A joint response on behalf of liver disease clinicians and patients by British Association for the Study of the Liver (BASL), British Liver Trust (BLT) and British Society of Gastroenterology (BSG) to the White Paper ‘Equity and Excellence: Liberating the NHS’

The British Liver Trust (BLT), the British Association for the Study of the Liver (BASL) and the British Society of Gastroenterology (BSG) welcome the opportunity to jointly comment on the Government’s White Paper ‘Equity and Excellence: Liberating the NHS’.

About the British Association for the Study of the Liver

The British Association for the Study of the Liver (BASL) represents nearly 800 hepatologists, surgeons, nurse specialists and scientists working across the UK. BASL’s roots date from 1961. It is dedicated to promoting the clinical and scientific understanding of liver disease as well as championing optimal care of patients in a challenging and rapidly evolving field.

BASL aims to:
• advise policymakers within the health service how to advance the provision of care for patients with liver disease within the UK

and in addition:
• disseminate research findings and clinical expertise in liver disease
• promote and provide opportunities for collaboration in liver research
• promote clinical trials in liver disease
• advise on standards of clinical care
• advise on training requirements for hepatology
• provide a voice that can advise and interact with the media to raise awareness of liver disease within the UK

About the British Liver Trust

The British Liver Trust aims to reduce the incidence of liver disease, and to help everyone affected by liver disease, through the provision of information, support and research.

The Trust was established to:
1. Undertake and promote medical and scientific research relating to liver diseases
2. To advance public education and awareness of diseases of the liver
3. To promote health education in subjects relating to the liver and to provide for the rehabilitation and relief of those who suffer from liver diseases.
In practice the Trust publishes a range of patient information publications on various liver diseases which are available free of charge to members of the public. These publications are also made available to a diverse range of healthcare providers. The Trust maintains a very popular website containing a large range of medical information as well as other information related to its activities. The Trust also provides a helpline providing medically-qualified telephone support for patients and their carers; it encourages and supports local liver support groups for patients and it provides modest funding for research into liver disease.

**About the British Society of Gastroenterology**

The BSG is a professional society dedicated to the advancement of standards of care, research, education and training in gastroenterology and hepatology with more than 3000 members, including physicians, surgeons, nurses, scientists and allied health care professionals. Gastroenterology is one of the bigger clinical specialties accounting for about 12% of medical consultations in primary and secondary care. Liver disease accounts for a further 3%. Approximately two thirds of liver disease in secondary care is delivered by gastroenterologists who also provide care for patients with intestinal disorders.

**The ‘Rising Tide’ of liver disease**

In a paper published jointly by the BASL and British Society of Gastroenterology in 2009 *(A time to act: Improving Liver Health and Outcomes in Liver Disease)* the rising impact of liver disease on the nation pointed the way for the vital need for a cohesive national strategy. The facts below set out the challenges:

- Liver disease is the only major cause of death still increasing year-on-year[^1]
- Liver disease is the fifth ‘big killer’ in England & Wales, after heart disease, cancer, stroke and respiratory disease[^2]
- 16,087 people in the UK died from liver disease in 2008[^3], a 4.5% increase since 2007
- The average age of death from liver disease is just 59 with all other major killers being over 70 and rising


[^3]: British Liver Trust analysis of official mortality statistics covering all deaths related to liver dysfunction covering ICD K70-76 and other codes including C22-24 (liver cancer), and B15-B19 (viral hepatitis), December 2009.


• Liver disease deaths have increased by 12% in just three years, since 2005, totalling 46,244 lives lost. If these rates continue, deaths from liver disease are predicted to double in 20 years.

• Twice as many people now die from liver disease as in 1991\(^1\)

• Liver disease kills more people than diabetes and road deaths combined\(^1\).

Against this background:

• 35% of men and 22% of women drink enough alcohol to put themselves at risk of alcoholic liver disease

• approximately 20% are at increased risk of liver disease because of obesity

• At least 150,000 patients, which may be an underestimate, have not been identified as having the hepatitis C virus (HCV)

• the conditions are fertile for an increase in hepatitis B (HBV) infection with the number of carriers integrating into a population that has not been vaccinated against HBV

• Figure 1: The rising tide of liver disease\(^7\)

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Figure 1 illustrates that liver disease is the only major cause of death still increasing year-on-year in comparison to the other main causes of death in the UK that are on the decline.

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British Association for the Study of Liver Disease, British Society of Gastroenterology 'A Time to Act: Improving Liver Health and Outcomes in Liver Disease 2009.'\(^7\)
Summary response

The British Association for the Study of Liver, British Liver Trust and British Society of Gastroenterology welcome the White Paper and the new energy given to reviewing the delivery of services and improving outcomes.

In particular, we feel that clinicians and patients working together in the context of a national strategy to review the treatment and prevention of liver disease under the overview of a National Clinical Director will release synergies and innovations that have not previously come to the fore.

