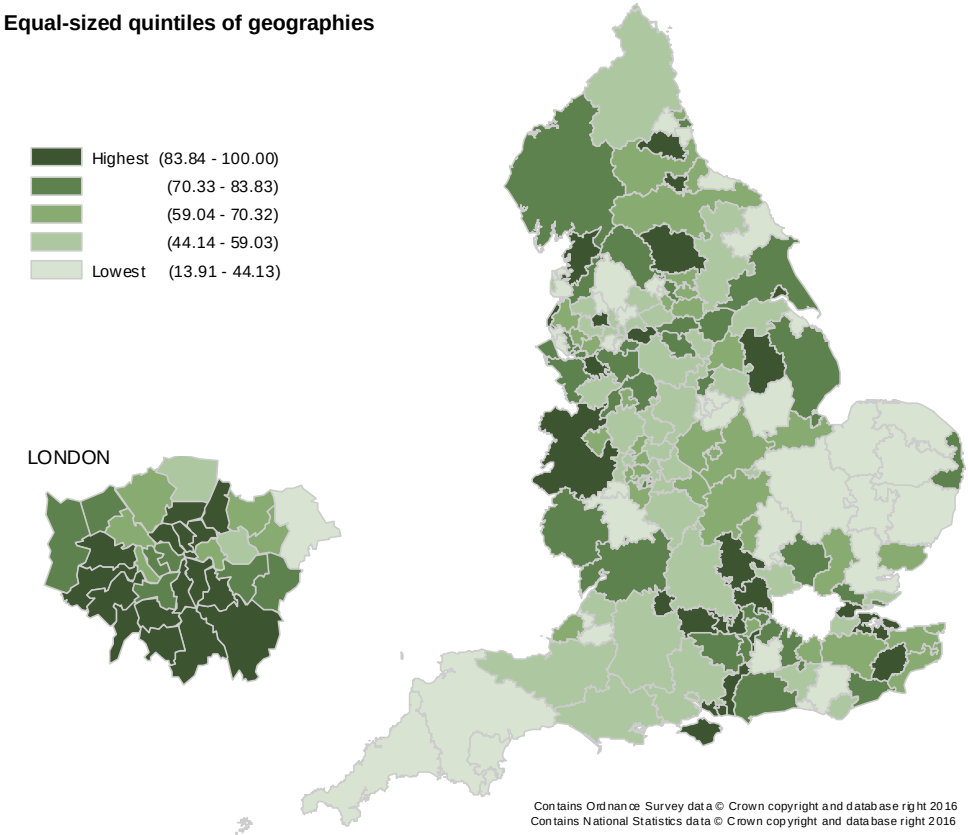
- Tripathi D, et al. UK guidelines on the management of variceal haemorrhage in cirrhotic patients. Gut 2015;64:1680–1704. http://dx.doi.org/10.1136/gutjnl-2015-309262
- BMJ Best Practice. Oesophageal varices – management approach. Updated Jan 12 2017. http://bestpractice.bmj.com/best-practice/monograph/815/treatment/step-by-step.html
- NICE. Cirrhosis in over 16s: assessment and management. NICE guideline [NG50]. July 2016. www.nice.org.uk/guidance/ng50
- NICE. NICE Interactive pathway. Cirrhosis overview. https://pathways.nice.org.uk/pathways/cirrhosis

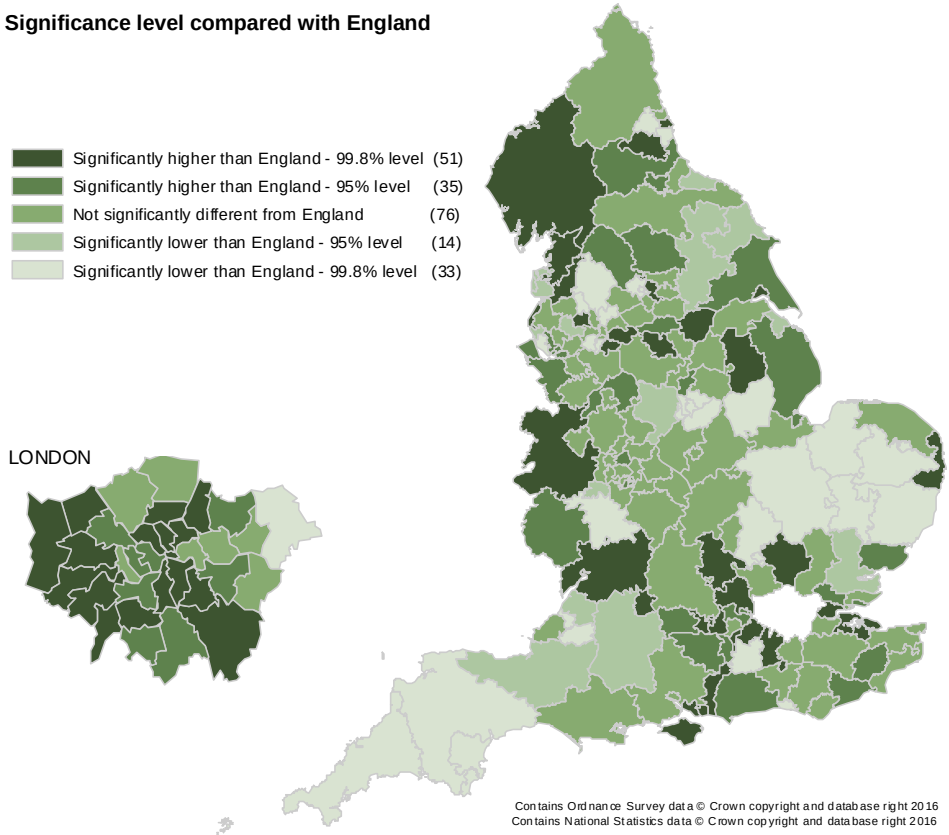
MANANGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

Map 26: Variation in percentage of admissions for paracentesis procedure that were emergency admissions by CCG (2014/15)

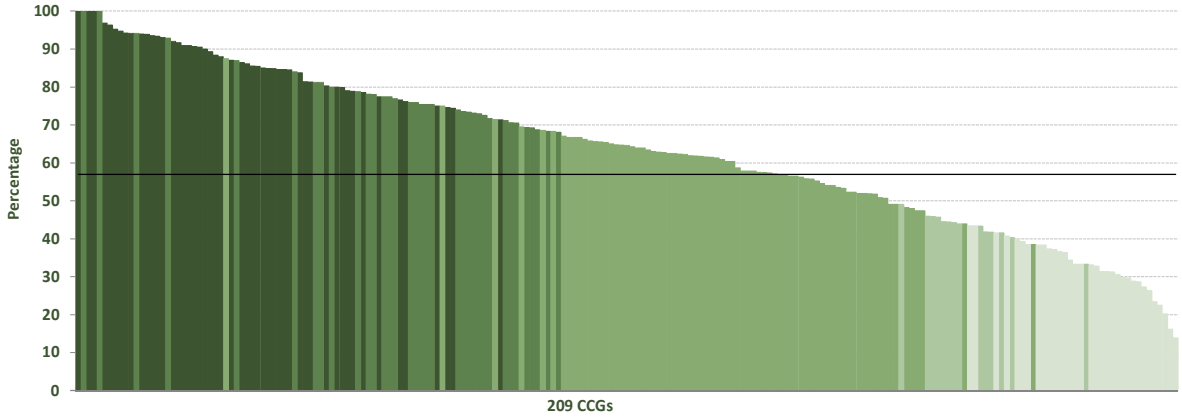
NHS Domain 1: Ensuring that people have a positive experience of care
NHS Domain 3: Helping people to recover from episodes of ill health or following injury
PHOF Domain 4: Healthcare public health and preventing premature mortality

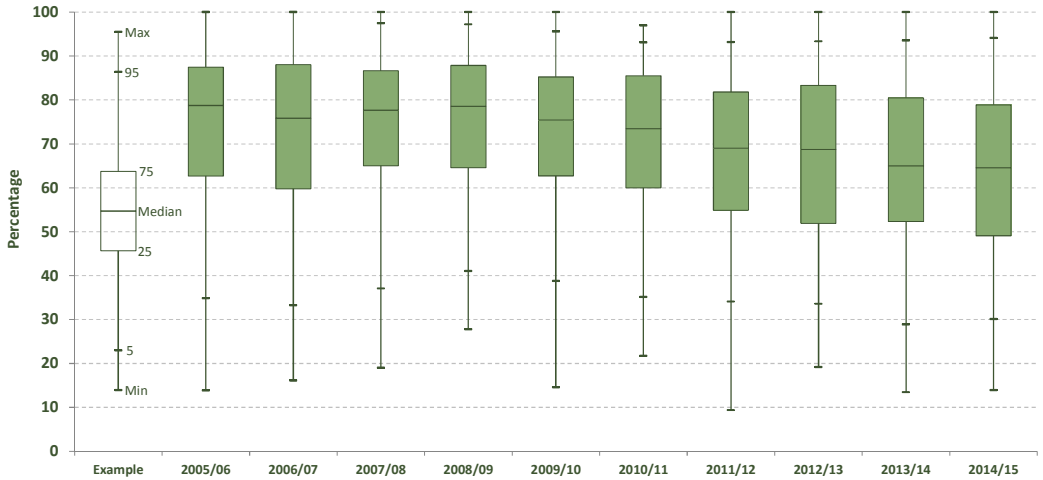
OPTIMUM VALUE: LOW





Variation in percentage of admissions for paracentesis procedure that were emergency admissions by CCG (2014/15)





Max-Min (Range)		86.2	83.9	81.0	72.2	85.4	75.2	90.6	80.9	86.6	86.1	No significant change
95th-5th percentile		65.1	66.8	60.4	56.1	56.8	57.9	59.1	59.8	64.7	64.0	No significant change
75th-25th percentile		24.8	28.2	21.6	23.3	22.5	25.5	26.9	31.4	28.2	29.8	No significant change
Median		78.8	75.9	77.7	78.6	75.4	73.5	69.0	68.8	65.0	64.6	DECREASING Significant

Context

Ascites is the accumulation of fluid in the peritoneal cavity, which develops as complication of portal hypertension.

Ascites is the most common complication of cirrhosis, and is associated with a poorer prognosis and an impaired quality of life.[1]

Ascites can cause a variety of symptoms including abdominal discomfort, poor appetite, shortness of breath, indigestion, nausea, and reduced mobility. Ascitic fluid can become infected (spontaneous bacterial peritonitis, SBP), which can be life-threatening unless treated with antibiotics.

To relieve the symptoms of ascites it is necessary to remove excess fluid from the abdomen. This can be done using treatment with diuretic drugs, usually spironolactone or furosemide, or by a large volume paracentesis procedure.

Large volume paracentesis involves insertion of a needle and tube into the peritoneal cavity to drain the fluid. It is a safe procedure and less than 1% of people experience a significant side-effect. Large volume paracentesis is a quick (6 hours) method of removing fluid from the abdomen and may be used when diuretic treatment:

- has caused side-effects
- has ceased to have an effect
- may take a long period of time (weeks) over which to have an effect

Patients can be managed as planned day cases but in many services they get repeatedly readmitted as

[1] Moore K.P. and Aithal G.P. Guidelines on the management of ascites in cirrhosis. GUT 2006;55;1-12; http://dx.doi.org/10.1136/gut.2006.099580

emergencies, often staying in hospital for several days while they have their paracentesis procedure.

Magnitude of variation

The maps and column chart display the data for 2014/15 for the percentage of admissions for paracentesis procedures that were emergency admissions to hospital, during which CCG values ranged from 13.9% to 100.0%, which is a 7.2-fold difference between CCGs. The England value for 2014/15 was 57.0%.

The boxplot shows the distribution of CCG values for the period 2005/06 to 2014/15. There was no significant change in any of the three variation measures between 2005/06 and 2014/15, however the median decreased significantly from 78.8% in 2005/06 to 64.6% in 2014/15.

