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Welsh Government

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Together for Health – Liver Disease Delivery Plan

A Delivery Plan for NHS Wales and its Partners to 2020

Ministerial Foreword

Deaths in Wales from chronic liver disease have more than doubled in the past twenty years¹. As with a number of other health conditions, the way we lead our lives affects the chances we will develop a liver disease, with excessive alcohol consumption, along with the emerging impact of obesity, still the biggest cause of liver disease in Wales.

Our prudent healthcare approach includes the need to minimise avoidable harm. Therefore, the Welsh Government will continue to encourage better lifestyle behaviours, through programmes and legislation; supporting and encouraging individuals to take responsibility for achieving better health. Where patients have consistently shown themselves, despite the availability of support, unable or unwilling to take responsibility for their risk factors then the health service should not be expected to provide high cost drug or surgical interventions at the expense of those who have attempted to manage those risk factors. However, we must recognise the significant number of non-lifestyle related reasons for the development of liver disease and work hard to reduce the stigma surrounding its causes if we are to tackle it effectively.

The prudent healthcare approach is also about co-producing services and means people are equal partners in their care. This will help to ensure people receive appropriate care and will give them greater control over their own health. This plan – one of a set of national service delivery plans – is designed to develop and improve services for people with liver disease.

It requires NHS Wales and its partners to:

- Assess population need and plan the delivery of liver disease services
- Work to reduce the burden of liver disease
- Deliver liver disease services to the highest possible standard
- Demonstrate improved outcomes for people with liver disease

We look forwards to seeing over time the improvements this plan will help us realise.

**Mark Drakeford AM,
Minister for Health and Social Services**

**Vaughan Gething AM,
Deputy Minister for Health**

¹ CMO Annual Report 2011-12, p26, Welsh Government

Chief Executive of NHS Wales Foreword

This Delivery Plan sets out our vision for liver disease services and focuses our efforts on how to prevent the disease in the first instance and also, where necessary, to ensure people have access to excellent care. By focusing on quality and individual experience we can deliver the improvements we all want to see.

Liver services must promote early diagnosis and referral, deliver expert and high standards of care, facilitate self-management and ongoing care, support the availability of quality information and help to target research into the disease. Therefore, the Plan is split into six themes:

- Preventing liver disease and promoting liver health
- Timely detection of liver disease
- Fast and effective care
- Living with liver disease
- Improving information
- Targeting research

For each theme this Delivery Plan sets out:

- Key service issues
- Specific priorities
- Population outcome indicators and NHS assurance measures

The NHS cannot deliver this plan on its own. It must work with partner organisations in the wider public and voluntary sectors. An NHS-led national implementation group will be established, including the main stakeholders, to take this plan forward. Health boards will be required to develop liver disease plans and report progress annually.

The implementation group will be accountable to health board chief executives and myself. It will produce an annual report detailing progress against the Liver Disease Plan and in turn I am accountable to Welsh Ministers for its delivery.

Dr Andrew Goodall
Chief Executive NHS Wales

A. Overview

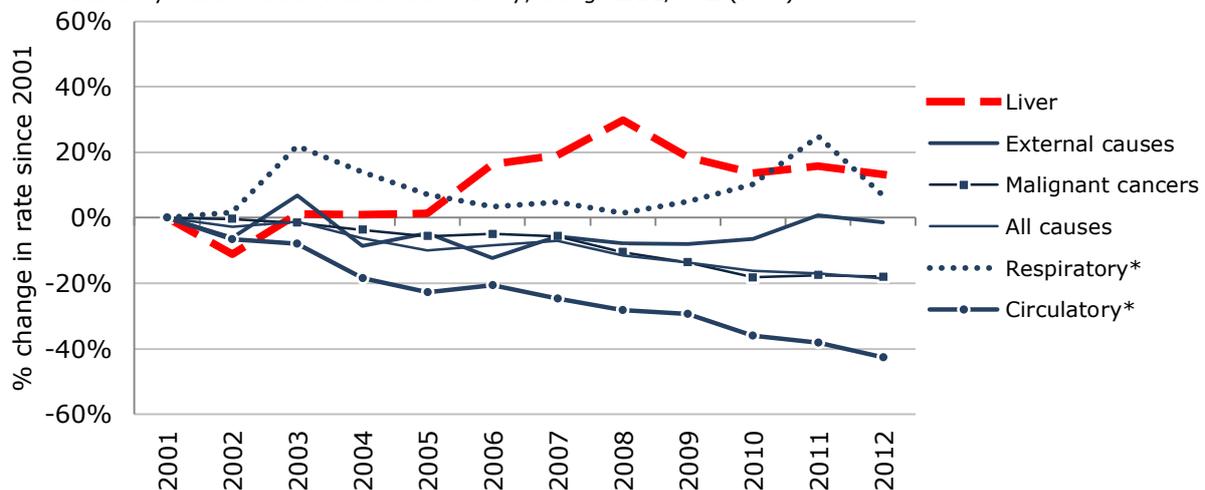
The liver is the second largest organ in the body and it performs hundreds of complex functions including: fighting infections and illness; removing toxins (such as alcohol) from the body; controlling cholesterol levels; helping blood to clot; and releasing bile (a liquid that breaks down fats and aids digestion).

There are many diseases that can affect the liver leading to chronic liver disease, cirrhosis, liver failure and potentially liver cancer. The main types of liver disease include:

- Alcohol-related liver disease – where the liver is damaged after years of alcohol misuse.
- Non-alcoholic fatty liver disease – a build-up of fat within liver cells, usually seen in overweight or obese people.
- Viral Hepatitis – inflammation of the liver caused by a viral infection.
- Autoimmune liver disease – where the body's immune system attacks the liver cells (Autoimmune hepatitis) or bile ducts (Primary Biliary Cirrhosis and Primary Sclerosing Cholangitis)
- 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.

