Williams, R; Alexander, G; Aspinall, R; Bosanquet, J; Camps-Walsh, G; Cramp, M; Day, N; Dhawan, A; Dillon, J; Dyson, J; Ferguson, J; Foster, G; Gardner, R; Gilmore, SI; Hardman, L; Hudson, M; Kelly, D; Langford, A; Liversedge, S; Moriarty, K; Newsome, P; O’Grady, J; Pryke, R; Rolfe, L; Rutter, H; Ryder, S; Samyn, M; Sheron, N; Taylor, A; Thompson, J; Verne, J; Yeoman, A (2016) New metrics for the Lancet Standing Commission on Liver Disease in the UK. Lancet. ISSN 0140-6736 DOI: https://doi.org/10.1016/S0140-6736(16)32234-6

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DOI: 10.1016/S0140-6736(16)32234-6

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The Lancet Commission

New Metrics for the Lancet Standing Commission for Liver Disease in the UK


Denotes first author

Affiliations

Institute of Hepatology, Foundation for Liver Research (Prof Roger Williams, Natalie Day); British Association for the Study of the Liver (Prof Graeme Alexander); Queen Alexandra Hospital, Portsmouth (Dr Richard Aspinall); Public Health England (Joanne Bosanquet, Liz Rolfe, Prof Julia Verne); Medical Marketing Consultants (Ginette Camps-Walsh); Plymouth Hospitals (Prof Matthew Cramp); King’s College Hospital, London (Prof Anil Dhawan, Prof John O’Grady, Dr Marianne Samyn); Medical Research Institute, University of Dundee (Professor John Dillon); Freeman Hospital, Newcastle (Jessica Dyson, Mark Hudson); Queen Elizabeth Hospital, Birmingham (James Ferguson); Queen Mary’s University, London (Prof Graham Foster); British Society of Gastroenterology (Richard Gardner) University of Liverpool (Prof Sir Ian Gilmore); NHS Bolton Clinical Commissioning Group (Lesley Hardman); Birmingham Children’s Hospital (Prof Deirdre Kelly); British Liver Trust (Andrew
Executive Summary

The format for this third annual report of the Lancet Commission follows the same pattern as in 2015 in concentrating on the main recommendations, all of which are evidence based and have been most carefully considered in terms of their ability to reduce the current burden of liver disease in the UK and its financial cost. The working groups set up around the recommendations have concentrated this year on producing a set of the main metrics which will enable further charting of disease prevalence and consequences on an annual basis. They have also identified those areas where important data is not being obtained and which needs to be rectified. The initial ten recommendations have been reduced from ten to eight because of some overlap between them and an awareness that certain of the measures were common to both. These are shown in Panel 1. The recommendations are also in agreement with the ongoing thinking and action of the All Party Parliamentary Group on Liver Health with which, as described in the Introduction, we are increasingly liaising.
For many of the recommendations there is as yet little progress to report as shown by the metrics in terms of reducing disease burden although together with the efforts of other bodies and agencies, there is some movement in that direction. Thus, with Recommendation 1 the recently published guidelines by NICE on fatty liver disease and the diagnosis of cirrhosis, are likely to help considerably in improving clinical management at general practitioner and community level, giving guidance as they do on the best pathways to follow for the early identification and treatment of liver disease. Similarly for Recommendation 2, on the very necessary need to improve hospital services, we can point to the completion of a major review of hospital staffing and facilities for the care of the sick liver patient in hospital. These will inform further efforts to improve hepatological expertise and facilities within the DGHs and the desired networks with specialist centres.

Figure 1:

The updated version of the maps published in last year’s report illustrates the considerable variation in levels of current provision and will be of value in discussions on rationalisation and avoidance of duplication in provision of acute services being proposed. The maps also illustrate the need for greater provision of liver services in the deprived areas which have the highest rates of liver disease morbidity and mortality. The number of District General Hospitals (DGHs) that do not meet the criteria for an acute liver service, is unacceptable.
Recommendation 3 relating to the national strategic review of liver transplantation in the UK is proceeding, albeit rather slowly. This is because of the need, with the financial constraints facing the NHS at present, for the costs of this procedure to be properly considered along with agreement on work packages. The recommendation remains that additional centres are set up to correct the present geographical inequalities and increase the number of liver transplants carried out. Of note here during the past year is the likely increase in the number of donor organs available as a result of new developments in organ perfusion which can return function to donor livers, particularly those obtained in by DCD donation (donation after cardiac death) that were previously considered too damaged for use. Furthermore, initial results of the introduction of presumed consent in Wales have shown a striking increase in the number of organs being donated over the first four months of its operation.

Recommendation 4 highlights again the ever increasing population of adolescents with liver disease requiring supervision and care arising from the better results of treatment of infants and children including the use of liver transplantation. The measures needed are outlined with some encouraging pilot statistics.
Recommendations, 5, 6 and 7. Sadly these sections on the consequences of the lifestyle issues of excess alcohol consumption and obesity, as well as viral hepatitis, make depressing reading. The section on liver disease due to alcohol shows the increase in alcohol consumption and hospital admissions that was predicted to follow removal of the escalator tax in 2014. The necessary measures to reverse this are again set out in this section including further information on the value of the MUP policy. A recently published, nationally commissioned representative survey of over 3000 respondents in Northern Ireland(1) again showed that the MUP policy targeted those suffering the greatest harm from drinking and would significantly reduce alcohol attributable mortality. Recent studies have also shown that the percentage of total alcohol consumed by the heavy drinkers has increased from 13% to 17% (see Table 6 later in this document).

Similarly there is little encouragement to report for Recommendation 6 on the introduction of effective measures to reduce obesity rates for the 60% of the population who are now in the overweight category. The outcry from the medical profession and public alike on the watering down of the sugar tax proposal is some indication of the realisation of the harmful effects of obesity in causing diabetes and heart attacks, let alone liver disease and primary hepatocellular carcinoma. Surveillance programmes for primary hepatocellular carcinoma in patients with cirrhosis as well as those with fatty liver disease, are still not being implemented in the DGHs despite the continued increase in the number of such cases. The enormous cost of obesity both to patient health, to the NHS and to society in general, are highlighted in the section and in the Introduction.

Recommendation 7 does portray a more hopeful note on the treatment of hepatitis C positive patients. The new drugs that have been introduced are proving in practice to be both efficacious and safe, with resulting high levels of viral clearance. Operational Delivery Networks are in place throughout England and the main issues relate to how many and which cases should be treated, with the limitation on total cost imposed by NHS England. The very high price of the medication imposed by manufacturers on the Western world remains difficult to justify.

For Recommendation 8, which relates to increasing public awareness of health problems from liver disease, there is undoubtedly very much more activity in the media on lifestyle healthcare issues. Most importantly the Commission is able to report considerable ongoing success in meeting with Parliamentarians. Engaging their support is essential if the necessary legislation and regulation are to be finally approved by Parliament. National Liver Disease Profiles detailing disease prevalence and mortality have been produced for each of the 533 Parliamentary constituencies and show a 17-fold difference in the rates for the most deprived areas.
Introduction

Am I being too much of an optimist in seeing a little light at the end of the tunnel for the efforts of the Lancet Commission to reduce unacceptable levels of morbidity and mortality from liver disease in the UK, which predominantly affects those still in working life and increasingly being seen in the young? Lifestyle issues of excess alcohol consumption, obesity and viral hepatitis responsible for the majority of liver illness in this country are increasingly being featured in the media. As yet, however, the long entrenched Government policies on alcohol and obesity, based on not wanting to increase the nanny state, remain in place and the all powerful lobbies of the food and drinks industry continue to have a major influence. The increasing demands on the NHS and the resulting financial pressures must be a strong argument for the introduction of measures that can significantly reduce the prevalence of disease. The health benefits and cost to the country from tackling smoking through regulation and taxation should be an encouragement to Parliament to follow similar initiatives for the other major lifestyle issues. £2.1billion is spent each year on the treatment of liver disease. Hospital admissions and mortality rates are increasing again, as described in this third report of the Lancet Commission. Being largely preventable, this cannot be justified, nor can the figure of nearly 60% of police officers time being spent on alcohol related offenses. Furthermore, according to the Treasury’s own figures, without the cuts and freezes in alcohol duty over the past few years, including those in the 2015 Budget, alcohol duty would have raised £770million more for the Government exchequer in 2016/17. As a result of scrapping the duty escalator, Government finances will be £2.9billion worse off by 2017/18(2). The costs of obesity alone amount to £5.1billion a year for the NHS with 40,000 deaths linked to people being overweight or obese. There were 440,288 admissions to hospitals in England in 2014-15 where obesity was the main reason for a person being admitted or was a secondary reason.

This year’s Lancet follow-up report with its emphasis on metrics, gives many other examples of the cost to the country of not taking the necessary measures over lifestyle issues. Sadly, the introduction of a sugar tax, proposed in the Queen’s Speech to Parliament, is now being watered down particularly with respect to important limits on advertising junk food although proposals on sugary drinks remain. How effective will be the targets set on the food industry for reducing sugar content of foods? Dame Sally Davies, Chief Medical Officer for England, has bravely reduced safe limits for alcohol consumption for both women and men, based on national and international evidence of the progressive increased risk of developing various cancers including the common ones of breast and colon.

On a more optimistic note, the two important guidelines for the investigation and management of liver disease have been published by NICE and one by the British Society of Gastroenterology should help in the earlier detection and management of liver disease.
This year has also seen the appointment of Dr Jez Thompson as the jointly funded British Liver Trust and Royal College of General Practitioners Clinical Champion of Liver Disease. Already he is making an impact as will be evident in his contribution to this year’s report. Improving healthcare for liver patients in the District General Hospitals is also of vital importance, as highlighted by the adverse NCEPOD reports and the new data from a comprehensive national survey of staffing and hospital facilities. This should provide the basis for better and more equitable planning of services particularly in deprived areas with high incidence of liver disease. Public Health England (PHE) launched in August a new tool to help local authorities prevent or reduce the impact of alcohol harm. Known as CLeaR and based on the success of the tobacco control CLeaR tool, it provides a framework for local partnerships to review local structures and alcohol services. In addition we are seeing Scotland moving forward again on introducing the minimum unit price for alcohol both Wales and Northern Ireland are pursuing major programmes based on strong Government support tackling the harms of liver disease. More information on the work going on in the devolved countries is considered in the relevant sections of this year’s report and in the general reviews.

Encouraging also this year and following on a start in 2015, has been the successful and increasing dialogue with Parliamentarians on raising awareness of liver disease in Parliament. The work has been greatly helped by the involvement of a lobbying agency, Incisive Health, to whom we are very indebted for their ability in making contacts and in following them through. This work has been greatly aided by an unrestricted educational grant from Norgine to the Foundation for Liver Research. Representatives of the *Lancet* Commission held sixteen one-to-one meetings with parliamentarians from both the Government and opposition parties. Amongst these were a number of high profile meetings with Lord Prior of Brampton (Parliamentary Under Secretary of State for Health), Heidi Alexander MP (then the Shadow Secretary of State for Health) and Dr Sarah Wollaston MP (Chair of the Health Select Committee). In addition to raising awareness of liver disease with them, the House of Lords had a debate on the implementation of the *Lancet* Commission’s recommendations and multiple Parliamentary Questions have been tabled both in the Commons and the Lords, on topics related to liver disease. In addition to private meetings, the *Lancet* Commission partnered with the All Party Parliamentary Group (APPG) on Liver Health in holding two parliamentary briefing events – one in the House of Lords (October
2015), and another in the House of Commons (July 2016). Both events sought to raise parliamentary awareness of the Lancet Commission’s blueprint for improvement and of the need to act to address the continuing liver disease crisis. Together these events were attended by 38 parliamentarians. In addition, we have been liaising closely with the Children of Alcoholics APPG which is being led by Liam Byrne, MP.

