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 Profiles⁶ 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.

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

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

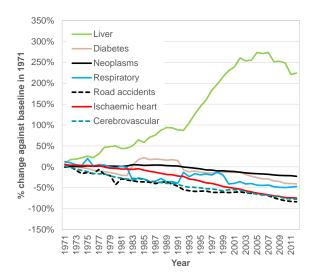
"the only major cause of mortality and morbidity which is on the increase in England whilst decreasing among our European neighbours."

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). 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, 1971–2013¹⁴



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.

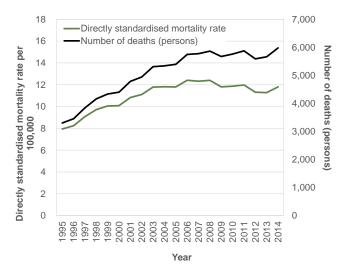
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¹⁴ World Health Organization. European health for all database (HFA-DB), July. www.euro.who.int/en/data-and-evidence/databases/european-health-for-all-family-of-databases-hfa-db

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), 1995-2014¹⁵



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% (R²=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

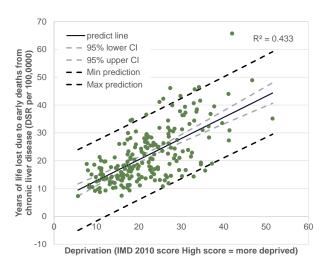
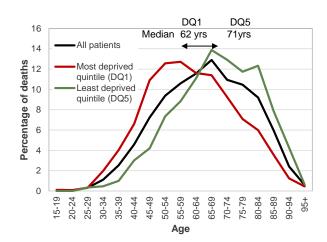


Figure A.4 shows a nine- year gap between the median ages at death for patients with liver disease who reside in the most deprived fifth (quintile) of an area compared to people from the least deprived fifth. There is a negative correlation between deprivation and age of death, this is even more pronounced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

Figure A.4: Age at death by deprivation quintile, for all liver disease¹⁸



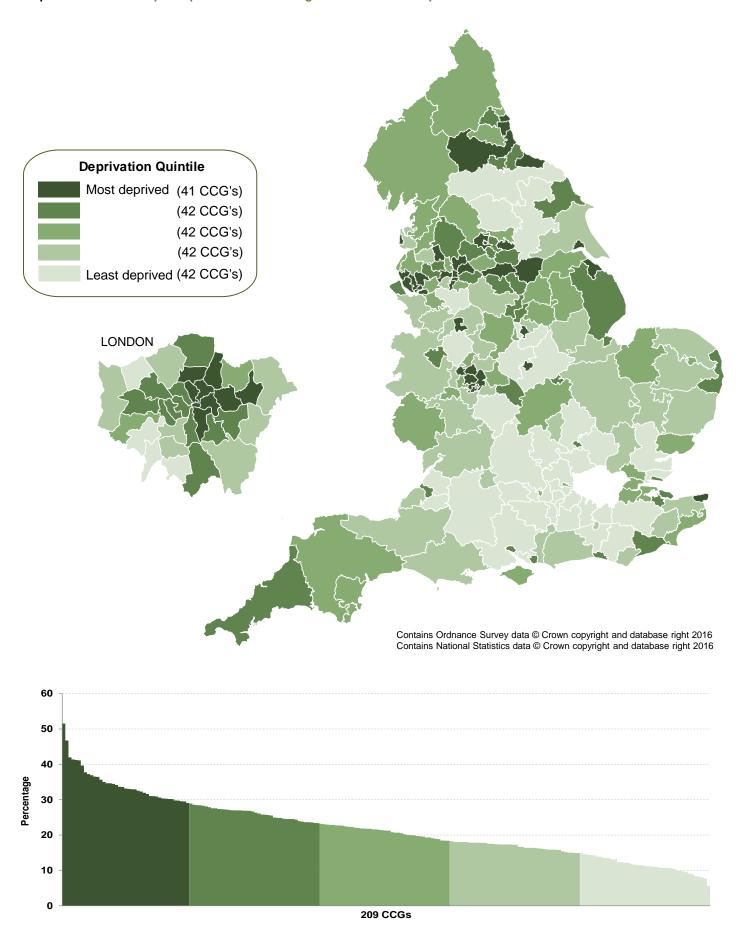
¹⁵ NHS Digital Indicator Portal. https://indicators.hscic.gov.uk/webview