Percentage change in European age-standardised mortality rates for various diseases from 2001 baseline, under 65s, Wales, 2001-2012

Produced by Public Health Wales Observatory, using ADDE/MYE (ONS)



Mortality² rates for liver disease in the UK have increased 400% since 1970 and liver disease is now a common cause of death after cancer, heart disease, stroke and respiratory disease.³ It is also the third biggest cause of premature mortality in the UK and accounts for 62,000 years of working life lost per year across the UK.

² 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. (Roger Williams et al; Lancet; 2014; 384: 1953–97)

³ <http://www.britishlivertrust.org.uk/about-us/media-centre/facts-about-liver-disease/>

Admissions to hospital because of liver disease are increasing with most patients admitted with end-stage disease, liver cirrhosis or liver failure. This is primarily the result of an increase of excess alcohol consumption and an epidemic of obesity in the population but viral hepatitis also plays a major role in terms of the burden of end stage liver disease.

The prevalence of key risk factors associated with liver disease and its outcomes are linked to social deprivation and inequality. Obesity is an increasing challenge in all age groups and may become the main cause of liver disease in the future. The most recent report from the child measurement programme for Wales indicated in 2012-13 26% of children age 4-5 were overweight or obese. There was variation across Wales with 21% being overweight or obese in the least deprived parts of Wales and 29% in the most deprived areas. Failure to address this problem will lead to an increase in the burden of obesity-related liver disease in the future.

There are also groups of individuals with higher risk of exposure to blood borne viral hepatitis who may have, or go onto develop, chronic viral hepatitis. The Welsh Government's Blood Borne Viruses Action Plan for Wales 2010-2015 provides a strong platform for further efforts in this plan to tackle liver disease related to blood borne viruses and the associated risk factors. Prevalence of hepatitis C is known to be higher among some populations, for example injecting drug users and those born in countries of high prevalence. Many of these populations have higher prevalence for different reasons and targeted action in different communities and settings will be required. The Welsh Government's Substance Misuse Delivery Plan 2013-15 has helped to tackle unsafe injector practice and excessive alcohol consumption.

B. Our Journey So Far

The Blood Borne Viruses Action Plan for Wales 2010-2015 and the Substance Misuse Delivery Plan 2013-15 have provided a strong platform for tackling blood borne viral hepatitis as a leading cause of liver disease. There is also important related work contained in the All Wales Obesity Pathway and other delivery plans covering Sexual Health, Stroke, Heart Disease, Diabetes, Cancer, the Critically Ill, End of Life Care and Organ Donation. This work will continue, and where relevant link across to this plan to tackle the burden of liver disease.

The Welsh Government's legislative programme has an increasingly important role to play, particularly in providing and promoting social conditions which are conducive to good health. The 2014 Public Health White Paper outlined a series of practical legislative proposals for addressing specific public health concerns, a number of which are directly relevant to this delivery plan. For example, the proposal to introduce minimum unit pricing of alcohol in Wales is a key strategic lever for preventing and addressing the health harms caused by alcohol misuse.

Important contributions to tackling liver disease have been made by the British Society of Gastroenterology in its reports: the National Plan for Liver Services UK (2009) and Alcohol Related Disease (2010); as well as the 2014 Lancet report 'Addressing Liver Disease in the UK'. A number of challenges in the provision of specialist care were also highlighted in the 2013 UK National Confidential Enquiry

into Patient Outcome and Death (NCEPOD) report into alcohol-related liver disease deaths.

The Chief Medical Officer's 2011 Annual Report recognised that standardised liver mortality in those under 65 years of age is rising at a rate that is disproportionately high compared with all other classes of disease. The 2012-13 report suggested the development of a liver plan would act as a focus for wide-ranging strands of work, build on what has been achieved to date, further improve the quality of services and reduce mortality from liver disease.

In April 2015, the Welsh Government announced the final agreed prudent healthcare principles to guide service planning and delivery:

- Achieve health and wellbeing with the public, patients and professionals as equal partners through co-production.
- Care for those with the greatest health need first, making the most effective use of all skills and resources.
- Do only what is needed, no more, no less; and do no harm.
- Reduce inappropriate variation using evidence-based practices consistently and transparently.

In addition, the concept of 'only do what only you can do' remains a powerful one, especially for a prudent health and social care workforce for the future. It will therefore be important to maintain the concept of professionals working at the top of their clinical license and not routinely providing a service which does not require their level of clinical expertise.

These principles guide the development of liver disease services in Wales as part of this delivery plan.

C. Our Vision for Liver Disease Services

Our high level aims for the plan are:

- Before 2020, halt the rise in morbidity and mortality related to liver disease.
- NHS Wales collaborates equally with its partners in social services and the third sector to provide seamless care to patients, where possible in the community.
- Clinical leadership and multi-disciplinary working helps improve the quality of the patient pathway and drive down harm, waste and variation.
- Better medical undergraduate, postgraduate and healthcare professional understanding of liver disease.
- Patients are responsible for their health have an equal voice in their treatment and through the third sector have shared responsibility to determine the shape of services for liver disease.