July 2016 saw the launch of the Lancet Commission’s most recent campaigning resource, Constituency Liver Disease Profiles, designed to bring to life the health and financial impact of liver disease on local communities and generate greater interest in liver disease amongst MPs. As well as the National Liver Disease profiles (shown in Figure 1) part of this initiative has been to produce a customised infographic for each of the 533 parliamentary constituencies in England, bringing together exclusive data provided by Public Health England and existing data intelligence to provide a concise summary of the impact of liver disease on local populations. The data collected as part of this exercise has been used in targeting MPs from the fifty areas with the highest burden of liver disease. The remarkable 17-fold difference between the burden of liver disease in the North West and rates in the Home Counties (Table 1) is a telling statistic and with its association with social deprivation shows also the need for wider social and public health measures in addition to reducing alcohol consumption and obesity.

The Constituency Liver Disease Profiles are publically accessible on the Foundation for Liver Research website(3) and available to the wider liver disease community to be used in the briefing of relevant political stakeholders on the burden of liver disease in their areas.

Going forward into 2017, the Commission will continue its engagement with Parliamentarians and it will explore other ways to communicate the burden of liver disease to key stakeholders, such as healthcare commissioners, local authorities and those charged with developing and implementing sustainability and transformation plans.
Recommendation 1: Improving expertise and facilities in primary care to strengthen detection of early disease and its treatment, and screening of high-risk patients in the community

Panel 2: Metrics for Recommendation 1

1.1 Percentage of adult patients in primary care who have had BMI recorded in the preceding year
1.2 Percentage of adult patients in primary care who have had a measure of alcohol consumption or risk in the preceding year
1.3 Percentage of adult injecting drug users who have had a recent HCV test
1.4 Percentage of adult injecting drug users who have had HBV immunisation
1.5 Introduction of a suite of Read Codes to cover liver disease risk factors, diagnoses and interventions to facilitate excellence of clinical care and practice audit and performance monitoring
1.6 To ensure that all children born at term in the UK with conjugated jaundice are referred to a National Paediatric Liver Unit before they are 8 weeks old.

- The most common forms of liver disease have risk factors which are shared with other co-morbidities typically already under primary care surveillance, and which can be identified and addressed within primary care to prevent liver pathology developing.

- Once developed, liver disease is typically slow to progress, and the patient with early disease may remain asymptomatic for years, while the disease itself is slowly advancing in severity. Early intervention, risk modification and treatment within primary care may prevent or retard progression to cirrhosis and end stage liver disease.

- Patients with advanced liver disease spend the majority of their lives within their own families and communities where they are registered with a GP. Though many with advanced liver disease attend secondary care outpatient clinics and some have repeated hospital admissions during acute crises, much of their healthcare is provided within community settings.
For these reasons clinicians working in primary care and other community services, including community drug services, have unique and important roles in the prevention, early detection and management of liver disease. Engagement will reflect local factors, including local prevalence, population demographics and level of prioritisation by local commissioners, as well as mechanisms to incentivise staff and investment in support services. Focusing on the key liver conditions, these roles and potential roles are:

- **Primary prevention of liver disease.** This includes screening for hazardous and harmful alcohol use and obesity(4) and having access to early in-house interventions or referral pathways to services to address these issues(5, 6). Hepatitis B immunisation for those at risk, including injecting drug users, is another form of primary prevention. Critical to primary care, and to pressing workload considerations, is the recognition that many risk factors for liver disease are also risk factors for other long-term conditions. Effective screening for liver disease risk factors does not necessarily mean ‘new work’, rather the linking of liver disease to current best practise and the monitoring and management of other conditions.

- **Secondary prevention of liver disease.** This includes screening for hepatitis C(7, 8) and hepatitis B infections in those who have been in the past, or are current, drug injectors or who have other risk factors(9), and onward referral if necessary(5). It also includes case-finding for early liver disease in those with high-risk obesity or alcohol use and providing appropriate interventions and ongoing monitoring(6, 10).

- **Tertiary prevention of the consequences of established and more severe liver disease.** This includes ongoing involvement in the support, monitoring and management of patients with more advanced liver disease, together with appropriate referral of patients to secondary care services(11). Further developments may include appropriately resourced and supported initiatives to move areas of care traditionally delivered within secondary care to primary care, such as hepatitis C treatment, building on innovative models and frameworks already in place(12-14).

Substantial work has already been done to raise the profile of these roles for primary care practitioners. The Lancet Commission publications have provided several recommendations with unique relevance to primary care(11, 15). In 2016 the Royal College of General Practitioners selected liver disease as a one of their Clinical Priority programmes(16) and, in partnership with the British Liver Trust, has recently appointed a primary care Clinical Champion for Liver Disease(17). This builds in part on the RCGP Nutrition for Health clinical priority programme (2011-2015), whose RCGP Nutrition Position Statement clarified the
need for greater primary care action on obesity and the role of obesity as a risk factor for liver disease(18). An RCGP Liver Disease position statement will be developed as part of this new Clinical Priority programme, in order to benchmark good practice in primary care, and to support the translation of new NICE NAFLD and Cirrhosis Guidance into service delivery, especially where investment in commissioning new diagnostic testing facilities is required.

Raising the profile of liver disease within primary care requires the development of robust guidance together with effective drivers to alter clinical practice(15). These include professional training, development of toolkits and pathways, and investment in services to facilitate increased management of liver conditions within primary care(15). Bold investment plus innovative local commissioning initiatives will be needed if traditional areas of secondary care management, such as hepatitis C treatment, are to feature more in primary care as the price of the next two antiviral agents falls and current arrangements through the Operational Delivery Networks (ODNs) are less necessary. Innovations require a full and realistic awareness of the large number of patients at risk of and with early liver disease, and the multiple competing workload pressures that already exist within primary care(11).

As part of moving forwards with the Lancet Commission recommendations, a number of metrics have been proposed, to assess where we are now, and to guide future developments. The metrics agreed to support the Lancet Commission’s Recommendation 1 are given in Panel 1.

**Metric 1: Percentage of adult patients in primary care who have had BMI recorded in the preceding year**

Non-alcoholic fatty liver disease (NAFLD) is an increasingly important cause of liver disease including cirrhosis as obesity rates rise at all ages within the UK, and for this reason assessing the percentage of adult patients in primary care who have had their BMI recorded in the preceding year is important(19). Primary care is uniquely placed to identify obesity and measuring and recording the BMI of a patient in the obese range is the first stage to providing in-house interventions or accessing a local tiered weight management pathway. Despite IT developments within primary care, full data on BMI recording in general practice are not easily accessible. The data are held neither at the level of the CCG or devolved nation equivalent, nor by the relevant national public health body for the four nations of the UK. Complete data sets are available at practice level, but to access them would require large-scale surveys of practices across the UK.

The literature suggests that GPs are not comfortable addressing obesity as a health issue. Ogden and Flanagan found that GPs are ambivalent about the effectiveness of obesity
interventions, finding that ‘obesity does not belong within the medical domain’(20, 21). In 2004 Hankey et al found that less than 10% of GPs had carried out any form of audit to determine the prevalence of overweight or obesity in their practice population, and that health professionals were generally unclear on how to deliver effective weight management advice(22). Other published evidence points to GPs’ concern about the potential for damaging their relationship with their patients by bringing up the thorny issue of obesity(23). More recent work has reiterated concerns about barriers to case finding and obesity management in primary care which centre on uncertainty about the evidence base, while signposting to useful resources to address sensitivities about raising the topic of obesity in consultations and other training resources(24).

The best data for this metric come from the financial incentive QOF target and payment scheme for GPs. One QOF target has been the establishment and maintenance of a register of patients aged 16 and over with a recorded BMI ≥30 in the preceding 12 months. QOF recorded prevalence for obesity in England in 2014/15 was 9%, representing 4.2 million patients, and obesity was the second highest recorded disease prevalence after hypertension(25). In Scotland the figure was 8% in 2014/15(26), and Wales 2014/15 9.5% (27). Northern Ireland data do not include easily available information on obesity as a record of disease prevalence. QOF data have limitations, and only relate to those people who have had a recent measurement and are therefore on each GP practice’s obesity register; it does not provide any information on BMI recording in those who are overweight, or on obese patients who are not on the practice’s obesity register. What they show is simply the number of obese people whose BMI is being measured and monitored in primary care each year.

The best estimate of the overall prevalence of obesity comes from survey evidence. The Health Survey for England report(28) cited an overall prevalence rate for obesity of 25% in England. Similar evidence in Wales gives an obesity prevalence of 24% (29) and 28% in Scotland(30).

Taken together these two groups of figures suggest that somewhere around a third of those who are obese have had measurement and recording of their BMI in primary care in the last 12 months and two thirds have not. In the UK the average person consults his or her GP 6 times a year(31) and there is some evidence to suggest that those who are obese see their GPs at a higher rate than average(32).

More work is clearly needed to explore the drivers and barriers to measuring and managing obesity in primary care, and the effectiveness of interventions provided.
Metric 2: Percentage of adult patients in primary care who have had a measure of alcohol consumption or risk in the preceding year.

The full range of practice-based data on alcohol use and morbidity recording in consultations is not easily available as is the case for obesity, though GPs regularly use standardised and coded tools to record alcohol use and related morbidities.

As considered elsewhere in this report, hazardous and harmful alcohol use is prevalent in the UK population. Survey statistics for Scotland demonstrate that nearly 1 in 4 men (23%) and around 1 in 6 (17%) women drink at harmful or hazardous levels (33). In England 18 per cent of men and 13 per cent of women drink at an increased risk of harm and 5 per cent of men and 3 per cent of women drink at higher risk levels (33). Figures for Wales (10) and Northern Ireland (1) are broadly comparable.

Alcohol use is related to many areas of social, physical and mental health problems, triggering high rates of consultation in primary care. Based on a survey conducted by the BMA, the Institute for Alcohol Studies estimates that in Scotland around 6% of GP consultations are related to ill health contributed to by alcohol use (34). An indirect estimate of the number of GP consultations contributed to by alcohol use within Leeds produced a figure of 10% of all consultations (35). Given average consultation rates of 5 per year per person, this totals up to 30 million appointments each year across the UK.

However, a consultation for an alcohol-related condition does not mean that alcohol use was discussed. In their study in 1998, Kaner et al found that GPs did not routinely enquire about alcohol use in their patients and only 1 in 5 GPs felt effective in helping a patient to reduce drinking levels (36). Rapley et al’s later survey found GPs were in fact routinely enquiring about alcohol use, but lack of time and the need to manage competing multiple problems within a single consultation were the main inhibitors to managing a greater number of risky drinkers (37).

Data on direct engagement with alcohol issues in a GP consultation can only be sourced indirectly. Until 2015 the Practice Team Information (PTI) system collected consultation data from general medical practices in Scotland. The most recent PTI figures on GP consultations give an estimate of 94,630 alcohol morbidity-coded primary care consultations by 48,420 patients in 2012/13, and for the purposes of this metric a coded consultation is taken as a proxy measure of a primarily alcohol-related consultation (38). Given that Scotland has a population of something over 4 million adults and a harmful and hazardous alcohol use prevalence of around 20% of these it can be estimated that there are 800 000 harmful and hazardous drinkers in Scotland. Given that just less than 50 000 patients had a primarily alcohol-related consultation in one year, this represents just 5% of the harmful and
hazardous drinking population of Scotland. Other evidence points to higher rates of engagement with alcohol consumption by GPs, and in a GP ‘exit poll’ of English patients in 2004 Aalto found that 11% of those visiting their GP had been questioned by their GP about their alcohol use, even if briefly(39). Further indirect evidence comes from a review of primary health care records for patients who died from alcohol-related conditions in Glasgow in 2003. Twenty one percent had no record at any time of having been advised to abstain from alcohol; 23% had received a brief intervention; and 58% had been referred to a specialist alcohol service, though 1/3 of these never attended(40).

However, local initiatives have demonstrated that it is possible to achieve significantly better performance in primary care in this metric area (box 2).

Panel 3: The Bolton CCG Implementation example (see Table 1 for data)

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National and local reports surrounding alcohol behaviours, suggest that Bolton is, along with several other parts of the North West, well above the national average for the prevalence of problem drinking. Alcohol harm is amongst the top 5 causes of the life expectancy gap for both males and females in the town(41). In order to better understand the drinking habits and patterns of use/misuse amongst Bolton’s adult population, a local project was developed.