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

- rates of advance care planning to work with patients to plan admissions rather than wait for emergency admissions
- the configuration of local services with differing availability of staff and facilities to provide day case paracentesis

Options for action

Prevention of ascites involves good management of liver disease, including aspects of self-management:

- dietary - reducing salt intake, and changing the type and amount of food eaten and number of times a day food is eaten (snacking on small amounts)
- abstinence from alcohol

When planning service improvement or development to reduce emergency admissions for paracentesis procedures, commissioners, clinicians and service providers need:

- to review the emergency admission rate for paracentesis in the locality
- to identify opportunities for establishing day case paracentesis procedures
- to consider discussing advance care planning with those patients not suitable for transplantation

RESOURCES

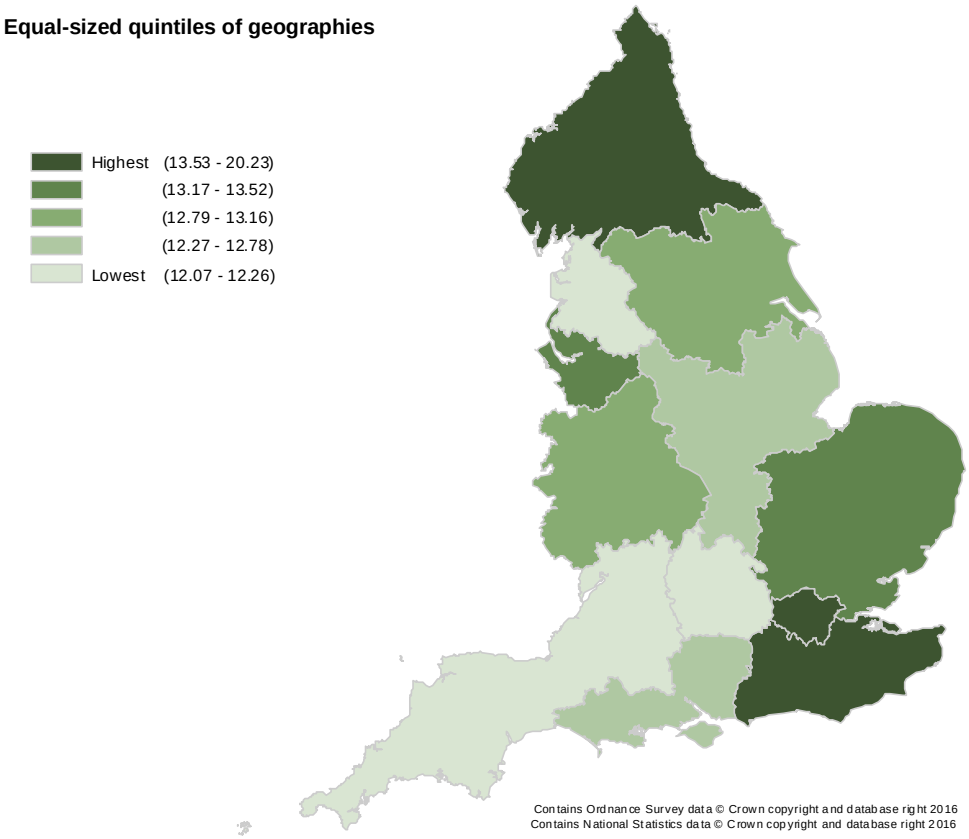
- Moore K.P. and Aithal G.P. Guidelines on the management of ascites in cirrhosis. GUT 2006;55;1-12; http://dx.doi.org/10.1136/gut.2006.099580
- NICE. Cirrhosis in over 16s: assessment and management. NICE guideline [NG50]. July 2016. www.nice.org.uk/guidance/ng50
- NICE. NICE Interactive pathway. Cirrhosis overview. https://pathways.nice.org.uk/pathways/cirrhosis
- Subcutaneous implantation of a battery-powered catheter drainage system for managing recurrent and refractory ascites. Interventional procedures guidance [IPG479]. February 2014. www.nice.org.uk/guidance/ipg479

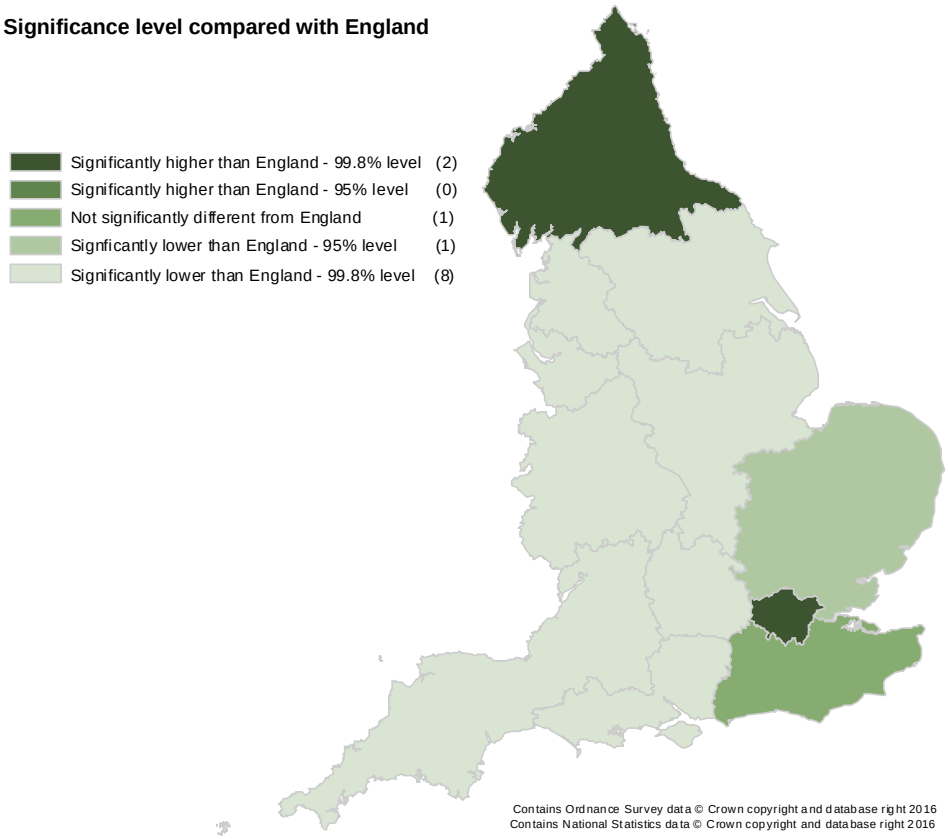
MANAGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

Map 27a: Variation in mean number of bed-days per liver disease patient admitted to hospital in the last year of life by Strategic Clinical Network (SCN) (2015)

NHS Domain 1: Preventing people from dying prematurely
NHS Domain 4: Ensuring that people have a positive experience of care
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION





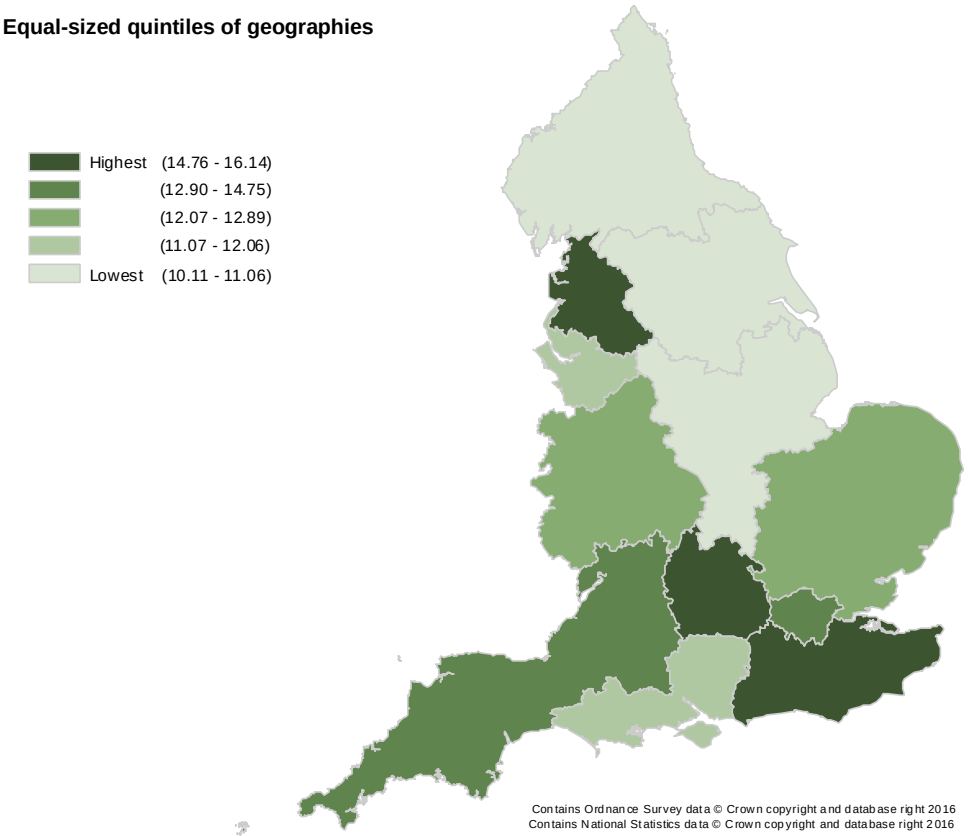
MANAGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

Map 27b: Variation in percentage of liver disease patients who died without being admitted to hospital in the last year of life by Strategic Clinical Network (SCN) (2015)

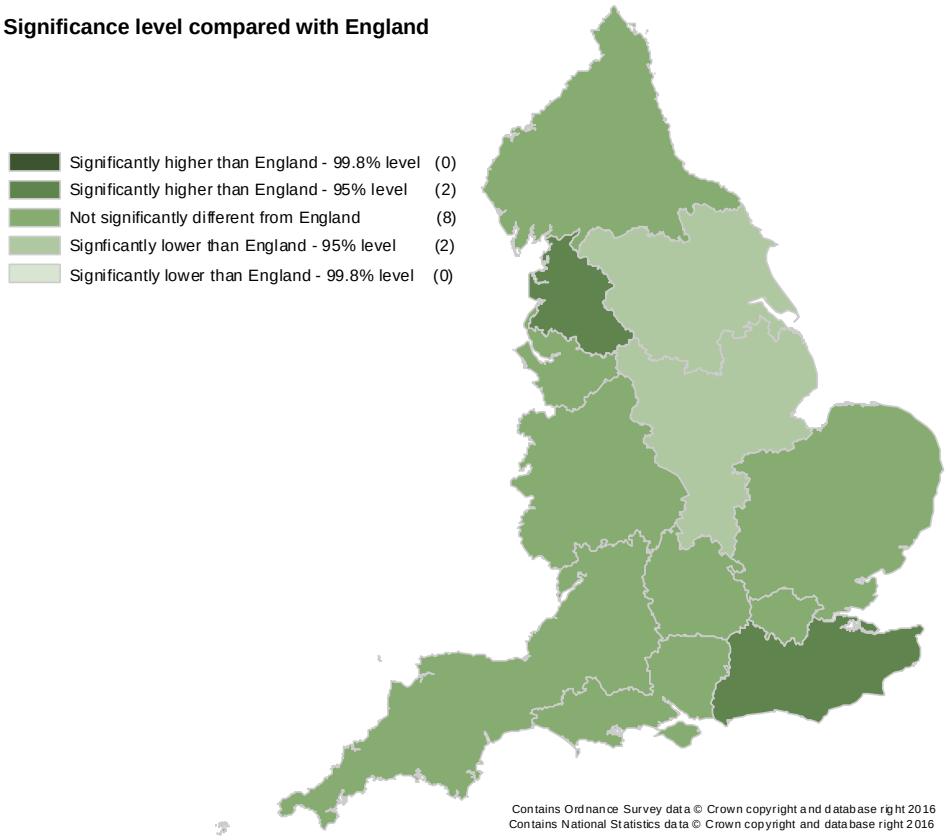
NHS Domain 1: Preventing people from dying prematurely
NHS Domain 4: Ensuring that people have a positive experience of care
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION

Equal-sized quintiles of geographies



Significance level compared with England



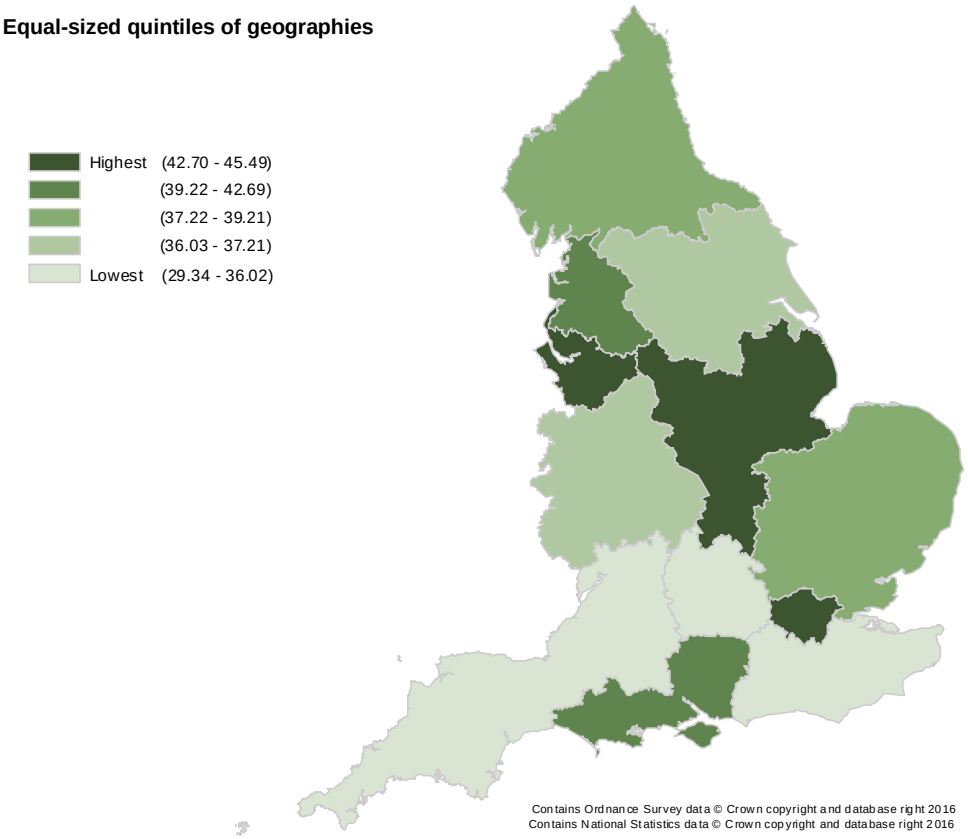
MANAGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

