



**LIVER DISEASE:
TODAY'S COMPLACENCY,
TOMORROW'S CATASTROPHE**

The All-Party Parliamentary Hepatology Group (APPHG) Inquiry
into Improving Outcomes in Liver Disease

About the All-Party Parliamentary Hepatology Group (APPHG)

The APPHG is a group of cross-party MPs and Peers with an interest in liver disease. Its purpose is “to promote discussion of hepatology, including viral hepatitis and related public health issues, and to raise matters of concern with, and make representations to, government and other policy makers”.

The Group is co-chaired by David Amess MP and Baroness Masham of Ilton. Jason McCartney MP and Virendra Sharma MP are vice-chairs of the group. The Hepatitis C Trust provides secretariat support to the group, helping to arrange meetings and to conduct research and write reports.

The APPGH Inquiry Committee

The APPHG Inquiry into Improving Outcomes from Liver Disease was chaired by David Amess MP, supported by Baroness Masham and the chief executives of two patient organisations, Charles Gore of The Hepatitis C Trust and Andrew Langford of the British Liver Trust. The analysis of the evidence and writing of the report was supported by Jane Cox of The Hepatitis C Trust.

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The APPHG would like to thank all of the organisations and individuals who submitted written evidence to this Inquiry, or who took part in the oral evidence sessions. We are delighted with the depth and breadth of evidence submitted and for the participation of such a wide variety of key organisations.

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The written evidence submissions and transcripts of the oral evidence sessions are available on the www.appghep.org.uk website.

Contents

Foreword

1	Executive summary	6
2	Recommendations	8
3	The broken promise of a National Liver Disease Outcomes Strategy	10
4	Progress in tackling liver disease since 2010	12
5	Opportunities for and threats to tackling liver disease within the new NHS structures	16
6	Opportunities for the early diagnosis and prevention of liver disease	19
7	How different organisations can improve liver disease outcomes	21
8	Avoiding unwarranted variation in liver disease outcomes across England	22
9	Examples of sections of the pathway that are working effectively in different areas of the UK	23
10	Conclusion	24
	Appendix	
i.	Questions for written evidence submissions	25
ii.	List of written evidence submissions	25
iii.	List of individuals who gave oral evidence to the Inquiry	26
	References	27

Foreword

Liver disease is increasing at an alarming rate. With deaths from liver disease having risen by 40% between 2001 and 2012, and as the only big killer where annual deaths are on the rise, it has the potential to become the UK's biggest killer within a generation.ⁱ Moreover, whilst deaths from liver disease have been steadily increasing in the UK, they have been decreasing among our European neighbours. Even more disturbing is the fact that the average age of death from liver disease is only 59 and continuing to fall.ⁱⁱ

The lack of concerted action to address this situation is scandalous. The vast majority of liver disease is preventable,ⁱⁱⁱ and yet most people at risk of developing serious liver disease, or who show early signs of liver damage, are not aware of the fact. This is a shameful waste of lives and NHS resources. So, why is more not being done?

Liver disease is mainly caused by alcohol misuse, obesity and viral hepatitis, all of which are preventable. Yet it has been consistently under-prioritised and it is the only major killer lacking a national strategy.^{iv} There have been successive government commitments to publish a national liver strategy since 2009 and considerable work has been invested by the Department of Health, charities and leading specialists, doctors and nurses from around the country into developing a national liver strategy. However, in November 2013 the Government announced that NHS England, who would now be responsible for leading such work, had no plans to publish a strategy.

Out of disappointment at the persistent failure to develop a comprehensive approach to tackling liver disease, The All-Party Parliamentary Hepatology Group (APPHG) decided to conduct a comprehensive inquiry into the growing epidemic of liver disease. We invited evidence from Royal Colleges, clinicians, patients, charities, relevant industry figures, the NHS, Public Health England and the Government, in order to establish what needs to be done to improve outcomes for liver disease patients and save lives.

In this Inquiry we have listened carefully to the accounts of all of these stakeholders, and the resounding message to emerge is that much, much more needs to be done at all levels of the health service to address liver disease. The rise of liver disease has been ignored for too long. If action is not taken now, before long every one of us will know somebody with cirrhosis, end stage liver disease or liver cancer.

The implementation of the Health and Social Care Act 2012 marks a turning point for the NHS. With concerted action, it could also pave the way for a turning point in tackling liver disease. The following report details clear recommendations for achieving a positive step-change in preventing liver disease and improving outcomes for liver patients.



David Amess MP

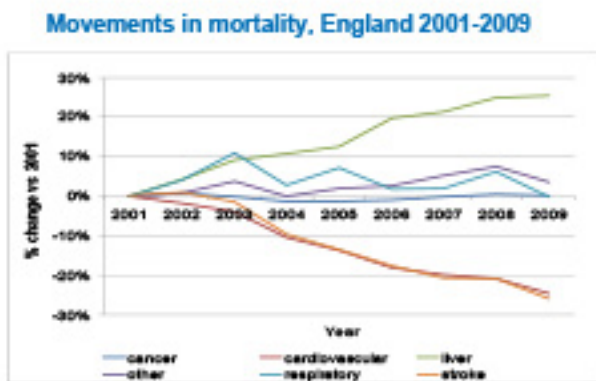
Baroness Masham of Ilton

Co-chairs, All-Party Parliamentary Hepatology Group

1. Executive summary

- The oral and written evidence submitted to this All-Party Parliamentary Hepatology Group Inquiry reveals an overwhelming consensus across the medical community on the urgent need for action on liver disease, as well as on the actions that are required.
- The scale of the crisis is evident from the statistics: the average age of death from liver disease is 59, compared with 82-84 for heart and lung disease or stroke.^v It is the fifth greatest cause of death in the UK, and the only one of the major five killers that is rising (see figure 1).^{vi} This is in contrast to the rest of Europe where deaths from liver disease are decreasing (see figure 1.2).^{vii}

Figure 1: Movements in mortality, England 2001 – 2009 (Source: ONS Mortality Data, from the National end of life care intelligence network)



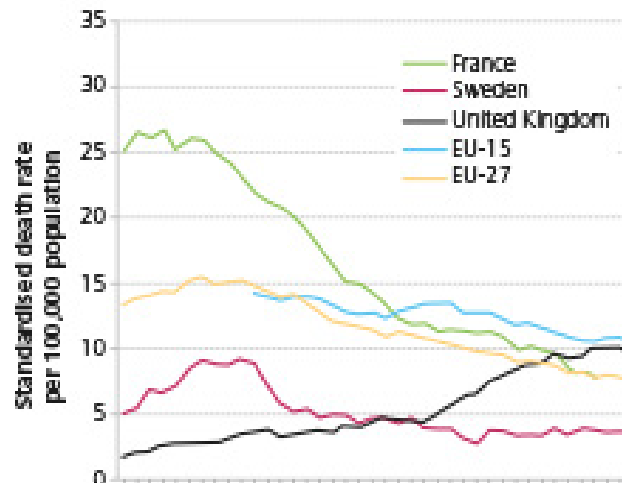
Source: ONS Mortality Data

- The three main causes of liver disease – alcohol misuse, obesity and viral hepatitis – are preventable. If detected early enough, most causes of liver diseases are also treatable. Therefore, a step change is needed in efforts to prevent the onset of liver disease, and to diagnose and treat those with early signs of the condition.
- Extensive and coordinated national action is urgently required. Stakeholders submitting to this Inquiry highlighted grave concerns about patchy service provision across the country, the late diagnosis of patients and a lack of the necessary central drive and prioritisation. Many expressed

disappointment that the promised National Liver Strategy, which had been developed by the Department of Health, leading clinicians and patient organisations between 2010 and 2012, will no longer be published and implemented (see p. 10 for details).