The initiative, which has been running now for 5 years, offers an AUDIT C test every 2 years, to all patients aged 16 years and over. Since this time, the Primary Care Development and Health Improvement Team, led by Dr Stephen Liversedge, has been working closely with GPs and all their staff to increase patient awareness of the dangers posed to good health and wellbeing from alcohol misuse. A pathway for Primary Care has also been developed.

The latest data show that since April 2014 129,867 patients have been supported to undertake an AUDIT C in Primary Care in Bolton. This accounts for 53.7% of the eligible population. Even though all 50 practices in Bolton participate enthusiastically in the initiative, some perform better than others. Table 1 demonstrates local data analysis. Practices are clustered according to deprivation, age and ethnicity as follows:
The variability of AUDIT C data that can be seen in table 1 demonstrates that practices with higher levels of deprivation within their population cohort can achieve high activity when appropriate support and modest incentives are in place.

As well as meeting the original aim of raising awareness of the dangers of alcohol misuse at a population level, this local project carries many other benefits:

- Provides patient education about the benefits of low risk consumption and information about the risks of excessive drinking
- Presents opportunities for patients who are AUDIT C positive (score ≥ 5) to have a comprehensive Health Trainer intervention at the surgery to modify unhealthy alcohol behaviours
- Patients who are high risk or dependent drinkers are signposted directly to local alcohol services
- Provides practices with an understanding of an individual’s alcohol behaviours which might assist with future healthcare
- Alerts clinicians to the need to advise individual patients whose alcohol consumption might adversely affect their medications
- Produces data which can inform commissioning for alcohol services
- Supplies information to inform future projects

**How was this project funded and incentivised?**

The initial scheme offered Practices £2.00 per AUDIT C completed. This was funded from Public Health, included a training day for all clinical staff and focussed on activity. The current scheme now sits within the Bolton Quality Contract, which commissions for outcomes across 20 standards and 40 Key Performance Indicators. All 50 Bolton Practices are signed up and alcohol screening is one of the KPIs. The local target for 2016-17 is to have 145,000 current AUDIT Cs completed (60% of the eligible population). Investment has been £68k over 2 years, which currently equates to £0.53p per AUDIT C completed.

Peer pressure amongst practices, arising from freely available local publication of the data for all 50 Bolton practices, has helped to drive engagement, as has the investment in availability of in-house Health Trainers to modify unhealthy alcohol behaviours.
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<tr>
<td>16</td>
<td>1,634</td>
<td>1,082</td>
<td>66.2%</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>3,236</td>
<td>2,048</td>
<td>63.3%</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>6,009</td>
<td>4,393</td>
<td>73.1%</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>6,476</td>
<td>4,171</td>
<td>64.4%</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>1,710</td>
<td>766</td>
<td>44.8%</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>2,752</td>
<td>1,469</td>
<td>53.4%</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>2,374</td>
<td>1,196</td>
<td>50.4%</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>3,152</td>
<td>2,025</td>
<td>64.2%</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>3,941</td>
<td>2,106</td>
<td>53.4%</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>9,378</td>
<td>5,229</td>
<td>55.8%</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>4,089</td>
<td>1,659</td>
<td>40.6%</td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>10,750</td>
<td>6,251</td>
<td>58.1%</td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>5,440</td>
<td>2,591</td>
<td>47.6%</td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>5,176</td>
<td>1,718</td>
<td>33.2%</td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>4,043</td>
<td>2,352</td>
<td>58.2%</td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>2,647</td>
<td>1,474</td>
<td>55.7%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Metric 3: Percentage of adult injecting drug users who have had recent HCV testing</td>
<td></td>
<td></td>
<td></td>
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<tr>
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<td>--------------------------------------------------------------------------------</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Chronic hepatitis C (HCV) infection is thought to affect 214 000 people in the UK, representing 0.3% of the UK population, and 90% of these infections have been acquired through injecting drug use. An estimated half of those with chronic hepatitis C infection are undiagnosed(42).</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A high proportion of current psychoactive drug users attend services for treatment and data on testing are routinely submitted to local commissioners by all drug services and collated by public health bodies in a number of reports. Further information is available via the Unlinked Anonymous Monitoring (UAM) survey of people who inject drugs in contact with drug services.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Drug misuse treatment is characterised by multiple treatment episodes and drug service patients have a comprehensive assessment at the start of each treatment episode which routinely covers HCV risk. In the UK in 2013/14 87% of patients had been offered a hepatitis C test at the beginning of their most recent treatment episode, and of those more than 2/3 (67%) accepted the offer(42). Around half of those who inject psychoactive drugs are typically found to be hepatitis C antibody positive(8).

In England and Wales, among those who inject only performance and image enhancing drugs, 3.6% have antibodies to hepatitis C. Only 32% report ever having been tested for hepatitis C. In Scotland, among those who had only injected image and performance drugs during the last six months, 5.1% had antibodies to hepatitis C in 2013-14 and just under a third (29%) reported ever being tested for hepatitis C. This had increased from 18% in 2010 (42). As this group does not use traditional drug services opportunities for HCV testing outside drug treatment facilities are needed.

Testing also takes place in general practice, and testing rates have increased year-on-year between 2010 and 2014, rising by 5% between 2013 and 2014 representing 60 000 tests across 23 sentinel laboratories each year(42). This suggests that awareness of hepatitis C infection in the primary care setting is increasing, and this is particularly important for those who have acquired hepatitis C infection from historical injecting drug use and who may not have attended drug treatment services for many years, and for those who have acquired the infection via an alternative route such as historical blood product transfusion, tattooing or body piercing. It has been estimated that around 50% of those with chronic hepatitis C infection are not in contact with drug treatment services, and accessing more comprehensive data on testing in primary care will be of increasing importance.

Testing for HCV infection in primary care provision in the prison setting is particularly important as the prison population represents a particularly high-risk group; however data from several different sources suggest significant and continuing under-testing of this population group(8). There has been a rise in hepatitis C tests performed from 5.3% of new admissions to prison in 2010/11 to 8.6% in 2013/14 suggesting recent increasing awareness within the prison estate about the need for HCV testing.

**Metric 4: Percentage of adult injecting drug users who have had HBV immunisation**

Hepatitis B virus is transmitted by parenteral exposure to infected blood or body fluids, and transmission in the UK is predominantly through sexual contact; as a result of blood-to-blood contact (e.g. sharing of needles and other equipment by injecting drug users or ‘needlestick’ injuries), and through perinatal transmission from mother to child. Data on hepatitis B immunisation in sexual health clinics and primary care practices are not
available, and the following metrics are focused on those who are at risk through injecting drug use and who are in contact with drug services. The data are taken from collated information provided routinely by drug services and from the Unlinked Anonymous Monitoring survey

In England, Wales and Northern Ireland, reported uptake of the hepatitis B vaccine for those who inject psychoactive drugs (i.e. receiving at least one dose of vaccine) increased from around half in 2004 to almost three-quarters in 2014. However, the level of uptake did decline from 76% in 2011 to 72% in 2014. Among injecting drug users surveyed in 2014 that had never been infected with hepatitis B and who had taken-up vaccination, 61% had received three or more doses of the vaccine and had completed the course of immunisation. Of those that had not taken-up vaccination 55% (219/396) were currently receiving a prescribed substitute drug as part of drug service provision. The non-immunised group did utilise other health services where vaccination could have been offered; 62% (247/397) had seen a general practitioner; 26% (103/397) had attended an emergency department; 14% (56/397) had used a walk-in/minor injury clinic; and 7.8% (31/397) had attended a genitourinary medicine clinic(42). These contacts represent lost opportunities for vaccination as part of primary prevention. Among people injecting image and performance enhancing drugs in England and Wales only 40% reported uptake of the vaccine against hepatitis B(42).

**Metric 5: Draft and adopt a suite of Read Codes to cover liver disease risk factors, diagnoses and interventions to facilitate excellence of clinical care and practice audit and performance monitoring**

Review by the commission team has identified an opportunity to develop a comprehensive set of Read codes relevant to both prevention and management of liver disease and associated risk factors. This project will be taken forwards by the Commission team over the next year.

**Metric 6: To ensure that all children born at term in the UK with conjugated jaundice are referred to a National Paediatric Liver Unit before they are 8 weeks old**

Currently all children with significant neonatal liver disease are referred to one of the three national liver units. National data is collected on the age of Kasai Portoenterostomy for Biliary atresia and the outcome. Between January 2009 and December 2013, 230 children were diagnosed with biliary atresia in England and Wales; 75 (i.e. 32.6%) were older than the recommended age for operation (>56 days old) at time of Kasai Portoenterostomy or laparotomy, 7/75 had a primary transplant (1). Further education and awareness of the
importance of early diagnosis of neonatal liver disease will be addressed through initiatives from PHE and the Children’s Liver Disease Foundation (CLDF).

Recommendation 2: Establishment of acute liver services in district general hospitals linked with 30 regional specialist centres for more complex investigations and treatment, and increased provision of medical and nursing training in Hepatology

Panel 4: Metrics for Recommendation 2
1. Number of DGHs with liver units (>2 consultant hepatologists)
2. Number of regional specialist units
3. Number of consultant hepatologists in post
4. Number of DGHs with 24hour emergency endoscopy cover
5. Number of DGHs enrolled into QuEST programme
6. Number of DGHs with multidisciplinary alcohol care teams

In presenting the metrics for this recommendation, Dr Mark Hudson and Dr Jess Dyson have obtained up to date figures on hospital staffing levels and facilities for liver disease in the UK through a new and complete survey of hospital trusts. Of the 207 hospitals approached, 100% provided information. Overall, a total of 221 whole time equivalent (WTE) consultant hepatologists and 305.7 gastroenterologists with an interest in hepatology were identified. The data for the devolved countries is provided in Table 2 and expressed as WTE per 10$^5$ population. The provision of liver services as defined by WTE staffing levels in the UK is summarised in Figure 2. Outside of transplant centres, only 21 (10%) of centres have ≥3 hepatologists, meeting the criteria for “large” units coming within the category of specialist regional centres. Only 16 of the remaining hospitals in the UK would meet the criteria for an adequately staffed acute service (2 hepatologists and 2 or more gastroenterologists with an interest in hepatology).

Considering England alone, a total of 193.8 WTE consultant hepatologists were identified as compared to 122 in 2010(43); a 59% increase. However, 54.7 (28%) of these were in the 6 English transplant centres and 69.6 (36%) were in the 18 “large” units within the category of specialist regional centres. Of the remaining 135 hospitals, only 16 (12%) meet the criteria for an adequately staffed DGH acute service (2 hepatologists and at least 2 gastroenterologists with an interest in hepatology). Table 2.
Table 2: Summary for UK and devolved nations of hepatologists per 10\(^5\) population, hepatology provision in terms of staffing levels, Level 2 services, endoscopy and TIPSS service and enrolment in LIVER QuEST

<table>
<thead>
<tr>
<th>Nation</th>
<th>Consultant Hepatologists (WTE)</th>
<th>Number of Acute DGH (≥2 WTE hepatologists &amp; ≥2 gastroenterologists with interest in hepatology)</th>
<th>Number of Regional Specialist Liver Units (services) LEVEL 2</th>
<th>Number of Regional Specialist Liver Units (≥3 WTE hepatologists) “LARGE”</th>
<th>Units (excluding large centres) with 24 hour OOH and n(%) able to manage varices</th>
<th>TIPSS Provision</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>221</td>
<td>16</td>
<td>23 (excluding 7 transplant centres)</td>
<td>21 (excluding 7 transplant centres)</td>
<td>143/183 (78%) [120/143 (84%)]</td>
<td>44/207 (21%)</td>
</tr>
<tr>
<td>England</td>
<td>193.8</td>
<td>16</td>
<td>18 (excluding 6 transplant centres)</td>
<td>18 (excluding 6 transplant centres)</td>
<td>117/135 (87%) [104/117 (89%)]</td>
<td>34 / 159 (21%)</td>
</tr>
<tr>
<td>Scotland</td>
<td>20.6</td>
<td>0</td>
<td>3 (excluding 1 transplant centre)</td>
<td>2 (excluding 1 transplant centre)</td>
<td>13/22 (59%) [8/13 (62%)]</td>
<td>8/22 (36%)</td>
</tr>
<tr>
<td>Wales</td>
<td>2.6</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>5/16 (31%) [5/5 (100%)]</td>
<td>1/16 (6%)</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>8/10 (80%) [3/8 (38%)]</td>
<td>1/10 (10%)</td>
</tr>
</tbody>
</table>

As well as stratifying centres in terms of the numbers of WTE consultant hepatologists, the survey also looked at the services provided. A Level 2 specialist centre is defined as one that provides out of hours (OOH) endoscopy including the management of varices; transjugular intrahepatic porto-systemic shunts (TIPSS); an HCC/HPB multi-disciplinary team meeting; medical loco-regional treatment for HCC; antiviral treatment for hepatitis C (in England as
part of an HCV ODN); liver histopathology; dedicated liver clinics, and a specialist nurse team.