Map 27c: Variation in percentage of liver cancer deaths that occurred in hospital among all care facilities by Strategic Clinical Network (SCN) (2015)

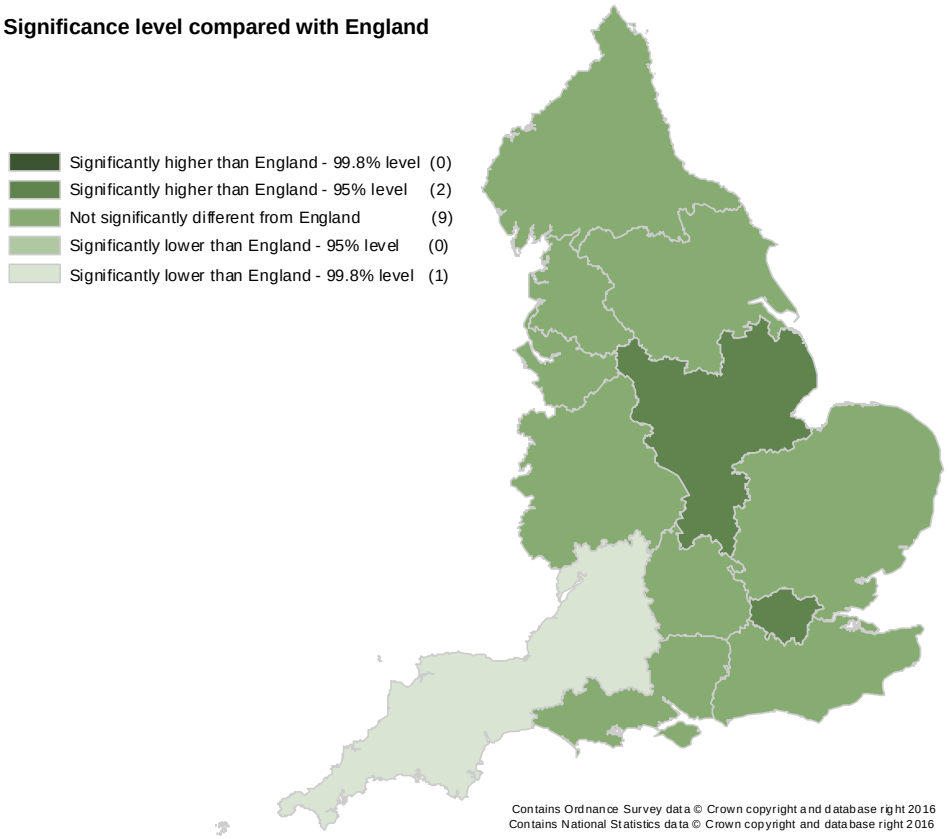
NHS Domain 4: Ensuring that people have a positive experience of care
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW

Equal-sized quintiles of geographies



Significance level compared with England



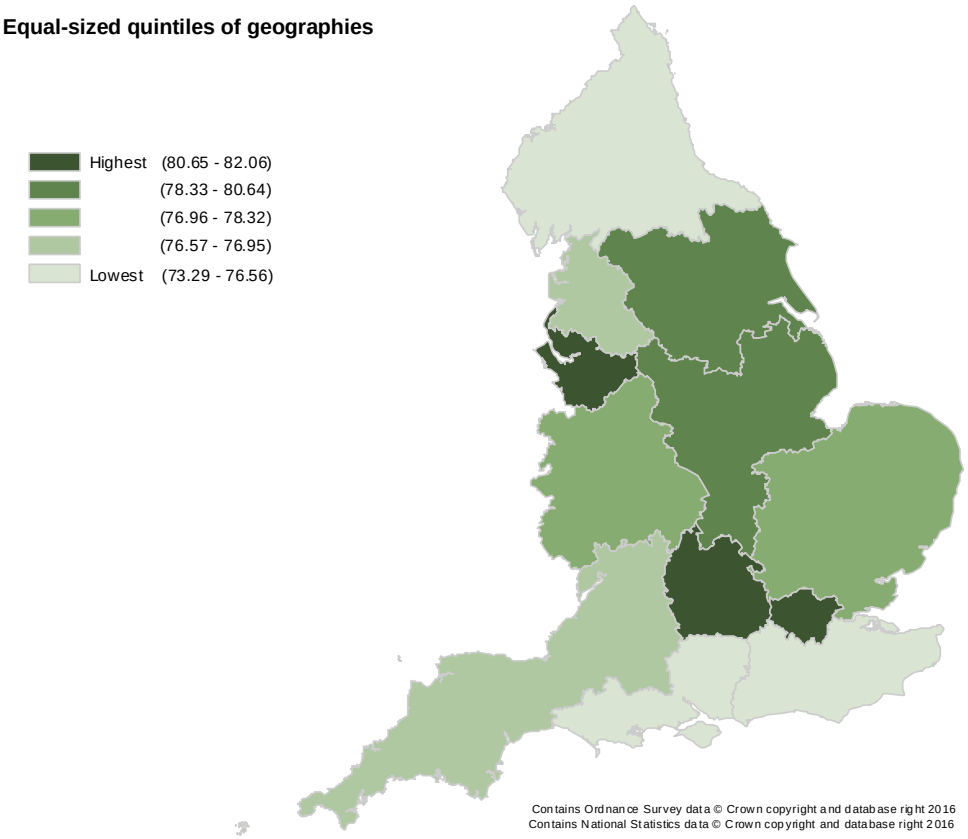
MANAGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

Map 27d: Variation in percentage of liver non-cancer deaths that occurred in hospital among all care facilities by Strategic Clinical Network (SCN) (2015)

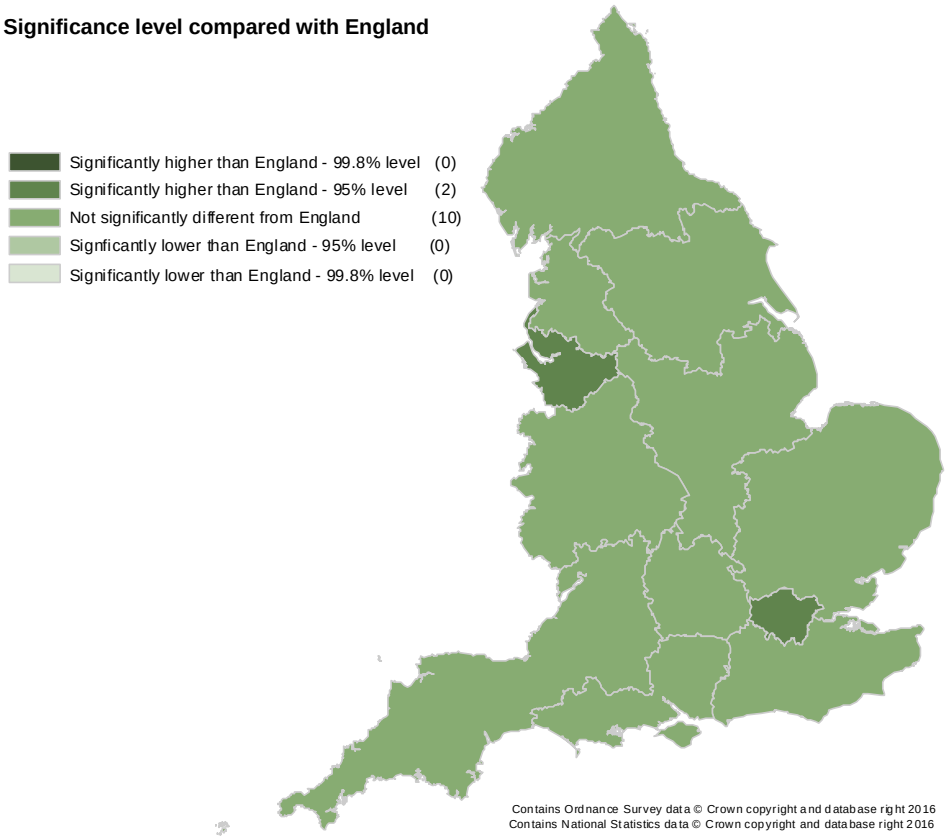
NHS Domain 4: Ensuring that people have a positive experience of care
PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW

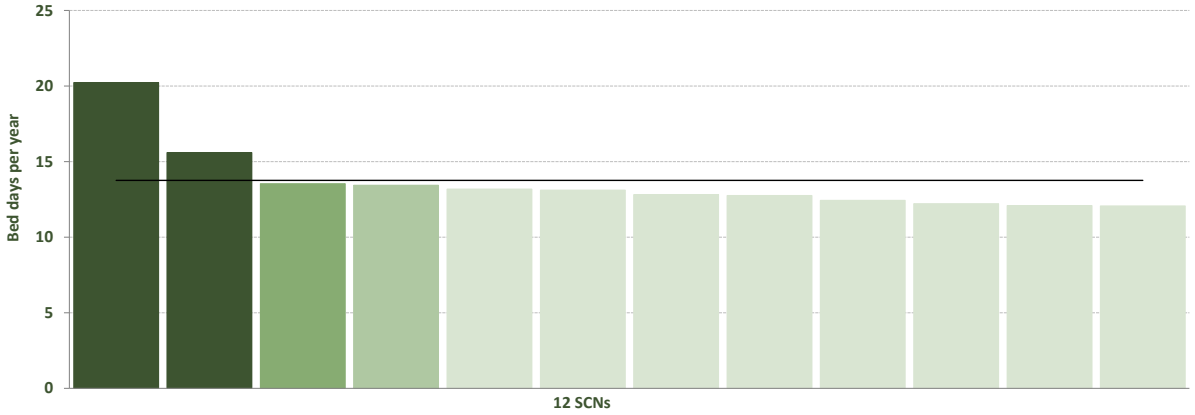
Equal-sized quintiles of geographies



Significance level compared with England



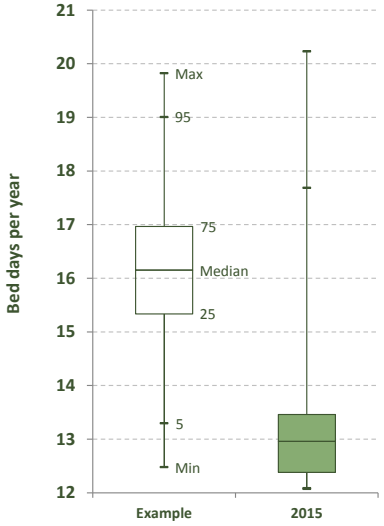
Variation in mean number of bed-days per liver disease patient admitted to hospital in the last year of life by Strategic Clinical Network (SCN) (2015)



Context

Liver disease is associated with an extensive illness burden towards the end-of-life. The typical clinical course is of gradual decline interspersed with episodes of acute deterioration – commonly requiring hospital admission.[1] Patients dying from end-stage liver disease suffer high levels of physical and psychological distress. Bereaved family members report poor experiences of end of life care for their loved ones and high levels of their own psychological distress.

Although a small proportion of patients with end-stage liver disease may be suitable for curative treatment through liver transplantation this option is unsuitable for the majority of patients. Patients, for whom curative options have been exhaustive, may stand to benefit from end-of-life care planning, in particular an exploration of their choices for place of care and death once they are made aware that their condition is likely to be fatal. These choices can be recorded in an Advance Care Plan or Directive which can be shared with other health professionals.