Our theme specific aims are:

- Delivery theme 1: The risk factors contributing to liver disease are being actively addressed and fewer people are at risk of developing liver disease.
- Delivery theme 2: People with liver disease are detected early and referred for treatment.
- Delivery theme 3: People with liver disease receive appropriate care by specialist multi-disciplinary teams.
- Delivery theme 4: People with liver disease are supported to manage their condition and reduce the risk of their disease progressing.
- Delivery theme 5: NHS Wales and its partners provide better information and support to people at risk of developing or already suffering with liver disease.
- Delivery theme 6: Active collaboration in research related to liver disease delivers improvements in diagnosis, treatment and management.

Delivery Theme 1: Preventing liver disease

The risk factors contributing to liver disease are being actively addressed and fewer people are at risk of developing liver disease.

Obesity, alcohol misuse and blood borne viral hepatitis are considered to be the key predisposing factors in the development of liver disease in the population of Wales. 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 disproportionately affect the poorest communities. Liver disease as a result of these three factors is almost entirely preventable and a concerted, multi-faceted approach is required to minimise their impact. Patients have equal responsibility under the principle of co-production for their health and care and must demonstrate reasonable action has been taken to manage their own risk factors or condition in order to benefit from drug or surgical interventions.

Obesity

Of the 25% of the UK population categorised as obese, most will have fatty liver disease, and many will have scarring and prolonged inflammation that will lead to cirrhosis. The All Wales Obesity Pathway sets out the national approach to the prevention and treatment of obesity, from community-based prevention and early intervention at Level 1 through to bariatric surgery at Level 4. Health boards deliver services against the pathway to support prevention and to help people attain a healthier weight to reduce their risk of fatty liver disease.

At a national level, opportunities to systematically tackle the obesogenic environment should be taken. This should include initiatives such as reducing access to food and drinks which are high in total fat, saturated fat and sugar and improving opportunities to lead physically active lifestyles. Developing good food habits from an early age is key to establishing a balanced healthy diet, which together with being physically active can prevent obesity. The Healthy Eating in Schools (Wales) Measure 2009 ensures that all schools in Wales offer balanced nutritious choices and the Welsh network of healthy schools schemes supports a whole-school approach to nutrition. Healthy workplaces that sign up to the corporate health standard can encourage healthy eating habits. There is also a national scheme of community nutrition skills training. This supports key areas such as Communities First and Flying Start staff to cascade evidenced-based messages to the local communities in which they work.

Change4life Wales is the Welsh Government's national social marketing campaign which supports societal shifts in health behaviour by encouraging people to eat better, move more, and live longer through fun, practical ideas to address diet, physical activity habits and alcohol intake. The Active Travel (Wales) Act 2013 and the Future Generations (Wales) Act will help to set a wider societal framework where open space, active travel and consideration of the long-term impacts on health will help to tackle the root causes of obesity. The Welsh Government's Physical Activity Executive Group is refreshing the national approach to tackling sedentary lifestyles and a cross-government Physical Activity Action Plan is in development to create a single, integrated approach to the problem.

Alcohol Misuse

A third of patients with alcohol-related liver disease have severe alcohol dependency or alcoholism and roughly 20–30% of lifelong heavy drinkers develop cirrhosis. Working Together to Reduce Harm is the Welsh Government's 10-year strategy to tackle the problems caused by drugs and alcohol in Wales. It sets out a clear national programme for tackling and reducing the harms associated with both substance and alcohol misuse. The strategy is supported by the Substance Misuse Delivery Plan 2013-15 and its successor three year plan, which details the specific actions being taken to reduce alcohol-related harm in Wales. These actions include the development of an alcohol-related death review process to learn the lessons from such deaths; supporting local alcohol action areas in Wales to reduce alcohol related harm in our towns and cities; and the launch of 'Add to Your Life' the online health and wellbeing self-assessment tool for people aged 50 and over in Wales.

These actions and the proposals consulted upon as part of the Public Health White Paper for a minimum unit price for alcohol will help to address alcohol-related liver disease. Drug and Alcohol Treatment Services also play an important role in identifying risk factors and helping people to deal with alcohol-related issues and therefore preventing liver disease. In 2013-14, 87% of all drug and alcohol misusers accessed substance misuse treatment within four weeks of being referred; access must be sustained to ensure people are supported to manage their risk factors.

A key recommendation of the National Confidential Enquiry into Patient Outcome and Death report was the need for alcohol care teams in hospitals. Currently the provision of these services within health boards is patchy and in some cases non-existent. This deficiency will need to be tackled to reduce the health burden of excess alcohol consumption. Alcohol liaison nurses are cost-effective and, within available resources, there is a need to move towards access for all relevant patients to an Alcohol Liaison Service prior to hospital discharge. Every opportunity to tackle alcohol misuse must be taken, including use of Brief Interventions, educating and informing young people through school-based programmes and other local public health approaches such as outreach with at risk communities like the homeless. There are also opportunities to influence the availability of alcohol through the health board role as a responsible authority on Local Authority licensing committees. This enables them to submit evidence under the four objectives of the Licensing Act 2003; as well as assessing planning applications, engaging in local development plans, working with local service boards and using Communities First partnerships.

Hepatitis

Roughly 400,000⁴ people in the UK are thought to be affected by hepatitis B or C. Efforts to reduce hepatitis infection are covered in several action plans, including the Blood Borne Viral Hepatitis Action Plan, the Substance Misuse Action Plan and the Sexual Health and Well Being Action Plan. The Blood Borne Viral Hepatitis and Sexual Health plans both come to an end in 2015 and have provided a sound base from which to continue efforts to reduce infection. It is important that all related services, play their role in combating the spread of blood borne viral hepatitis. There is a higher prevalence of hepatitis among certain sections of the population and

⁴ 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. (Roger Williams et al; Lancet; 2014; 384: 1973-1975)

there should be targeted and tailored awareness raising and testing in different setting and communities. There also needs to be a particular focus on provision of hepatitis B vaccination and targeted roll out of new hepatitis C antiviral drugs.