Using this definition, only 18 centres in England and 3 in Scotland (outside of the liver transplant centres), 1 in Wales and 1 in Northern Ireland meet the Level 2 criteria for a specialist liver unit. It is also noteworthy that 5 of the 21 “large” centres (who have ≥3 hepatologists) in the UK do not meet these criteria although 7 of the 179 centres that have <3 WTE hepatologists can provide these services. Mapping of the district general hospitals (DGHs) and regional specialist centres against liver disease hospital admissions and standard mortality rates for liver disease in England are shown in Figures 1 and 2. The maps suggest that there is now reasonable availability of specialist liver services in the majority of regions in England. This is particularly so if the hepatitis C operational delivery networks (ODNs) are included. However, there remain many DGHs that have inadequate hepatology support. In England, 55% (88) of all hospitals do not have a specialist hepatologist and 47 (30%) hospitals do not have a dedicated liver clinic (excluding viral hepatitis).

Figure 4: Provision of liver services as defined by WTE staffing levels in the UK (large centre = ≥3 WTE hepatologists, DGH = 2 hepatologists and ≥2 gastroenterologists with an interest in hepatology, none = no WTE hepatologists or gastroenterologists with an interest in hepatology, in between = anything between DGH criteria and none)

The NCEPOD(43, 44) report in July 2015 highlighted major deficiencies in the care received by patients suffering severe gastrointestinal haemorrhage as a consequence of cirrhosis and variceal bleeding. The mortality rate was high at 32% with 37% not receiving prophylactic antibiotics despite recommendations in all guidelines and strong evidence that this reduces mortality(45, 46). Despite the failure to control bleeding in almost a third of patients, only
13 hospitals were reported to have a 24/7 TIPSS service. The findings in the liver survey with respect to OOH provision for endoscopy are summarised in Table 2. The data for England excludes the transplant and large units. The provision of out of hours (OOH) endoscopy services varied widely between the devolved nations. In England, 117 (87%) of hospitals provide emergency 24 hour endoscopy cover although only 104 of these can manage varices. In Scotland, Wales and Northern Ireland, 59% (62%), 31% (100%) and 80% (38%) of centres provide 24 hour endoscopy cover, respectively (with the figures in brackets representing the proportion of endoscopists who are able to manage varices). Of the 34 centres in England recording a TIPSS service, 14 perform <10 procedures per year, and in Scotland, 3 of the 8 centres providing TIPSS performed <5 in the past year (Table 2) which must raise concerns as to the safety and sustainability of such services. In Wales and Northern Ireland, there are single centres for the whole country making access for emergency procedures difficult.

The survey also collated information regarding numbers of liver nurse specialists and viral hepatitis nurse specialists. These are presented in Table 3, which again highlights the wide variation between the devolved nations per $10^5$ of the population.

Table 3: Summary for UK and individual home nations of specialist nurse provision, alcohol liaison services and liver fellows

<table>
<thead>
<tr>
<th></th>
<th>Liver Nurse Specialists</th>
<th>Viral Hepatitis Nurse Specialists</th>
<th>Alcohol liaison service</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UK</strong></td>
<td>163.5</td>
<td>223.5</td>
<td>171/207 (83%)</td>
</tr>
<tr>
<td></td>
<td>0.25 per 100,000</td>
<td>0.34 per 100,000</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(64.9 million)</td>
<td>(64.9 million)</td>
<td></td>
</tr>
<tr>
<td><strong>England</strong></td>
<td>134</td>
<td>175</td>
<td>133/159 (84%)</td>
</tr>
<tr>
<td></td>
<td>0.24 per 100,000</td>
<td>0.32 per 100,000</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(54.7 million)</td>
<td>(54.7 million)</td>
<td></td>
</tr>
<tr>
<td><strong>Scotland</strong></td>
<td>18</td>
<td>31</td>
<td>18/22 (82%)</td>
</tr>
<tr>
<td></td>
<td>0.34 per 100,000</td>
<td>0.58 per 100,000</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(5.3 million)</td>
<td>(5.3 million)</td>
<td></td>
</tr>
<tr>
<td><strong>Wales</strong></td>
<td>9.5</td>
<td>15.5</td>
<td>12/16 (75%)</td>
</tr>
</tbody>
</table>
Number of DGHs with multidisciplinary Alcohol Care Teams

The proportion of hospitals providing some level of alcohol liaison service is similar across each of the nations in the UK. However, the number of hospitals with formal, multidisciplinary alcohol care teams (ACTs) is uncertain. The evidence base for the role of ACTs, together with the 6 key elements of a model team, are well described(47). The establishment of a consultant-led, multidisciplinary ACT and a 7-day alcohol specialist nurse (ASN) service were also 2 of the principal recommendations of the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report (48) which highlighted the delays in referral of patients for specialist care and missed opportunities for brief interventions during previous admissions. The present survey shows that the number with formal multidisciplinary Alcohol Care Teams was uncertain although some level of alcohol team was present in the majority of hospitals in England and the devolved nations. In a small, local, London-based survey in 2009, only 10% of hospitals surveyed had a multidisciplinary alcohol care team consultant lead and 42% had an alcohol specialist nurse service(49).

In 2014, Public Health England (PHE) published data on hospital alcohol care teams and alcohol specialist nurses(50). Encouragingly, in a 2015/16 follow-up survey, at least 76 out of a total of 116 hospitals surveyed (66%) had a consultant lead. Around 45% were gastroenterology/hepatology led, 18% by psychiatry and 11% by emergency medicine. Almost a quarter of services were clinically led by nurses. However, only 68% of hospital that responded to PHE’s 2015 survey have teams staffed adequately to provide seven day cover and deliver the potential impact demonstrated by Royal Bolton or Salford(47).

PHE analysis of secondary care alcohol specialist services has identified that, regardless of geographical location or size of hospital, the most impactful alcohol care teams and those providing a seven day service, led by a senior clinician with dedicated time for the team and evidence-based interventions. Alcohol care teams facilitate identification of alcohol misusers in hospitals and deliver appropriate packages of care provided by multidisciplinary teams. This requires dedicated sessional input from senior clinicians and at least three other clinical staff in order to facilitate seven day working throughout the year.
**Care bundles and Liver QuEST accreditation**

Some progress has been made during this year with development of the “Cirrhosis Care Bundle” to standardise early treatment (within 24 hours of admission to hospital) for patients with decompensated cirrhosis. Results of implementation of the “bundle”, which has been piloted in the Newcastle upon Tyne NHS Hospitals Foundation Trust as a successful CQUIN target, show that patients with a completed care bundle are more likely to have appropriate management. A comparison of pre- and post-bundle audit data from three English hospitals showed that patients with a completed care bundle are significantly more likely to undergo a diagnostic ascitic tap to exclude spontaneous bacterial peritonitis (p=0.020), have an accurate alcohol history documented (p<0.0001) and be given prophylactic antibiotics following variceal haemorrhage (p=0.0096)(51).

Some progress has also been made in implementation of the Liver Quest project for accreditation of hospital services. Liver QuEST(52) is an evolving quality assurance framework that aims to improve the care of patients with liver disease across England. The project is sponsored by the Royal College of Physicians and has the backing of the patient groups, the British Society of Gastroenterology, The British Association for the Study of the Liver and the Lancet Commission. This process has been piloted in 6 units across England and the learning from these visits was recently reviewed. Early themes arising from the process include an underutilisation of information technology and a failure in demonstrating performance against simple key performance indicators in emergency care (such as antibiotic prescription in variceal bleeding). To date 24 hospitals have engaged with Liver QuEST including 8 DGHs. Currently it is in the process of utilising the operational delivery networks associated with Hepatitis C. It is also working with NHS Wales to involve their liver services within the scheme with a plan to encompass the other devolved nations over the coming year.

**Recommendation 3: A national review of liver transplantation to ensure better access for patients and to increase capacity**

<table>
<thead>
<tr>
<th>Panel 5: Metrics for Recommendation 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1 Number of patients treated</td>
</tr>
<tr>
<td>3.2 Transplant activity normalised to waiting list</td>
</tr>
<tr>
<td>3.3 Waiting time to transplant normalised by blood group</td>
</tr>
<tr>
<td>3.4 Primary offer acceptance rate of used whole organs</td>
</tr>
<tr>
<td>3.5 Utilisation of marginal donors</td>
</tr>
</tbody>
</table>
The rate of liver transplant activity is the primary metric of performance and the number of transplants performed in 2015-6 was 917 and in line with activity over the last three years. There was a modest 4% decrease in the number of patients on the waiting list on the 31st March 2016. There transplant rates fall short of the targets set by the NHS Blood and Transplant T2020 strategic review.

The Lancet Commission continues to hold the view that liver transplant services should be subjected to a fundamental review but there is no evidence to date that this will be forthcoming. However, the first formal peer review process of individual programmes is scheduled for late 2016. An extensive range of quantitative measures will be evaluated that measure performance against agreed national service specifications as well as outcomes. There may also be an opportunity during this review to scope capacity for expansion if the hoped for increase in donor organs materialises.

Equity of access to liver transplant services and the rate of organ utilisation across all the programmes are cardinal metrics of performance. The most recent report on liver transplantation published by NHS Blood and Transplant confirms the continuing crude differences by geographical region and access to liver transplantation. The highest transplant rates per million population were in Scotland (19.1) and Northern Ireland (17.9) and the lowest in the South of England (9.3). The remaining Strategic Health Authority areas had rates in the 13.0-14.4 range.

Waiting times and the risk of death on the waiting list are also dimensions of equity of access and historically there have been significant differences between centres with respect to these parameters. The metrics designed to monitor this aspect are transplant activity rates normalised to the size of the waiting list and the waiting times to transplantation for each of the blood groups. However, significant progress has been made to preferentially direct organs to the patients most likely to benefit from the transplant and a new national offering sequence is scheduled to operate from summer 2017. The initial offer will no longer be directed to centres but to the highest ranked patient in the country. The principle of directing the organs to those most likely to benefit will be balanced with the objective of maximising utilisation of donated organs. The new system should improve equity of access and is expected to reduce mortality on the waiting list by 50%. Another dimension of equity of access is the demonstration of consistency in the co-morbidity profiles considered acceptable in patients being listed for liver transplantation.

The percentage of livers retrieved but not transplanted has increased from 8.2% to 16.6% over the past decade, with a 4% point increase in the last two years. While the cause of this trend is likely to be multifactorial, the possibility that it includes an element of impaired ability to cope within the service needs to be given due consideration. However, organ utilisation should be consistent across the service and 2 metrics to track this have been designed:
the acceptance rate on first offer of a whole organ,

- the utilisation of organs falling within an agreed definition of marginal organs.

At present, there is considerable variance in practice between centres with declines rates being higher in those with shorter waiting lists. The extent to which these differences are logistical or cultural needs to be clarified.