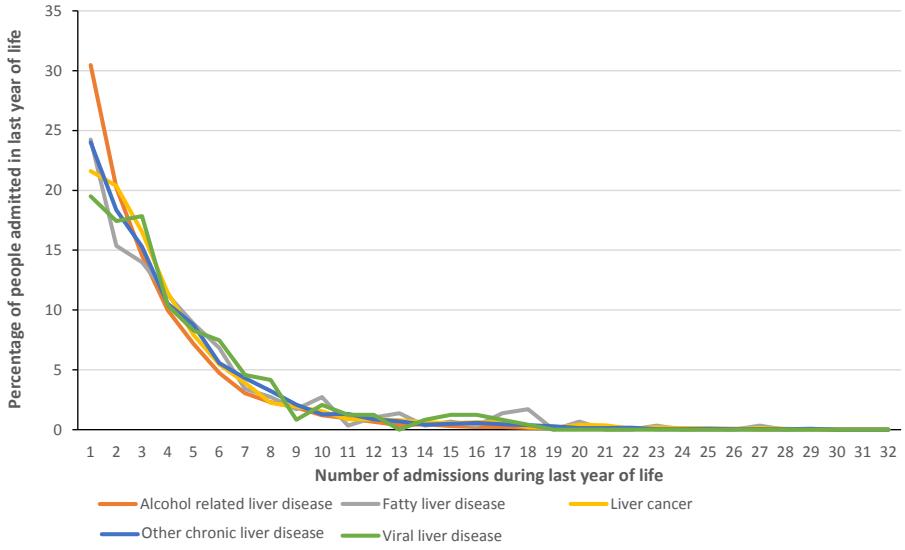


Max-Min (Range)		8.2
95th-5th percentile		5.6
75th-25th percentile		1.1
Median		13.0

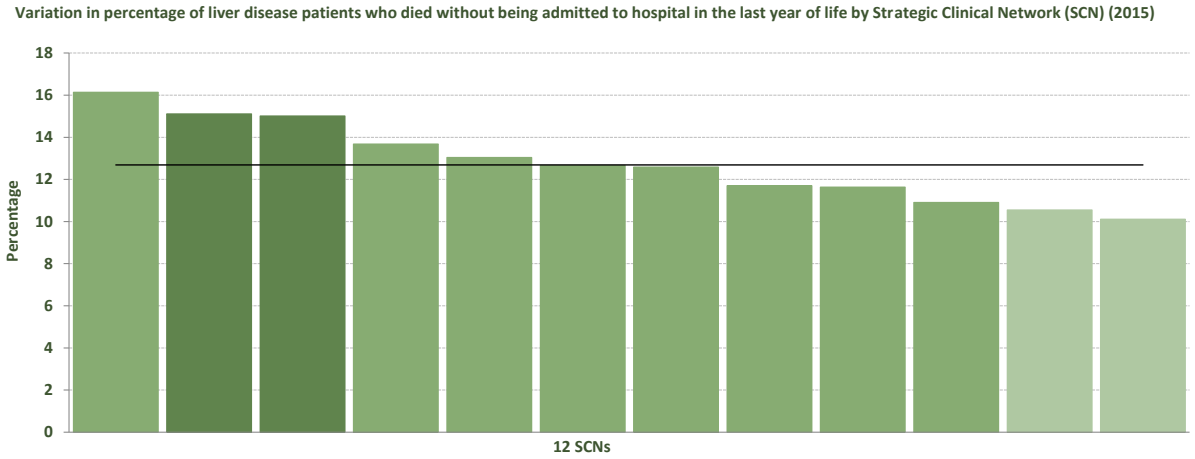
The majority of liver disease patients (90%) are admitted into hospital in the last year of life and many have multiple admissions as illustrated in Figure 27.1 below.

1 in 5 people who die from liver disease have five or more admissions in their last year of life.

Figure 27.1: Distribution of people who died from liver disease by number of hospital admissions in last year of life

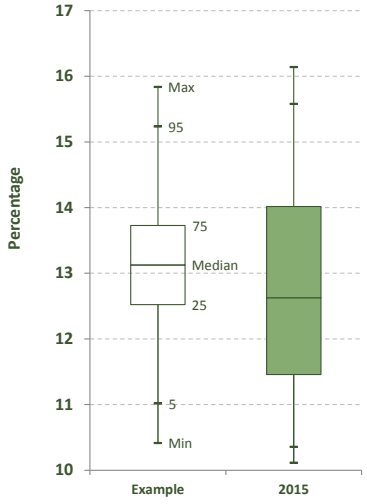


[1] Kendrick E. Getting it right: Improving end of life care for people living with liver disease. *London: Department of Health* 2013.
www.yhln.org.uk/data/documents/2013/NHS%20Liver%20Care,%20Getting%20it%20Right%20-%20Improving%20End%20of%20Life%20Care%20for%20People%20with%20Liver%20Disease.pdf



The mean number of bed-days (Map 27a) per liver disease patient admitted to hospital in the last year of life is a proxy measure of quality. Several factors may influence the mean number of bed-days including number of admissions, severity of disease, social circumstances and support and provision of health and social care in the community. This indicator also reflects the pressure placed on acute hospital services related to the inpatient care of liver disease patients in their last year of life. It is notable because of the degree of geographical variation.

In sharp contrast, Map 27b focuses on variation in the percentage of liver disease patients who died without being admitted to hospital in the last year of life. This new indicator looks at the percentage of patients who died with liver disease recorded as the underlying cause of death but who were not admitted to hospital in their last year of life.



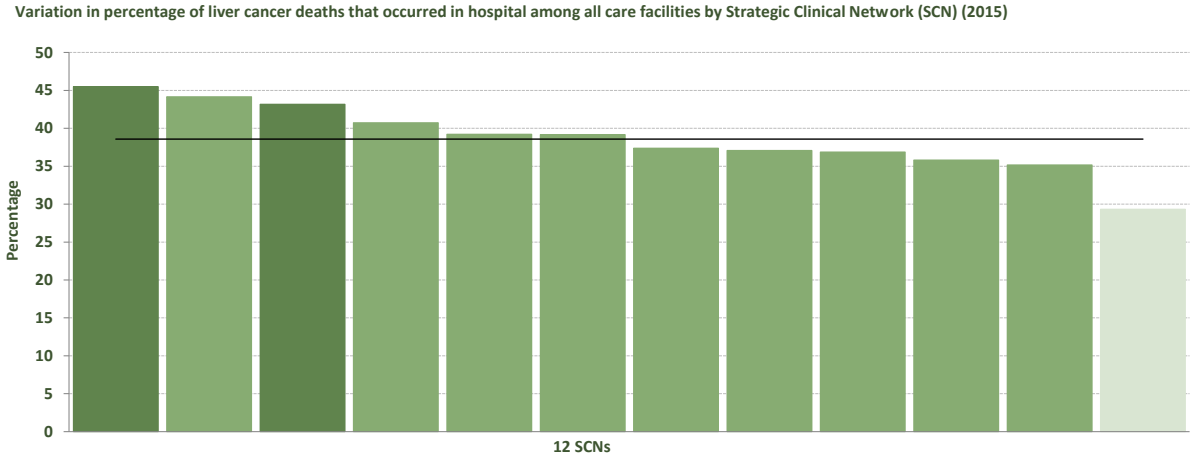
Max-Min (Range)		6.0
95th-5th percentile		5.2
75th-25th percentile		2.6
Median		12.6

It is presented by Strategic Clinical Network, as the number of patients not admitted is small. Statistically significant variations are still seen. Around 1,500 (1 in 10) people die from liver disease each year without being admitted to hospital.

Given the severity of the burden of disease experienced by people with end-stage liver disease prior to death, it could be surprising that they have not been admitted to hospital. However, it is also known that for a proportion of patients, because cirrhosis is a silent condition, their first presentation may be with a life threatening complication of decompensation.

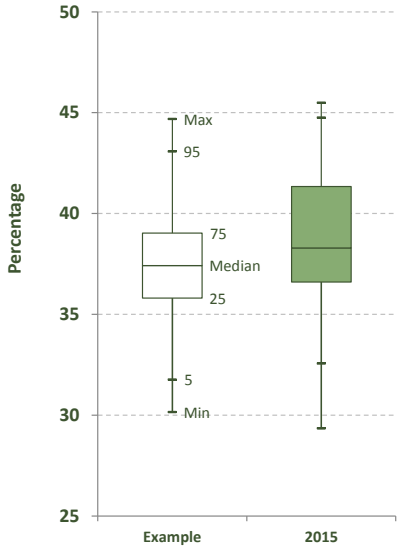
It has already been shown that there is a strong correlation between deprivation and mortality from liver disease. Many patients who die from liver disease come from particularly marginalised groups such as the homeless and those with an alcohol and/or drug dependency.

These patients often have chaotic interactions with health services and poor levels of access. The variation is important with two SCNs (Greater Manchester, Lancashire and South Cumbria, and South East Coast) having statistically higher rates than the England.



Over two-thirds of deaths secondary to liver disease (over 80% for alcohol related liver disease – ArLD) occur in hospital.[2] Patients with Hepatocellular Carcinoma (HCC) are more likely to be referred to Specialist Palliative Care Services (SPCS) than those with non-cancer end-stage liver disease and therefore have a greater chance to be engaged in Advance Care Planning.

This may offer patients a greater chance of a death outside hospital, either at home or in a hospice if that is their preference. The proportion of HCC patients dying in hospital is 38.6% and among those with non-cancer liver disease, this figure is 78.0%. Maps 27c and 27d show variation in the percentage of liver cancer deaths and liver non-cancer deaths respectively which occur in hospital.



Max-Min (Range)		16.2
95th-5th percentile		12.2
75th-25th percentile		4.7
Median		38.3

Magnitude of variation

Map 27a: Average number of bed days per liver disease patient admitted to hospital in the last year of life

The maps and column chart display the latest period (2015), during which SCN values ranged from 12.1 to 20.2 bed days, which is a 1.7-fold difference between SCNs. The England value for 2015 was 13.8 bed days. The boxplot shows the distribution of SCN values for the period 2015.

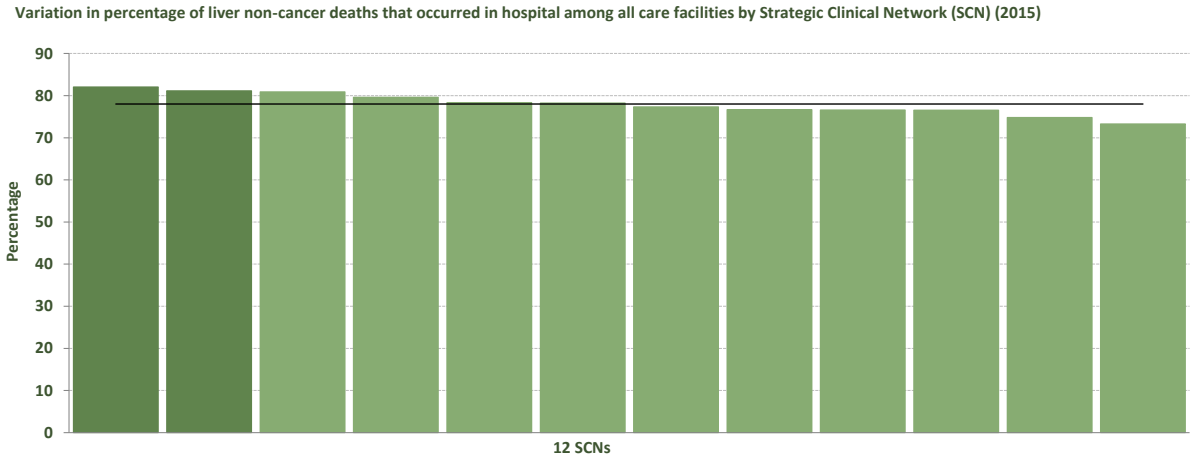
Map 27b: Percentage of liver disease patients who died without being admitted to hospital in the last year of life

The maps and column chart display the latest period (2015), during which SCN values ranged from 10.1 to 16.1 %, which is a 1.6-fold difference between SCNs. The England value for 2015 was 12.7 %. The boxplot shows the distribution of SCN values for the period 2015.

Map 27c: Percentage of liver cancer deaths that occurred in hospital among all care facilities

The maps and column chart display the latest period (2015), during which SCN values ranged from 29.3 to 45.5 %, which is a 1.6-fold difference between SCNs. The England value for 2015 was 38.6 %. The boxplot shows the distribution of SCN values for the period 2015.