Culturally sensitive community based approaches should be developed to reach individuals born in countries of high prevalence. Services should be developed for those in initial accommodation centres for asylum seekers. Outreach is needed for the homeless, through settings such as hostels. Treatment plans should ensure they continue to adhere to their treatment regimen. The prison population is a key cohort in terms of prevalence of infection and accessibility for testing and treatment. Targeting injecting drug users represents the biggest opportunity to prevent onward transmission of hepatitis C. Babies born to a mother with hepatitis B must receive follow up vaccination and serological testing.

The National Institute for Health and Care Excellence (NICE) and the All Wales Medicines Strategy Group is considering a number of new treatments that can clear hepatitis C virus from the liver and reduce the risk of liver disease. Further work will need to be undertaken by the implementation group and the Welsh Health Specialised Services Committee to prepare best for the use of new medicines, to be rolled out in a phased manner, and targeted at high risk populations where the greatest gain from preventing disease progression and onward transmission can be made.

Stigma and deprivation

Attention must be given to reducing the stigma of blood borne viral hepatitis infection. To encourage individuals to come forward for testing, the different reasons for higher prevalence in different populations should be acknowledged to facilitate community interventions and break down barriers in secondary care. As well as individual education, broader public awareness campaigns and education for health providers will improve understanding of the condition and reduce stigma.

Given the link between deprivation and poor lifestyle behaviours, broader system effort should seek to reduce inequities and compensate with targeted investment in deprived communities. The Welsh Government's broader efforts to tackle health inequality under the Achieving Fairer Health Outcomes for All Framework and Tackling Poverty Action Plan will help to address these societal factors in the long-term. Community Pharmacy has an important role to play given its presence in deprived communities, through its health promotion work, lifestyle information, medicines advice and other opportunistic interventions. Assistant Medical Directors for Primary Care and the GP Quality and Outcomes Framework will play key roles in driving appropriate community-based risk management. Liver disease needs to be more overtly recognised in the management of risk factors commonly associated with cardiovascular disease.

Given the ageing population of Wales, it is important that prevention services do not overlook risk factors in the over 50s population. Treatment services should be delivered in a way which addresses the needs of the young and old alike.

It is not the role of this plan to drive the separate legislation or action plans that will address liver disease risk factors. It is to augment it with specific work

such as action to prevent the spread of hepatitis or support the development of level three obesity services. This Liver Disease Delivery Plan sits *alongside* work done to date on the primary, secondary and tertiary prevention of obesity, alcohol misuse, blood borne viral hepatitis and related determinants of health. Close liaison between the implementation group, health boards and Public Health Wales is needed to ensure health improvement programmes are contributing to the reduction in risk factors for liver disease.

Specific Priorities

- i) Work with the Public Health Wales Health Improvement Programme to ensure appropriate effort is allocated to reducing the risk factors for liver disease and programmes reflect the potential contribution to reducing liver disease. This work should include optimisation of services and strategies for the primary prevention of liver disease, as well as increasing awareness of liver disease throughout the pathway and related pathways.
- ii) Take forward the legacy of the Blood Borne Virus Hepatitis Action Plan in all relevant settings and continue the effort to eradicate viral hepatitis; including working to identify and treat individuals with a diagnosis of hepatitis B or C infection and working with the Welsh Health Specialised Services Committee and All Wales Medicines Strategy Group on the phased introduction of new hepatitis C drugs.
- iii) Further develop the opportunistic assessment of alcohol intake in different settings and develop in house alcohol care teams within health boards to provide timely interventions as appropriate; including helping to take forward the systematic process for reviewing alcohol-related deaths and make recommendations about how Substance Misuse Services and Alcohol Liaison Services can better assist the management of risk factors for liver disease.
- iv) Examine opportunities and make costed recommendations to increase the availability of targeted community testing for viral hepatitis and fatty liver disease particularly in areas of socio-economic deprivation to address health inequity; including the community availability of non-invasive testing (NITs) for liver fibrosis among high risk populations.
- v) Continue to review and monitor the content of the online over-50s health and wellbeing assessment Add to Your Life in relation to risk factors for liver disease.
- vi) Develop an approach to help de-stigmatise liver disease.

Responsibility to develop and deliver actions

Health boards, working with partners such as local government, with leadership from Public Health Wales and Welsh Government.

Population outcome indicators

- Proportion of children obese or overweight
- Proportion of adults obese or overweight
- Proportion of adults who self-report drinking more than twice the daily guidelines for alcohol
- Proportion of injectors in Substance Misuse Services testing positive for HCV antibody
- Rate of alcohol specific admissions to hospitals
- Rate of alcohol attributable admissions to hospital

NHS assurance measures

- All health boards in Wales have services available as outlined at each level of the obesity pathway.
- Proportion of case closures of individuals referred to alcohol services where the reason for closure was planned.
- Time from referral to treatment for individuals referred to alcohol services.
- Proportion of people identified as hazardous or harmful drinkers who receive brief intervention.
- Proportion of people in the local population estimated to be dependent on alcohol that access specialist alcohol services.
- Proportion of people who inject drugs who access needle and syringe programmes.
- Proportion of babies born to HBV-positive mothers receiving a blood test to determine infection/immunity status by 18 months.
- Proportion of those at risk of BBV infection and seen by substance misuse services who are tested for HCV.
- Proportion of those at risk of BBV infection and seen by substance misuse services who are fully vaccinated against HBV infection.
- Proportion of prisoners who are tested for HCV.
- Proportion of prisoners who are fully vaccinated against HBV infection
- Proportion of those diagnosed with active infection with HCV referred for specialist assessment.
- Proportion of those diagnosed with HBV infection referred for specialist assessment.
- Proportion of individuals referred for assessment who are commenced on treatment for HCV infection.
- Proportion of those commenced on treatment for HCV who clear the virus following treatment.