Figure 1.2 Image taken from Liver Disease: The NHS Atlas of Variation in Healthcare for People with Liver Disease 2013

FIGURE 1.2: PREMATURE MORTALITY FROM CHRONIC LIVER DISEASE AND CIRRHOSIS IN PEOPLE AGED UNDER 65 YEARS IN THE UK AND EUROPEAN UNION (EU) COUNTRIES (EU-15, EU-27, AND FRANCE AND SWEDEN)

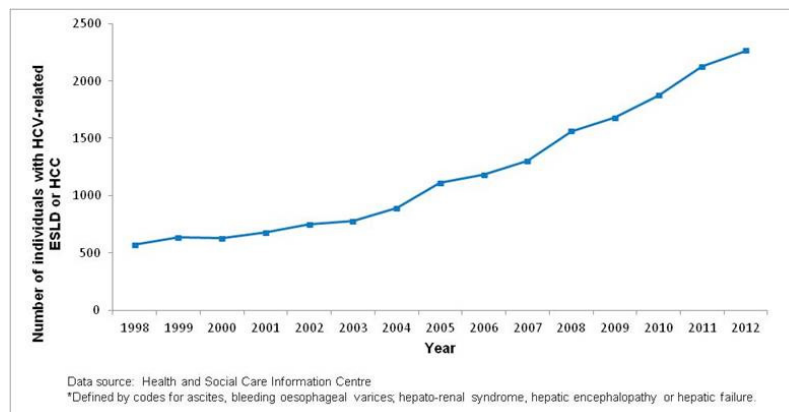


- Many stakeholders highlighted the fact that liver disease disproportionately affects the poorest in society. People in the most deprived quintile of the population are 2.3 times more likely to die from liver disease.^{ix} There is concern and disappointment around the fact that, despite the commitment embodied in the NHS reforms to ‘improve the health of the poorest fastest’,^{ix} rates of liver disease continue to climb.
- Chapters 3 to 7 summarise the evidence submitted under each question posed to stakeholders. The questions for written evidence submissions are in appendix i, and the lists of those who gave oral and written evidence to the Inquiry are in appendixes ii and iii.

The growing epidemic of liver disease

- By 2012 the number of people dying with an underlying cause of liver disease had risen to almost **11,000** ^x
- In the past 10 years there has been a **five-fold** increase in cirrhosis for people between the ages of 35 and 55 ^{xi}
- Alcohol health problems cost the NHS **£3.5 billion** a year ^{xii}
- **Around a quarter** of adults in England are obese and at serious risk of developing liver disease ^{xiii}
- More than **30** people a day are dying of liver disease, most of which is preventable and treatable ^{xiv}
- Annual deaths from hepatitis C have almost **quadrupled** since 1996 ^{xv}

Figure 3: Hospital admissions for end-stage liver disease* or hepatocellular carcinoma in individuals with hepatitis C in England 1998-2012



2. Recommendations

Having analysed the evidence submitted to the Inquiry, the APPHG make the following recommendations:

Prioritisation of liver disease

Recommendation 1: The Department of Health, NHS England and Public Health England should recognise liver disease as a priority area for action and initiate a taskforce to coordinate a national approach, based on the evidence collected for the draft National Liver Strategy, to improve outcomes for liver disease patients across the country.

Recommendation 2: In recognition of the importance of reducing mortality from liver disease in line with the aspirations set out in the Secretary of State's mortality challenge, the Department of Health should establish a dedicated liver disease policy team to oversee progress and ensure accountability.

“More testing, more treatment.

That's it. The cost of doing nothing

is going to be catastrophic.”

Professor Graham Foster

Recommendation 3: Health and Wellbeing Boards should prioritise actions on preventing, identifying and treating liver disease, as recommended by the Chief Medical Officer. Health and Wellbeing Boards should monitor early detection, treatment and mortality rates from liver disease. Assessing progress on tackling liver disease should be made a mandatory part of the joint strategic planning process for CCGs and local authorities.

Recommendation 4: In order to support health services in tackling all aspects of liver disease, NICE should publish a suite of quality standards addressing different aspects of liver disease. In order to ensure the timely availability of guidance to health services, NICE should accredit standards published by other bodies where necessary.

Monitoring of liver disease

Recommendation 5: Public Health England should address the worrying lack of data on all aspects of liver disease by developing a dataset to allow performance management of liver disease across CCGs, local authorities and Health and Wellbeing Boards. The Atlas of Variation for Liver Disease should be updated annually.

Recommendation 6: The opportunity created by the development of care data should be harnessed to identify people at risk of liver disease or who have been diagnosed with liver disease but have yet to receive effective treatment. The NHS needs to capture the power of big data to improve patient outcomes.

“Liver disease is a problem that will not go away, that in fact will continue to escalate until it is taken as seriously as heart disease or cancer by NHS England. It kills patients at a younger age than either and is responsible for a significant amount of premature mortality, especially in disadvantaged groups.”

*Professor Martin Lombard,
National Clinical Director for Liver Disease
2010-13*

Improvements in prevention

Recommendation 7: The Government should implement a minimum unit price for alcohol of 50p per unit, as recommended by 70 leading alcohol and health related organisations.

Recommendation 8: The UK should introduce universal hepatitis B vaccination, as recommended by the World Health Organisation.

Recommendation 9: Public Health England and NHS England should set a clear goal of eliminating hepatitis C within the next 15 years and should set out joint plans for achieving this goal.

Recommendation 10: Public Health England should ensure that all obesity reduction programmes include poor liver health as a significant risk stemming from obesity.

“One of the stand-out features of liver disease is that it impacts the lower socioeconomic groups hardest. So if we really do want to improve the health of the poorest fastest – rather than just talking about it - liver disease is an area – possibly the area – to make a big difference.”

*Charles Gore,
Chief Executive of The Hepatitis C Trust*

Improvements in early diagnosis

Recommendation 11: GPs should be incentivised to identify patients with liver disease through the Quality and Outcomes Framework scheme.

Recommendation 12: GPs should use every opportunity to screen their patients for liver disease, including conducting brief interventions for alcohol, offering blood borne virus testing if the patient has been at risk of infection, and testing obese and type 2 diabetes patients for signs of liver damage.

Recommendation 13: Liver function tests should become part of standard medical assessments alongside blood pressure and urine tests. Clear protocols for people with abnormal liver function test results should be developed in order to aid GPs and ensure that patients are correctly referred.

Recommendation 14: In recognition of the critical importance of improving liver health and the fact that many liver diseases can be effectively managed and indeed reversed if identified early enough, liver function tests should be piloted as part of the national Health Check programme for people over 40.

Recommendation 15: Hepatitis C testing should be included in the opt-out routine antenatal tests alongside hepatitis B and HIV tests.