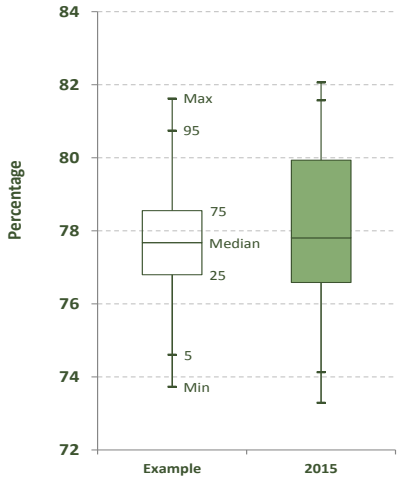
[2] National End of Life Care Intelligence Network. Deaths from Liver Disease: Implications for end of life care in England 2012. www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease



Map 27d: Percentage of liver non-cancer deaths that occurred in hospital among all care facilities

The maps and column chart display the latest period (2015), during which SCN values ranged from 73.3 to 82.1 %, which is a 1.1-fold difference between SCNs. The England value for 2015 was 78.0 %.

The boxplot shows the distribution of SCN values for the period 2015.



Max-Min (Range)		8.8
95th-5th percentile		7.4
75th-25th percentile		3.4
Median		77.8

Options for action

- Improve early detection of cirrhosis to reduce the risk of patients presenting for the first time with late stage irreversible liver disease or for the first time with life threatening complications and so that their disease can be managed proactively and for some patients even reversed
- Ensure that local trusts have appropriate policies in place to reduce preventable deaths in patients with liver disease. These were highlighted in two NCEPOD Reports.[3,4] This will include the timely recognition of patients with the complications of advanced liver disease in A&E[5] and appropriate management of patients presenting with alcohol related liver disease and upper gastrointestinal bleeding.[3,4] Variceal bleeding and ascites can also be managed proactively with appropriate planning and patient involvement (see maps 25 and 26)
- Review average number of bed days in last year of life for patients dying from liver disease
- Review the number of people who die from liver disease without an admission in the last year of life and the circumstances surrounding this perhaps through local audit
- Review the proportion of liver disease patients who die in hospital in the local area from cancer and non-cancer related liver disease
- Review local policies for end-stage liver disease patients in relation to national guidance for end of life

[3] National Confidential Enquiry into Patient Outcome and Death. Alcohol Related Liver Disease: Measuring the Units. 2013. www.ncepod.org.uk/2013arld.html

[4] National Confidential Enquiry into Patient Outcome and Death. Gastrointestinal Haemorrhage: Time to Get Control? 2015. http://www.ncepod.org.uk/2015gih.html

[5] BSG - BASL Decompensated Cirrhosis Care Bundle - First 24 Hours http://www.bsg.org.uk/care-bundles/care-bundles-general/decompensated-cirrhosis-care-bundle-first-24-hours.html

care for liver disease patients,[1] national policy and NICE Guidance

- Work with local charities and statutory bodies working with vulnerable groups with high risk of liver disease to ensure good access to health services and good end of life care

RESOURCES

- Kendrick E. Getting it right: Improving end of life care for people living with liver disease. *London: Department of Health* 2013.
- National End of Life Care Intelligence Network. Deaths from Liver Disease: Implications for end of life care in England 2012 www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease
- National Confidential Enquiry into Patient Outcome and Death. Alcohol Related Liver Disease: Measuring the Units. 2013. www.ncepod.org.uk/2013arld.html
- National Confidential Enquiry into Patient Outcome and Death. Gastrointestinal Haemorrhage: Time to Get Control? 2015. www.ncepod.org.uk/2015gih.html
- BSG - BASL Decompensated Cirrhosis Care Bundle - First 24 Hours www.bsg.org.uk/care-bundles/care-bundles-general/decompensated-cirrhosis-care-bundle-first-24-hours.html
- The Choice in End of Life Care Programme Board. What's important to me. A Review of Choice in End of Life Care. 2015. www.gov.uk/government/publications/choice-in-end-of-life-care
- National Palliative and End of Life Care Partnership. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. 2015. http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf
- NICE End of life care for adults. Quality standard [QS13] November 2011. www.nice.org.uk/guidance/qs13
- NICE Care of dying adults in the last days of life. Quality standard [QS144] March 2017. www.nice.org.uk/guidance/qs144
- Office for National Statistics. National Survey of Bereaved People (VOICES): England, 2015. April 2016. www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015

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, the PHE Atlas Team have composed and provided a definition. Where definitions have been adapted from the published literature, they are presented with the source acknowledged.

Access to healthcare

Facilitating access is concerned with helping people to access appropriate healthcare resources to preserve or improve their health. Access is a complex concept and there are at least four aspects.

1. If services are available in terms of an adequate supply, a population may have theoretical access to healthcare.
2. The extent to which a population gains access to healthcare also depends on 'health literacy', which in turn depends on educational level and language competency. These affect an - individual's ability to understand their own needs and to communicate these or to understand, and take action in response to, medical advice. Effective services must be acceptable to the population if they are to make use of them. Acceptability may be influenced by social and cultural norms. Population access may vary due to physical accessibility, in particular, travelling distance. Financial, organisational and social or cultural barriers may also limit utilisation. Thus utilisation is dependent on many factors and not the adequacy of supply. These factors may be unequally distributed across the population and lead to inequalities in access.
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.

Equity of access may be measured in terms of the availability, utilisation or outcomes of services. Both horizontal and vertical dimensions of equity require consideration.

Adapted from: Gulliford M, Figueroa-Munoz J, Morgan M, et al. What does 'access to healthcare' mean? J Health Serv Res Policy 2002; 7: 186-188.

Appropriate

A procedure is termed appropriate if its benefits sufficiently outweigh its risks to make it worth performing …

Source: Kahan JP et al. Measuring the necessity of medical procedures. *Medical Care* 1994; 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. Quality, Risk and Control in Health Care. Open University Press: 2005, page 128.

Average, *see* ***Mean***

Box and whisker plot

See ***Introduction to the data*** section.

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)] www.who.int/healthpromotion/about/HPG/en

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. Integrated Care Pathways: effective tools for continuous evaluation of clinical practice. *J Eval Clin Pract* 1996; 2: 65-69.

Clinical guidelines

Systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific circumstances.

Source: Timmermans S, Berg M. The Gold Standard. The challenge of evidence-based medicine and standardization in health care. Temple University Press, Philadelphia: 2003.

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. 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. Commissioning [Archived content]. 2010. http://webarchive.nationalarchives.gov.uk/+/http://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. *Testing Treatments. Better Research for Better Healthcare*. The British Library. 2006.

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).

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. *The Corporate Culture Survival Guide*. John Wiley & Sons. 1999, page 186.

Deprivation

See also ***English Indices of Deprivation 2015***

Deprivation is considered to be a multi-dimensional problem, encompassing a range of domains, such as financial, health, education, services or crime. … income and employment … . These are both major drivers of deprivation, …

Source: Office for National Statistics. UK Indices of Multiple Deprivation – a way to make comparisons across constituent countries easier. Health Statistics Quarterly, No. 53, Spring 2012 release. http://webarchive.nationalarchives.gov.uk/20160107054137/http://www.ons.gov.uk/ons/rel/hsq/health-statistics-quarterly/no--53--spring-2012/uk-indices-of-multiple-deprivation.html

Directly age-standardised rate

Directly age-standardised rates express an indicator in terms of the overall rate that would occur in a standard population age-structure if it experienced the age-specific rates of the observed population.

Source: Public Health England. Technical Guidance. APHO Technical Briefings. APHO Technical Briefing 3 – Commonly used public health statistics and their confidence Intervals. http://fingertips.phe.org.uk/profile/guidance

Effective care

The extent to which an intervention, procedure regimen, or service produces a beneficial outcome under ideal circumstances (eg in a randomized controlled trial).

Source: Canadian Agency for Drugs and Technologies in Health. *Optimal Therapy Report: Cost effectiveness of blood glucose test strips in the management of adult patients with diabetes mellitus*. Volume 3, Issue 3, May 2008. www.cadth.ca/cost-effectiveness-blood-glucose-test-strips-management-adult-patients-diabetes-mellitus

Efficiency

See also ***Productivity***

… efficiency can be defined as maximising well-being at the least cost to society.

Source: Mitton C, Donaldson C. *Priority setting toolkit. A guide to the use of economics in healthcare decision making*. BMJ Publishing Group. 2004.

English Indices of Deprivation 2015

See also ***Deprivation***

The English Indices of Deprivation 2015 are based on 37 separate indicators, organised across seven distinct domains of deprivation which are combined, using appropriate weights, to calculate the Index of Multiple Deprivation 2015 (IMD 2015). This is an overall measure of multiple deprivation experienced by people living in an area and is calculated for every Lower layer Super Output Area (LSOA), or neighbourhood, in England. Every such neighbourhood in England is ranked according to its level of deprivation relative to that of other areas.

Source: Department for Communities and Local Government. The English Indices of Deprivation 2015. Statistical Release. 30 September 2015. www.gov.uk/government/statistics/english-indices-of-deprivation-2015

Equity

'Fair' distribution of health/healthcare resources or opportunities according to population need.

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. *Leadership Commitments to Improve Value in Health Care: Finding Common Ground: Workshop Summary*. National Academies Press. 2009. Free to download at: 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. www.who.int/governance/eb/who_constitution_en.pdf

Health needs

... objectively determined deficiencies in health that require health care, from promotion to palliation.

Source: World Health Organization (WHO) Health Systems Strengthening Glossary. www.who.int/healthsystems/hss_glossary/en

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. www.who.int/healthinfo/statistics/indhale/en

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. Integrated care: meaning, logic, applications and implications – a discussion paper. *International Journal of Integrated Care* 2002; 2: 1-6.

International Classification of Diseases (ICD)

ICD is the foundation for the identification of health trends and statistics globally, and the international standard for reporting diseases and health conditions. It is the diagnostic classification standard for all clinical and research purposes. ICD defines the universe of diseases, disorders, injuries and other related health conditions, listed in a comprehensive, hierarchical fashion that allows for:
- easy storage, retrieval and analysis of health information for evidenced-based decision-making;
- sharing and comparing health information between hospitals, regions, settings and countries; and
- data comparisons in the same location across different time periods.

Uses include monitoring of the incidence and prevalence of diseases, observing reimbursements and resource allocation trends, and keeping track of safety and quality guidelines. They also include the counting of deaths as well as diseases, injuries, symptoms, reasons for encounter, factors that influence health status, and external causes of disease.

Source: World Health Organization. Classifications. www.who.int/classifications/icd/en

Interquartile range (IQR)

The interquartile range (IQR) is a measure of variability, based on dividing a data set into quartiles. Quartiles divide a rank-ordered data set into four equal parts (numbers of observations). The values that divide each part are called the first, second and third quartiles, denoted by Q1, Q2 and Q3, respectively:

- Q1 is the 'middle' value in the first half of the rank-ordered data set
- Q2 is the median value in the set
- Q3 is the 'middle' value in the second half of the rank-ordered data set

The interquartile range is equal to Q3 minus Q1.

Adapted from: Stat Trek. Statistics and Probability Dictionary. http://stattrek.com/statistics/dictionary.aspx?definition=Interquartile%20range

Life-expectancy

*See also **Healthy life-expectancy***

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

Mean (average)

The mean is the sum of values, e.g. total size of summed populations, divided by the number of values, e.g. number of populations in the sample.

Median

A value or quantity lying at the midpoint of a frequency distribution of observed values or quantities, such that there is an equal probability of falling above or below it.

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. *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press. 2010.

Needs assessment

The purpose of needs assessment in healthcare is to gather the information required to bring about change beneficial to the health of the population. It is generally, but not universally, accepted that this takes place within the context of finite resources. 'Health gain' can therefore be achieved by reallocating resources as a result of identifying four factors:

- *Non-recipients of beneficial interventions (that is, unmet need)*
- *Recipients of ineffective health care (and releasing the resources for unmet need)*
- *Recipients of inefficient health care (and releasing the resources for unmet need)*
- *Recipients of inappropriate health care (for whom the outcomes could be approved)*

Source: Stevens A, Gillam S. Needs assessment: from theory to practice. BMJ 1998; 316: 1448. www.bmj.com/content/316/7142/1448

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***

Overdiagnosis

A condition is diagnosed that would otherwise not go on to cause symptoms or death.

Source: Elmore JG, Fletcher SW. Overdiagnosis in Breast Cancer Screening: Time to Tackle Underappreciated Harm. Annals of Internal Medicine 2012; 156; 536.

Overuse

*See also **Underuse***

Overuse describes a process of care in circumstances where the potential for harm exceeds the potential for benefit. Prescribing an antibiotic for a viral infection like a cold, for which antibiotics are ineffective, constitutes overuse. The potential for harm includes adverse reactions to the antibiotics and increases in antibiotic resistance among bacteria in the community. Overuse can also apply to diagnostic tests and surgical procedures.