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

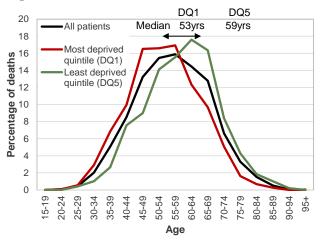
Map A.1: Index of Multiple Deprivation 2015 average LSOA score CCG quintiles¹⁹



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

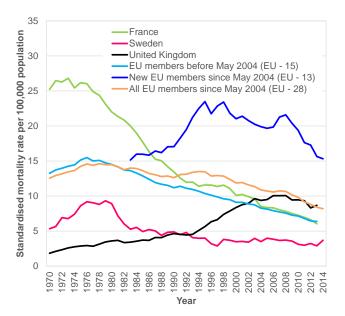
This Atlas compares geographical areas with the England value. Even some of the better performing localities in England cannot be complacent about the need to tackle liver disease because comparisons with other European Union countries reveal stark differences in mortality trends, age at death and age-specific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

As highlighted in the Chief Medical Officer for England's 2011 Annual Report²⁰ 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, 1970-2014²¹

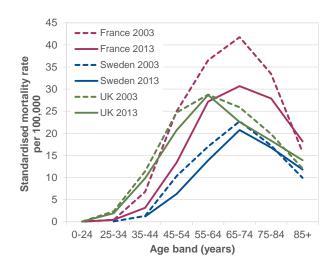


There is also a striking difference in the age at death and gender differences between the UK, France and Sweden. Figure A.7 shows that for all persons the peak of age—specific standardised mortality was much younger in the UK and has shown little change in the decade between 2003 and 2013 compared with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

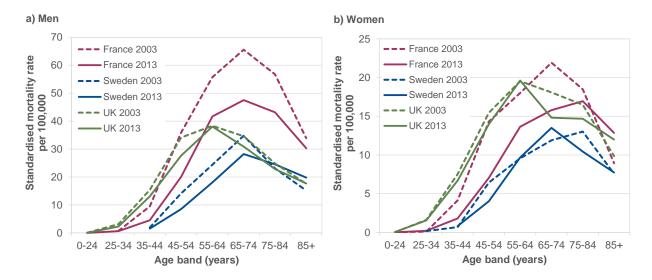
The demonstration of geographical variation in health risk factors, treatment and outcomes is important because it highlights the need for local solutions. It enables commissioners, clinicians and providers to compare themselves with the national picture and their peers and highlight issues for more 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.

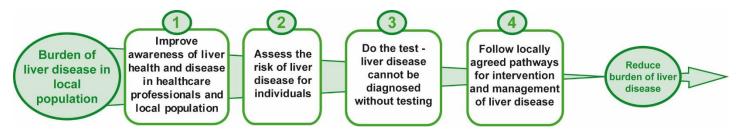
Tips for using the atlas of variation in risk factors and healthcare for liver disease in England to deliver healthcare improvement

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 England³⁰
- Obesity data³¹
- Viral hepatitis monitoring³²
- The National Cancer Registry and Analysis Service (NCRAS) – data on liver cancer³³
- National Antenatal Infections Screening.³⁴
- NHS RightCare Where to Look packs³⁵
- NHS RightCare Long Term Conditions packs³⁶

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 2013/14³⁸. 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 categories³⁹, 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 nonelective 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

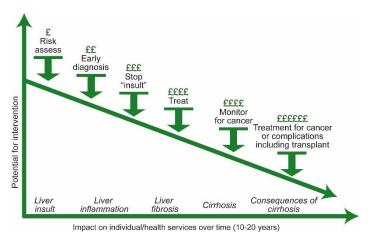
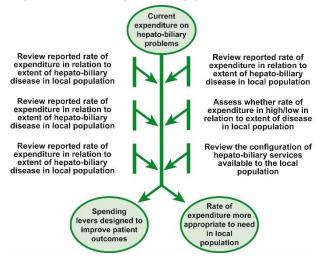


