Together for Health

Liver Disease Annual Report 2016 – Setting the Baseline
1.0 Introduction

In Wales, we want to reduce the number of people getting and dying from liver disease. We want to ensure people whatever their age value good liver health, and are aware of the dangers of excess alcohol, obesity and blood borne viral hepatitis. We want everyone to take personal responsibility for their lifestyle choices and reduce the risk of acquiring preventable liver disease. Where treatment or care is required we will aim to ensure that people have timely access to high-quality care, irrespective of where they live and how these services are delivered, and that they can maximise the benefits of any treatment and care they may require.

In 2014, 808 people died from liver disease, an increase of 132 deaths (20%) over the past five years. The Welsh Health Survey 2015, which includes information on lifestyle, reveals that 40% of adults reported drinking above the guidelines on at least one day in the past week, including 24% who reported drinking more than twice the daily guidelines (sometimes called binge drinking), and it reports the prevalence of overweight and obese adults as 59%. Both excess alcohol consumption and obesity are major contributory factors to liver disease. Reducing the levels of liver disease amongst the population in Wales is a major challenge. If done well it is an opportunity to improve the lives of patients and their families.

“Together for Health: A Liver Disease Delivery Plan” published in May 2015, seeks to address the rise in liver disease and liver related deaths, give patients more support, improve the quality of services, improve specialist knowledge in liver disease throughout the health service, and encourage patients to take responsibility for their health. The implementation of this plan will help prevent disease, and facilitate better care for patients with liver disease and improve outcomes.

The liver disease delivery plan provides a framework for action by health boards and their partners. It sets out the Welsh Government’s expectations for the planning and delivery of person-centred care and focuses on meeting population need, tackling variation in access to services and reducing inequalities across a number of themes:

- preventing liver disease
- timely detection of liver disease
- delivering fast, effective treatment and care
- supporting people living with liver disease
- improving information
- targeting research.

This is the first annual report about liver disease in Wales, as required by the delivery plan. It provides a national overview, complementing the individual reports, which have already been produced by individual health boards. Taken together, the reports demonstrate our commitment in Wales to improving care for those with liver disease and report on progress over time.

The publication of this first all-Wales report brings together information about how NHS Wales services for people with liver disease are performing. It highlights the progress we have made in this area and identifies areas for future improvement. It demonstrates how
health boards are taking local ownership, through their own delivery plans, to improve services for people and drive up standards of patient care in their communities.

We have developed a number of outcome and assurance measures, which together will demonstrate how services for people with liver disease are improving in Wales. Some progress against these measures has been made, giving us reassurance that care for those with liver disease in Wales is developing in line with our vision:

- alcohol-related liver disease accounts for over a third of liver disease deaths. There has been a 7% reduction in the number of alcohol-related deaths in the past five years, from 494 deaths in 2010 to 459 deaths in 2014
- over the past five years, there has been a reduction in alcohol consumption above the recommended guidelines, from 44% in 2010 to 40% in 2015
- in 2013-14 the rate of hospital admissions for liver disease per 100,000 of the population in Wales was 91.4, which was below the English rate of 115.8
- there were 459 alcohol-related deaths registered in Wales in 2014, representing a fall of 1.7 per cent compared with 2013 when 467 alcohol-related deaths were registered
- in 2014-15 there were 29 liver transplants performed on Welsh residents (figure 19).

We need to continue to make improvements in these areas as well as ensuring that progress is made where performance has not been at as good a level as anticipated:

- people living in areas of deprivation tend to be more overweight than those in other parts of Wales
- the alcoholic disease mortality rate for those aged under 75 in Wales is consistently above the rate in England
- the number of emergency admissions needs to reduce, as there are around 3,000 hospital admissions for liver disease and just over half of these are emergency admissions
- there has been an increasing trend in both mortality and incidence of liver cancer over the past 10 years. In 2005, 168 people were diagnosed with liver cancer, 93 men and 75 women. By 2014 this had risen by 57%, to 264 people being diagnosed with liver cancer. The growth is almost entirely amongst men. The number of people dying from liver cancer has increased from 159 in 2005 to 290 in 2014, an increase of 82%
- the amount of time an individual spends in hospital with liver disease over the last five years has been around 12 days. The amount of time that a person spends in hospital following an emergency admission is slightly higher at around 13 days, whereas planned admissions are lower at eight days
- recruitment to clinical liver disease research studies decreased in 2014 -15 by 66 compared to the previous year.

It is important to recognise the valuable work undertaken by the third sector in supporting and caring for people with liver disease and their families. This support is an essential element of the delivery plan, without which the NHS would struggle to deliver such excellent service.

Over recent years, considerable investments have been made to the support services available in Wales to reduce excessive alcohol consumption and improve individuals’ lifestyles, including alcohol intervention teams and lifestyle management. Whilst this will have a positive impact, it is important to remember the important role that each person has to play in preventing and minimising liver disease.
Through this and future annual reports, the Welsh Government aims to give a clear account of how well the NHS is caring for and supporting people with liver disease, and indicate to the NHS where it is doing well and where it needs to improve care. Information like this is the best way to support continuous improvement in services.