Improvements in service provision and patient care

Recommendation 16: Health Education England should coordinate an education drive for health professionals on the causes of, and treatments for, liver disease.

Recommendation 17: Given the impact of liver disease in hospitals, the Care Quality Commission should make the quality of services for liver disease a mandatory component of its hospital inspection framework. The Care Quality Commission should conduct a themed review of the quality of liver care in the NHS.

Recommendation 18: CCGs and local authorities should set out plans to improve the quality of alcohol treatment services including, where necessary, making investments to improve the capacity of services.

Recommendation 19: In recognition of the critical importance of patient experience in managing liver disease, NHS England should initiate a national patient survey for liver patients, as has been conducted for cancer patients. Results should be published at provider and CCG level.

Recommendation 20: NHS England should publish a series of CQUIN schemes relating to liver services which are commissioned at a specialised level. The purpose of these schemes should be to incentivise efficient, high quality and patient-centred care. Potential themes could include submission of data to relevant audits, improving patient experience, effective management of patients with more than one liver risk factor, and developing new models of care that better support the complex needs of patients.

The APPHG plans to revisit this report next year, when it will assess progress towards improving outcomes in liver disease and the implementation of these recommendations.

“The major causes of liver disease are all preventable – we must tackle these causes head on and reverse the increasing amount of people with and dying from liver disease.”

*Andrew Langford,
Chief Executive of the British Liver Trust*

3. The broken promise of a National Liver Disease Outcomes Strategy

Despite cross-party support and support across the medical professions for a national strategy to improve outcomes in liver disease, in November 2013 plans by the Government and NHS England for a National Strategy for Liver Disease Outcomes were dropped, even though the development of a multi-stakeholder supported strategy was at its final draft stage. This was highlighted as a major disappointment within many of the evidence submissions.

In October 2009 the Labour Government announced the development of a National Liver Disease Strategy, and appointed a National Clinical Director for Liver Disease to oversee its development.

“Liver disease is the only one of the top five causes of death which is continuing to affect more people every year at an increasingly young age... By appointing a National Clinical Director to oversee the development of a strategy we will ensure that clinical evidence and outcomes for patients are at the heart of our work to improve the quality of services to tackle liver disease.”^{xvi} (Health Minister Ann Keen)

In November 2010 and 2011 the Coalition Government re-confirmed the commitment to developing a strategy for this increasing killer:

“Professor Martin Lombard, national clinical director for liver disease is currently leading work with the national health service and public health specialists to ensure that our response to the rising demand for liver disease services is evidence based, and that we also work to improve the quality and productivity of services. We expect that first formal proposals will be published for consultation in 2011.”^{xvii} (Health Minister Simon Burns, November 2010)

“The vision for the national liver strategy is to improve the patient pathway for people with liver disease so as to minimise unnecessary effort and expense, improve prevention and identification activity and improve treatment, care and support services from diagnosis to end-of-life care.”^{xviii} (Health Minister Anne Milton, November 2011)

In July 2011 the Prime Minister David Cameron gave a message of support for World Hepatitis Day confirming the Government’s intention to develop a strategy:

“We are looking at how we can strengthen efforts to prevent and control hepatitis C in the future, as part of our strategy for combating liver disease.”^{xix}

In April 2012 the Health Minister Simon Burns stated that, “the liver strategy will be published in due course”.^{xx} However, in November 2013 the Minister for Public Health Jane Ellison stated:

“Responsibility for determining the overall national approach to improving clinical outcomes from healthcare services lies within NHS England. NHS England advises that it is adopting a broad strategy for delivering improvements in relation to premature mortality. It is generally avoiding trying to work in a condition specific way and has no plans to produce a liver specific strategy.”^{xxi}

The case for a national drive to tackle liver disease remains strong. It is still the only one of the major 5 killers without a national strategy, and is the only one of those killers that is increasing.

“The absence of the publication of the National Liver Strategy, announced with some fanfare in 2009-10, is deeply disappointing for the BSG and its members... Although a focus on local solutions is important, an overarching national framework for action on liver disease is urgently required and Clinical Commissioning Groups and local authorities need much more guidance than they are currently receiving.”

*Written evidence from the British Society of Gastroenterology,
September 2013*

“A tremendous amount of work by doctors, nurses, patients and charities went into developing a strategy that would improve liver disease outcomes. The work has been done, the blueprint for better services is there – it just needs to be published and implemented.”

Evidence from Dr Martin Lombard,

National Clinical Director for Liver Disease 2010-13

4. Progress in tackling Liver Disease since 2010

1. The evidence presented to the Inquiry, summarised below, highlights several positive developments in tackling liver disease since 2010. However, the inquiry also unearthed many concerns around the patchy nature of improvements, the postcode lottery of care, the need for more preventative measures and earlier intervention, and concerns about the sustained increase in the incidence of and mortality from liver disease in the period since 2010.

2. Rising premature morbidity and mortality from liver disease: Almost all of the evidence submissions received by the APPHG Inquiry draw attention to the increasing problem of liver disease. The growth in premature morbidity and mortality as a result of liver disease was illustrated using a variety of statistics, including those on increasing hospital admissions, increasing deaths, and the decreasing age at which people are experiencing serious liver disease problems. For example, the British Liver Trust highlighted the fact that liver disease is the only one of the five biggest killers in the UK to be increasing year-on-year. Alcohol Concern noted that, alarmingly, the last decade has seen a 117% overall increase in alcohol liver disease hospital admissions in England amongst the under 30 age group, rising to 400% in the North East of England.

3. Government recognition of liver disease as a major cause of premature mortality: The inclusion of liver disease in the Public Health and NHS Outcomes Frameworks and in the Secretary of State's 'Mortality Call to Action' sends a welcome signal that the reduction of deaths from liver disease is being prioritised at a high level alongside the other five major killers. As the Deputy Chief Medical Officer explained, "First of all, the rise in particular in alcohol related liver disease is very concerning and is something that public health, ministers, everybody, is concerned about." Participants of this Inquiry emphasised the need for such fine rhetoric to be translated into positive and coordinated cross-country action on liver disease.

4. Lack of national coordination on liver disease: Most stakeholders from whom we heard evidence expressed significant disappointment regarding the news that the planned National Liver Disease Strategy will no longer be published and implemented.

5. The British Society of Gastroenterology stated that, "the absence of the publication of the National Liver Strategy, announced with some fanfare in 2009-10, is deeply disappointing for the BSG and its members" and the British Liver Trust believes that a strategy would have "at least offered a direction of travel and commitment to improvement". The Royal College of Physicians states that, "it is probably right that solutions will need to be local but central assistance will certainly be required to

direct/progress this". Likewise, the Institute of Alcohol Studies agrees that, "although a focus on local services is important, an overarching national framework for action on liver disease is urgently required."

6. Postcode lottery of care: A significant number of those who gave evidence to the APPHG Inquiry raised grave concerns about the vastly differing standards of care available to patients with liver disease depending on where they live. The British Society of Gastroenterology states that "there is effectively, at present, a "postcode lottery" for liver disease services, as evidenced in the NHS Atlas of Variation in Healthcare for People with Liver Disease^{xxii}. This concern was echoed in many other submissions and was emphasised by clinicians in the oral evidence sessions. For example, Professor Marsha Morgan from the Institute of Alcohol Studies explained when giving oral evidence that "the saddest thing of all was that where there is good practice, often that is dependent on one enthusiastic individual and when that individual disappears, so does the service in that area."