**Recommendation 4: Specialist paediatric services & continuity of care in transition arrangements for children with liver disease reaching adult life**

<table>
<thead>
<tr>
<th>Panel 6: Metrics for Recommendation 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Reduction in out-patient DNA rates in patients transitioned to adult services in the 3 main liver centres to less than 15%.</td>
</tr>
<tr>
<td>4.2 Reduction in graft loss and/or death in 16-24 year olds post transition</td>
</tr>
<tr>
<td>4.3 Educate adult physicians in paediatric liver disease/transition by supplementing adult curriculum</td>
</tr>
</tbody>
</table>

Between 2008 and 2015, 667 young people transitioned into adult services at Birmingham Children’s Hospital (BCH) and Kings College Hospital (KCH), of whom 17 died (2.5%) (Table). Historic data from all three national centres (BCH, KCH and Leeds) demonstrated that approximately 22% did not attend outpatient clinics in adult services despite a specialist transition service(53, 54), demonstrating the need for more focussed management and support.

The 3 national paediatric liver centres are now using a validated self-management tool to empower young people to manage their condition and identify specific areas where more multidisciplinary support is required to facilitate the transition process.

Recognition that additional education and training for adult hepatologists on childhood liver disease is needed has led to the development of a draft curriculum which has been submitted to the relevant specialist committees to be included for ‘core’ training for Gastroenterology and Hepatology trainees.
Table 4: Outcome for Young People attending two national Paediatric Liver Units# in England post Transition to Adult services

<table>
<thead>
<tr>
<th>2008 – 2013</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Transferred to Adult services</td>
<td>667</td>
</tr>
<tr>
<td>Deaths post Transition</td>
<td>10</td>
</tr>
<tr>
<td>Post-Transplant</td>
<td>8</td>
</tr>
<tr>
<td>Liver Disease</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1.5%</strong></td>
</tr>
</tbody>
</table>

# Birmingham Children’s Hospital (BCH), Kings College Hospital (KCH)

**Recommendation 5: Measures to reduce overall alcohol consumption in the country**

Panel 7: Metrics for Recommendation 5

5.1: Policy metrics
5.2: Overall alcohol consumption in country
5.3: Number of admissions from alcoholic liver disease
5.4: Number of deaths directly due to alcohol consumption
5.5: In hospital ALD mortality
5.6: Hospital and Community Alcohol Services
5.7: Survivals for liver admissions
**Metric 5.1: Policy metrics**

Table: Policy Metrics

<table>
<thead>
<tr>
<th></th>
<th>England</th>
<th>Wales</th>
<th>Scotland</th>
<th>N Ireland</th>
</tr>
</thead>
<tbody>
<tr>
<td>MUP</td>
<td>Opposed to MUP</td>
<td>Legislation in progress</td>
<td>MUP bill passed, legal verdict awaited</td>
<td>Legislation in progress</td>
</tr>
<tr>
<td>Taxation</td>
<td>Not devolved, Tax cuts to drinks industry worth £3.55 billion according to 5 year Treasury projections since 2013</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The UK government theoretically remains committed to the Alcohol Strategy published in March 2012 in which David Cameron stated: "When beer is cheaper than water, it's just too easy for people to get drunk on cheap alcohol at home before they even set foot in the pub. So we are going to introduce a new minimum unit price (MUP). For the first time it will be illegal for shops to sell alcohol for less than this set price per unit. We are consulting on the actual price, but if it is 40p that could mean 50,000 fewer crimes each year and 900 fewer alcohol-related deaths a year by the end of the decade." Mr Cameron went on to say: "Of course, I know the proposals in this strategy won't be universally popular. But the responsibility of being in government isn't always about doing the popular thing. It's about doing the right thing." However, MUP was postponed indefinitely following lobbying from the drinks industry (55, 56) and the Government has made no moves to bring forward any effective measures since, including protection of children from alcohol marketing.

There have been two subsequent developments, Public Health England (PHE) were commissioned by the UK and devolved governments to produce two reports one of UK alcohol policy and a further report of alcohol related harm to third parties, i.e. people harmed as a result of drinking by other people. PHE have formally reviewed the evidence for alcohol policy, and are due to publish this report in autumn 2016.

The UK Chief Medical Officers published reviewed drinking guidelines in January 2016, stating that any amount of alcohol intake can increase the risk of developing a range of illness including cancer, recommending a weekly intake of no more than 14 units with several drink free days each week(57). The report did not address higher risk and harmful drinking, but did conclude that since the previous guideline in 1995(58) new evidence has outlined that the risk of cancer starts from zero alcohol, intake and rises in a linear fashion. The report also addresses the putative health benefits of alcohol, concluding that this evidence was considered less strong than previously, and that a reduced risk in the UK is significant only for women aged 55 or older. The 14 unit guideline on regular drinking would
be consistent with a little under a 1% lifetime risk of death from alcohol for people who follow this consistently (57).

**Metric 5.2: Alcohol consumption**

Sources of data for alcohol consumption include HMRC receipts and population surveys, with surveys recording 55-60% of the consumption recorded by HMRC. Overall HMRC receipts increased until 2008, when a 2% above inflation duty escalator was introduced at the same time as the economic downturn, and are now increasing once more (Figure 1).

*Figure 5: Data from HMRC clearance show gradually increasing consumption of alcohol in the UK until 2008 when the 2% above inflation duty escalator was introduced, since when consumption transiently decreased, but is now rising strongly once more. There has also been marked shift towards the consumption of stronger alcohol, with a decrease in consumption of beer, and increased consumption of wine, spirits and cider (59)*
The UK Opinions and Lifestyle Survey (OPN) found that 58% of the UK population had drunk in the previous week, with around 18% of the highest earners drinking on 5 or more days, compared with 8% of lowest earners. Wales (13%) had the highest proportion of people drinking more than 14 units / week, compared with Scotland (12%) and England (8%).

Analysing HSE data from 2014 for the total amount of alcohol consumed by drinkers categorised by level of weekly consumption (Table 1) reveals that 24% of alcohol was consumed by low risk drinkers, 76% was consumed by higher risk drinkers, of which 52% was consumed by people drinking more than twice the recommended guideline(60). Comparing the distribution with HSE data from 1991-2, the proportion of alcohol consumed by extreme drinkers drinking more than 75 units /week has increased from 13% to 17%.

### Table 6: Analysis of HSE data from 1991-2 and 2014 with total amount of weekly units consumed categorised according to weekly alcohol rating. The proportion of teetotallers doubled, extreme drinkers increased slightly from 1.2% to 1.3% whereas the proportion of total alcohol consumed by extreme drinkers increased from 13% to 17% (Yates Chi Sq p<0.0001).

### Metric 5.3 and 5.4: Alcohol related hospital episodes and deaths

Trends in alcohol related hospital episodes for England show a steady increase peaking in 2012, and relatively stable in the 2 years since. Directly attributable alcohol related deaths increased steadily in England and Wales throughout the 1980’s, 1990’s and 2000’s. The majority of these deaths were a result of alcohol related liver disease, and there is a self-evident relationship between alcohol-related deaths and increasing affordability of alcohol as alcohol duties were not increased in line with incomes (Figure 3). The patients dying of directly alcohol related are extreme drinkers, the average weekly consumption of patients with alcohol related cirrhosis is around 150 units, and of patients with alcohol dependency even higher at around 180 units, and so on the whole these patients are drinking the cheapest alcohol they can find(61, 62). Alcohol related deaths are strongly linked to health
inequalities, many of these patients are already spending much of their disposable income on alcohol and are sensitive to price changes\cite{63,64}.

In the budget of 2008 alcohol duty was increased and a 2\% above inflation escalator introduced, the subsequent decrease in affordability coincided with a change in the trend in alcohol related mortality. We have hypothesised that this change was a direct result of changes in the price of alcohol combined with the impact of an economic downturn on incomes\cite{65} and predicted that alcohol mortality would rise following the repeal of the 2\% duty escalator in 2013 and the subsequent tax cuts. Alcohol related deaths increased in 2014 (reported November 2015) and the figures for 2015 will be reported in November 2016\cite{66,67}.

![Figure 6: Trends in wholly attributable hospital admission episodes](image-url)
**Metric 5.4: Number of deaths directly due to alcohol consumption (ONS)**

Data for Scotland for this metric, compiled from data collected by the Office for National Statistics(69), is presented in graphic form within the Report from Scotland later in this document. The graph shows the number of deaths registered each year against the 5-year moving average and demonstrates a year on year increase from 1992 peaking in 2002. Since that date there has been a series of staggered decreases to the present level (2015) of around 1100 deaths per annum.

**Metric 5.5: Alcohol related deaths**

In 2015, there were 1,150 alcohol-related deaths, on the basis of the current definition a decrease of 2 (0.2 per cent) compared with 2014, and the third lowest annual total since 1997. The number of alcohol-related deaths was relatively stable, at roughly 600 per year, during the 1980s. It then increased rapidly during the 1990s and early 2000s, to around 1,500 per year in the mid-2000s. The figure of 1,546 in 2006 was the largest so far recorded: since then, the trend has appeared to be generally downward, as the rises in some years have been small (compared to the falls in the other years) and could well be due to year-to-year variability. Deaths in 2015 consisted of 764 male deaths and 386 female deaths, continuing a long term pattern(70).
There were approximately 16 chronic liver disease deaths per 100,000 population in Scotland in 2014, similar to the rate in 2013. In 2014, male mortality rates for CLD were twice as high as those reported for women (21 per 100,000 compared to 10 per 100,000 population). Between 1993 and 2003, there was a sharp increase in CLD mortality rates overall and in both men and women: for men, the mortality rate increased from 14 per 100,000 to 35 per 100,000 population and for women, from 8 per 100,000 to 16 per 100,000 population. Since 2003 the rates have decreased for both men and women. In 2014, CLD mortality rates were highest in people aged 55-64 years (36 per 100,000 population).

**Metric 5.6 Hospital and Community Alcohol Services**

The most effective and cost effective means to reduce alcohol related deaths and admissions is to reduce alcohol consumption in extreme and harmful drinkers by increasing the price. We also need to detect and intervene earlier in liver disease. Once patients present with liver disease it is tragically too late in most cases, and there is little evidence that any of our therapeutic strategies improve survival, but we do know that the main determinant of long term survival is whether the patient abstains from drinking(71). As a result efforts have been made to integrate alcohol treatment services with liver units in acute trusts. Data obtained from Iain Armstrong at Public Health England indicate that of 192 district general hospitals in England, currently (2015-16 financial year) 10-13 hospitals are known to have no service. 116 are known to have an alcohol service in March 2016 a further 42 were known to have services in 2014. So the total number of hospitals with services is probably between 116 and 158. Since 2014, 6 hospitals are known to have lost funding for their alcohol specialist services, while 2 now have services that previously did not. Funding is generally a mixed economy from LA public health and CCGs or provider trusts, often in partnership. In December 2015, a third of services were secure in their funding beyond 2018/19, nearly half were secure until at least 2018/19. However, a good deal of funding is short term and over a third were not assured of funding beyond the next financial year (2016/17) and 20 had

![Figure 8: In-hospital mortality of liver disease for acute trusts in England](image-url)
no funding identified for the coming financial year (2016/17).

There is concern that further local authority cuts will result in a significant loss of alcohol services in England. This contrasts with N. Ireland and Wales, where alcohol services are attracting significant Health Board investment and are being progressively developed. The Wales Liver Plan has made a firm commitment to develop ACTs embedded in secondary care with assertive outreach teams, a clinical lead has been appointed in 3 of the 6 health boards so far and alcohol specialist nurses have increased from 13 to 17. In N. Ireland 10 alcohol specialist nurses will increase from 10 in 2013 to 18 in 2016, aiming eventually for 28 to ensure a 7-day alcohol specialist nurse service. In Scotland the current Alcohol strategy is undergoing a refresh and proposals for such teams are being considered.

**Metric 5.7: Survival of alcohol related liver disease admissions**

The NCEPOD report of 2013 identified a number of shortcomings in the hospital treatment of patients with alcohol related liver disease, and in previous Commission reports we have outlined the variation in-hospital mortality rates between trusts, with recommendations for more specialist liver units across the UK(48). However there have been steady advances in the management of patients with alcohol related liver disease, endoscopic banding of varices, Terlipressin treatment of hepatorenal syndrome and intensive care(72-74). As a result of these or other factors there have been steady year on year improvements in in-hospital mortality across acute trusts in the UK (figure 4).