Andrew Goodall  
Chief Executive, NHS Wales

Sara Hayes  
Chair, Liver Disease Implementation Group
2.0 What is liver disease?

The liver is the largest gland and solid organ in the body, weighing some 1.8 kg in men and 1.3 kg in women. It holds approximately 13% of a person’s total blood supply at any given time and has over 500 functions.

Some of the main liver functions include:

- fighting infection and disease
- destroying poisons and drugs (including alcohol)
- cleaning the blood
- controlling the amount of cholesterol
- processing food once it has been digested.

There are more than 100 types of liver disease, which together affect at least two million people in the UK.

The main types of liver disease include:

**Alcohol-related liver disease** – where the liver is damaged after years of alcohol misuse. Alcohol is the most common cause of liver disease. The more someone drinks, the higher their risk of developing liver disease.

**Hepatitis B** - this virus is transmitted through contact with infected blood or other body fluids. Infection can lead to chronic disease and during the acute phase of infection the majority of people are asymptomatic; only a third of adults and a smaller proportion of children develop symptoms, which may include fever and jaundice. Most acute symptomatic infections are acquired through adult risk behaviours such as injecting drug use and sexual contact. The risk of developing chronic hepatitis B infection depends on the age at which infection is acquired. Chronic infection occurs in up to 90% of children who acquire the infection under the age of 5 years, but less than 10% of people infected as adults. Chronic infection can lead to chronic liver disease and liver cancer. Hepatitis B vaccines are available and highly effective and immunisation is recommended for high risk groups.

**Hepatitis C** – this virus is mainly transmitted through contact with infected blood. Injecting drug use is the most important risk factor for infection within the UK. Hepatitis C is often asymptomatic, and symptoms may not appear until the liver is severely damaged. Around 20-30% of infected people clear their infection naturally within the first six months of infection. For the remainder, hepatitis C is a chronic infection which can lead to liver disease and liver cancer. Very effective treatments which can clear the virus and reduce the risk of further liver disease are available.

**Non-alcoholic fatty liver disease** - obesity is an important risk factor for non-alcoholic fatty liver disease (NAFLD), a term used to describe accumulation of fat within the liver that is not caused by alcohol consumption. It is usually seen in people who are overweight or obese. Most people with NAFLD never experience any symptoms from the condition, a minority, however, may progress to a more serious form of the disease known as non-alcoholic steatohepatitis, which may ultimately lead to fibrosis and, in a small number of cases, cirrhosis and/or liver cancer.
**Autoimmune liver disease** – this is when the body’s immune system attacks the liver cells (autoimmune hepatitis) or bile ducts.

**Inherited metabolic liver diseases** such as haemochromatosis, alpha-1 antitrypsin deficiency or Wilson’s disease – these disorders occur due to inherited abnormalities of metabolism leading to accumulation of abnormal products within the liver and lead to its damage.
3.0 How well are we doing in caring for those with liver disease in Wales?

3.1 Overview

An understanding of how many people suffer from the conditions that may result in liver disease, how many die from liver disease as well as the number of times people with liver disease have hospital admissions, all provide an important insight into the effectiveness of our work to prevent, detect and treat liver disease, and to support those living with a long-term liver related health condition.

This analysis highlights the prevalence of the main causes of liver disease is increasing. Deaths from liver disease are rising, and most of this increase is avoidable.

3.2 Incidence of liver disease

Liver disease is sometimes referred to as the ‘silent killer’ as there are often only vague symptoms until liver damage is quite severe. Early symptoms can include feeling generally unwell or tired, having poor appetite, weight loss, a tender abdomen, feeling itchy or vomiting. These are also symptoms that are common in other medical conditions as well. Most people with liver disease only find out during tests for an unrelated illness or a medical check-up. When liver damage is quite severe, people can experience some of the following symptoms, including yellow eyes and skin, called jaundice; bleeding problems; vomiting blood; drowsiness and confusion; fever; swollen abdomen and legs; and tarry black stools.

The three most common causes of liver disease in the UK are obesity, alcohol misuse and blood borne viral hepatitis.

In 2015, 24% of adults in Wales were categorised as obese¹, an increase from 19% in 2005-06. Many of these may have fatty liver disease, as well as scarring and prolonged inflammation that may lead to cirrhosis. Figure one, clearly shows that those individuals living in the most deprived parts of Wales are more likely to be obese than those in the least deprived parts of Wales. These individuals are at a higher risk of having liver disease and therefore health boards will need to ensure that their preventative strategies impact upon the needs of these individuals.

¹ Welsh Health Survey 2015
Every week in Wales, 29 deaths are wholly or partly attributable to alcohol; around 1 in 20 of all deaths. In fact, most result from long-term drinking and its role in increasing risks of diseases such as cancer and cardiovascular disease, which contribute to the total of alcohol-attributable deaths. Alcohol-specific deaths, account for about 1 in 4 (26%) of these deaths.