7. Indeed, the Institute for Alcohol Studies point to two examples of local initiatives aimed at improving services for liver disease: "Liverpool PCT-CCG has promoted risk assessment and early recognition of liver disease through the use of a locally enhanced service payment to minimise late diagnosis, while in Nottingham all CCG referrals from individual practices are screened by a general practitioner with an interest in gastroenterology and only referred onwards if indicated." These initiatives are welcome and should be promoted and rolled out across the country.

8. Greater public and professional awareness of liver disease: Several stakeholders noted improvements in the level of awareness around the issue of liver disease among commissioners and primary and secondary care practitioners. Several tools for professionals have recently been developed with the aim of raising the profile of different aspects of liver disease and educating and up-skilling the workforce in this area. For example, the Alcohol Use Disorders Identification Test (AUDIT) is now available to GPs and is included in the Quality and Outcomes Framework (QOF) system of remuneration for practices. In addition, the Royal College of General Practitioners (RCGP) has developed online learning certificates in the diagnosis and management of hepatitis B and C, which have been completed by over 1,000 health professionals since the programme's launch in 2011.

“There has been too little progress in tackling liver disease since 2010. There is no national liver disease strategy and no National Clinical Director solely for liver disease. The proposal to introduce minimum unit pricing for alcohol which may have helped reduce alcohol consumption has still not been taken up. In relation to hepatitis, the burden of chronic infection continues to rise....”

Public Health England, written evidence

“I think that’s the important thing – the statistics are changing. And whereas we are making progress in most areas, we are clearly not making progress – in fact things are getting worse – with liver disease.”

Professor David Walker, Deputy Chief Medical Officer, oral evidence session

9. There has been considerable information published since 2010 on both the antecedents of liver disease and on liver disease itself from a variety of sources, including NICE Clinical Guidelines on alcohol-use disorders, alcohol dependence and hepatitis B; NICE Public Health Guidance on preventing type-2 diabetes, obesity, and ways to promote testing of hepatitis B and C; and NICE Quality Standards on alcohol dependence. The Department of Health has also been involved in the development of an Alcohol Strategy (2012-13), A Call to Action on Obesity in England (2011) and the NHS Atlas of Variation for Liver Disease (2011).

10. However, there remains an urgent need for much greater public and patient awareness of liver disease. Professor Michael Glynn, National Clinical Director for Liver Disease and GI Medicine, summarises this point clearly: “Most patients hardly know what the liver is and what it does, let alone that you can have serious disease with no symptoms... Amongst non-specialists (including GPs), I also believe there is poor understanding of liver disease in general and of the fact that outcomes can be very good if the cause (for example, alcohol misuse or hepatitis C) is removed. There is also evidence, particularly within the recent NCEPOD report, that there is a judgemental and nihilistic attitude towards patients with alcohol-related liver disease amongst non-specialists.”

11. Disappointment at the apparent abandonment of minimum unit pricing for alcohol: Many health professionals and professional organisations expressed strong disappointment that the Government has postponed any action to bring in a minimum unit price (MUP) for alcohol. The Institute for Alcohol Studies states that, “the Government’s complete U-Turn on minimum pricing, which was one of the main tenets of NICE Public Health Guidance (PH24), has removed the single most effective proposed measure for combating not only alcohol misuse per se but also alcohol-related liver disease”. Indeed, Alcohol Concern predicts that a 50p MUP in England would prevent more than 3,000 alcohol-related deaths and 98,000 hospital admissions each year.

12. The Deputy Chief Medical Officer clarified that the Government had postponed making a decision on minimum unit pricing pending more evidence and that the policy was still under consideration: “My humble view as an individual is that there is enough evidence to show that MUP could be beneficial and that we should do it, and I am already on record saying that. The Government’s view is that they haven’t decided not to do that, they have just deferred the decision whilst awaiting further information. Indeed, waiting for some information from other countries on whether this actually makes a difference.”

13. Improvements among alcohol specialist services and alcohol care teams: According to the Alcohol Health Alliance, widespread implementation of Alcohol Specialist Services and Alcohol Care Teams has taken place across the country in recent years, although the service is still patchy in some parts of the country and under-funded in others. The British Society of Gastroenterology points to improvements in the implementation of Alcohol Specialist Nurses (implementation up from 42% in Trusts in 2009 to 79% in 2011) and highlights Alcohol Care Teams^{xxiii} as “examples of highly-effective and evidence-based interventions that should be rolled out more widely”.

14. Whilst these are welcome improvements, alcohol services are still chronically underfunded and Alcohol Concern estimate that only 5.6% of dependent or harmful drinkers access treatment each year. They highlight that the latest available figures show that local PCTs spend an average of £600k a year on alcohol treatment and counseling services, representing just 0.1% of a typical PCT’s yearly expenditure-.

15. Lack of a single approach to tackling liver disease: The oral evidence sessions highlighted considerable concern about the lack of a single approach to tackling liver disease. The overlaps between the different aspects of liver disease need to be recognised and addressed, whereas currently they are tackled separately. For example, the calorie content of alcohol can be a significant contributor to weight gain and obesity, and drinking alcohol can accelerate liver damage in a hepatitis C patient. As Andrew Langford, CEO of the British Liver Trust explained, “we would certainly welcome someone having responsibility for liver disease and coordinating all the different aspects. I think that without that, we’ve seen time and time again that it doesn’t get coordinated properly and fails to reflect a holistic approach.”

16. The development of a new generation of hepatitis C anti-viral therapies: Numerous stakeholders highlighted the introduction of “first generation protease inhibitors” for genotype 1 hepatitis C patients, which NICE approved in April 2012 and which have improved cure rates for this patient group, as one of the most important positive developments in improving liver disease outcomes since 2010. Several stakeholders also pointed to the ‘second wave’ of new hepatitis C treatments currently being developed and which, it is hoped, will allow for the effective elimination of hepatitis C. For example, Professor Roger Williams at the Institute of Hepatology states, “since 2010 there has been major progress in tackling one area of liver disease, namely that due to hepatitis C. This is because of the introduction of more effective

anti-viral agents by Big Pharma and it is very likely that next year, with the second wave of new anti-HCV agents that will be licensed in America and Europe, there will be opportunities for eradicating hepatitis C infections.”

“A tremendous amount of work by doctors, nurses, patients and charities went into developing a strategy that would improve liver disease outcomes. The work has been done, the blue print for better services is there – it just needs to be published and implemented.”

*Professor Martin Lombard,
National Clinical director for Liver Disease
2010-13*

“The single legislative measure that the profession believes would have the greatest immediate effect (minimum unit pricing), and for which the Canadian evidence is very strong, has not been adopted by Government for the time being. In my view the specialist profession feels let down by this decision, but has the clear resolve to carry on tackling these issues in a raft of different ways”.

*Dr Michael Glynn,
National Clinical Director for Liver Disease and
GI*

“There are not enough of the higher grade clinicians to go round, so the juniors have to look after you. It can be very dangerous. I am knowledgeable and confident and I question a lot of decisions. For instance, six weeks after transplant I was told that I didn’t need to be seen for another six months. Now that is not the protocol: I needed to be seen in a couple of weeks’ time and I had to sit and wait for another doctor and have a huge argument about it. It was a junior doctor, she wasn’t trying to do me any harm but she didn’t have the education.”