Delivery Theme 2: Timely detection of liver disease

People with liver disease are detected early and referred for treatment.

Liver disease is usually asymptomatic in the early phases, meaning patients have few clinical signs and this makes early detection difficult. 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.

Opportunistic identification in primary care is one key to ensuring individuals at high risk of developing liver disease and those with existing liver disease are identified and managed at an earlier stage. In order to do this, primary and community care need to be knowledgeable in the identification of risk factors for liver disease, have adequate opportunity to arrange appropriate testing, be confident in interpreting results and know how to rapidly refer patients into the correct pathway. Individuals identified with risk factors need to be made aware of their risk of liver disease so that they can be supported in lifestyle changes to minimise ongoing risk in order to reduce potential further damage to their liver. In addition there is a potential role for community pharmacy and community outreach teams working with known at risk groups to also help identify, refer and manage those most at risk in the broader population.

Secondary care, such as Sexual Health Services, already screen patients for hepatitis B and C as appropriate, and those patients identified with infection need appropriate referral for treatment. Level 3 and 4 obesity services could 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 will see large numbers of patients with higher risk of alcohol-related liver disease. Easy access to liver function testing by these respective services should be available for at risk groups in order to improve detection. Fatty liver disease is frequently discovered incidentally during ultrasound, CT or MRI scanning. Such patients may have normal liver function tests but this does not preclude advanced liver disease. Hence a robust risk assessment strategy is needed for patients with incidentally discovered fatty liver.

As well as lifestyle interventions, there are also a number of rarer conditions, such as autoimmune and metabolic liver diseases, that health care professionals need to be aware of in order to detect early. This is critically important as such individuals will typically not be considered at risk of liver disease. Clinicians, particularly in primary care and Emergency Departments, must be sufficiently aware of these other causes of liver disease in order to refer patients for appropriate specialist assessment and management.

A robust and comprehensive pathway is needed for the prevention and detection of liver disease. The pathway should integrate with and strengthen existing initiatives and pathways aimed at preventing and managing obesity, metabolic syndrome, alcohol and substance misuse, and blood borne viral hepatitis. A greater focus on detection among high risk populations is needed, particularly populations which see higher rates of blood borne viral hepatitis infection as outlined under theme one.

Culturally sensitive detection approaches should be available and targeted at these communities.

Consideration needs to be given by health boards as to how to deal with the impact on primary care, laboratory service and hospital-based specialist services from an increased need for testing. Referral guidance will need to be developed, ideally on a national basis, and hospital-based services will need to offer prompt access to diagnostic and treatment services for cases that cannot be managed in primary care. Laboratory services will need to be able to respond to increased demand for tests, both at diagnosis and during management of the disease, and have robust transport and communication infrastructure to allow prompt support to the pathway. This pathway must be coproduced with patient groups and focussed on the principles of avoiding harm, the minimum appropriate intervention and ensuring equity.

Specific Priorities

- i) Improve provision of assessment and testing of those at highest risk of developing liver disease.
- ii) Improve awareness and understanding of liver disease among primary and community care, and local government partners to help detect early liver disease and make appropriate referral.
- iii) Develop a nationally agreed care pathway for patients with abnormal liver function tests and develop a national audit to support this.
- iv) Develop a nationally agreed care pathway for the risk assessment of those incidentally found to have fatty liver disease.
- v) Develop nationally agreed referral guidelines to improve consistency and quality in referral practices, manage demand and minimise inappropriate investigation of those at low risk. This will include appropriate links to guidance and related care pathways and service frameworks
- vi) Develop a costed proposal for identifying those at greatest risk of fatty liver disease.
- vii) Encourage primary care clusters/locality groups to identify a champion for liver disease who will work with the health board liver disease team to improve risk management, detection and referral practices.
- viii) Undertake a cost assessment of improving the effectiveness of the routine use of risk assessment tools (such as routine provision of AST/ALT ratio) to identify those at greatest risk of significant liver disease.
- ix) Measure performance against key standards in the developed national audit of the care pathway for the investigation and management of abnormal Liver Function Tests, across primary and secondary care.

Responsibility to develop and deliver actions

Health boards working in conjunction with Public Health Wales and the implementation group, substance misuse services and area planning boards.

Population outcome Indicators

- Rates of hospital admission for liver disease, grouped by disease type.
- Rates of new diagnoses of cirrhosis, grouped by disease type.

NHS assurance measures

- Proportion of admissions attributed to liver diseases that are emergency admissions.
- Rate of people admitted to hospital at least once for cirrhosis.
- The performance against key standards in the developed national audit of the care pathway for the investigation and management of abnormal Liver Function Tests, across primary and secondary care.

Delivery Theme 3: Fast and effective care

People with liver disease receive appropriate care by specialist multi-disciplinary teams.

The delivery of fast and effective care for patients with liver disease must be based on prudent healthcare principles. With support patients must ensure they take responsibility for reducing their risk factors by accessing relevant programmes and addressing poor lifestyle choices in order to achieve maximum benefit from treatments.