Baseline data for longer term survival has been calculated using NHS data (2005-2014) supplied by liver units in Southampton, Plymouth, Newcastle and Sunderland (Figure 5), 5 year survivals remain poor varying from around 85% for viral hepatitis, to 65% for alcohol related liver disease and 35% for primary liver cancer.

One year survival metrics will be used to measure improvements in survival against the 2005-2014 baseline (Figure 6). The very high one year mortality of patients with alcohol related, cryptogenic liver disease and primary liver cancer reflects the late diagnosis of the majority of liver cirrhosis.
Figure 9: Kaplan Meier survival plots (months) from the time of first liver admission of patients from Southampton, Plymouth, Newcastle and Sunderland, admitted between 2005-2014.

Case Processing Summary

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<tr>
<th>Liver diagnosis from ICD</th>
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<th>Censored</th>
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<td></td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>Primary liver cancer</td>
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<td>966</td>
<td>524</td>
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<td>2967</td>
<td>5617</td>
</tr>
<tr>
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<td>3055</td>
<td>4704</td>
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<td>4932</td>
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<td>1314</td>
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<td>376</td>
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<tr>
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<td>453</td>
<td>1018</td>
</tr>
<tr>
<td>Overall</td>
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<td>9705</td>
<td>20268</td>
</tr>
</tbody>
</table>
Data from Scotland relating to Metric 3:

**Number of admissions from alcoholic liver disease**

![Graph showing trends in stay rates for four conditions: alcoholic liver disease, alcoholic liver failure, Alcoholic acute hepatitis and alcoholic cirrhosis. EASR European age standardised rate](image)

**Figure 10:** shows the trends in stay rates for four conditions; alcoholic liver disease, alcoholic liver failure, Alcoholic acute hepatitis and alcoholic cirrhosis. EASR European age standardised rate(69)

In 2014/15, there were 35,059 alcohol-related general acute hospital stays in Scotland; a standardised rate of 672 stays per 100,000 population. This is a continuation of the fall in rates seen since 2007/08. However, in 2014/15 rates for stays were still more than four times higher than at the beginning of the time trend. The decrease since 2007/08 has been predominantly driven by the reduction in more ‘acute’ conditions, such as Harmful Use and Toxic Effect, whereas the more ‘chronic’ conditions, such as Alcohol-related Liver Disease have increased. The increase in hospital stays seen up to 2007/08 has been driven to a large extent by repeat visits rather than new patients being admitted to hospital. In 2014/15, alcohol-related stays in general hospitals were nearly 8 times more frequent for individuals living in the most deprived areas compared to the least deprived areas. The rate for alcoholic liver disease 6,963 stays in 2014-2015 has increased over the last two years and showed a much flatter curve in the previous years than for alcohol-related conditions overall. The breakdown of alcohol related liver disease shows most of the rise is due to cirrhosis and to repeat admissions, with the number of new patients being relatively static. Suggesting that we are not reducing the number of patients developing alcohol related cirrhosis but they are more likely to survive there first admission.
Recommendation 6: Promotion of healthy lifestyles to reduce obesity & the burden of NAFLD

Panel 8: Metrics for Recommendation

6.1 Prevalence of child and adult obesity
6.2 Adoption of Health Select Committee priorities for childhood obesity
6.3 Prevalence of NAFLD/NASH in secondary care
6.4 Number and proportion of patients with NAFLD as a diagnosis assessed for liver transplantation
6.5 Number of bariatric surgery operations per 100,000 population

Obesity and its effects on health, such as non-alcoholic fatty liver disease, continues to be a major burden to the UK which will require concerted efforts by government, healthcare professions and the public if it is to be addressed. This section will provide objective assessments of the prevalence of obesity in children and adults in the UK as well as data on the subsequent downstream consequences of obesity on liver disease.

**Metric 6.1: Prevalence of child and adult obesity**

Data from Health Survey England (HSE) along with that from equivalent surveys in Wales, Scotland and Northern Ireland demonstrate the scale of the problem affecting both adults and children (*Figure xx*). Ongoing monitoring of these data will be an important guide to the current burden of obesity as well as providing a critical benchmark to assess the impact of strategies to reduce it over the longer-term.

Data on childhood obesity are not available from all of the UK at this stage. Collation of these data along with cross-referencing with data from the National Child Measurement Programme (NCMP) will be important to build an accurate picture of childhood obesity.
Metric 6.2: Adoption of Health Select Committee priorities for childhood obesity.

The recent Health Select Committee report(75) identified key overarching objectives to protect families from the pressures of unhealthy food marketing by changing the obesogenic environment; to enable individual choice by making healthy food choices and access to opportunities for physical activity easier; to inform families of the risks associated with poor diet and physical inactivity; and to support children and families to lose weight and maintain a healthy weight. The government published its childhood obesity plan(76) in 2016. Table 7 assesses the extent to which the plan meets recommendations from the Health Select Committee. Very few of the recommendations are addressed in the Plan, and most of those that are, rely on voluntary commitments from industry.
Table 7: Measures in the government’s child obesity plan measured against recommendations of the Health Select Committee.

<table>
<thead>
<tr>
<th>Recommendations of Health Select Committee</th>
<th>Government’s Child Obesity Plan</th>
<th>Traffic Light Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong controls on price promotions of unhealthy food and drink</td>
<td>Not included</td>
<td>RED</td>
</tr>
<tr>
<td>Tougher controls on marketing and advertising of unhealthy food and drink</td>
<td>Not included</td>
<td>RED</td>
</tr>
<tr>
<td>A centrally led reformulation programme to reduce sugar in food and drink</td>
<td>Launch of a voluntary sugar reduction programme with aim of reducing overall sugar by at least 20% by 2020, including a 5% reduction in year one. Not clear what fines/levies will be implemented if targets are not achieved.</td>
<td>AMBER</td>
</tr>
<tr>
<td>A sugary drinks tax on full sugar soft drinks, in order to help change behaviour, with all proceeds targeted to help those children at greatest risk of obesity</td>
<td>A soft drinks industry levy will be introduced in England from 2018, with the revenue from it invested in programmes to reduce obesity and encourage physical activity and balanced diets for school age children.</td>
<td>GREEN</td>
</tr>
<tr>
<td>Labelling of single portions of products with added sugar to show sugar content in teaspoons</td>
<td>Establish a review of additional opportunities to go beyond current labelling scheme. Examples given include clearer visual labelling, such as teaspoons of sugar in packaged food and drink.</td>
<td>AMBER</td>
</tr>
<tr>
<td>Improved education and information about diet</td>
<td>Discussion of use of information technology such as the Change4Life Sugar Smart app. No further investment nor new programme.</td>
<td>RED</td>
</tr>
<tr>
<td>Universal school food standards</td>
<td>Funding generated from the sugar levy will be diverted towards the Primary PE and Sport Premium which includes school healthy breakfast clubs. From September 2017, a voluntary health rating scheme for primary schools will be taken into account during Ofsted inspections. The new School Food Standards will be updated in the light of refreshed government dietary recommendations.</td>
<td>AMBER</td>
</tr>
<tr>
<td><strong>The majority of schools are subject to the School Food Standards. However, some academies and free schools are not. There will be a campaign by the Secretary of State for Education encouraging all schools to commit to the standards.</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| **Greater powers for local authorities to tackle the environment leading to obesity** | **No change in local authority power. There will be further encouragement for local authorities to adopt the Government Buying Standards for Food and Catering Services (GBSF) standards, particularly in leisure centre vending machines. This will be accompanied by the full uptake of GBSF in central government departments.** | **RED** |

| **Early intervention to offer help to families of children affected by obesity and further research into the most effective interventions.** | **Re-committing to the Healthy Start scheme, which provided an estimated £60 million worth of vouchers to families on low income across England in 2015/16. These can be exchanged for fresh or frozen fruit or vegetables and milk. No other plans.** | **RED** |

**Metric 6.3: Prevalence of NAFLD/NASH in secondary care**

Hospital episodes statistics (HES) data provide information on patients admitted to hospital with NAFLD/NASH as a diagnosis. Whilst these data will be influenced by greater coding of NAFLD/NASH they do capture the increased morbidity/mortality of patients with NAFLD/NASH, providing information on the burden of NAFLD/NASH on hospital bed usage.
At present there is significant variation in the identification and referral of patients with NAFLD reflecting the lack of clear guidance. A BSG-led group with representation from the relevant stakeholders, including patient groups, is reviewing evidence and best-practice on the management of abnormal liver function tests and will report in late 2016 with new guidance. This should help standardise care, reduce unnecessary referrals and ensure that patients needing further investigation are identified at the appropriate stage.

**Metric 6.4: Number and proportion of patients with NAFLD as a diagnosis assessed for liver transplantation**

This metric provides information on the impact of obesity on inducing end-stage liver disease due to NAFLD, as well as providing a measure of the provision of adequate services for such patients with NAFLD/NASH.
As a proportion of all elective cases on the liver transplant waiting list, those with NAFLD as a primary/contributory factor still account for a relatively small amount. This may reflect a low number of patients with end-stage liver disease due to NAFLD or challenges with identifying/referring and listing such patients for transplantation. Further exploration of these data is required to ensure equity of access to transplantation for such patients, although the likely higher presence of co-morbidities is a relevant consideration.

**Metric 6.5: Number of bariatric surgery operations per 100,000 population**

This metric is a measure of the extent of service provision for those in clear need of further support and intervention. Referral to weight management services and consideration of bariatric intervention is strongly supported by an evidence base.

The current rate of service provision is much less than 1% of those with a BMI $\geq 40$ kg/m$^2$ and more recent data from the Health and Social Services Information Centre indicate an almost 10% fall in the number of NHS bariatric surgery procedures (Figure 14). Notably, the rate of surgery in Sweden which is a similar European country was 78 procedures per 100,000 population in 2013 (data from Scandinavian Obesity Surgery Register(77)). This would equate to a figure of 49,000 procedures per annum for the UK which is >6 times the current rate of service provision. There is no justification for such a difference, especially...
when the higher rate of obesity in the UK is taken into account, testifying to the marked under-provision of bariatric surgery in the United Kingdom.

Figure 14: Hospital Episode Statistics (HES) data on FCE for patients admitted for bariatric surgery.

Recommendation 7: Eradication of chronic HCV infection from the country by 2030 and a major reduction in the burden of disease for hepatitis B

Panel 9: Metrics for Recommendation 7

7.1: Number of HCV infected patients treated with new HCV DAAs and number of patients achieving cure / SVR12.
7.2: Number of patients diagnosed with HCV and HBV
7.3: Mortality from HCV and HBV - number of HCV or HBV associated HCC’s, number of transplants for HCV or HBV and HES data for bed days associated with HCV and HBV infection
7.4: Numbers of infants starting and numbers completing a course of HBV vaccination
7.5: Universal HBV vaccination offered by region – yes / no

The Lancet Commission on Addressing Liver Disease in the UK from 2014(11) made a number of key recommendation for viral hepatitis – including eradication of infections from chronic hepatitis C virus in the UK by 2030 using antiviral drugs; reducing the burden of hepatitis B virus; target high-risk groups for these viruses, including immigrant communities; use of a
universal six-in-one vaccination for infants for hepatitis B. This report looks at metrics to measure progress towards these goals.

In May 2016, 194 governments, including the UK, adopted the WHO’s first ever Global Health Sector Strategy for Viral Hepatitis (GHSS) at the 69th annual World Health Assembly. The strategy sets a goal of eliminating hepatitis B and C by 2030 and includes prevention and treatment targets(78).