Hepatitis C patient Susan McCrae

“At the moment my view would be that in many parts of the country the service is not fit for purpose.”

Professor Graham Foster,

consultant hepatologist at The Royal London Hospital

5. Opportunities for, and threats to, tackling liver disease in the new NHS structures

17. The implementation of the Health and Social Care Act 2012 marks a turning point for the NHS. With the correct action, the APPHG believes it can also be a turning point for liver disease. However, many of the opportunities for addressing liver disease presented by the new structures could also be a threat to progress if liver disease is not adequately prioritised and coordinated across all the new structures. The APPHG hope that, by examining these opportunities and threats in this Inquiry, the new organisations can ensure that the opportunity for improved prevention, detection and management of liver disease is maximised.

18. Clinical Commissioning Groups (CCGs) and local authority commissioning: The devolution of NHS commissioning to CCGs and public health commissioning to local authorities is viewed by some as a potential opportunity for tackling liver disease, as services will be able to directly target the needs of their community. Public Health England outline many of the actions that CCGs and Health and Wellbeing Boards could take to reduce liver disease in their areas, including adapting local licensing policies, promoting physical activity, the provision of alcohol detox services and testing for groups most at risk of viral hepatitis. The British Liver Trust believe that, “health promotion could benefit from investment by local authorities in targeted initiatives, including creating healthy communities with better local control of alcohol and fast food outlets, more support for healthy living schemes and co-ordinated health and social care packages including prescribed exercise programmes.”

19. However, the evidence submitted to the Inquiry revealed a great deal of concern about the potential fragmentation of services due to this devolution of responsibilities, and a resulting inequity of access and provision for liver disease patients. The Alcohol Health Alliance warn that the devolution of public health services to local authorities and of commissioning to CCGs could lead to “...unjustifiable variation, piecemeal and fragmented service provision, an absence of quality evaluation metrics, and a lack of information-sharing and best practice. Leaving it to each individual council to decide on priorities may result in some choosing to ignore alcohol harm, even where significant problems exist. There must be robust measures for holding local authorities to account for these decisions.”

20. Professor Roger Williams at the Institute of Hepatology also warns that “the many competing priorities for Clinical Commissioning Groups to consider make it likely that liver disease will remain under-prioritised”. Worryingly, Public Health England shares their concern that localities will fail to

prioritise and take action on liver disease: “The biggest threat is failure to prioritise prevention and treatment of liver disease at a local level. This is exacerbated by the lack of: a national strategy, a National Clinical Director solely for liver disease, guidance on the prevention of liver disease from the National Institute for Health and Care Excellence and national policies to reduce alcohol consumption (e.g. minimum unit pricing). Recent changes to the health care system have led to the fragmentation of multi-professional partnerships/networks which previously coordinated the response to issues such as hepatitis. There is also a dearth of information on the number of chronic hepatitis B and C cases that have accessed treatment and treatment outcomes.”

“We are concerned there isn’t sufficient in the way of prevention so patients are being referred to us very very late.”

Professor Marsha Morgan

21. The problems presented by the lack of the National Liver Strategy were reiterated by many stakeholders when considering opportunities and threats to tackling liver disease in the new NHS. Indeed, the Alcohol Health Alliance state, “...the biggest threat to tackling liver disease is the absence of any national framework or strategy for coordinating an effective response to the growing burden of disease.”

22. Commissioning of prison healthcare: Centralised commissioning of prison healthcare through NHS England presents a new opportunity to improve blood borne virus (BBV) testing and treatment among the prison population. Several stakeholders emphasised what an important opportunity this was due to the high prevalence of BBVs in the prison population and the historically low proportion of prison testing. For example, a Department of Health survey in 1997 showed a hepatitis C prevalence of 9% in prisons, and yet Health Protection Agency figures show that only 6% of prisoners were tested for hepatitis C in 2011^{xxiv}. As the pharmaceutical company Boehringer Ingelheim state, “There is clearly an opportunity to improve screening in the prison population, commence treatment programmes and rehabilitate prisoners into the community virus-free – avoiding further spread of the infection”. The new centralised commissioning structure for prison healthcare will allow NHS England to commission services across the country with the universal offer of an opt-out blood borne viral test when people enter prison, and a care pathway for those who test positive.

23. Commissioning of hepatitis C treatment: Proposals for the centralised commissioning of hepatitis C treatment were seen as both an opportunity and a threat to progress in tackling hepatitis C among those who gave evidence to the Inquiry. The Hepatitis C Trust stated that: “we believe hepatitis C treatment should be centrally commissioned to avoid unwarranted variation in access across the country. However, to ensure patients can

access treatment close to where they live and to minimise the burden on specialist hepatitis C services, it is vital that treatment is delivered, through the support of networks, in community settings as close to patients as possible.” Public Health England echoed this view: “treatment of HCV infection in people who inject drugs can impact on the incidence and prevalence of HCV infection. As such, commissioners should consider expanding the provision of hepatitis C treatment in non-traditional settings, including primary care, drug treatment settings and prisons, to make treatment more accessible”. Dr Iain Brew, a GP at HMP Leeds National Clinical Assessment Service, also warned that “NHS England may feel that hepatitis C treatment (especially for complex cases) should be limited to large centres [but] the very group most likely to suffer with the disease...is the group least likely to engage with Secondary Care.”

24. Due to the development of new drugs, the elimination of hepatitis C in the UK will soon become a viable goal that Public Health England and NHS England can work towards. Several stakeholders highlighted the advent of new treatments for hepatitis C which are expected to become available in the next few years, and which have cure rates of up to 95%. The British Society of Gastroenterology stated that: “recent technological advances mean that this [hepatitis C] is completely curable, and open up the prospect of completely eradicating the disease.” The Hepatitis C Trust similarly stated that, “With concerted action over the next 15 years we could consign hepatitis C in the UK to the history books. If we focus on diagnosing and offering treatment to hepatitis C patients, we will reduce the prevalent pool of infection to practically zero and effectively eliminate the virus in the UK. This will save the NHS millions in the long term, as well as saving thousands of lives.”

25. **The NHS and Public Health Outcomes Frameworks:** The NHS and Public Health Outcomes Frameworks contain the high-level objective to decrease premature mortality from liver disease. As these frameworks act as a major policy driver within the new NHS structures, the inclusion of this objective is viewed by many stakeholders as providing a major opportunity for tackling liver disease, one which should lead to an increased focus on addressing liver disease. Boehringer Ingelheim believe it should mean that “in the coming years there is an increase in the number of local, regional and national strategies to tackle the issue”, although Roche cautions that “the real test of whether these frameworks have any traction will be the extent to which

“It’s trying to get them to recognize that if you pay now you save later on. It’s trying to get that message across. Because in my experiences there is incredible nihilism that still exists especially in primary care and some aspects of secondary care for liver disease.”

Dr Mark Hudson

they influence provider contracts for service provision and change local protocols on diagnosis and treatment”.