Alcohol-related liver disease accounts for over a third of liver disease deaths. Figure two shows that alcohol related deaths have increased by 13% over the past 10 years. However there has been a 7% reduction in the number of deaths in the past five years, from 494 deaths in 2010 to 459 deaths in 2014.

Source: Welsh Health Survey 2015
An estimated 12,000 to 14,000 people in Wales are chronically infected with hepatitis C virus. The World Health Organization (WHO) estimates that in the UK the prevalence of chronic hepatitis B infection is between 0.1% and 0.5% of the UK population.

Liver disease as a result of the factors above (obesity, excess alcohol consumption and blood borne viral hepatitis) is almost entirely preventable. The co-existence of more than one factor may lead to more serious liver disease and higher rates of liver cancer. These underlying causes of liver disease are linked to social deprivation and therefore may disproportionately affect the poorest communities.

### 3.3 How many people die from liver disease each year?

In 2014, 808 people died from liver disease in Wales, an increase of 132 deaths (20%) since 2010. As well as considering the actual number of deaths, crude mortality rates offer an indication of the change in liver disease deaths over time. Figure three shows the increasing trend in both numbers and crude mortality rate per 100,000 population since 2010.

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4 Blood borne viral hepatitis action plan for Wales 2010-2015

Figure three shows that the rate of deaths from liver disease for those aged under 75 in Wales is consistently above the rate in England.

Figure four shows that the rate of deaths from liver disease for those aged under 75 in Wales is consistently above the rate in England.

Source: NHS Wales Informatics Service

Source: NHS Wales Informatics Service and Public Health England – Liver profiles
3.4 What is the rate of hospital admissions for people with liver disease?

With strengthened preventative and early detection strategies, as well as improved services and support for those with established liver disease, a decrease in the number of individuals admitted to hospital with liver disease would be expected over time.

Figure 5: Hospital admissions all liver disease, age standardised rate per 100,000 persons, all ages, 2013-14


Figure five highlights in 2013-14 the rate of hospital admissions for liver disease across Wales was 91.4 per 100,000, considerably below the English rate of 115.8. Across Wales, variation between health boards can be seen with Cwm Taf having the highest rate.

6 http://fingertips.phe.org.uk/profile/liver-disease
4.0 What is happening across Wales to help improve services for individuals with liver disease?

A Liver Disease Implementation Group has been established to support the implementation of the liver disease delivery plan. This Group includes wide representation including the Wales Association of Gastroenterology and Endoscopy, British Liver Trust, Children’s Liver Disease Foundation, Welsh Government and also individuals from health boards and Public Health Wales.

£1 million has been allocated annually to support the delivery of the priorities identified by the Liver Disease Implementation Group. This is being used to support the development of the following projects and priorities:

- the establishment of hospital alcohol care teams
- education and awareness raising for the prevention of liver disease
- strengthening early detection of liver disease
- developing integrated and streamlined pathways
- the implementation of satellite liver transplant outpatient clinics
- the appointment of a part time national clinical lead for liver disease.

All health boards have been challenged to improve their services for liver disease patients aligned to the priorities in the Liver Disease Delivery Plan.

Clinical audit and outcome review is critical to continuous service improvement. Health Boards are then expected to act upon the outcomes. This is monitored by the Liver Disease Implementation Group.

The Liver Disease Implementation Group recognises the need to develop new partnerships with industry partners. Working together will deliver better healthcare outcomes resulting in the redesign of clinical pathways. Funding will be allocated to support industry partnerships over the next two financial years.

The Blood Borne Virus Hepatitis sub group recently issued a call to industry partners regarding joint working opportunities that will design, develop and pilot new clinical pathways for viral hepatitis.
5.0 Preventing liver disease

As with a number of other health conditions, the way individuals lead their lives affects their risk of contracting liver disease. The three main causes of liver disease are:

- sustained high levels of alcohol consumption, which can lead to alcohol related liver disease
- obesity, which can lead to non-alcohol related fatty liver disease
- blood borne viral hepatitis; one of the main risk factors for acquiring blood borne viral hepatitis in the UK is associated with substance misuse.

The evidence indicates that the behaviours that contribute to these conditions can be prevented, which could lead to a reduction in the cases of liver disease in Wales.

Deprivation is associated with poor health and there is a need to make continued efforts to lift people out of poverty.

The overarching aim of the integrated and inclusive education and awareness raising for the prevention of liver disease scheme is to ensure that relevant professionals and practitioners, and the wider population, are aware of the risk factors for, and mechanisms and interventions designed to prevent, the development of liver disease. A significant element of this scheme will build on existing effective campaigns such as ‘Change4Life’ and the hepatitis C campaign, and will link to the relevant work in Public Health Wales including the ‘making every contact count’ programme being undertaken across Wales.

This scheme will include education and raising awareness around blood borne viral hepatitis, alcohol misuse and obesity. It will encompass three main approaches:

- targeted interventions and campaigns aimed at higher risk groups to include individuals born in countries with higher prevalence of blood borne virus infection, black, asian and minority ethnic communities, and those with problematic drug and alcohol use
- targeted awareness raising and education amongst all relevant professionals
- general awareness raising amongst the whole population.