Like a variety of colleagues in professional and patient organisations we have our concerns about the speed that changes are to be rolled out and the need to move carefully to ensure that it is in harmony with the momentum developing behind the emerging plan for a coherent national approach to tackling liver disease. Members of BASL, BSG and BLT are working actively with the Department of Health (DH) as part of the emerging liver strategy to help build an effective framework.

Liver disease overview

Liver disease is now the fifth biggest killer in the UK. Although liver deaths may have increased fivefold in the UK as a result of increased alcohol consumption at a population level – they have fallen in the EU as a whole. The three main causes of liver disease; alcohol, obesity and blood borne infections are amenable to effective public health policy, and thus the majority of end stage liver disease is entirely preventable. Liver disease targets young and economically productive individuals. People with liver disease currently die on average, aged 59, and this age is still falling. Typically, patients with liver disease are ill for 3-5 years before death but may have experienced many years of chronic disease with a slowly eroding ability to work and function fully. The extended economic burden of liver disease is considerable. There are also huge health inequalities related to liver disease and a significant overlay of disproportionate liver disease in spearhead areas.

Liver disease is nascent in primary care and there are interesting and innovative ideas and tools under development, which are likely to lead to earlier disease prevention, with related cost-efficiencies in shifting the demand curve left. There is massive potential for vast improvements in patients’ outcomes which, at the same time, will reduce the burden and cost in secondary care.

The proposals in the White Paper will support the need to take the task of detecting, and intervening in, liver disease into primary care. GPs tend to be uncomfortable with liver disease (probably based on the complexity of advanced disease) but few realise that:

- up to 20% of their adult patients will have abnormal liver function tests
- liver disease is entirely silent until very advanced
- 67% of heavy alcohol consumers will moderate or abstain

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• 45% of alcohol dependents can be successfully treated
• the vast majority of patients with chronic hepatitis B or C can be treated
• early insight into risk of diabetes and cardiovascular disease can emerge from investigation of abnormal liver function tests.

The rising tide of liver deaths dramatically illustrates how liver disease has ‘missed the boat’ in the past in relation to National Service Frameworks (NSFs), Quality Outcome Frameworks (QOFs) indicators and other levers. Fortunately the DH has recognised this and BASL, BSG and BLT are heavily involved in the development of a new National Liver Strategy under the guidance of the new National Clinical Director for Liver Services.

In secondary and tertiary care, the management of advanced liver disease and its complications is resource intensive and expensive. A typical patient with liver disease will have 5-10 acute hospitalisations before dying from the disease. Thousands of patients with cirrhosis will be enrolled in surveillance programmes to detect hepatocellular carcinoma (liver cancer arising as a complication of cirrhosis) that is potentially curative. A fortunate 700 will receive liver transplant and this figure may rise to 1,200 per year. This represents a lot of resource to release for other healthcare objectives.

Need to develop outcome frameworks

BASL, BSG and BLT are very happy to work with GP Commissioning consortia and the NHS Commissioning Board to develop a meaningful outcomes framework both for liver patients and those at risk of developing liver disease within the five outcome domains.

Clinicians and patients feel strongly that there should be an identified improvement area for liver disease in the outcome measures proposed in Domain 1: Preventing People from Dying Prematurely. We support the definition of mortality amendable to healthcare as an overarching indicator, based on the assumption that this is healthcare in its broad meaning, encompassing appropriate and proportional health measures. However we have major reservations about the way this is interpreted in the White Paper. In particular (i) the use of “under 75” biases priorities towards conditions such as ischaemic heart disease and stroke which predominantly affect older populations and away from liver disease that has a much younger average age at death (59 versus 82-84); and (ii) the definition of “amenable to health care” is based on outdated medical practice and ignores recent development in screening, diagnosis and treatment, all of which are particularly relevant in liver disease.

Equally we feel that there should be a liver-related improvement area for Domain 2: Enhancing Quality of Life for People with Long Term Conditions.

From designated improvement areas we are determined to deliver better patient outcomes cost effectively that are related to mortality and improved quality of life and societal contribution.

In addition, we see an opportunity to drive down the escalating bill related to liver disease which is estimated by the DH to be £1 billion by 2015-16, see figure 2. With GP commissioning there is a golden opportunity to shift the demand curve left to detect liver disease earlier, intervene less at less cost, while also bridging the knowledge gap in primary care.
The importance of secondary prevention

There is an important role for secondary care in aiding prevention of ill-health which is under-emphasised in the proposals. We understand that a future White Paper will address Prevention but it seems likely that this may focus on primary prevention in the community. Outcome measures should include measures that assess Secondary Prevention e.g. support for patients who make contact with secondary care with alcohol problems, provision of surveillance and widespread access to treatments that prevent progression of hepatitis through cirrhosis to liver cancer.

We are particularly concerned to see improved services for patients with alcohol-related problems, across the primary care-secondary care interface and have produced a Strategy document “Alcohol Related Disease 2010” showing how cost-effective improvements can and should be introduced (see: http://www.bsg.org.uk/clinical/publications/index.html).