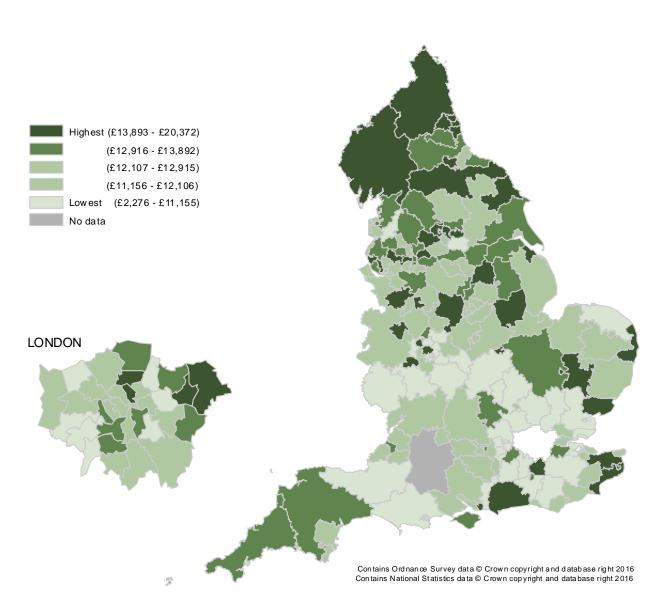
Figure A.12: Options for action when investigating expenditure on hepatobiliary problems



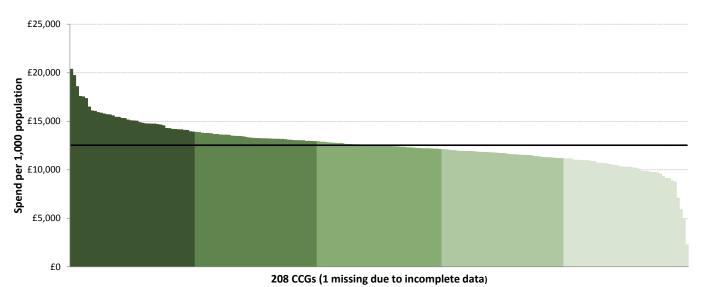
⁴⁰ Spend and Outcome Tool: www.gov.uk/government/publications/spend-and-outcome-tool-spot

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

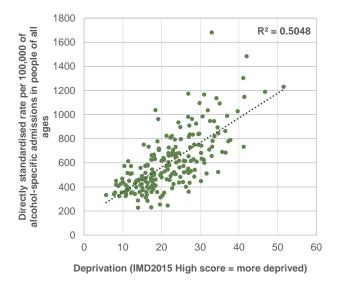
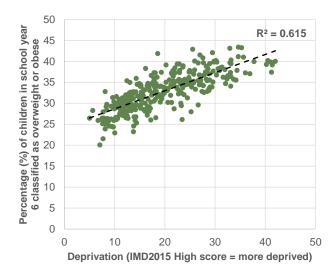


Figure A.14: Association between childhood obesity (year 6) and deprivation by lower tier local authority



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

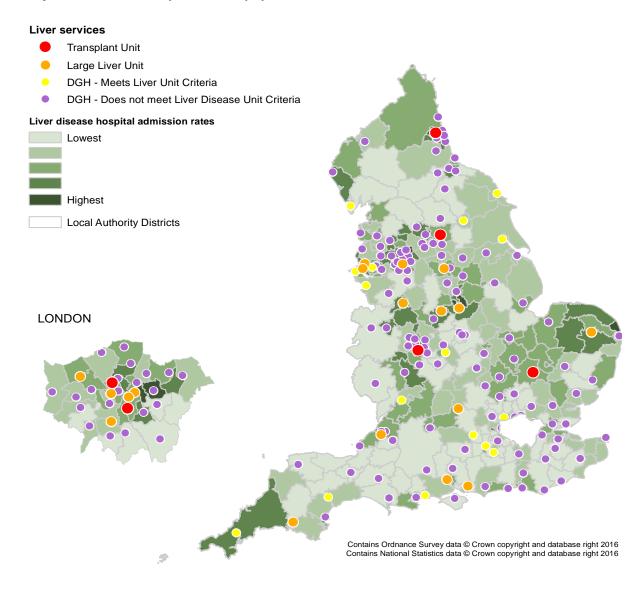
⁴³ NHS England Service specification for Liver Transplantation Service in Adults www.england.nhs.uk/wp-content/uploads/2017/04/liver-transplantation-service-adults.pdf

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.