This scheme will raise awareness and knowledge of risks and likely consequence; and educate on risk and behaviour change for prevention of liver disease and wider health consequences.

People in Wales need to be aware of, and take action to minimise their risk of, liver disease through healthy lifestyle choices. Reducing obesity and alcohol consumption will have the greatest impact.
5.1 Tackling childhood obesity

Prevalence of childhood obesity is an ongoing concern in Wales. Children who are obese are reportedly being diagnosed at a much younger age, resulting in a risk of developing liver disease.

The Child Measurement Programme for Wales is an annual programme that identifies the prevalence of overweight classification and obesity amongst children. 32,889 children aged 4 and 5 participated in the programme in 2014-15. Key findings are:

- nearly three quarters of the children measured (72.9%) had a body mass index (BMI) classified as being of a healthy weight
- the prevalence of those overweight or obese in Wales in reception year (26.2%) was significantly higher than that for England (22%). It was also significantly higher in Wales than in any of the individual English regions, where the highest prevalence was 24%
- there is a strong relationship between levels of obesity and deprivation. 28.4% of children living in the most deprived areas of Wales were overweight or obese, compared to 20.9% in the least deprived areas (figure six). For obesity alone, 13.2% of children in the most deprived areas were obese, compared to 8.6% in the least deprived areas.

Figure 6: Proportion of children aged 4-5 years who are overweight or obese, Welsh Index of Multiple Deprivation quintiles, Child Measurement Programme for Wales, 2014/15

Source: Public Health Wales Observatory, using CMP data (NWIS) and WIMD 2014 (WG)
5.2 Tackling adult obesity

24% of adults in Wales are obese (24% of women and 23% of men)\(^7\). Some of these will have fatty liver disease, and a proportion will have scarring and prolonged inflammation that will lead to cirrhosis.

Losing weight and increasing levels of physical activity can help to lower the risk of having liver disease.

Figure seven clearly shows that the risks of obesity are greater for those individuals living in the most deprived parts of Wales than those in the least deprived parts of Wales. These individuals are at a higher risk of becoming diabetic and therefore health boards will need to ensure that their preventative strategies focus upon the needs of their residents in areas of deprivation.

**Figure 7:** Age-standardised percentage of adults who reported key health-related lifestyles, by deprivation in 2015

The Welsh Government’s physical activity plan, ‘Creating an Active Wales’, aims to make physical activity a natural part of people’s lives. This means creating an environment that:

- makes it easier for people to be more physically active
- supports children and young people to lead active lives
- encourages more adults to be more active
- increases people’s participation in sport.

\(^7\) Welsh Health Survey - 2015
It is envisaged that this, in addition to the full implementation of the All Wales Obesity Pathway, will decrease the prevalence of obesity within the population and also reduce the number of individuals suffering from conditions related to this in Wales.

### 5.3 Reducing alcohol consumption

Over the past five years, there has been a reduction in the percentage of adults in Wales whose alcohol consumption was above the recommended guidelines, from 44% in 2010 to 40% in 2015. A third of patients with alcohol-related liver disease have severe alcohol dependency or alcoholism and roughly 20 to 30% of lifelong heavy drinkers develop cirrhosis.\(^8\) Adults who reported binge drinking has fallen consistently over the past five years. Figure eight highlights that there is a variation in levels of binge drinking between those people living in areas of least deprivation compared to those in other parts of Wales.

**Figure 8:** Adults who reported binge drinking on at least one day in the past week, age standardised by Welsh index of multiple deprivation quintile

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\(^8\) Together for Health – Liver Disease Delivery Plan
The impact of alcohol on health also creates enormous pressures on health systems. Every week hospitals in Wales handle almost 1,000 admissions related to alcohol. In addition there are many more presentations at emergency departments, ambulance requests and GP appointments, that all result from alcohol. If our strategy is effective we would expect to see the number of emergency attendances and hospital admissions related to alcohol fall.

In 2012-13, more than 10,500 people were admitted to hospital with alcohol-specific conditions (15% of these are estimated to be due to alcoholic liver disease) and over 34,000 people were admitted to hospital with alcohol-attributable conditions.

Over the past five years the rate of alcohol specific and alcohol attributable admissions has increased by 4 and 5% respectively. The rate of alcohol specific admissions in Wales is around 7% lower than in England.

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\[^{9}\] Alcohol and health in Wales 2014: Wales profile. Figure 13, alcohol-specific hospital admissions 2012-13.

\[^{10}\] Alcohol and health in Wales 2014: Wales profile. Figure 15 alcohol-attributable admissions (broad) 2012-13.
Figure 9: Rate of alcohol specific hospital admissions

Source: Public Health Wales Observatory, using PEDW (NWIS), fractions (PHE) & MYE (ONS), Public Health England – Liver profiles

Drink Wise, Age Well is a major new, multi component programme of work which aims to address the challenges of alcohol-related harm in older adults. Cwm Taf is one of five demonstration sites across the UK to deliver the programme.