Source: Robert Wood Johnson Foundation. Quality/Equality Glossary. April 24, 2013. www.rwjf.org/en/library/research/2013/04/quality-equality-glossary.html

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. Developing a quality criteria framework for patient decision aids; online international Delphi Consensus process. *British Medical Journal* 2006; 333: 417-427.

Population healthcare

The aim of population healthcare is to maximise value and equity by focusing not on institutions, specialties or technologies, but on populations defined by a common symptom, condition or characteristic, such as breathlessness, arthritis or multiple morbidity.

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. *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press. 2010.

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. Toward the 'Tipping Point': Decision aids and informed patient choice. Health Affairs 2007; 26: 716-725.

Prevalence

Prevalence refers to the total number of individuals in a population who have a disease or health condition at a specific period of time, usually expressed as a percentage of the population.

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

An agreed framework outlining the care that will be provided to patients in a designated area of practice. They do not describe how a procedure is performed, but why, when, where and by whom the care is given.

Source: Ebling Library, University of Wisconsin. Nursing Resources: Standard, Guideline, Protocol, Policy. http://researchguides.ebling.library.wisc.edu/c.php?g=293229&p=1953402

Public health

The science and art of promoting and protecting health and well-being, preventing ill-health and prolonging life through the organised efforts of society.

Source: The Faculty of Public Health. What is public health. www.fph.org.uk/what_is_public_health

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). www.who.int/mental_health/media/68.pdf

Quintile

Quintiles are calculated based on the percentile method. Any of the 100 equal parts into which the range of the values of a set of data can be divided in order to show the distribution of those values. The percentile of a given value is determined by the percentage of the values that are equal to or smaller than that value. Quintiles separate the distribution of values into five groups. The values that divide each part are called the first, second, third, fourth and fifth quintiles.

Adapted from: The American Heritage Science Dictionary. Houghton Mifflin. 2002.

Range

See also ***Interquartile 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.

Region

Government offices for the regions (GOR) were established across England in 1994. Nine GORs are presented in the atlas.

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. *Patient Safety*. Churchill Livingstone. 2006.

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. Self-Management Education: History, Definition, Outcomes, and Mechanisms. *Annals of Behavioural Medicine* 2003; 26; 1-7. doi 10.1207/ S153124796ABM2601_01

Shared decision-making

In a shared decision, a health care provider communicates to the patient personalised 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. *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press. 2010.

Standard deviation

See also ***Variance***

The standard deviation is a measure of spread, and is the square root of the variance.

Standardised Years of Life Lost (SYLL)

A measure of premature mortality. The concept is to estimate the length of time a person would have lived if they had not died prematurely. By inherently including the age at which death occurs, rather than just the fact of its occurrence, the calculation is an attempt to better quantify the burden, or impact, on society from the specified cause of mortality. SYLL is age-standardised to eliminate the effects of differences in population age structures between areas, allowing geographical comparisons of premature mortality.

Source: NHS Digital indicator portal https://indicators.hscic.gov.uk/download/NCHOD/Specification/Spec_25B_067DR.pdf

[1] Examples of other quality of life definitions can be found at: www.scotland.gov.uk/Publications/2006/01/13110743/11

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. To Err is Human. Building a Safer Health System. National Academy Press, Washington. 2000.

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. *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press: 2010.

Surgical signature

Surgical signatures reflect the practice patterns of individual physicians and local medical culture, rather than differences in need – or even differences in the local supply of surgeons.

Source: Dartmouth Medical School, Center for the Evaluative Clinical Sciences. The Dartmouth Atlas of Health Care 1998. AHA Publishing Inc.

Sustainability and Transformation Partnerships (STPs)

The NHS and local councils have formed partnerships in 44 areas covering all of England, to improve health and care. Each area has developed proposals built around the needs of the whole population in the area, not just those of individual organisations. The STPs have set out their proposals in Sustainability Transformation Plans which the public can feedback on before they are implemented.

Adapted from: NHS England
www.england.nhs.uk/stps

System

A system is a set of activities with a common set of objectives for which an annual report is produced.

Underuse

See also ***Overuse***

Underuse refers to the failure to provide a healthcare service or for patients to accept and take up such a service when it would have produced a favourable outcome for a patient. Standard examples include failure to provide or low uptake of, appropriate preventive services to eligible patients (eg cervical smears, influenza vaccinations for older people, screening for hypertension) and proven medications for longterm illnesses (steroid inhalers for people with asthma; aspirin, beta-blockers and lipid-lowering agents for people who have had a recent myocardial infarction).

Adapted from: Robert Wood Johnson Foundation. Quality/Equality Glossary. April 24, 2013.
www.rwjf.org/en/library/research/2013/04/quality-equality-glossary.html

Unwarranted variation

Variation in the utilisation of health care services that cannot be explained by variation in patient illness or patient preferences.

Source: Wennberg JE. *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press. 2010.

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. Learning Healthcare System Concepts v. 2008. The Roundtable on Evidence-Based Medicine, Institute of Medicine. Annual Report.

Value for money

… 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. Excellence and fairness: Achieving world class public services. 2008, page 12. http://webarchive.nationalarchives.gov.uk/20090121123402/http:/cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/publications/world_class_public_services.pdf

Variation

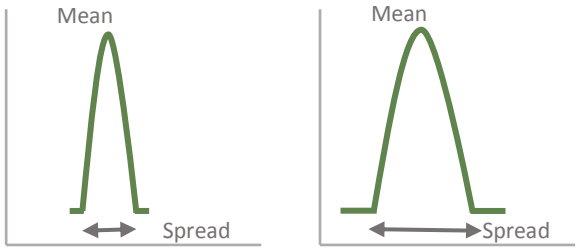
Everything we observe or measure varies. Some of this is random variation. Some variation in healthcare is desirable, even essential, since each patient and population is different and should be cared for uniquely. New and better treatments and improvements in care processes result in variation during the early phases of their introduction.

Adapted from: Neuhauser D, Provost L, Bergman B. The meaning of variation to healthcare managers, clinical and health-services researchers, and individual patients. BMJ Qual Saf 2011; 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 graph on the right shows greater variation than that on the right.

Additional terms and acronyms can be found here:

NHS Digital Glossary of acronyms and abbreviations http://content.digital.nhs.uk/article/2994/Glossary-of-acronyms

Glossary of Terms Relating to Liver Disease

Ablation
Ablation is a form of treatment for liver and other tumours in which the tumour is destroyed. If the tumour is destroyed using heat it is known as radiofrequency ablation.

Acute liver failure
Acute liver failure is the appearance of severe complications rapidly after the first signs of liver disease (such as jaundice), and indicates that the liver has sustained severe damage (loss of function of 80–90% of liver cells).

Alagille syndrome
Alagille syndrome is a disorder that can affect the liver, heart and other parts of the body. A major feature of this syndrome is damage to the liver caused by abnormalities in the bile ducts, which may be narrowed, malformed or reduced in number. Bile builds up in the liver and can cause scarring of the liver tissue.

Alcohol-related admissions to hospital
Alcohol-related admissions to hospital are those for which an alcohol-related disease, injury or condition is the primary reason for admission or a secondary diagnosis.

Alcohol-specific admissions to hospital
Alcohol-specific admissions to hospital are those for conditions where alcohol is the sole cause, eg alcoholic liver disease, and thus the reason for admission is wholly attributable to alcohol.

Alpha-1 antitrypsin deficiency
Alpha-1 antitrypsin deficiency is a rare inherited condition that may cause lung disease and liver disease. Alpha-1 antitrypsin (AAT), a protein mainly produced by the liver, controls enzyme activity to prevent damage to the lungs. In alpha-1 antitrypsin deficiency the AAT is abnormal and cannot be secreted by the liver cells; AAT builds up in the liver and can cause damage to the liver tissue. In some affected individuals this damage can lead to cirrhosis; individuals are also at risk of developing hepatocellular carcinoma.

Ascites
Ascites is the accumulation of fluid in the abdomen. It is a complication of advanced liver disease.

Autoimmune hepatitis
Autoimmune hepatitis is an uncommon but chronic condition in which the liver cells are inflamed as a result of attack by the body's own immune system, mainly by the white blood cells or lymphocytes. Over time persistent inflammation causes damage to the liver and can lead to cirrhosis. Autoimmune hepatitis is thought to arise from a combination of genetic predisposition and environmental triggers.

Barcelona Clinic Liver Cancer staging system
The Barcelona Clinic Liver Cancer staging system links the stage of liver cancer to a specific treatment strategy. The classification uses variables related to the stage of the cancer, the functional status of the liver, the person's physical status and cancer-related symptoms. There are five stages: stage 0 where patients have very early hepatocellular carcinoma and are optimal candidates for resection; stage A where patients have early hepatocellular carcinoma and are candidates for radical therapies (resection, transplantation or percutaneous treatments); stage B where patients have intermediate hepatocellular carcinoma and may benefit from chemoembolisation; stage C where patients have advanced hepatocellular carcinoma and may receive new therapeutic agents in the setting of a randomised controlled trial; stage D where patients have end-stage disease and will receive symptomatic therapy.

Biliary atresia
Biliary atresia is a rare disease in infants in which one or more bile ducts are narrowed, blocked or missing, leading to biliary obstruction. Owing to obstruction bile builds up in the liver causing damage, which can lead to cirrhosis and eventually liver failure.

Bloodborne viruses (BBVs)
Hepatitis B and hepatitis C are two of the most common bloodborne 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.

Choledochal cyst

Choledochal cyst is a rare congenital condition in which part or all of the bile duct is dilated or cysts form on the ducts, affecting the flow of bile from the liver to the gallbladder, and thence to the small intestine. The bile ducts can become inflamed or infected, known as cholangitis; over time there can be damage to the liver tissue, which can lead to cirrhosis.

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.

Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy is a therapeutic approach that changes maladaptive thinking to lead to a change in effect and behaviour.

Congenital hepatic fibrosis

Congenital hepatic fibrosis is a condition in which the bile ducts and the blood vessels of the hepatic portal system are malformed; in addition there is a build-up of scar tissue (fibrosis) in the portal tracts, structures in the liver that bundle together the vessels transporting blood, lymph and bile. The combination of malformed bile ducts and fibrosis of the portal tracts increases blood pressure in the hepatic portal system leading to portal hypertension and its complications, including oesophageal varices. Congenital hepatic fibrosis can occur alone or more frequently with genetic syndromes that affect the kidneys.

Cystic fibrosis and liver disease

Some children and young people with cystic fibrosis develop liver disease, which may be more likely in children who have had meconium ileus as a baby. In children and young people who are affected the bile is thick and as a result there are difficulties with its secretion from the liver into the bile ducts. There is a build-up of bile in the liver, which may lead to inflammation and scarring of the liver tissue. A small percentage of children and young people develop severe cystic fibrosis-related liver disease or cirrhosis.

Decompensated liver disease

Decompensation is the failure of an organ, particularly the liver or the heart, to compensate for the functional overload that results from disease. People with chronic liver disease can present with acute decompensation due to various causes. Decompensation may be manifest as various complications including oesophageal varices, ascites, spontaneous bacterial peritonitis, hepatic encephalopathy and hepatocellular carcinoma.

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.

Drug resistance

Drug resistance results when microorganisms, such as viruses and bacteria, mutate and change form in ways that render ineffective medications which were previously used to treat the infections that those microorganisms caused.

Encephalopathy

*See **Hepatic encephalopathy***

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.

Fatty liver disease

*See also **Non-alcoholic fatty liver disease (NAFLD)** and **Non-alcoholic steatohepatitis (NASH)***

Fatty liver, or steatosis, is a term that describes the build-up of fat in the liver. There are various types of fatty liver disease including alcoholic fatty liver disease, non-alcoholic fatty liver disease (NAFLD) and non-alcoholic steatohepatitis (NASH).

Fibrosis of the liver

Liver or hepatic fibrosis is characteristic of most types of liver disease resulting from the liver's response to chronic injury, particularly inflammation. Fibrosis is the excessive accumulation of connective tissue (extracellular matrix proteins including collagen) at the sites of injury. Liver fibrosis can lead to cirrhosis or portal hypertension.

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 cancers, 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 underestimate 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 (14 units per week). 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 the impact of life-events or it may be habitual.

Hepatic encephalopathy

Hepatic encephalopathy can occur during advanced liver disease when liver function is compromised and the liver is not able to remove certain toxins from the blood. There is a build-up of toxins in the blood, which then enter the brain across the blood-brain barrier. Symptoms vary from person to person and can develop rapidly or relatively slowly over time. Mild symptoms include mild confusion, forgetfulness and personality or mood changes; severe symptoms include extreme anxiety, severe confusion and severe personality changes.