Bridging the knowledge gap in primary care

We know from our experience as both patients and clinicians that, as well as being uncomfortable with liver disease, GPs have relatively little knowledge of liver disease in primary care. There is also a common misconception that liver disease is ‘all about alcohol’. This stigmatisation of liver disease and liver patients is not unique to primary care. It extends to many levels of the healthcare system. These perceptions may even lead to the sense that nothing can be done for these patients – something that could not be further from the truth. Given the liver’s powers of regeneration, when the underlying aetiology can be successfully tackled patients with even the most advanced liver disease can recover to lead full and productive lives. It is almost never too late to intervene.

If GPs are responsible for commissioning liver disease diagnosis and treatment, their relatively undeveloped sense of what can be achieved in primary care and in clinical settings

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Figure 2: Projection of overall current cost (£ million) to the NHS of liver disease

BY 2015 THE COST OF LIVER DISEASE COULD EXCEED £1 BILLION

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Estimate of 10% CAGR based on increase in HES K70-76 in-patient liver disease codes between 2003-2007. SOURCE: HES data
has the potential to disadvantage patients and lead to further health inequalities. We need to ensure that effective strategies, including GP training, are put in place to ensure fair commissioning of liver services throughout the UK to guard against a ‘postcode lottery’ effect in the commissioning and delivery of liver services. However, we see no reason why the new commissioning framework alongside an emphasis on appropriate liver improvement areas would not give us the opportunity for fresh, innovative thinking designed to boost outcomes and patient and clinical satisfaction, while driving down the burden of liver disease and the costs associated with it.

Public health

While we recognise that the public health is not the focus of the White Paper, we believe it to be important to highlight the importance of the public health dimension to tackling liver disease, which is especially amenable to interventions in primary and secondary care.

There are key challenges affecting the nation’s health relating to liver disease:

- the growth of alcohol-related liver disease
- the rise in blood borne hepatitis
- obesity leading to fatty liver disease, cirrhosis and cancer.

Members from BASL, BSG and BLT are working actively with the DH to propose cost-effective strategies based on ‘what really works’ while maximising synergies with other health and prevention initiatives already underway.

Alcohol-related liver disease

Alcohol-related liver disease is a major driver of mortality and NHS costs. There is also increasing recognition of a harmful but not disruptive pattern of daily alcohol consumption in the home (‘middle-class’ or ‘suburban’ alcohol overuse). Programmes of early detection, intervention and treatment of harmful drinking and dependence have been supported by NICE, shown to be highly cost effective and are well supported by patients. We are keen to work with policy teams to ensure that recent gains made in our understanding and developing practice do not get lost in the emerging twin tracks of public health and NHS service delivery. This is particularly so where activities in primary prevention have the potential to assist in the early detection of liver disease before it becomes expensive to treat.

Innovative and considered approaches are been proposed, for example in Alcohol Related Disease: Meeting the challenge of improved quality of care and better use of resources.

Viral hepatitis

In spite of the Hepatitis C Action Plan being published in 2004 and NICE recommending cost effective anti-viral therapies, the incidence of chronic hepatitis C is set to double in the next decade.7 We welcome the fact that NICE Public Health has recently established a Programme Development Group to evaluate the most cost effective approach to case

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7 Moriarity K. J., 2009. Alcohol Related Disease: Meeting the challenge of improved quality of care and better use of resources. A joint position paper from BSG, BASL and the Alcohol Health Alliance.
identification which should, in combination with the Action Plan and NICE HTA recommendations on the cost effectiveness of therapy, substantially increase the numbers of those receiving therapy; this will also address the rising incidence. It is clear that a similar action plan and case identification programme for Hepatitis B is likely to result in reduce costs and better clinical outcomes. One of the risks of the proposed new structure is that emerging knowledge and practice will be lost to relatively local level GP commissioners. Where a disease area such as liver disease is growing exponentially, costing the taxpayer more and more each year, and where patients already suffer significant health inequalities, it is vital that the NHS Commissioning Board is enabled to take a strategic view and actively foster innovative and cost effective solutions. Because of the lack of appreciation amongst GPs that chronic viral liver disease is a treatable condition resulting in markedly improved survival and the fact that these infections afflict disadvantaged groups (first generation migrants in addition to IVDUs), in the interests of equity of health care, the Commissioning Board should require continual audit of the quantity and quality of the service provided by the GP Consortia. In this way the UK will achieve a similar quality of service as has been achieved elsewhere in Europe driving down incidence and prevalence, morbidity and mortality and ultimately cost.

Obesity related liver disease

The impact of obesity is less understood in liver disease than its impact on other organs and disease areas. Understanding the impact of being overweight or obese as well as drinking too much and/or having underlying viral liver disease is a behaviour change lever that remains untested and offers the potential for targeted and cost-effective prevention.

Closing remarks

The public, both as taxpayers and individuals at risk of liver disease, existing and future patients and clinicians treating liver disease welcome this opportunity to join together to accomplish a win-win for patient outcomes and the public purse in developing and delivering a National Liver Disease Strategy for England.

The BSG is also submitting a response in relation to gastroenterology and hepatology. Its views and those of BASL and BLT are complementary.