The programme has received Big Lottery funding for a total of 5 years for programme development and delivery and 7 years for an accompanying research component. Betsi Cadwaladr UHB area acts as the control site for research purposes in Wales.

The partner organisations delivering the Programme within Cwm Taf are Drugaid, Kaleidoscope, TEDS, WCADA and The Royal Voluntary Service. The locality manager, Richard Broadway manages a team of 17 staff within Cwm Taf. This team delivers services across four key work streams - prevention and campaigning, training and education, building resilience and direct engagement and support.

The team has delivered a wide range of interventions under these work streams since operational commencement in June 2015, engaging with over 2000 individuals. Five local media campaigns have also been undertaken. 277 individuals have been referred for direct support. The volunteer aspect of the programme is developing with seven volunteers recruited to offer befriending services to individuals at danger of isolation.

As part of the research element a large scale survey led by the University of Bedfordshire, with over 16,000 respondents, has been undertaken to explore the drinking behaviours of over 50’s. The resulting report is available on the programme website [www.drinkwiseagewell.org.uk](http://www.drinkwiseagewell.org.uk)
5.4 Preventing viral hepatitis

Viral hepatitis is a group of viruses (A-E) that can infect the liver. If left untreated, viral hepatitis infection can cause serious and potentially life-threatening damage to the liver. With modern treatments it's often possible to cure the infection and most people with it will have a normal life expectancy.

It is possible to be infected with hepatitis B and C through contact with the blood or body fluids of an infected person. The main ways of getting infected with hepatitis B and C are:

- from mother to baby at the birth
- from child to child
- sharing unsterilised needles, particularly needles used to inject recreational drugs
- through unprotected sex.

In the UK, most hepatitis C infections occur in people who inject drugs, or have injected them in the past. It is estimated that around half of those who inject drugs have the infection.

Each year Public Health England, supported by Public Health Wales, undertake an anonymous monitoring survey of people who inject drugs which aims to measure the level of HIV, hepatitis B and hepatitis C amongst this population.

Figure 10 Survey of people who inject drugs in Wales

Source: Unlinked Anonymous Monitoring Survey of People who Inject Drugs in contact with specialist services

Figure 10 shows that the prevalence of both hepatitis B and C amongst people who inject drugs is 11% and 50% respectively, compared with 15% and 50% respectively in England. The uptake of the hepatitis B vaccine in Wales was 76% in 2014, 4 percentage points higher than in England, and the uptake of the voluntary test for hepatitis C was 85%, 2 percentage points higher than England.
Figure 11: Percentage of those who had injected in the preceding four weeks reporting

Source: Unlinked Anonymous Monitoring Survey of People who Inject Drugs in contact with specialist services

Figure 11 highlights the high proportion of drug users who use shared needles and syringes; the level of direct and indirect sharing at 41% in Wales in 2014 is 3 percentage points higher than in England, and the level of direct sharing at 22% is 6 percentage points higher than England.

Local strategies have been put in place to reduce substance misuse by adults and children. Through the Substance Misuse Action Fund, Welsh Government invests in services across Wales which aim to reduce the harm associated with substance misuse. Contributions have also been made towards primary prevention of alcohol misuse through collaborative work between stakeholders to map data regarding incidents e.g. by South Wales Police Crime Commissioner and Public Health Wales, establishment of Community Safety Partnerships and tackling availability of alcohol to young people through the Substance Misuse Area Planning Boards.

It is important to ensure that where appropriate that prisoners are fully vaccinated against hepatitis B. Delivery and monitoring of HBV hepatitis B vaccinations has been taken forward in each prison. There has been a large increase in the proportion of individuals who have received a full course of HBV vaccination increasing from 10% in 2012 to 36% in 2014 as shown in figure 12.
5.5 What is being done to prevent liver disease?

There are many good examples of local activity which are contributing to the primary prevention of liver disease:

- North Wales alcohol demand reduction workshops – focussing on what can be done with existing resource collectively across North Wales to help reduce the demand for alcohol
- Local alcohol action area pilots – Welsh Government are working with the Home Office and Public Health Wales to support four alcohol action area pilots in Wales. These will tackle alcohol-related crime and disorder, reduce alcohol-related health harms, and promote growth by establishing diverse and vibrant night-time economies
- Community safety partnerships are responsible for developing local strategies for reducing substance misuse amongst adults
• Sports Wales has developed a Community Sports Strategy\(^\text{i}\) which highlights the need for better communication and close, effective collaboration between partners, with an emphasis on encouraging young people to participate in sport
• Structures exist in Wales to tackle substance misuse amongst children and young people, for example the substance misuse education steering group and local safeguarding children boards
• Awareness of the harms associated with alcohol and substance misuse have also been addressed in Wales through the Welsh substance misuse helpline and rehab online, a directory of rehabilitation residential services for adult drug users.