Hepatic fibrosis

*See **Fibrosis of the liver***

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. When acquired in infancy or early childhood the infection becomes chronic in 85% of individuals; when acquired in adulthood the infection becomes chronic in up to 10% of individuals. About 15–20% of people with chronic infection who became infected as adults will develop cirrhosis, and about 10% of people whose condition progressed to cirrhosis will develop hepatocellular carcinoma.

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 and 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. The infection remains chronic in about 70-75% of people. In the UK people who inject drugs are the main group at risk of infection from hepatitis C.

Hepatitis C antibody test, polymerase chain reaction (PCR) test and genotyping

*See also **RNA amplification***

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.

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.

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.

Injection scleropathy

Scleropathy for oesophageal varices involves injecting a sclerosant into the veins and/or the area beside the distended vein. If injected directly into the vein the sclerosant causes the blood to clot and stop the bleeding; if injected into the area beside the distended vein the sclerosant stops the bleeding by thickening and swelling the vein to compress the blood vessel.

Liver transplant

Surgery to remove a diseased liver and replace it with a healthy liver (or part of one) from a donor.

Liver transplant waiting list

Owing to the lack of available organs, it is rarely possible for a person to have a liver transplant as soon as it is needed; people are usually placed on a waiting list. Depending on the clinical need for a liver transplant, people are placed on a high-priority or medium-priority waiting list.

Non-alcoholic fatty liver disease (NAFLD)

Non-alcoholic fatty liver disease (NAFLD) is the term used for a range of conditions caused by an accumulation of fat within the liver cells. It is usually seen in people who are overweight or obese.

Non-alcoholic steatohepatitis (NASH)

Non-alcoholic steatohepatitis (NASH) is a form of non-alcoholic fatty liver disease in which there is inflammation and liver cell damage, in addition to fat in the liver. Inflammation and liver cell damage can cause fibrosis, or scarring, of the liver. NASH may lead to cirrhosis or liver cancer.

Notifiable disease and notifiable organism

A notifiable disease is a disease with significant public health implications, usually a highly infectious disease, about which it is required by law to report to the local authorities. Registered medical practitioners have a statutory duty to notify the 'proper officer' at the local council or local health protection team of suspected cases of certain infectious diseases. Acute infectious hepatitis is a notifiable disease. All laboratories in England that perform a primary diagnostic role must notify Public Health England on confirmation of a notifiable organism. Hepatitis B and hepatitis C are notifiable organisms.

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, that is, their body mass index (BMI) is 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 BMI 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.

Organ donation after brain death

Organ donors for whom death was confirmed following neurological tests and who had no absolute medical contraindications to sold organ donation.

Organ donation after circulatory death

Organ donors who had treatment withdrawn and death was anticipated within 4 hours, with no absolute medical contraindications to sold organ donation.

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.

Paracentesis

A procedure in which a needle or catheter is inserted into the peritoneal cavity to obtain fluid which has accumulated in the abdominal cavity (ascites).

Polymerase chain reaction (PCR) test

*See **Hepatitis C antibody test***

Portal hypertension

Portal hypertension is an increase in blood pressure in the portal venous system, comprising veins from the stomach, spleen, intestine and pancreas which feed into the portal vein and then branch into smaller vessels which run through the liver. The most common cause of portal hypertension is cirrhosis of the liver.

Primary biliary cirrhosis

*See **Primary biliary cholangitis***

Primary biliary cholangitis

Primary biliary cholangitis, previously referred to as primary biliary cirrhosis, is a chronic condition in which the bile ducts become damaged as a result of attack by the body's own immune system. The bile ducts become swollen and scarred, and bile builds up in the liver, which can damage the liver tissue and may lead to cirrhosis.

Primary sclerosing cholangitis

Primary sclerosing cholangitis is a chronic condition in which the bile ducts within and outside the liver become inflamed, causing scarring which leads to a hardening and narrowing of the ducts. As a result bile builds up in the liver, which can damage the liver tissue and may lead to cirrhosis. In many people with primary sclerosing cholangitis there is coexisting inflammatory bowel disease.

Progressive familial intrahepatic cholestasis

Progressive familial intrahepatic cholestasis is a condition in which the liver cells are less able to secrete bile, which then builds up in the liver causing damage to liver tissue which can progress to cirrhosis rapidly or relatively slowly. There are three main forms of progressive familial intrahepatic cholestasis, each of which has a different genetic cause. Few people with progressive familial intrahepatic cholestasis survive into their third decade unless treated.

Resection

Surgical removal of all or part of an organ, tissue or structure.

RNA amplification

RNA amplification is part of the polymerase chain reaction (PCR), and is the process by which many identical copies of RNA can be generated from a sample even if it is present in only trace amounts. These copies are then used to identify the source of the RNA, for instance, to which pathogen the RNA belongs.

Sclerosant

A sclerosant is an irritating solution used in the treatment of oesophageal varices, enlarged veins in the lower part of the oesophagus, which can bleed during acute episodes. The sclerosant is injected into the vein and/or the area near the distended vein to stimulate the formation of a blood clot as a means of stopping the bleeding.

Structured treatment

Structured treatment for people with alcohol use problems involves psychological and pharmacological interventions that can increase people's motivation to

change behaviour patterns and reduce alcohol consumption.

Sustained viral/virological response (SVR)

Sustained viral/ virological response is the goal of hepatitis C treatment; it means there is no detectable virus in the blood on completion of treatment. It has been found that with a 6-month SVR (ie no detectable virus in the blood for 6 months after finishing treatment) relapse occurred in only 1–2% of patients.

Transjugular intrahepatic portosystemic shunt (TIPS)

A transjugular intrahepatic portosystemic shunt (TIPS) is a procedure in which under imaging guidance the portal vein is connected to the hepatic vein in the liver. The shunt is kept open by means of a stent. The TIPS procedure is performed to reduce portal vein blood pressure in people with complications from portal hypertension, the main complication of which is upper gastrointestinal bleeding from oesophageal varices.

Vertical transmission

Vertical transmission of the hepatitis B virus is positivity of the hepatitis B surface antigen or of hepatitis B DNA in an infant aged 6-12 months born to a mother with hepatitis B infection.

Wilson’s disease

Wilson’s disease is a rare genetic disorder in which the liver is unable to metabolise and remove excess copper and it builds up in the body, mainly in the liver and brain. In the absence of treatment the build-up of copper causes serious symptoms. Wilson’s disease can be treated effectively if diagnosed early enough.

Introduction to the data

Denominators

Indicators have been calculated using a variety of population denominators including resident CCG populations, upper and lower-tier local authority, strategic health authority, NHS area team, strategic clinical networks, regions and new strategic and transformation partnership (STP) populations.

Data sources

The data for the indicators in the 2nd Atlas of variation in risk factors and healthcare for liver disease in England, has been provided by a range of organisations: Public Health England (PHE), The Office for National Statistics (ONS), The Home Office, NHS Blood and Transplant (NHSBT), National Treatment Agency for Substance Misuse, NHS Digital, NHS England (NHSE), NHS RightCare and Sport England from a variety of sources including:

- Hospital episode statistics (HES)
- ONS mid-year population estimates
- ONS Annual Birth and Mortality statistics
- Cover of Vaccination Evaluated Rapidly (COVER) statistics
- National Child Measurement Programme (NCMP)
- Sport England Active People Survey
- Home Office alcohol and late night refreshment licensing statistics
- Ordnance Survey data

A metadata document with methodology, data extraction coding schemes and data sources for each indicator is available at: https://fingertips.phe.gov.uk/profile/atlas-of-variation

The data analysis, column charts and boxplots were produced using Microsoft Excel 2013. The maps were created using ArcGIS version 10.2.

Innovations in statistical methods and presentation in this Atlas

In the 2nd edition of the Atlas two innovations in analysis and presentation have been introduced:

- the presentation of one map and the column charts has changed: shading is now based on statistical significance (difference from the England value)
- the introduction of time series analyses in the form of repeated box and whisker plots, revealing trends in the level and spread of local area indicator values across England

In the statistical significance map and column charts, the England value is used as the statistical benchmark against which organisations are compared. It is important to note that this does not imply that the England rate is the optimal or aspirational level for that indicator, as this value is often not established, but gives a sense of the performance of organisations compared with the national value.

Maps

For each indicator, data is presented visually in the form of thematic maps and a column chart. London is shown as an enlarged page inset on selected maps to show detail that might otherwise be lost.

Interpretation of the maps

For each indicator, two maps have been presented, one is a quintile map and the other is a statistical significance map. For both type of maps, the data presented is that for the most recent time period shown in the corresponding box and whisker plot time series. The maps present an overall value for each geographical area, however note that variation will also exist within each area.

Quintile maps

The quintile maps use a method to split the organisations into equal groups of fifths (20%) based on the range of data. Five equal counts of areas or ‘quintiles’ are classified, however, as most of the indicators include a total number of areas that are not divisible by five (e.g. 209 CCGs), 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 groups using a percentile calculation in Excel.

The legends for the quintile maps may appear to have overlapping boundaries between quintile groupings, this is because we have rounded the legend quintile groups to two decimal places, whereas quintile groupings have been calculated based on the unrounded number.
We have chosen this method as rounding the actual values before assigning to quintiles would introduce unnecessary rounding error.

A disadvantage of quintile grouping of data is that it does not take into account the distribution of data and quintiles 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 dark green (highest value) to light green (lowest value) on the quintile maps (See Table B.1)

Statistical significance maps

For each indicator, individual CCGs (or other geographies) are allocated to one of five groups (see Table B.1) based on comparing the confidence interval of the estimate with the England value to indicate how statistically significantly different their value is from the England value (the horizontal black line across the column charts). The column charts and significance maps are identically colour classified into thematic displays according to that significance banding. Where data is unavailable for an area/organisation, the corresponding map area/symbol is shaded grey. All data values including the significance banding can be downloaded at:
http://www.fingertips.phe.gov.uk/profile/atlas-of-variation

The intensity of shading of each area indicates the degree of statistical significance of each indicator value in terms of its difference from the England value. The key to the map shows the significance level for each of the five shades compared with the England value for that indicator. The two darkest shaded bars indicate that an indicator value is significantly higher than the England value at the 99.8% and 95% significance levels. The two lightest shades indicate that an indicator value is significantly lower than the England value at the 99.8% and 95% significance levels. Mid-shaded areas are those with an indicator value that is not significantly different to the England value.

Table B.1 below, shows the shading used to correspond with either the degree of statistical significance or quintile grouping associated with the maps. The column charts all use the statistical significance shading in their presentation.

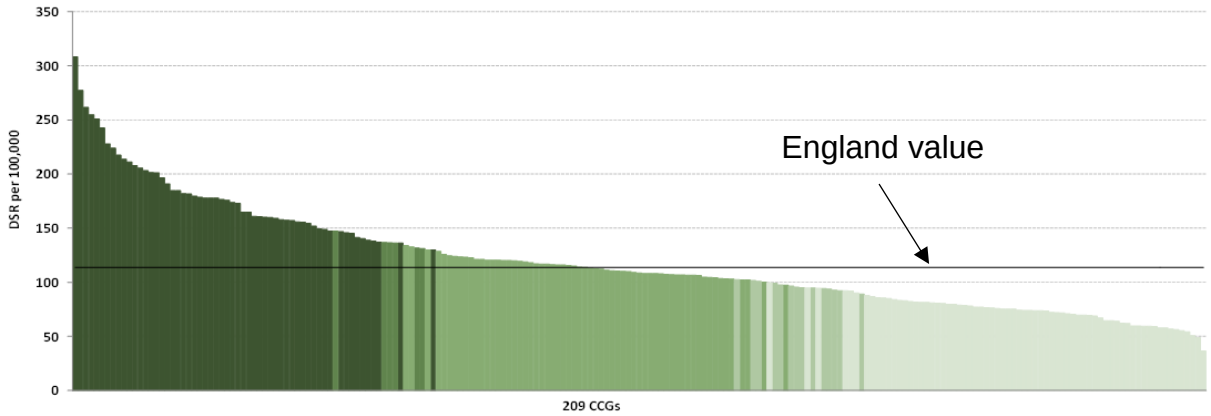
Table B.1: Five shade quintile and significance bands used in the maps and column chart

Shade	Quintile	Significance Band
	Highest 20%	Significantly higher than England at the 99.8% level
		Significantly higher than England at the 95% level
		Not significantly different from England
		Significantly lower than England at the 95% level
	Lowest 20%	Significantly lower than England at the 99.8% level

When comparing the maps side by side, there will be examples where on the quintile map an area will have the darkest shading indicating it has one of the highest values of all the organisations, but on the significance map it may have one of the lighter shades denoting that it is not statistically significant and vice versa. At a local level, organisations will need to consider whether having a higher or lower value is important even if statistically they are not different to the England value. The same is true, where an area is statistically significantly different to the England value, but the actual value is within the mid-range, locally decision makers will then need to decide whether this warrants further investigation.