26. Several stakeholders made it clear that they do not believe the mentions of liver disease in the NHS and Public Health England Outcomes Framework supplant the need for national strategic direction on liver disease. For example, The Hepatitis C Trust stated that: “liver disease is the only one of the five major killers without a national strategy. The fact that reducing premature deaths from all these 5 killers, liver disease included, is a major aim of the NHS and Public Health Outcomes Strategies is welcome but it does not compensate for the urgent need for detailed national and regional strategic direction.”

27. Furthermore, the paucity of incentives to improve national outcomes in liver disease was highlighted by The Hepatitis C Trust and the British Society of Gastroenterology as a reason for the lack of progress in this area to date, with both expressing a fear that there is nothing currently planned in the new NHS to address this barrier to improvements. Many stakeholders recommend that liver disease be included in the Quality and Outcomes Framework of payments in primary care.

28. **The creation of Public Health England:** The separation of public health from the NHS through the creation of Public Health England can be seen as a potential opportunity for liver disease. By providing the evidence base and a strong voice on public health issues such as viral hepatitis, alcohol harm and obesity, PHE has the potential to drive forward improvements in almost all aspects of liver disease. The Hepatitis C Trust point to areas where Public Health England has already taken a positive and proactive lead in pushing for improvements in hepatitis C services: “We have been impressed by the work of Public Health England on viral hepatitis to date. For example, they are leading work across the new NHS to improve blood borne virus testing in prisons. There is a great opportunity for PHE to lead the NHS and local authorities in addressing hepatitis C by urging them to prioritise the virus and equipping them with all the relevant data and knowledge.”

29. It is clear that it is essential for PHE and NHS England to work together in a coordinated manner to tackle liver disease. The British Society of Gastroenterology suggests that: “PHE can work with the NHS to help tackle liver disease, for example through joint training in public health for hospital consultants (and vice versa to some extent), and joint training in gastroenterology and hepatology in substance misuse.” The Society welcomed Lord

Darzi's suggestions in the NHS Next Stage Review report "High Quality Care for All" that there should be opportunities for doctors to train jointly in a clinical specialty and public health: "some continuing clinical commitment to individual patients for trained public health doctors would help their perspective too...Public health training with a special focus on alcohol and obesity would help to promote effective and robust pathways within local health systems."

30. **Addressing health inequalities in the new NHS:** The prioritisation within the new NHS of reducing health inequalities in terms of access to health services and healthcare outcomes was welcomed by many stakeholders. The 2012 Health and Social Care Act contained specific legal duties for the Secretary of State, NHS England and CCGs to reduce health inequalities, and there is a strong link between deprivation and liver disease, indeed perhaps the strongest of any disease area. Indeed, the Deputy Chief Medical Officer stated that, "with regards to health inequalities, I agree because if I'm talking about health inequalities, this [liver disease] is the example I always use." He explained to the Inquiry that five or ten years ago, smoking was seen as the major cause of health inequality but, as smoking has been tackled fairly aggressively and smoking rates have come down, alcohol is now overtaking tobacco in some areas. He cites work by the North West Observatory that suggests alcohol is now their biggest cause of inequality.

31. The APPHG received a broad range of evidence drawing attention to the link between liver disease and deprivation. People in the most deprived quintile of the population are 2.3 times more likely to die from liver disease.^{xxv} Alcohol Concern drew attention to the Marmott Review, which highlights the fact that people with lower socio-economic status who consume alcohol are more likely to have problematic drinking patterns and experience dependence. The Hepatitis C Trust and MSD pointed to new research showing that almost half of people with hepatitis C admitted to hospital are from the poorest fifth of society. Clearly, if the health service is to reduce health inequalities, then liver disease must be addressed as a matter of priority.

32. Some stakeholders suggested that the fact that liver disease and its causes are stigmatised, and that it disproportionately affects the poorest in society, is the reason why it has been continually overlooked and under-prioritised. For example, when asked by David Amess MP "why do you think this is the only major disease which is on the increase compared to the others?" by Professor Graham Foster replied, "I think it is frank discrimination. The support we provide to people with liver disease is dominated by an appearance that says alcohol is the main driver of liver disease and it's their own fault. Firstly, that's factually incorrect; there are many things that cause significant liver disease other than drink. I think people with drink problems have other mental health problems, psycho-social problems that drive them to drink, but certainly there are significant co-morbid factors. So the idea that liver disease is all someone's fault couldn't be more wrong. But that perception overrides the whole structure."

"With hepatitis C, with the sorts of drugs we now have available, we can cure eight out of ten patients and that will only get better with time. Proper treatment of hepatitis B can prevent progression to end stage liver disease. So these are controllable conditions. And if we catch drinkers early there's a good chance we can help, likewise fatty liver disease, so the real premium is on getting to people before they get to us."

Professor Graham Foster,

consultant hepatologist at the Royal London

6. Opportunities for the early diagnosis and prevention of liver disease

33. The vast majority of liver diseases are preventable. The APPHG received unanimous and compelling evidence on the pressing need to address the prevention and early diagnosis of all liver diseases. To achieve this, far more must be done across the NHS and local and national government.

34. **Preventing alcohol related liver disease:** Preventing and limiting alcohol misuse must be prioritised in order to reverse the increasing rates of liver disease. The introduction of a minimum unit price for alcohol is viewed by the health community as critical in reducing alcohol consumption and the number of related hospital admissions.

35. Screening and effective early intervention for harmful and hazardous drinkers, as well as follow-ups over the longer term, are regarded by health stakeholders as another vital component of decreasing harm from alcohol. The NCEPOD review of patients who died with alcohol related liver disease (2013) has been called “a study of missed opportunities” where “there was a failure to screen adequately for harmful use of alcohol and even when this was identified, patients were not referred for support.”^{xxvi} The National Clinical Director for GI and Liver Disease highlighted this review, explaining that the NCEPOD report shows “sensible health professionals were clearly being judgemental, and either writing people off too early or simply not offering them what they should have been offered in terms of care.”

36. This failure to screen and provide early interventions for people with alcohol related liver disease is costing lives. Professor Marsha Morgan explained to the APPHG that, “there’s a remarkable turnaround if you can get individuals to stop drinking. You go from someone who is moribund to someone leading a very reasonable life - it’s quite miraculous. It’s a fairly emotive word to say but it really is.”

37. The Alcohol Health Alliance’s ‘Health First: an evidence-based alcohol strategy for the UK’, published in March 2013 by over 70 health related organisations, was highlighted by several stakeholders who gave evidence to the inquiry. It sets out 30 evidence based recommendations for policies that would change the environment in which people drink and reduce alcohol harm

in the UK. These include recommendations on health warnings on labels for alcohol drinks, licencing restrictions, actions for health and social care professionals in identifying and giving brief interventions to people drinking at hazardous levels, and setting a minimum unit price for alcohol of 50p a unit.

38. **Preventing non-alcoholic fatty liver disease (NAFLD):** Tackling obesity was also seen as a priority among stakeholders. Several of those who gave evidence highlighted that there is poor

general awareness of the link between obesity and liver disease and yet, as the obesity crisis continues to grow, so will related liver disease. Addressing the obesity epidemic is therefore seen as a priority for tackling liver disease. However, as explained by the Deputy Chief Medical Officer, addressing obesity is not an easy task: “When it comes to obesity, I think that is actually much harder, and if you look at the evidence base around the world, nobody really knows how at a population level to effectively reduce obesity. There’s lots of research and some things that appear to be effective but if you look at the success that governments around the world have had in tackling this, it’s not great. So I think this is an area where we do need more research, we do need more effort. It’s hard to target your resources without a very clear plan of what works and what you are going to do.”