Hywel Dda University Health Board aims to roll out alcohol care teams to all acute units, and introduce alcohol screening and alcohol brief interventions at the same time. Working with public health, primary care and the third sector, general alcohol advice, harm reduction and education is forming a major part of their approach to address the increases in alcohol consumption that need to be addressed.

\(^{\text{i}}\) \url{http://sport.wales/community-sport/sporting-communities/community-strategy.aspx}
6.0 Timely detection of liver disease

Early detection of liver disease is difficult, as it is usually asymptomatic in the early phases and patients will have few clinical signs. Most patients present at a late stage of cirrhosis and usually at hospitals with bleeding varices, ascites or encephalopathy. By this stage, substantial morbidity and high mortality rates are likely.

Primary care has an important role to play in ensuring individuals at high risk of developing liver disease, and those with existing liver disease, are identified and managed at an earlier stage. Individuals identified with risk factors need to be made aware of their risk of liver disease and be supported in lifestyle changes that will help reduce potential further damage to their liver.

Level 3 and 4 obesity services support the early detection and treatment of liver inflammation associated with fatty liver disease by referring appropriate patients. Alcohol liaison services, alcohol specialist nurses and emergency departments see large numbers of patients with higher risk of alcohol-related liver disease.

It is estimated that a general practitioner will have between eight and 18 HCV infected individuals\textsuperscript{12} amongst their patients (based on an average patient list size of 1,800). In August 2014, Welsh Government wrote to GPs across Wales requesting that they review arrangements for identifying and testing patients who may have current or historic risk factors for hepatitis B or C infection. Where results indicate infection, patients should be referred to one of the specialist services in Wales for treatment. GPs are encouraged to review their records to identify patients who may have been previously diagnosed with hepatitis B or C and consider referring the following for specialist assessment:

- patients diagnosed prior to treatment being available
- patients who have never undergone specialist assessment
- patients who dropped out of treatment before clearing the virus
- patients who have not completed the investigation process to confirm that the virus has been cleared.

Dried blood spot testing (DBS) for HCV, HBV and HIV was rolled out by Public Health Wales in October 2010. An education programme and guidance document to support the use of this testing was also introduced. It is estimated the number of individuals tested by DBS was 1,531 in 2011, 1,675 in 2012, 1,874 in 2013 and 1,639 in 2014 (based on samples attributed to substance misuse services or prisons). Work continues to promote testing within substance misuse services. It is estimated the number of individuals with a first reactive test for HCV antibody from DBS testing within each year was 19% in 2011, 12% in 2012, 10% in 2013 and 11% in 2014.\textsuperscript{13}

The DBS testing method has been made available in each prison. Data collected over 2013-14 demonstrates that both dried blood spot and venepuncture methods are being used:

\textsuperscript{12} Royal College of General Practitioners guidance
\textsuperscript{13} Report on Blood Borne Viral Hepatitis Action Plan for Wales 2010–2015
Table 1: Blood borne virus testing in Welsh prisons

<table>
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<tr>
<th>Year</th>
<th>Total number tested</th>
<th>Number of DBS tests</th>
<th>Number of venepuncture tests</th>
<th>Proportion of admissions screened</th>
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<td>2013</td>
<td>1255</td>
<td>424</td>
<td>831</td>
<td>13%</td>
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<td>2014</td>
<td>1150</td>
<td>538</td>
<td>612</td>
<td>14%</td>
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The liver service at Aneurin Bevan University Health Board provides a wide array of diagnostic and therapeutic options for patients with liver disease. The liver unit was the first in Wales to have a Fibroscan and the first to have a portable Fibroscan for use in prisons and remote sites. In addition to a full array of relevant diagnostic tests (including transjugular liver biopsy which is not universally available) the liver unit is the only centre in Wales able to offer both radiofrequency ablation and transarterial chemoembolisation for patients with primary liver cancer.

Figure 13 highlights the high proportion of hospital admissions for liver disease that can be attributed to alcoholic liver disease and liver cirrhosis. Rates of hospital admissions for liver disease give a good indication of how effective early detection strategies are in Wales. As NHS Wales gets better at detecting and preventing liver disease then the rate and number of hospital admissions should fall over time. The number of admissions to hospital due to liver disease is around 3,000 each year. This equates to a rate of 93 per 100,000 in 2013-14, considerably less than the rate of admissions in England, which was 115.8 per 100,000.

![Figure 13: Hospital admission rates per 100,000 for:](source)

*Source: NHS Wales Informatics Service*
Figure 14 compares the hospital admission rates for three liver related conditions in Wales with the rates in England for the last two years.

**Figure 14:** Hospital admission rates per 100,000 for:

![Hospital admission rates graph](chart)

- **Hepatitis B related end stage liver disease / hepatocellular carcinoma**
- **Hepatitis C related end stage liver disease / hepatocellular carcinoma**
- **Non-alcoholic fatty liver disease**

**Source:** NHS Wales Informatics Service and Public Health England, Liver profiles

The Liver Disease Implementation Group has set early detection as one of its priorities. It is supporting a programme of work that will facilitate collaboration with key stakeholders in health and social care, communication across the health and social care pathways and coordination of all activities across sectors. This will involve undertaking pilot projects to build and create appropriate pathways and networks.

