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

Equal-sized quintiles of geographies

Significance level compared with England

LONDON
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

Equal-sized quintiles of geographies

Significance level compared with England

Significantly higher than England - 99.8% level
Significantly higher than England - 95% level
Not significantly different from England
Significantly lower than England - 95% level
Significantly lower than England - 99.8% level
No data
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/


\(^3\) Analysis conducted in 2010 by Tom Kennel, North West Public Health Observatory.
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
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)

<table>
<thead>
<tr>
<th>Cause</th>
<th>Men Years of life lost (rate per 10,000 population)</th>
<th>Women Years of life lost (rate per 10,000 population)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-harm / undetermined intent</td>
<td></td>
<td></td>
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<tr>
<td>Lung cancer</td>
<td></td>
<td></td>
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<tr>
<td>Chronic liver disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accidental poisoning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colorectal cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke</td>
<td></td>
<td></td>
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<tr>
<td>Land transport accidents</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pneumonia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oesophageal cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain cancer</td>
<td></td>
<td></td>
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<tr>
<td>Breast cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lung cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic liver disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-harm / undetermined event</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colorectal cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accidental poisoning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pneumonia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ovarian cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pancreatic cancer</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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](https://indicators.ic.nhs.uk/webview)
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

Equal-sized quintiles of geographies

Significance level compared with England

- Significantly higher than England - 99.8% level (58)
- Significantly higher than England - 95% level (6)
- Not significantly different from England (62)
- Significantly lower than England - 95% level (14)
- Significantly lower than England - 99.8% level (69)
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. Alcohol-use disorders: diagnosis and management of physical complications. Clinical guideline [CG100]. Published date: June 2010. http://guidance.nice.org.uk/CG100
- PHE. Alcohol Learning Resources. Improving Local Alcohol Interventions. www.alcohollearningcentre.org.uk/
- NICE. Non-alcoholic fatty liver disease (NAFLD): assessment and management. NICE guideline [NG49]. Published date: July 2016. www.nice.org.uk/guidance/ng49
- British Society of Gastroenterology. www.bsg.org.uk
**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/](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

Equal-sized quintiles of geographies

Significance level compared with England

- Significantly higher than England - 99.8% level (38)
- Significantly higher than England - 95% level (12)
- Not significantly different from England (42)
- Significantly lower than England - 95% level (17)
- Significantly lower than England - 99.8% level (99)
Although liver disease in children is rare, with only 1,000 children a year diagnosed in the UK, prevalence is increasing, and childhood liver disease is a growing problem. 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. Children's liver disease includes a range of disorders (see Table 3.1).

Table 3.1: Liver diseases in childhood

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

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

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

**Table 3.2: Signs of liver disease in children**

<table>
<thead>
<tr>
<th>Need for identification and assessment</th>
<th>Need for referral</th>
<th>Need for A&amp;E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jaundice</td>
<td>Jaundice</td>
<td>Changes in mental state</td>
</tr>
<tr>
<td>Pale stools</td>
<td>Abdominal pain</td>
<td>Vomiting blood</td>
</tr>
<tr>
<td>Itchy skin</td>
<td>Fever</td>
<td>Blood in the stools</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>Swelling of the abdomen</td>
<td></td>
</tr>
<tr>
<td>Bleeding and/or bruising easily</td>
<td>Poor growth</td>
<td></td>
</tr>
<tr>
<td>Poor growth</td>
<td>Bone fractures</td>
<td></td>
</tr>
</tbody>
</table>

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.\textsuperscript{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.\textsuperscript{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

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. 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. 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. 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. Hepatitis B. Quality standard [QS65]. Published date: July 2014. www.nice.org.uk/guidance/qs65
- Children’s Liver Disease Foundation. Yellow Alert. For professionals. www.yellowalert.org/For-Professionals