Column charts

Figure B.1: Example column chart to show statistical significance compared to the England value



The range of local area indicator values and the England value are presented in the column chart accompanying both maps. The same statistical methodology is used to determine the shading in the significance map and column chart. This is based on statistical significance of difference from the England value.

It is important to note that due to the change in statistical presentation, maps and column charts from the first iteration of the Liver Atlas should not be compared with those presented in this Atlas.

Interpretation of the column charts

For each indicator, the data presented in the column charts is that for the most recent time period shown in the corresponding box and whisker plot time series. The column chart visualisations give the reader two sets of information about the data:

- the height of each bar in the chart shows the indicator value for each geography (such as a clinical commissioning group (CCG) or local authority (LA) – the columns are ordered from the highest value on the left to the lowest value on the right
- the shading of each column indicates the degree of statistical significance of each indicator value in terms of its difference from the England value (the black horizontal line across the chart). The colour shading used in the column charts is the same as that used in the corresponding significance map. The two darkest shades indicate that an indicator value is significantly higher than the England value at the 99.8% or 95% significance level and are towards the left-hand side. Bars with the two lightest shades indicate that an indicator value is significantly lower than the England value at the 99.8% or 95% level and are towards the right-hand side (see Figure B.1). Mid-shade bars are those areas with an indicator value that is not significantly different from the England value

Conventional column charts might display the confidence interval for each column to enable the reader to determine whether or not the local area value is significantly higher or lower than the national value represented by a horizontal line. However, column charts in this Atlas have so many columns and utilise two sets of local area confidence intervals (95% and 99.8%) that it would be very difficult for the reader to assimilate this information. The five green shades replace the use of displayed confidence intervals on column charts in this Atlas. Consequently the column charts in this Atlas differ from those in previous atlases in terms of methodology and interpretation.

The significance band does not indicate whether a high or low value represents good or bad performance, merely whether or not the indicator value is significantly higher or lower than the England value, and the degree of statistical confidence that the difference is not due to random variation.

- Indicator values that are not significantly different from the England value (mid-shade) are said to display ‘random’ variation alone

- Indicator values that are higher or lower than the England value at the 95% significance level are deemed statistically significantly different. However, as so many indicator values (209 in the case of CCGs) are being simultaneously tested against the England value, the likelihood of finding indicator values that are significantly different from the England value is raised by chance alone. For this reason a more stringent 99.8% significance level is also applied
- There is much greater certainty that indicator values found to be different from the England value at the 99.8% significance level (the lightest and the darkest shades) are due to a systematic non-random variation that requires investigation. In these localities it is likely that the process or system of generating these values is markedly different from that in other CCGs

If there is a large number of indicator values significantly different from the national value at the 99.8% level this may be due to what is known as overdispersion, characterised by many localities having indicator values at the extremities of the distribution, and fewer indicator values around the central value of the distribution.

Overdispersion typically occurs when there are factors influencing the values that have not been accounted (or adjusted) for in the method of calculating the statistic, such as demographic risk factors, casemix or localised service configuration, which is particularly relevant to specialised services. These factors may account for the larger than expected number of areas with values greatly different from the England value. Wherever possible statistics presented in this Atlas have been adjusted for known influences, such as locality based variations in age structure, using techniques such as standardisation (see below). It is important to consider whether all known warranted factors have been adjusted for when assessing whether the observed variation is unwarranted.

Figure B.1 is an example of the column charts presented in this Atlas. It shows that differently shaded columns are mixed at both ends of the chart, rather than same-shaded columns appearing in adjacent blocks. This is because being statistically significantly different from the England value depends not only on the magnitude of the indicator value, but also on statistical confidence. This may be influenced by the size of the population for which the indicator value is shown, as smaller populations tend to have wider confidence intervals.

Box and whisker plots

For each indicator, data is presented visually in a time series of box and whisker plots that shows the median and spread of local area values across England at consecutive time points. Importantly, the tables accompanying the box and whisker plots show whether there has been any statistically significant change in the median, or in the degree of variation over time. It should be noted that the England value is not represented in the box and whisker plots.

Interpretation of the box and whisker plots

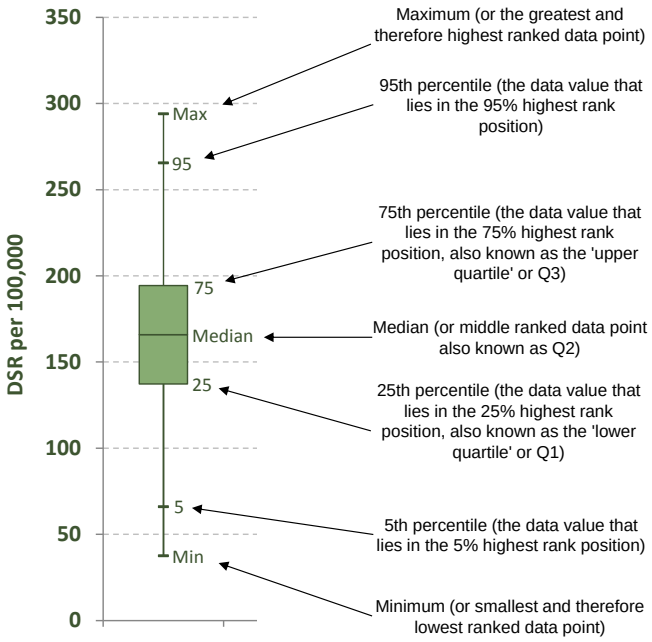
This is the second time that we have presented time series data in the Atlas series, the first being in the 2nd Atlas of variation in NHS Diagnostic Services, published in January 2017. Time series data is presented in the form of box and whisker plots (referred to as boxplots in following sections). The purpose of the box and whisker plot is to give an impression of the level and spread, or distribution, of the data points. The box and whisker plots presented in this Atlas are a customised version of conventional box and whisker plot used elsewhere (see Figure B.2). The box and whisker plots use a methodology which is unrelated to the method determining the map and column chart shading. The box and whisker plots do not represent statistical significance. They represent the data value at key rank positions when the geographical areas are rank-ordered according to data value size. This graphic shows how variable the indicator is across all of the geographical areas. A single box and whisker plot is displayed for each time period so that comparisons can be made through time of the level and spread of values.

The 'box' and its 'whiskers' represent the data values of the following rank positions in the data:

- maximum (or the greatest and therefore highest ranked data point)
- 95th percentile (the data value that lies in the 95% highest rank position)
- 75th percentile (the data value that lies in the 75% highest rank position, also known as the 'upper quartile' or Q3)
- median (or middle ranked data point also known as Q2)
- 25th percentile (the data value that lies in the 25% highest rank position, also known as the 'lower quartile' or Q1)
- 5th percentile (the data value that lies in the 5% highest rank position)
- minimum (or smallest and therefore lowest ranked data point)

The 'box' runs from the upper quartile (Q3 or 75th percentile) to the lower quartile (Q1 or 25th percentile) and represents the middle 50% of data points. The height of the box between Q1 and Q3 is known as the interquartile range (IQR) and is calculated as Q3 minus Q1.

Figure B.2: **Example box plot**



Inside the box is a horizontal line, which shows where the median (or Q2) lies. The median is the middle point of the dataset. Half of the data points are above the median and half of the data points are below it.

The 'whiskers' extend out from either end of the box and show the highest and lowest values contained within the dataset, in other words they show the entire range of values contained within the dataset.

Box and whisker plots split the data presented into four equal parts in terms of the number of data points represented. Twenty-five per cent of data points lie between the maximum and the upper quartile, 25% of data points lie between the upper quartile and the median, 25% of data points lie between the median and the lower quartile, and 25% of data points lie between the lower quartile and the minimum. An unconventional aspect of the box and whisker plots presented in this Atlas, is that the 95th percentile and the 5th percentile are also represented by tick marks on the 'whiskers".

A box and whisker plot enables the user to obtain information about the shape or spread of the data points and in particular, whether or not the data points have a symmetric or skewed distribution. A dataset with a normal distribution is symmetric (non-skewed) around the mean (average), the mean and the median are equal to each other, and each half of the distribution is a mirror-image of the other half. In a distribution that is skewed there is a lack of symmetry between the upper and lower halves of the dataset. The median and the 'box' is not centrally located between the maximum and minimum.

Box plot summary statistics table

Presented below the boxplot time series is a table of statistics summarising the trend in the absolute degree of variation and the median:

- **max–min (Range)**: This is the absolute difference between the maximum value and the minimum value of the dataset, ie the full range of the data. However, extreme outliers can heavily influence this statistic and consequently mislead about the extent of variability across the majority of the dataset. It may therefore be more helpful to use the 95th to 5th percentile (see below)

- **95th–5th percentile**: This shows the range of the data between the 95th percentile and the 5th percentile of the dataset; if there are extreme outliers this statistic may give a better impression of variation across the majority of data values because the highest 5% of values and lowest 5% of values have been discounted
- **75th–25th percentile**: These percentiles are the upper and lower limits of the middle 50% of data values. This statistic indicates the dispersion or spread of the data for the middle 50% of values. The absolute difference between these percentile is also known as the interquartile range (IQR). It is related to the median (see below): if the IQR is small it indicates that the central 50% of data values are close to the median; if the IQR is large it indicates that the data is spread out from the median and there is more dispersion in the middle 50% of values in the dataset
- **median**: The median is the middle value in a dataset, identified by arranging each of the values in ascending order from the smallest value to the highest value. If there is an even number of values the median will be the average of the two central data points. It is not the mean or average

The final column of the table is a summary of whether each of these four statistics is narrowing or widening (or median increasing/decreasing) and whether the trend is statistically significant at the 95% level. The statistical significance was determined using a two-tailed t-test on the slope of a linear regression line fitted to the values in the table over time, where the null hypothesis is that the slope equals zero. The significance test is only performed for indicators with data at three or more time periods. This regression line and the detailed results of the t-test are not presented in this Atlas.

Data frequency

The data frequency, ie the length of the time period for which data is presented, directly affects the number of observations represented in the visualisations. Statistical power, ie the ability to detect true differences, tends to increase with an increasing number of observations. The following 'data frequency' selected for each Atlas indicator is intended to yield a sufficiently large enough number of observations to reveal patterns and trends that are statistically robust.

Standardisation

Differences in the number of events, for example incidence of disease, can be strongly related to the age structure of that population.

In an attempt to identify variation that is beyond that related to different patterns of need, a technique called standardisation is used. This enables the level of testing to be compared between populations with different demographic structures producing a more level playing field.

For instance if we compare two population groups, A and B, and population A has a higher rate of deaths when compared with population B we could conclude that population A has worse mortality outcomes in comparison with population B. However, if population A has a much higher proportion of older people in it we would expect population A to have a higher mortality rate when compared with population B because mortality rates are linked to increasing age. Therefore, it would be misleading to infer that people in population A are dying at a faster rate than people in population B.

There are two main methods of calculating standardised rates:

- direct standardisation
- indirect standardisation

Only direct standardisation has been used within this Atlas and so only this method is discussed here.

Directly standardised rates may adjust for the differences in age and sex distribution in a population and are usually expressed, for example, as a number of infections per 100,000 population. To calculate a directly standardised rate the observed number of cases from the study population (eg CCG) in each age-band (usually five-year age-bands) is divided by the number of the local population for that age-band and the multiplied by the standard population (in this case the European Standard Population) in the same age-band. These calculations are then summed

across the relevant age-bands and usually expressed as a weighted rate per 100,000 population.

This method of direct standardisation has been used for Maps 1a-c, 2, 4a-c, 19a, and 20.

Confidence intervals

Confidence intervals are used to represent the level of uncertainty of an estimate value (the calculation). Statistical uncertainties usually arise because the indicators are based on a random sample or subset from the population of interest or over a defined time period, both of which may not be representative of the whole population. A smaller confidence interval indicates that the estimate is more reliable, and a larger confidence interval indicates that the estimate is less reliable. Although none of the charts in the 2nd Atlas of variation in are displayed with confidence intervals, confidence intervals were used to determine the shading in the column charts and the significance maps. The two main methods of calculating confidence intervals in this Atlas are:

- the Wilson score method for maps[1,2]
- the Byar's method for maps[2,3]

[1] Wilson EB. Probable inference, the law of succession, and statistical inference. J AM Stat Assoc 1927; 22: 209-212
[2] APHO Technical Briefing 3 – Commonly used public health statistics and their confidence intervals https://fingertips.phe.org.uk/profile/guidance
[3] Breslow NE, Day NE. Statistical methods in cancer research, volume II: The design and analysis of cohort studies. Lyon: International Agency for Research on Cancer, World Health Organization; 1987: 69

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