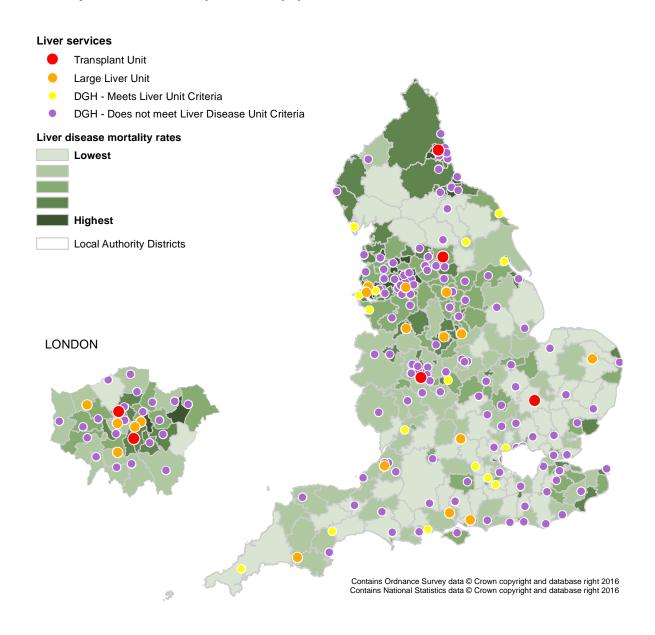
Map A.3: Liver services in England in relation to liver disease admissions in people of all ages, directly standardised rate per 100,000 population, 2014-15



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.

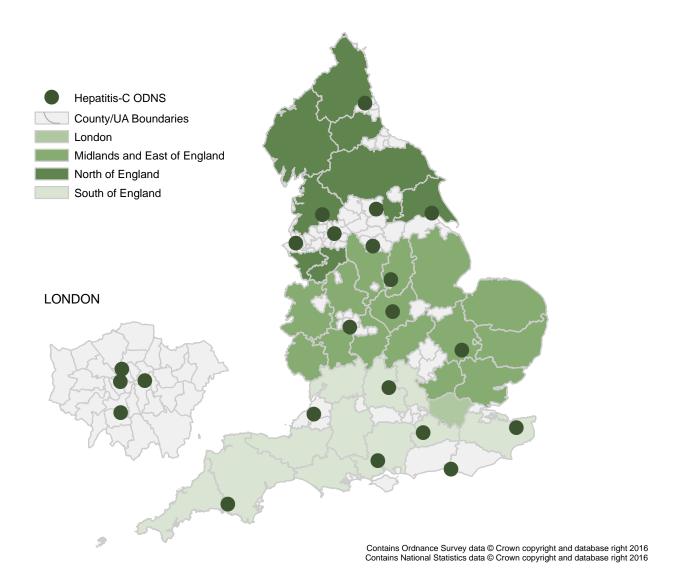
Liver transplant centres and the corresponding referral patterns can have a major impact on the quality of adult liver services and level of expertise available in the referring hospitals, especially as they play a central role in the training of hepatologists. Commissioners need to

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"

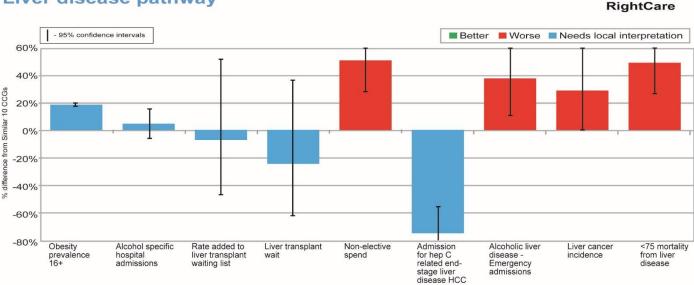
Phase 3 of the NHS RightCare approach involves taking forward opportunities and making them happen. This is achieved through outlining the case for change and making sure impact assessments and assumptions are explicit. This phase involves ensuring that there is clinical leadership of the change and 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

NHS

Figure A.15: NHS RightCare Liver Disease pathway⁴⁶

Liver disease pathway

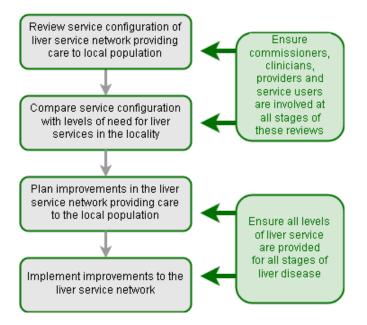


 $^{^{46}}$ NHS Rightcare, Where to Look packs - www.england.nhs.uk/rightcare/products/ccg-data-packs/where-to-look-packs

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 cirrhosis⁴⁸ 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 region⁴⁹ and West Midlands region⁵⁰ 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 Commission⁵³

- 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 Disease⁵⁴ and Cirrhosis⁵⁵ 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.

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