An expert patient programme is now available for patients and their families with liver disease in Cardiff and Vale University Health Board. This programme will support and educate them on how to manage, recognise and control their symptoms in a timely fashion.

A primary care referral pathway for abnormal liver function tests or suspected chronic liver disease has been developed in Cardiff and Vale University Health Board. This aims to strengthen the referral process and reduce the number of inappropriate referrals as it helps the primary care physicians to identify, investigate and refer to secondary care hepatologists. This new pathway will reduce the number of unnecessary investigations and improve access times to see a specialist.
7.0 Delivering fast and effective care

A full time hepatologist has been recruited by Cardiff and Vale Health Board. This has helped streamline existing liver services in the Health Board and has significantly contributed to the reduction in waiting times for patients needing urgent liver care. Clinics take place at both University Hospital Wales and Llandough.

Patients with chronic liver disease suffer from high levels of morbidity as a consequence of either complications of cirrhosis or the development of liver cancer. Complications associated with cirrhosis often occur unexpectedly and can progress rapidly. The appropriate management of patients with chronic or acute liver disease requires an integrated approach involving voluntary services, community and primary care, specialised hepatology services, laboratory staff, diagnostic and interventional radiology and critical care services. Where possible, services should be delivered using the expertise of people trained to deal with the needs of different age groups, and be in a position to coordinate or treat their wider health needs.

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report identified widespread failings in the care provided to patients with alcohol-related liver disease. One of the major recommendations from this report is the need for patients to be seen within 24 hours of admission by someone with an appropriate level of specialist knowledge, due to the unique challenges patients with complications of cirrhosis may present with. This should be undertaken by a hepatologist or a gastroenterologist with appropriate training in managing liver disease.

All health boards with a treatment centre now have access to a fixed and portable specialist scanner, minimising the need for invasive liver biopsies while supporting patient management.

Improvement in delivering effective care along with strengthened prevention strategies and early detection should result in a reduction in the number of individuals admitted as emergencies as a result of liver disease. Where admission is necessary, these should be timely and planned in line with clinical need. Figure 15 highlights that each year there are around 3,000 hospital admissions for liver disease and just over half of these are emergency admissions. The challenge is to reduce the number of emergency admissions in the future.
Effective diagnosis supported by timely planned treatment and immediate lifestyle changes is the best form of treatment. However, as already highlighted, many people are unaware that they may have liver disease until they need urgent help.

Effective self care and treatment should, over time, reduce the average length of time a person needs to spend in hospital. Each year there are around 3,000 admissions for people with liver disease conditions. Figure 16 indicates that the amount of time an individual spends in hospital with liver disease has been around 12 days for the past five years, for each admission. The amount of time that a person spends in hospital following an emergency admission is slightly higher at around 13 days; planned admissions are lower at eight days.

Cardiff and Vale University Health Board hosts the hepatocellular carcinoma (HCC) multi disciplinary team (MDT) every week. This is the only MDT for HCC in Wales and all patients with proven or suspected HCC are discussed and treatment plans developed. The MDT is attended by hepatologists, liver surgeons, interventional radiologists, cross sectional radiologists and specialist nurses in hepatology and liver surgery. Cardiff is the designated liver surgical centre in Wales and offers liver resection for suitable patients with HCC. Surgical portosystemic shunts are offered to suitable patients with severe portal hypertension secondary to liver disease. It offers portal vein embolization to enable liver resection in some patients and transarterial chemoembolisation for patients not suitable for surgery. Cardiff also performs transjugular intrahepatic portosystemic shunt to patients as either a treatment for patients with severe portal hypertension or as a bridge to liver transplantation.

**Figure 15: Liver disease - all hospital admissions and emergency admissions**

Source: Patient Episode Database for Wales, NWIS
The Health Boards in Wales have committed to delivering the new all oral highly effective treatments for hepatitis C through a roll out programme that is designed to produce equitable and transparent access to treatment across Wales. The roll out programme will ensure that those patients most in need receive treatment first whilst also ensuring that all patients will be able to access these therapies in due course.
8.0 Living with liver disease

Liver disease is complex, varied and fluctuates. Unfortunately there is no simple cure for most liver diseases. However there are things which could benefit individuals with liver disease. These include, for example, eliminating or reducing alcohol consumption, losing excess weight, getting daily exercise, as well as having appropriate vaccinations.

Understanding their own liver condition will help a person manage their daily life. People need to be equal partners in their care. This will help ensure that they receive appropriate care and give them greater control over their own health. Education is key to managing liver disease and the associated symptoms. Having confident and informed patients at the centre of the decision-making processes will allow them to take ownership of their conditions leading to fewer unplanned primary care consultations, reductions in visits to emergency departments, reductions in visits to outpatient departments, reduced hospital admissions and reduced length of stays in hospital. Self care and co-production are key elements of prudent healthcare, the principles of which include avoiding harm, minimal intervention and agreeing treatment plans.