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. The complications of cirrhosis often occur unexpectedly and can progress rapidly. Consequently, 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 NCEPOD report into deaths from alcohol-related liver disease identified widespread failings in the care provided to patients. 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. This should be undertaken by a hepatologist or a gastroenterologist with appropriate training in managing liver disease. It is recognised at present the availability of such a service is limited by the availability of appropriately trained specialists. Increasingly nurses and other healthcare professionals, as part of advanced practice programmes, are extending their roles to undertake activities which would otherwise have to be dealt with by specialists and thereby releasing specialist capacity to focus on diagnosis and treatment / management of complex cases. However, each health board needs to develop centres of specialist knowledge to enable standards of service to improve, deal with the management of complex cases and support the wider multi-disciplinary team.

Patients with advanced or complicated liver disease or those with related malignancy should be referred for specialist assessment and appropriate treatment. There is variation across Wales in access to hepatocellular carcinoma services and a national centre of excellence structure would significantly improve the quality of care provided to patients. The liver surgical services within Wales are currently being reviewed by Welsh Health Specialised Services Committee and the findings of this review will need to be considered by the implementation group.

Some patients whose liver disease has an irreversibly progressive course may benefit from a liver transplant. At present, both rates of referral and rates of liver transplantation for residents in Wales are lower than expected for the population size. Improvements in the quality of liver services in Wales will, in all likelihood, result in more patients being assessed as meeting the indications for liver transplantation, and this should result in more individuals being referred early enough to provide

them with the best chance of receiving a transplant. To this end close links with a regional liver transplant centre are essential and should involve each health board having direct access to outreach clinics with transplant physicians present to facilitate initial assessment and aftercare. Emergency Department awareness of transplantation should be improved in order to increase the availability of organs; the Wales Transplantation Advisory Group is leading work in this area on the organ donation strategy.

Emergency Departments need to be supported to identify individuals with cirrhosis and know when to refer patients to specialist services. Consultant or nurse-led alcohol care teams, with addiction psychiatric support, are cost-effective ways to reduce demand on secondary care among patients with cirrhosis. Interventional radiology also plays an important role in minimally invasive image-guided procedures to diagnose and treat diseases in nearly every organ system; these services should be configured to respond to the demand related to patients with liver disease. Better access to ITU, high dependency and endoscopy is warranted. Patients with complicated or non-curable liver disease should also be referred to third sector support groups to help educate about the condition and provide support.

Liver disease in the neonatal and paediatric populations is rare. Consequently specialised neonatal and paediatric liver services including transplantation and hepatobiliary surgery, is managed at three centres in England with Birmingham providing services to Wales. These centres provide internationally recognised outcomes and high value education programmes. Outreach centres in Wales should link in, spread good practice and support awareness of neonatal liver disease, particularly the identification of biliary atresia, through implementation of the relevant NICE guidelines.

Specific Priorities

- i) Plan to establish a liver disease unit in each health board staffed by at least one consultant hepatologist supported by additional consultant hepatologists or gastroenterologists with appropriate training in managing liver disease. Each unit should provide support to primary care clusters and through a hub and spoke arrangement support neighbouring hospitals to facilitate high quality inpatient care.
- ii) Health boards review liver disease pathways, including adoption of the BSG/BASL care bundle for decompensated cirrhosis patients, and take forward work to optimise the pathway efficiency and link to related pathways.
- iii) Health board liver disease units to work with WAGE to meet common standards and meet routinely to share best practice and assess performance against standards.
- iv) Improve access to related services such as diagnostics (particularly fibroscan and biopsy, including transjugular biopsy), dietetics and interventional radiology.
- v) Implementation group to support the development of regional networks to facilitate optimal service delivery and improvement including outreach services with transplant centres.
- vi) Implementation group to support access to national or regional hepatocellular carcinoma Multi-Disciplinary Teams.

Responsibility to develop and deliver actions

Health boards in conjunction with Implementation Group, Public Health Wales and Welsh Health Specialised Services Committee

Population outcome indicators

- Liver disease mortality rates grouped by disease type; including those related to paracetamol overdose.
- The incidence of cirrhosis.
- The incidence of hepatocellular carcinoma.
- 1, 3, 5 and 10 year survival for liver cancer and cirrhosis.

NHS assurance measures

- Referral to treatment times.
- Performance against agreed key standards in audits of admissions for liver disease.
- Liver transplantation rate.
- Proportion of those with variceal bleeds receiving endoscopy within 24 hours of admission.
- Proportion of liver admissions reviewed by hepatologist within 24/48/72 hours.
- Proportion of admissions with decompensated cirrhosis receiving care bundle.

Delivery Theme 4: Living with liver disease

People with liver disease are supported to manage their condition and reduce the risk of their disease progressing.

There are many challenges to living with liver disease both for patients and their family or carers. The unpredictable nature of deterioration in organ function and the potential for recovery from life threatening situations can leave sufferers leading an existence of profound uncertainty. There are a number of services that can support patients with liver disease and their families to optimise quality of life, including social services, charities and benefit funds. These services need to be accessible and complement one another in order to achieve better patient and carer experience for all individuals with liver disease, including those with more complex medical needs.

All health care professionals should be aware that alcohol-related liver disease is often associated with mental health-related conditions such as alcoholic dementia, Wernicke's encephalopathy or Korsakoff's syndrome. As these conditions are potentially reversible relevant symptoms should be taken very seriously and managed in line with NICE guidelines. For other conditions such as symptoms of paranoia or concerns about depressive symptoms, specialist mental health advice should be sought.

Primary and community care must be empowered to manage chronic liver disease and delay or prevent progression of the disease. Up to 80% of admitted patients with liver disease require dietetic intervention and thought needs to be given to how best dietetic services can support patients to manage their condition through better nutritional behaviours. Other elements to consider include services such as rehabilitation, psychological support services and the provision of appropriate vaccines to those with liver disease.