The metrics shown in Panel 9 were selected to align both with the Lancet Commission’s recommendation and the GHSS. The first 4 link with the 10 core indicators for monitoring and evaluating HBV and HCV infection recommended in a recent WHO document (Monitoring and Evaluation for viral hepatitis B and C: recommended indicators and framework) and will facilitate comparisons with other countries and allow year by year monitoring of progress made. According to the WHO report the 10 core indicators are 1) prevalence, 2) infrastructure for testing, 3) vaccination coverage of newborns for HBV, 4) needle – syringe distribution, 5) facility level injection safety, 6) people diagnosed, 7) treatment coverage/ initiation, 8) HCV cure and HBV suppression numbers, 9) incidence of new infection, 10) attributable mortality and morbidity.

**Metric 7.1: Number of HCV infected patients treated with new HCV DAAs and number of patients achieving cure / SVR12 (links with WHO 8)**

- allows a direct comparison of numbers cured with numbers of newly diagnosed HCV infections as an indicator of progress towards eradication and reduction in prevalence
- allows comparison of treatment numbers with other in other European countries and the impact of any initiatives for testing and treating HCV

Treatment numbers in the UK are rising. As of 22 August 2016, in England 3482 patients with HCV have been initiated on treatment since 1st April (2.2% of the estimated 160,000 chronically infected cases [81], with a target of 10,000 to be treated by the end of March 2017 (6.3% of the prevalent population). The present focus of NHS England is on patients with advanced liver disease and plans to increase the proportion of patients on therapy year on year are dependent on an anticipated fall in drug costs as a consequence of increased competition. Despite the rise in therapy, eradication of HCV in England by 2030 is unachievable with these numbers as it will take until 2032 to treat the known patient pool, without treating any new infections, and either a marked increase in funding or a reduction in the cost of treatment will be needed to achieve the goal of eradication. There are no new widespread testing programmes in place in England currently to increase diagnosis.

In Scotland in 2015, 1700 patients with HCV were treated with similar numbers expected for 2016. This represents about 4.5% of the estimated 38,000 chronically infected cases (data from John Dillon). In Wales, central funding was provided from 2015/16 with 464 patients
treated and funding to treat 900 in 2016/17 (data from Brendan Healy). This represents 7.5% of the estimated 12,000 chronically infected cases.

By comparison, in Australia (where the price of therapy is capped to allow unlimited access) 22,470 individuals were started on treatment from March to June 2016, close to 10% of the total infected population of 230,000 in just 4 months (The Kirby Institute. Monitoring hepatitis C treatment uptake in Australia (Issue 4)(79). In Germany (where expenditure on antiviral drugs is estimated to be five times greater than in England) treatment numbers are estimated to be stable at 25,000 per year since 2015, 10% annually of their estimated prevalent pool of 250,000(80). In Australia and Germany all of the known diagnosed HCV cases will be treated within a few years and there are plans for widespread testing programmes to diagnose the remaining cases.

*Figure 15: UK Treatment numbers – from Hepatitis C in the UK – annual report 2016(81)*

Sustained viral response (SVR) rates for treatment initiated in the current year are not yet known but the earlier NHS England Early Access Programme for advanced liver disease which treated 467 patients (409 with decompensated cirrhosis) achieved an overall SVR rate of 81.6% (381/467). For genotype 1 infection SVR was 90.5% (209/231) and 68.8% for genotype 3 (132/192)[78].

**Note to the editor:** Gaps: SVR data for NHS E treated cases – we should have SVR 12 data for patients treated between April and June/July before publication in December.
Metric 7.2: Number of patients diagnosed with HCV and HBV (ties in with WHO 2 and 6)

In England and Wales there were 11,626 laboratory reports of newly diagnosed HCV infection in 2015 (11,997 in 2014). Some of these will be recent infections and others previously undiagnosed long standing chronic HCV. This is greater than the number of patients being treated.

Table 8: Laboratory reports of hepatitis C by region, England and Wales (2006-2015) – from Laboratory reports of hepatitis A infection, and hepatitis C: 2015, PHE

<table>
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<th>PHE Centre</th>
<th>Year</th>
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<th>2007</th>
<th>2008</th>
<th>2009</th>
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<td>588</td>
<td>576</td>
<td>515</td>
<td>673</td>
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<td>1507</td>
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<td>1470</td>
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<td>1326</td>
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<td>8,983</td>
<td>8,193</td>
<td>10,393</td>
<td>11,362</td>
<td>11,761</td>
<td>11,997</td>
<td>11,626**</td>
</tr>
</tbody>
</table>

Nearly all new cases of HCV infection arise in injection drug users with incidence remaining relatively stable at 8/100 person years in 2015 and 7/100 person years in 2011. The prevalence of HCV in injection drug users also shows no sign of reducing with around 25% of injection drug users being HCV antibody positive within 3 years of first injecting –see figure:

Figure 16: Estimated UK-wide prevalence of antibodies to hepatitis C among people who began injecting drugs in the previous three years, 2008-2015.*
For 2015, a total of 457 cases of acute/probable acute HBV infection were reported – an annual incidence of 0.83/100,000 population/year (Acute hepatitis B(England): annual report for 2015 – PHE(8)).

**Metric 7.3: Mortality from HCV and HBV - number of HCV or HBV associated HCC’s, number of transplants for HCV or HBV and HES data for bed days associated with HCV and HBV infection (WHO 10)**

The PHE annual report on Hepatitis C in the UK for 2016 presents a new evaluation of HES data that allows estimation of the number of new cases of end stage liver disease or hepatocellular carcinoma arising as a consequence of HCV infection. There are some limitations due to variations in datasets between UK countries. However, these show a fairly constant number of approx. 1800 new cases each year since 2010.
Between 2005 and 2014, deaths annually from HCV-related ESLD and HCC in the UK rose from 215 to 457. Although 2015 data are preliminary and should be interpreted with caution, it is encouraging to see an observed fall in mortality of 11%. It is possible that this fall is the result of new DAA drugs introduced from 2014/2015, particularly for those individuals with advanced disease.
In the year to March 2015, 119 (19% of total) HCV infected adult patients underwent an elective liver transplant, in 2014 the figure was 133 (21%).

Note to editor: data for HBV from HES data is due to be published and will be available for insertion into paper before publication

**Metric 7.4: Numbers of infants starting and numbers completing a course of HBV vaccination (WHO 3)**

Public Health England reports vaccine coverage data in England for three doses of hepatitis B vaccine in infants born to hepatitis B surface antigen (HBsAg) positive mothers who reached the age of one year in this quarter (i.e. those born between January to March 2015), and coverage of four doses of vaccine in infants who reached two years of age (i.e. those born between January to March 2014). The 2015-15 data shows 86% vaccine completion (1699/1987 infants) at 12 months and 74% completion (1681/2275) at 24 months. For the first quarter of 2016, the 12 and 24 month returns (data from 127 and 122 of 151 former PCTs respectively) shows 91% of 481 infants received 3 doses of vaccine by 12 months and 69% of 495 infants received all 4 doses by 24 months.
**Metric 7.5: Has Universal vaccination for HBV been introduced – yes / no**

At the time of writing, the Government has accepted universal immunisation for hepatitis B but this has not been introduced.

**Recommendation 8:** Increasing awareness of liver disease in the general population, within the NHS and, vitally, with governments. Increasing the inclusion and involvement of liver patients and patient groups in new developments and on-going work with national and local initiatives.

<table>
<thead>
<tr>
<th>Panel 10: Metrics for Recommendation 8:</th>
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</thead>
<tbody>
<tr>
<td>1. Government Supported National Liver Plans</td>
</tr>
<tr>
<td>2. Regional variation in PHE health profiles</td>
</tr>
<tr>
<td>3. Inclusion and involvement of patient and patient support groups</td>
</tr>
<tr>
<td>4. PH sponsored campaigns in obesity and alcohol</td>
</tr>
</tbody>
</table>

**Metric 8.1: Government Supported National Liver Plans**

The initial Lancet Commission on Liver Disease’s report highlighted that the increasing burden of liver disease in the UK was getting worse and that currently liver disease is the third most common cause of premature death and the trajectory has been a 400% increase since 1970 and that trajectory continues to climb ever higher. In order to decrease this and improve the care, treatment and support those with and affected by liver disease receive National Liver Plans have got to be developed to clearly outline government supported actions and improvements for liver health right from prevention through to cure, long term support and end of life care include all liver health issues for children and adults. To support the Plan a multidisciplinary implementation committee, with patient representation, needs to be formed to deliver and monitor their success. In addition to support the clinical elements of the Plan’s recommendations a National Clinical Director for Liver Health needs to be appointed to lead on the improvements needed. The current situation is outlined in the table below.
<table>
<thead>
<tr>
<th></th>
<th>ENGLAND</th>
<th>NORTHERN IRELAND</th>
<th>SCOTLAND</th>
<th>WALES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implementation</td>
<td>No published plan</td>
<td>No published plan</td>
<td>No published plan</td>
<td>Developed with patient representation</td>
</tr>
<tr>
<td>National Clinical</td>
<td>No published plan</td>
<td>No published plan</td>
<td>No published plan</td>
<td>Dr Andrew Yeoman appointed 2016</td>
</tr>
<tr>
<td>Director</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

The value and impact of the work on the Welsh Liver Plan’s recommendations is already having a positive effect in Wales and provides a benchmark for what the other countries need to develop.

**Metric 8.2: Geographical variation in Liver Disease Mortality: Public Health England Local Authority Liver Disease Profiles**

Variations in mortality rate from liver disease persist between Local Authorities in England with a fourfold variation in mortality rates for males and females - variation is 3.8 for males (Blackpool rate 52 per 100,000 compared to Buckinghamshire rate 13.7), variation 4.3 for females (Blackpool rate 28 compared to rate of 6.6 for Barnet). The variation is even more stark when years of life lost under 75’s are compared, with an eight fold variation - variation is 8.4 (Blackpool 89.3 YLL per 10,000 compared to Rutland 10.5). These variations reflect both variation in risk factors but also variation in access to NHS Services. PHE will publish an updated Atlas of Variation in Liver Disease.

The commission recommends that all countries develop local liver health profiles and use them to address inequalities and prioritise improvements with annual updates to evaluate success.
Table 10: Introduction of Local Liver Health profiles across devolved countries

<table>
<thead>
<tr>
<th></th>
<th>ENGLAND</th>
<th>NORTHERN IRELAND</th>
<th>SCOTLAND</th>
<th>WALES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Local Liver Health Profiles</strong></td>
<td><a href="http://bit.ly/ZY2i6y">http://bit.ly/ZY2i6y</a></td>
<td>Not done yet</td>
<td>Not done yet</td>
<td>Not done yet</td>
</tr>
</tbody>
</table>

**Metric 8.3: Inclusion and involvement of patient and patient support groups**

In order to best address the holistic needs of patients it is vital to have their involvement and input into new developments, service design, on-going governance etc. There is still a need to ensure this happens and all health officials and clinicians need to advocate for this when it is not present. In the Liver QuEST(52) project to support the improvement of hospital liver services, the peer review teams include patients but so far, as described earlier, only a small number of DGHs have been visited.

It should also be noted that in England there has also been the development of 22 Hepatitis C Operational Delivery Networks with the aim of 100% patient involvement as soon as possible with the help and support of the Hepatitis C Trust, to date this has not been audited but will be before the next Lancet liver commission update.

**Metric 8.4: PH sponsored public awareness campaigns for obesity and alcohol**

To inform and raise public awareness, campaigns about the two main causes of liver disease, alcohol and obesity, need to be developed and further promoted effectively to ensure the public is as informed as possible and people are empowered to make beneficial improvements to their lifestyle. Ongoing and frequently updated national campaigns are vital to reverse the increasing burden of preventable liver disease.