39. Dr Harry Rutter, Senior Strategic Adviser to Public Health England and a specialist on obesity, echoes this worrying lack of clarity on what needs to be done to address the obesity crisis: “From a non-alcoholic fatty liver disease perspective, there is no consensus on exactly what is going on or on the numbers. We’re really in early days, I think, of understanding and getting to grips with the nature of the problem. We do know that it is a big and growing problem. There’s been something like a twelve fold increase. When I was a medical student we didn’t even know this thing existed.”

40. Two solutions offered were that, when someone is identified as obese or having type 2 diabetes, they should automatically be screened for liver disease (British Liver Trust) and that work could be undertaken around the availability and advertising to children of high energy-dense foods to begin to change the culture (Dr Paul Cosford, PHE).

“It’s never too late to stop people drinking. So there are people that are on the borderline of transplantation who then stop drinking and then by the time their transplant comes up they actually don’t need it; they’ve got better.”

Dr Michael Glynn

41. Preventing hepatitis B: Preventing hepatitis B by implementing a policy of universal vaccination was highlighted by clinicians, patients and patient organisations as an important measure in preventing the transmission of hepatitis B. The World Health Organisation recommends universal vaccination against hepatitis B for all countries, but currently the UK is one of the very few Western countries not to implement this. In the clinician oral evidence session, Professor Graham Foster explained, “my own children are vaccinated against hepatitis B... It’s monstrous to put them at risk of an infection which is very easily prevented. So I think everyone should be offered that.” The National Clinical Director for Liver Disease and GI, Dr Michael Glynn, stated: “Most other Western countries have adopted a policy of universal vaccination against hepatitis B, whereas in England the policy has been to target vaccination to those deemed to be at higher risk. Given the safety and efficacy of the vaccine, this policy could be revisited”.

42. Currently only people deemed to be at risk of infection, such as healthcare workers, prisoners and injecting drug users, are offered free hepatitis B vaccination. The Deputy Chief Medical Officer recognised that the uptake of vaccination for all high-risk groups was not universal and that “we probably need to do more in terms of prevention and screening in the community”.

43. Preventing hepatitis C: Preventing hepatitis C through harm reduction measures in drug services is seen as vital, as around half of injecting drug users have hepatitis C. The Hepatitis C Trust believes that more needs to be done to train drug services staff, and all staff involved in needle exchanges, in hepatitis C prevention messages.

44. Stakeholders highlighted the fact that most people living with hepatitis C in the UK, and many people living with hepatitis B, are unaware of their infection. Therefore, increasing the diagnosis rate and treating people is a crucial preventative measure, as by decreasing the prevalent pool of infection of viral hepatitis transmissions will decrease. Several simple policy recommendations were made to increase testing and diagnosis of hepatitis B and C, including:

- The introduction of routine ante-natal testing for hepatitis C (alongside hepatitis B and HIV which are already part of routine antenatal tests)
- Introducing the routine offer of an opt-out test for hepatitis B and C in prisons
- Incentivising hepatitis B and C testing by GPs through the Quality and Outcomes Framework
- Improving testing in drug services by monitoring testing uptake, results and referral rates

45. Encouraging the earlier diagnosis of patients within primary care services: Improving clinical awareness of liver disease in primary care services and ensuring the earlier identification of liver disease was highlighted by many stakeholders, including the British Society of Gastroenterology, the British Liver Trust, Alcohol Concern and The Hepatitis C Trust, as an essential step to improving outcomes. Dr Michael Glynn, the National Clinical Director for Liver Disease, highlighted the issue that there is currently poor understanding of liver disease amongst non-specialist health professionals and a lack of understanding in particular that outcomes can be very good if the cause (e.g. alcohol or hepatitis C) is removed.

46. Alcohol Concern highlighted the practice of brief interventions which have been shown to be particularly effective in reducing alcohol consumption and related harm in a variety of settings, including in emergency departments, general medical hospital wards and workplaces, and in supporting individuals to change their drinking behaviours before significant health harms have developed.

47. The British Society of Gastroenterology and Professor Roger Williams at the Institute of Hepatology drew attention to tests that GPs can use that enable the early identification of severe liver disease. However, Professor Williams warns that the use of these “is dependent on general practitioners becoming more interested in this area of medicine, of which currently they have shown, to date, little evidence”.

48. Increasing awareness: Developing targeted awareness campaigns with government support was suggested as an important preventative measure by The Hepatitis C Trust and the British Liver Trust, both patient organisations. The National Clinical Director for Liver Disease highlighted a poor public understanding of what liver disease is, what it does, and that it is possible to have advanced liver disease which carries risks of serious complications and shortened life without experiencing any symptoms.

7. How different organisations can improve liver disease outcomes

49. The stakeholders who contributed to this Inquiry made numerous constructive recommendations on the support, tools and measures required to assist the different parts of the NHS in improving liver disease outcomes. Once again, stakeholders highlighted the need for a national liver framework to coordinate and drive improvements in all areas of service provision across the country. Other key recommendations were focused on support for GPs, for liver networks and for commissioners:

50. **Support for GPs:** The need for increased awareness of liver disease and its treatments among GPs was a recurring theme of the evidence submitted to the Inquiry. To assist this, the following suggestions were made:

- Including liver function testing in Health Checks, with clear protocols for the next steps for people with abnormal liver function test results
- Including testing for hepatitis C in the GP Quality Outcomes Framework
- Roll-out of training for GPs through protected learning time slots and through increased uptake of related RCGP online modules

51. **Support for Liver Networks:** Due to the lack of a national liver strategy and concerns about the piecemeal and inadequate response thus far to rising liver disease, several stakeholders highlighted the need for coordinated regional or local liver networks to ensure a collaborative approach between PHE, NHSE, CCGs and local authorities. The British Liver Trust envisage that this will “provide co-ordinated and supportive groups that can share and monitor good practice, plan to meet the needs and deliver in a cost effective way services that give the best possible care, treatment and support for those with, and affected by, all liver disease”. Similarly, the British Society of Gastroenterology recommended that, “at a local level there needs to be a trained clinical lead for liver disease, responsible for composing and monitoring the outcomes of a local “liver plan” to meet liver disease needs”. The British Liver Trust, British Society of Gastroenterology and The Hepatitis C Trust emphasise that these would need central direction, support and funding to ensure they are sustained and consistent across the country.

52. **Support for commissioners:** Increased support for commissioners in the form of improved epidemiological data on all forms of liver disease, improved commissioning guidance from NHS England and partnerships with patient groups, were seen as vital to improving services and outcomes for liver patients. For example, Alcohol Concern recommend that the

NHS Commissioning Board should provide local commissioning groups with guidance on the best practice for commissioning comprehensive alcohol treatment services, based on the NICE guidance and the forthcoming quality standard on alcohol dependence. The British Liver Trust recommends that commissioners and providers need to work far more closely with patients and service users to develop appropriate stakeholder commissioning groups that assess the local need, create development plans and develop effective Patient Related Outcome and Experience Measures (PROMs and PREMs) ^{xxvii} to monitor service delivery.