Special consideration needs to be given to young people who are transitioning from paediatric services to adult services, as this can be a difficult and challenging time. Therefore, there should be better links established between the adult and paediatric services to facilitate effective handover and the provision of holistic, high quality care to young people in line with guidelines under development by NICE.

Chronic liver failure is associated with a two year survival of around 50% and the majority of these individuals are not eligible for liver transplantation. Half of patients with alcohol-related cirrhosis who become abstinent still die before their liver recovers⁵. Where appropriate, early discussion and arrangements should be made for palliative and end of life care in line with the End of Life Care Delivery Plan.

⁵ Verrill C, Markham H, Templeton A, Carr NJ, Sheron N. Alcohol-related cirrhosis—early abstinence is a key factor in prognosis, even in the most severe cases. *Addiction* 2009; 104: 768–74.

Specific Priorities

- i) Facilitate the strengthening of the co-productive approach to designing services and treatment plans.
- ii) Consider the feasibility of developing one-stop-shop cirrhosis clinics where patients can have their disease monitored and surveillance ultrasound scans undertaken as appropriate.
- iii) Examine opportunities to encourage and support better primary care management of those diagnosed with liver disease including improved uptake of appropriate vaccinations.
- iv) Improve access to specialist dietetic advice and psychological support, especially for patients with cirrhosis and chronic liver failure so that they can better self-manage their condition.
- v) Support the provision of palliative care services for patients with chronic liver failure.
- vi) Encourage each health board to engage community support groups to help patients manage their condition in the community.

Responsibility to develop and deliver actions

Health boards in conjunction with the Implementation Group and the Palliative Care Implementation Board

Population outcome indicators

- Premature liver disease mortality rates grouped by disease type.
- The number of years of life lost due to liver disease.

NHS assurance measures

- The proportion of secondary care outpatient attendances for the management of cirrhosis which take place in a specialist cirrhosis clinic.

Delivery Theme 5: Improving information

NHS Wales and its partners provide better information and support to people at risk of developing or already suffering with liver disease.

People at high risk of developing liver disease and those with early liver disease must be provided with clear and up to date information about their treatment options and be able to fully participate in decisions about their treatment. Patients with established liver disease must have the information and support they need to manage their condition and be equal partners in their care.

Specialist liver services need to have agreed and published standards and guidance to refer to. At present few health boards have in-house liver-related guidelines on their websites to aid the management of liver disease. There is an opportunity to develop and audit all Wales guidelines in line with that from specialist liver groups. Accredited awareness and disease specific information needs to be available and promoted on an all Wales basis.

Improvements in data systems and coding across health services, both in primary and secondary care, need to be reviewed and a national patient database is needed.

Specific Priorities

- i) Review the quality of existing data systems for the reporting of liver-related morbidity, mortality and associated risk factors and make recommendations for improvement
- ii) Develop a clinical management system to support the care of individuals with chronic liver disease, provide measurement of health outcomes and support high quality audit and research.
- iii) Develop information to increase public awareness of risks factors related to these conditions in a way which is specific and relevant to each of the at risk communities; this work must have as its focus the de-stigmatisation of liver disease and its causes.
- iv) Develop national management guidelines facilitating the assessment of individuals with abnormal LFTs; these should include guidelines for the management of common complications of liver disease and indicators for referral.
- v) Develop and implement electronic alerts for patients with abnormal liver function tests linked to national pathway guidance directing the requesting clinician to advise on further investigation and, if necessary onwards referrals to specialist services.
- vi) Health boards work to increase awareness of relevant educational material for staff (e.g. RCN liver disease toolkit, RCGP online resource on Hepatitis B and C: Detection, Diagnosis and Management). Increase provision of medical and nursing training in hepatology and introduce wider educational opportunities for clinicians to increase awareness of liver disease, its risk factors and symptoms.
- vii) To develop the delivery plan set of measures in order to understand the current situation and the size of the issue; including:
 - Identify existing care pathways for the investigation and management of chronically elevated LFTs and map local provision of services.

- Establish the number of people diagnosed with cirrhosis in each health board.
- Establish and report the waiting time measures for patients referred for outpatient specialist assessment.
- Collated data on admissions related to liver disorders
- Estimated number of years of life lost from liver disease in Wales.
- Geographical deprivation gaps for liver disease morbidity and mortality.

Responsibility to develop and deliver actions

Health boards in conjunction with the Implementation Group, Public Health Wales and NWIS.

Population outcome Indicators

NHS assurance measures

The performance against key standards in audits of electronic alerts for patients with abnormal liver function tests

Delivery Theme 6: Targeting research

Active collaboration in research related to liver disease delivers improvements in diagnosis, treatment and management.

With the standardised mortality rate related to liver disease increasing there is a need to actively engage in research in this area and ensure relevant learning is incorporated into Welsh services.

Research should include considering the risk factors for liver disease and how to tackle the associated lifestyle choices, particularly related to alcohol consumption.

Specific Priorities

- i) Undertake a gap analysis and identify key pieces of research needed and work with NISCHR to develop opportunities to address such gaps.
- ii) Explore the utilisation of data linkage to better understand liver disease and its risk factors.
- iii) Establish a database for liver disease to facilitate all Wales research and funding; including mechanisms for the application of research findings.
- iv) Explore undertaking research into methods for improving surveillance strategies in hepatocellular carcinoma.
- v) Explore undertaking research into the relationship between lifestyle choices and liver disease and how these can be tackled.
- vi) Assess the impact of the “Have a Word” brief intervention training programme.
- vii) Increase the number of joint academic appointments between health boards and local universities.