Examples of government funded national campaigns are in the table below, in addition many charities, including Alcohol Concern, CRUK, Diabetes UK and the British Liver Trust, have national campaigns that highlight the detrimental effects obesity and alcohol have on our health.
### Table 11: National awareness campaigns

<table>
<thead>
<tr>
<th>National obesity campaign</th>
<th>ENGLAND</th>
<th>NORTHERN IRELAND</th>
<th>SCOTLAND</th>
<th>WALES</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>National alcohol campaign</th>
<th>ENGLAND</th>
<th>NORTHERN IRELAND</th>
<th>SCOTLAND</th>
<th>WALES</th>
</tr>
</thead>
</table>

### General Policy Strategy in the Devolved Nations

#### 1. Scotland

Professor John Dillon writes that liver disease in Scotland as in the UK is driven by alcohol, obesity and hepatitis C with all three being more prevalent in Scotland than the rest of the UK. As in the rest of the UK the natural history of liver disease is of late presentation with decompensated liver disease or hepatocellular carcinoma, with a pressing need to develop strategies for earlier detection and more effective intervention. Scotland does not have an integrated liver plan but has a series of activities that cover the major causes and management of liver disease. These include an “Alcohol strategy”, “the sexual health and blood borne virus framework” and a department of health initiative to improve outpatients, the “National Delivering Outpatient Integration Together (DO IT) Programme” with a work stream focussed on abnormal LFTs.
The current Scottish alcohol strategy is undergoing a review, this is not planned to be a whole new strategy but an opportunity to add to and adjust the existing policies in the light of experience with the strategy. Scottish Health Action on Alcohol Problems (SHAAP) with the support of Scottish Government has brought together a working group that has produced recommendations for a focus within the strategy on alcohol related liver disease, as this is a major driver for mortality and costs, the major recommendations are for an assessment of liver fibrosis in all those presenting with alcohol excess and a prioritisation for alcohol treatment in those with evidence of advancing fibrosis. It will further recommend that those admitted to hospital with the consequences of alcohol related liver disease receiving high quality standardised management in accordance with the BSG/BASL care bundle and that they are in contact with alcohol services prior to discharge with effective follow-up treatment plans in place. How these interventions are delivered either with in-reach from existing alcohol treatment services or the development of formal alcohol teams, as developed in other parts of the UK, is under consideration.

The policy planks of the existing alcohol strategy have had significant impacts on reducing alcohol related mortality. In 2015, there were 1,150 directly related alcohol deaths, (this definition is largely driven by alcohol related liver disease), the third lowest annual total since 1997, compared to the peak of 1,546 in 2006 (Figure 20) it is speculated that the fall is
secondary to the increases in the price of alcohol due to the economic down turn and policies banning alcohol multi-buy promotions, which were not subject of legal challenge. It provides further in-direct evidence that price is a key lever for change in alcohol related mortality. Minimum Unit Pricing could have an even greater impact, however it remains under a prolonged process of judiciary review, but the government is still committed to its implementation.

At the World Hepatitis summit the Scottish Government signed the Glasgow Declaration committing to the elimination of HCV, it remains committed to removing HCV as a significant public health issue in Scotland. They have committed to achieving sufficient patients diagnosed and treated to reduce HCV related liver failure and HCC by 75% by 2020 form 2015 levels. HCV treatment targets have been exceeded, even with a focus on treating those with most fibrosis first, this combined with increased HCV prevention activity has seen year on year falls in the prevalence of HCV. There is also early evidence of a fall in the numbers of patients presenting with HCV related liver failure.

The management of abnormal LFTs continues to be a major challenge with many not being investigated and only 1.4% converting into a liver diagnosis in some series. The liver work stream of the “DOIT” program is focussed on the management of abnormal liver function tests, ensuring all with significant liver disease are investigated, while limiting the impact on hepatology services from non-significant abnormality of LFTs. A pilot project currently nearing completion is using a minimal set of diagnostic criteria for liver diseases combined with automatic cascading of “liver screen” investigations on the original sample when first discovered to be abnormal. In preliminary results the process is assigning a liver diagnosis to over 50% of patients based just on the liver screen and aetiological information. While the full results of the pilot are awaited “DOIT” has started planning for implementation of this diagnostic pathway.
Figure 20: Alcohol-related deaths registered in Scotland, 1979 to 2015, with five-year moving average, and showing the likely range of values around the moving average. Definition of alcohol-related deaths as used by the Office for National Statistics in 2006. (82).

2. Wales

Dr Andrew Yeoman has written as follows: In 2015 the Welsh Government launched a national strategy, the “Together for Health: Liver Disease Delivery Plan”, as a means of tackling the rise in morbidity and mortality related to liver disease observed in Wales which has mirrored that seen across the United Kingdom. The publication of the plan was the culmination of a collaboration between Public Health Wales and the Welsh Association of
Gastroenterology and Endoscopy (WAGE) and involved consultation with key stakeholders. In late 2015 an implementation group was convened to oversee delivery of the plan and to identify appropriate ways to invest the £1 million per year allocated to the plan by Welsh Government.

The plan aims to improve activity across six key areas: Prevention, Early Detection, Fast and Effective Care, Living with Liver Disease, Improving Information and Targeting Research. Each of these has major objectives and metrics associated with them. The implementation group has supported the development of specific sub-groups with defined remits and those formed to date include the blood borne virus sub-group as well as early detection and clinical services subgroups. Recently, a national clinical lead (0.2 whole time equivalent) has been appointed and a full time administrator is soon to be appointed to support the delivery of objectives determined by the implementation group.

Although still in the relatively early stages of the plan, there have been areas of significant progress in relation to the care of patients with liver disease in Wales. First among these is undoubtedly the work of the Wales blood borne virus network. This network consists of representatives from each of the 6 Health Boards in Wales as well as an external advisor, Professor David Mutimer from the Birmingham Liver Unit. Criteria (Fibroscan >9.5kPa or other urgent need for therapy) were set and patients were discussed by panel for appropriateness if discordant or extenuating circumstances were apparent. This collaborative has therefore ensured equitable access to new therapies across the whole of Wales and has been supported by an excellent, established network of specialist nurses.

This approach was supported by central government funding and, for the financial year 2015-2016, delivered directly active anti-viral therapy to 464 patients in Wales, mainly with cirrhosis or advanced fibrosis. For 2016-2017 further negotiated funding has been agreed to treat approximately 900 patients and the access criteria relaxed (Fibroscan 6kPa). Importantly, treatment of this number of individuals on a recurrent basis should lead to a reduction in the population prevalence of the disease.

The success to the network is also evident in the development of a series of industry partnerships which has led to specific initiatives around improving detection and provision of treatment too difficult to challenging groups such as prisoners or injecting drug users. Five of the six Welsh treatment centres are involved in these initiatives as pilot sites with the learning to be shared across Wales.

Also in the field of viral hepatitis, funding agreed through the liver plan has been awarded to modify the Wales Harm Reduction Database to include a comprehensive blood borne virus module. The module will cover the initial screening, consent and testing, diagnosis and
referral to specialist treatment services for hepatitis B, hepatitis C and HIV. It is expected that the module will be fully implemented, following training across Wales, early in 2017. A blood borne virus specific electronic clinical management system is also in development.

Liver plan funding has also been allocated to developing point of care testing in viral hepatitis that does not rely on venous samples or dried blood spot tests being sent to a laboratory, thus streamlining the pathway.

Outside of viral hepatitis, a key early priority identified in relation to liver disease in Wales was the support for the development lack of secondary care based alcohol care teams. Prior to support from the liver plan such services were extremely patchy and in some Health Boards non-existent. The plan has supported clinicians in Health Boards to develop their own regional plans for alcohol care teams including ensuring alcohol misuse becomes an organisational priority in their Integrated Medium Term Plans. To start this process the liver plan has allocated £1 million of funding over a 2 year period to “pump prime” the ongoing development of alcohol care teams in each Health Board in Wales. To date, 4 Health Boards have had funding approved for this purpose with the remaining 2 plans being in an advanced stage of development.

In regards the early diagnosis of liver disease and to improve links with primary care, a pilot is currently running in one Health Board to ascertain the utility of “reflexly” measuring the AST when an ALT is found to be elevated so enabling calculation of the AST/ALT ratio which was supported in the first iteration of the Lancet commission as having the potential to earlier identify those with advanced fibrosis or cirrhosis and so those with a ration of >1 are referred for further assessment.

Given that the majority of patients with cirrhosis are diagnosed at the time of an admission with decompensation, it is hoped that not only will this work lead to an earlier diagnosis of cirrhosis but avoid the need for the patient to return for a second blood test. In addition this approach has the potential to not only reduce GP workload (via reduced patient recall) but re-inforce the knowledge that minimal elevations of ALT can be associated with serious disease.

This work will also feed into the planned development of an all Wales pathway for the management of abnormal liver function tests. In this regard, a dedicated Hepatology away-day (including contributions from several Lancet Commissioners), is taking place in October 2016 and has a strong focus on pathway development.

Other work currently being developed is a collaboration to improve public and patient knowledge of the risks of and care of liver disease, as well as the development of mature
patient and carer support groups across the whole of Wales. An opportunity is also being explored with fledgling wellness services to link the lifestyle factors recorded in such consultations with risks of liver disease. Finally, work is being undertaken to improve access to liver transplantation for patient in Wales via the establishment of stronger regional networks and outreach clinics with transplant physicians.

Hence, whilst much remains to be done to tackle the burden of liver disease in Wales, there is firm political support and an increasing body of multi-disciplinary professionals with the commitment to do so.

3. Northern Ireland

Dr Neill McDougall, Clinical Lead for Hepatology in Northern Ireland, has written as follows: Northern Ireland is well behind England with respect to screening for early liver disease in the community, partly due to the different structures. I am due to meet one of our commissioners in next few weeks regarding the two recent NICE guidances (NAFLD and diagnosing cirrhosis) but we are nowhere near implementation. Also we have not fully implemented the NICE guidance on hepatitis B (due to resource implications for Fibroscans).

With respect to provision of services (Recommendation 3) Northern Ireland has a single regional liver unit in Belfast. NO OTHER hospitals have >2 hepatologists although most of the 9 hospitals outside Belfast have one gastroenterologist with a liver interest. This has been a definite improvement over the past 5yrs due to recent appointments.

In relation to specialist paediatric services and continuity of care in transition to adult services, Northern Ireland is currently well served by the special arrangement it has with Kings College Hospital, functioning as an outreach centre. There are weekly meetings via video conference to the Kings OLT listing meeting, a joint Kings-Belfast clinic every 2 months and Northern Ireland is the single biggest referrer of patients to Kings. The last UK data from 2015 showed the highest number of patients listed per head of population (if you exclude Isle of Man) although numbers transplanted fell back into the main stream, with 20-24 transplants per year. Survival data on 255 patients transplanted up to 2012 (90.9% 1yr survival, 80.2% 5yr survival, EASL 2014) showed that shared care arrangement deliver outstanding results.

Paediatric liver transplant work is done through Birmingham (historical arrangement). And there is a very good transition arrangement with the hepatologists from Birmingham and we join them in seeing adolescent patients over 1-2yrs at the paediatric clinic before they transition to the adult transplant service for follow-up.
On alcohol care services Northern Ireland is making excellent progress and the Chief Medical Officer, Dr Michael McBride, has been a strong supporter of this work. Data on the number of specialist nurses and Alcohol Care Teams is covered in Recommendations 2 and 5. Dr Roger McCorry, who leads the Belfast Trust Alcohol Care Team, reports that very recently THREE consultant led Alcohol Care Teams have been established in Northern Ireland, one in Belfast and in 2 of the other 4 Trusts. A regional alcohol care-pathway has also recently been completed with a view to standardising alcohol screening and care across the province.

Northern Ireland has an excellent HCV treatment programme which is able to provide all NICE approved treatments for NI patients. There is a single virology laboratory so that all results go through one centre and all treatment is delivered through the Regional Liver Unit in Belfast. There is also a Hepatitis Network for NI – a collaborative effort between Public Health and ourselves that helps to address the wide range of issues with viral hepatitis including screening, prevention, treatment pathways etc.
Acknowledgements:

We thank Carla Lloyd (Birmingham Children’s Hospital) for her contribution to data for Recommendation 4 and Helen Harris and Koye Balogun for their contributions to Recommendation 7. Our thanks also go to Norgine for their unrestricted grant to the Foundation for Liver Research which has enabled the Commission to work with Incisive Health in bringing the work of the Commission to the attention of Parliamentarians. Incisive Health have also produced the Constituency Liver Profiles referred to in the Introduction.
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