We are using months of life lost as an indicator of how effective we are at both preventing and supporting those with liver disease. Over time, with the implementation of our plan, we would expect to see a reduction in the number of months that have been lost due to liver disease. The months of life lost due to alcohol is an estimate of the increase in life expectancy at birth that would be expected if all alcohol-attributable deaths among persons aged under 75 years were prevented.

The number of months of life lost in 2012-13 due to alcohol in Wales, with 13.5 months for males and 6.5 months for females, was higher than in England with 11.5 months for males and 5.4 months for females.

**Figure 17:** Months of life lost due to alcohol, males and females aged under 75, 2010 - 2012

![Bar Chart](image)

*Source: Public Health Wales Observatory, using ADDE, Life Tables for Wales & MYE (ONS)*
8.1 Liver cancer

Preventing liver disease from advancing to cirrhosis and liver cancer is very important for those living with a chronic liver disease.

Figure 18: Liver cancer, incidence and mortality, European age standardised rates per 100,000

Figure 18 shows the increasing trend in both mortality and incidence of liver cancer over the past 10 years. In 2005, 168 people were diagnosed with liver cancer, 93 men and 75 women. By 2014 this has risen by 57% to 264 people being diagnosed with liver cancer, the increase is almost entirely amongst men. The number of people dying from liver cancer has increased from 159 in 2005 to 290 in 2014, an increase of 82%.

Liver cancer has poor survival rates. Less than one third of people survive for one year after being diagnosed with liver cancer. The five year survival rate is very poor at 6.5%. With the exception of pancreatic cancer, liver has the worst survival rates of all cancers.

8.2 Liver transplant

Some patients whose liver disease has an irreversibly progressive course may benefit from a liver transplant.
In 2014-15 there were 29 liver transplants (figure 19) performed on Welsh residents, all of these were deceased donor first liver only transplants (including liver only transplants due to intestinal failure). The waiting list for a liver transplant grew by 7 people between 2013-14 and 2014-15.

The unadjusted national (UK) rates of patient survival 90 days after first liver transplantation from deceased donors were 97% for adult elective. The unadjusted national (UK) rates of graft function 90 days after first liver transplantation from deceased donors were 95% for adult elective.
9.0 Targeting research

Research is critical to support effective care for people with liver disease. The NHS needs to respond to the latest research evidence in the planning and delivery of its services.

![Figure 20: Recruitment to liver disease health and care research Wales clinical research portfolio studies](image)

Source: Health and Care Research Wales

Figure 20 shows that recruitment to clinical liver disease research studies decreased by 66 in 2014-15 compared to the previous year. More needs to be done to improve participation in clinical trials.

Aneurin Bevan University Health Board will continue to host the Wales Liver Fellow for the fourth year in succession. This post allows for dedicated training in hepatology, and clinical research time is built in to this post. Previous holders of the post have produced and had accepted abstracts on acute kidney injury in cirrhosis, management of HCC outside of a transplant setting, safety of terlipressin therapy, management and outcomes of autoimmune hepatitis for national and international meetings. Current work underway involves evaluating the outcomes of de novo cirrhosis in the elderly.
10.0 Conclusion and looking ahead to 2016/17

Over the last 12 months we have made plans to make progress in improving the care of people with liver disease in Wales. We have delivered a rollout programme to enable those in most need to have access to new more effective treatments for hepatitis C infection. We have now established firm foundations for further positive development and this will include working with staff in the NHS, other parts of the public sector and also working with other invaluable partners in the community and voluntary sector. We now have a strong sense of strategic direction, and have produced some key performance indicators that will help us to track the developments on our journey to achieve our vision.

Our delivery plan and this first annual report takes forward the Chief Medical Officer’s recommendation to develop a liver disease plan. In doing so, we are the first UK country to respond substantively to the Lancet’s campaign for action on liver disease.

Responding to the challenge of liver disease is important and this annual report highlights the proactive approach in Wales. Our aspirations can only be achieved through close working with patients. Co-production is about patients being equal partners in their own health and care. Our strategy for a liver disease plan is underpinned by patients taking increased responsibility for reducing their risk factors and playing their role in self-managing their condition.

Moving forward, we recognise the need to help support people to live independently with their condition; the need to deliver highly specialist care such as paediatric surgery and liver surgery; and, when necessary, to support people to deal proactively with the end of their life.

The Liver Disease Implementation Group has reviewed progress made over the last year and identified key areas where focus across Wales needs to be maintained over the coming year. In order to prevent liver disease, maximise liver disease services and patient care, the priorities over the next year will be:

- awareness raising of risk factors and lifestyle changes to prevent liver disease
- transforming early diagnosis through better awareness, training, resources, access to testing
- redesigning the pathway and the development and implementation of standards.

The challenges ahead are many and significant but we can look to the future with a sense of shared direction and confidence. NHS Wales cannot do this on its own and we will continue to develop the co-production of services and will work closely with the third sector to ensure services are improved for everyone. We must maintain this momentum to deliver sustainable improvements.

In next year’s annual report we will review the investment made and look at how we have progressed during the year.