Responsibility to develop and deliver actions

Health boards in conjunctions with Public Health Wales, Universities, Welsh Government and the implementation group

Population outcome Indicators

NHS assurance measures

Number of patients with liver disease, or at high risk of liver disease, recruited to research studies.

D. Working together

This Delivery Plan, and the implementation group that will be brought together to take it forward, is designed to ensure ongoing improvements in patient experience and outcomes, reduce health inequalities and minimise variability in access to services. The plan will rely on strengthened multi-agency working and be delivered using existing resources. Health boards and their partners should work with the clinical, public health, and wider communities to prioritise resources and/or re-organise service delivery in order to optimise population level health gain. Many of the anticipated improvements in population outcomes will only be seen over the longer-term. The Welsh Government expects to see clear progress against this plan demonstrated through annual reports.

Each person has a role to play in preventing liver disease by adopting healthy lifestyle choices and addressing the harm caused by alcohol, obesity and substance misuse. It is recognised that gains in health can be achieved through individuals working to reduce their own risk factors. Self care and co-production are key elements of prudent healthcare, the principles of which include avoiding harm, minimal intervention and agreeing treatment plans between individuals and their clinician.

Welsh Government is responsible for strategic leadership through setting the health outcomes it expects for the people of Wales. It holds the NHS to account on how well it delivers these outcomes. The lines of accountability are via the chairs of the health boards and trusts to the Minister for Health and Social Services; as well as via Chief Executives and the Implementation Group to the Chief Executive of NHS Wales. The implementation group will review health board liver plans and annual reports, and produce a national annual report demonstrating how well the national plan is being implemented. The group will be chaired by an NHS executive director, include service representation from health boards, third sector representation, the Chair of the Gastroenterology National Specialist Advisory Group and a representative of the Wales Association Gastroenterology and Endoscopy (WAGE).

Health boards are responsible for planning efficient and cost effective services to meet population need and reduce variability of services. They also have a leadership role, working with partners to consider which organisation is best placed to deliver each service and to utilise appropriate mechanisms to foster shared responsibility for the delivery of high quality preventative, diagnostic, treatment and supportive services. In Powys it is recognised that many of the services are provided by other health boards in Wales and also link with services provided in England.

At local level, leadership by the clinical community will be vital to the success of the plan. A lead clinician in each health board will lead a working group of a wide range of stakeholders including public health, local service planners, primary care, local government and third sector representatives, to coordinate and drive forward improvements at local level. The arrangements for Powys Teaching Health Board will differ and the implementation group will work with the health board to support the development of an appropriate model for the population of Powys.

A local delivery plan will be produced by the local clinical lead with appropriate support from an executive lead in each health board. An annual report will be provided by the clinical lead in each health board to the implementation group reporting progress against the actions laid out in this delivery plan.

Welsh Health Specialised Services Committee (WHSSC) is responsible for the joint planning of Specialised and Tertiary Services on behalf of health boards. It will need to develop any necessary plan relating to liver services and support health boards with any nationally commissioned arrangements.

Public Health Wales is responsible for providing leadership, data collation, research and policy development and the dissemination of knowledge and intelligence.

The Welsh Ambulance Service NHS Trust plays a vital role in providing frontline management and transport for patients to the most appropriate care.

The **NHS Wales Informatics Service (NWIS)** supports health boards in the collecting and reporting of information.

Those involved with commissioning substance misuse services, including **Area Planning Boards**, have a key role in improving the key functions of planning, commissioning and performance management within substance misuse services.

Local Authorities are responsible for shaping many of the determinants of liver disease, working with other bodies to provide an environment that makes healthy choices easy, including having a healthy alcohol intake, encouraging weight optimisation and reducing harm associated with substance misuse.

The Third Sector deliver services, particularly substance misuse services including alcohol, and provide service user perspectives to inform the development of improved services and better patient experience. The sector can add real value in terms of patient education and emotional support to patients and carers to complement clinical care.

Appendix 1 - Glossary

Asymptomatic is when an individual is not aware of any symptoms related to their condition

Autoimmunity is an immune response against the body's own cells and tissues

Bariatric is the branch of medicine that deals with the causes, prevention and treatment of obesity

Blood Borne Viruses (BBVs) are viruses that can be spread through contamination by blood and other body fluids, examples are HIV, hepatitis B, hepatitis C

Cirrhosis of the liver is scarring of the liver as a result of continuous, long-term liver damage

Diabetes is a chronic condition that occurs when the pancreas does not produce enough insulin or when the body cannot effectively use the insulin it produces

Fibrosis is the formation of excess fibrous connective tissue in an organ or tissue

Gastroenterology is a branch of medicine focused on the digestive system and its disorders

Haemochromatosis is an inherited disorder in which iron levels in the body slowly build up over many years

Hepatitis is inflammation of the liver

Hepatocellular carcinoma (HCC, also called malignant hepatoma) is a type of cancer of the liver and is the most common primary liver cancer

Liver Function Tests (LFTs) are blood tests that look at markers related to the functioning of the liver

Metabolic syndrome is the medical term for a combination of diabetes, high blood pressure and obesity. It puts you at greater risk of heart disease, stroke and other conditions affecting blood vessels

Obesity is a term used to describe somebody who is very overweight with a high degree of body fat

Palliative care is an area of healthcare that focuses on relieving and preventing the suffering of patients near the end of life

Tertiary Care is highly specialised consultative care, usually on referral from primary or secondary care