“Since I was diagnosed my care has been fantastic but my experience of trying to get diagnosed was rather painful. I was misdiagnosed four times over a period of about six months and told I had irritable bowel syndrome, and told I was depressed. Finally, when I was so ill I could barely pull myself out of bed I insisted on seeing a different GP in the same surgery who was fantastic and by a process of elimination found out what it was a couple of weeks before she left the surgery.”

Hepatitis B patient, Simon Marks

8. Avoiding unwarranted variation in liver disease outcomes across England

53. The fact that there is unwarranted variation in liver disease outcomes in England is well documented by the NHS Atlas of Variation in Healthcare for People with Liver Disease (March 2013). This Atlas was welcomed by stakeholders and several commented that it should be updated annually to track progress. As explained in the foreword to the Atlas by three patient charities, the variation in outcomes is often a result of variations in care: “We hear first-hand through our helplines and in forums and networks how variations in liver services affect patients across England: there is variation in when and how people are diagnosed, the information they receive on diagnosis, access to treatments, the support they are offered, their experiences with doctors and nurses, in hospitals and during end-of-life care”.

54. It is universally accepted that unwarranted variations in outcomes from liver disease need to be addressed. Public Health England summarises the actions required to reduce unwarranted variation in liver disease outcomes:

“To avoid unwarranted variation in liver disease outcomes across England, we need to concentrate resources in those areas with the highest prevalence and ensure that these areas have good quality information and practical solutions. We also need to develop, implement and monitor quality standards for commissioning prevention and treatment services across England, underpinned by a comprehensive liver disease strategy.”

55. National direction and prioritisation of liver disease and its causes: The evidence submitted to the Inquiry strongly supports the development of a National Liver Disease Strategy. However, in the absence of this, many stakeholders recommend national direction and prioritisation of liver disease so that Public Health England, NHS England, CCGs and local authorities make improving outcomes from liver disease a clear priority with dedicated leads for liver disease.

56. Service based reviews for liver disease: The British Society of Gastroenterology suggested leading service-based reviews for liver disease where mortality is high or is an outlier, in a similar vein to the work Professor Mike Richards is conducting as Chief Inspector of Hospitals. They identify the lack of detailed service and outcomes data in liver disease as a key problem. The BSG would support the establishment of improved data collection methods, and is willing to play a leading role in driving this forward. The BSG and partners recently launched the Inflammatory Bowel Disease Registry to support service improvement and research. A similar model could be adopted with regards to liver disease.

“My experience is patchy care that has been too reliant on individuals. I have been put in serious, life-threatening danger two or three times in the process. But at the same time, the NHS has saved my life because I got a liver transplant.”

Susan McCrae, hepatitis C patient

9. Examples of sections of the pathway that are working effectively in different areas of the UK

57. Stakeholders submitted several examples of services and pathways that are working well for different elements of liver disease treatment in different parts of the country. Indeed, the Royal College of Physicians state that, “in our experience there are pockets of good practice in most areas (some are mentioned in the Atlas of Variation) but the services as a whole are far from optimum”. The main examples given to the Inquiry are included in this chapter.

58. The North East Liver Network^{xxiii} was highlighted by the British Liver Trust as an example of good practice: “It helps clinicians and others to remain up to date with regional and national policies, as well as reviews which may impact on liver services within the network. The network encourages collaboration and builds partnerships between patients, providers and other key stakeholders. In addition, the network works across traditional service boundaries and facilitates the sharing of best practice to reduce variation and create consistently excellent services. The network leads on the development of network strategies that reduce variation in care of patients with liver disease, standardise liver care across the North East and Cumbria and develop pathways to ensure that excellent care is achieved.”

59. The British Liver Trust’s ‘Love Your Liver’ campaign was highlighted for its success in raising the profile of liver health through effective local and national media campaigns and through the Love Your Liver roadshow. Approximately 25% of the 1,500 people screened by ultrasound test in the roadshow showed signs of liver disease and were recommended to seek medical advice. This approach proves that great success can result from raising awareness and prevention and through screening people effectively by going out into local communities and providing easy access to services.

60. Several stakeholders, including Boehringer Ingelheim, Gilead and The Hepatitis C Trust, highlighted Scotland’s Action Plan on Hepatitis C as an example of good practice. The Action Plan has increased the number of people diagnosed with hepatitis C by a third and increased the number of people receiving treatment by 120%. This has been internationally recognised as an example of good practice.^{xxix}

61. Hepatitis C treatment is being successfully delivered in some, although not all, prisons. Three successful models were described by Dr Iain Brew, a specialist GP at HMP Clinical Assessment Service in Leeds, who highlighted that treating patients in prison can work well because of the supportive, stable environment for patients, as well as leading to cost savings due to patients no longer needing to be seen at an outside hospital. The three examples of successful models of treatment in prisons are:

- Hepatology Specialist nurse / consultant in-reach, which has been in operation at HMP Manchester for some time
- Infectious Diseases Specialist nurse / consultant in-reach, which has been in operation at HMP Hull for at least eight years under the direction of Dr Peter Moss
- In-house treatment provision as offered by a Nurse Specialist and GP with Special Interest at HMP Leeds / Wealstun, which has treated over 100 patients during the past five years.

62. Professor Roger Williams at the Institute of Hepatology highlighted Bolton’s pioneering inpatient and outreach liver services for alcoholic liver disease, which has led to a considerable improvement in the number of admissions and to the quality of care delivered.

63. Dr Ulrich Thalheimer highlighted the Royal Devon and Exeter Hospital’s Hepatology team, which includes dedicated Liver Nurse support, as an example of good practice. It has a hub and spoke arrangement with the Royal Free Hospital whereby cases are regularly discussed with the tertiary centre and outreach clinics are held for complicated cases. This ensures the provision of Hepatology care of the highest standard for the population of a large area in East, North and South Devon.

10. Conclusion

70. The APPHG is encouraged that reducing premature mortality from liver disease is an outcome indicator in the Public Health Outcomes Framework, NHS Outcomes Framework and the Secretary of State's 'Call to action to reduce avoidable mortality'. However, unless targeted national action is taken, with clear direction and improved monitoring systems for CCGs and local authorities, the APPHG fears that the burden of liver disease will continue to escalate.

71. The APPHG believes that liver disease and liver disease patients have been shamefully overlooked. It is unacceptable that hospital admissions and deaths continue to rise for what are usually preventable conditions. We call on the Government, Public Health England, NHS England, CCGs and local authorities to work together to prioritise and drive improvements in all aspects of liver disease prevention, early detection and management. Otherwise, the consequences of continued inaction will be catastrophic.

Appendix i: Questions for written evidence

1. What is your assessment of progress in tackling liver disease since 2010?
2. Looking at the reforms to health and social care, what are
 - i. the biggest opportunities for tackling liver disease?
 - ii. the biggest threats to tackling liver disease?
3. What support do different organisations need in improving liver disease outcomes? [For example, commissioners, providers, GPs, prisons, drug action teams]
4. What opportunities do you see for early diagnosis and/or prevention of liver disease?
5. How can we avoid unwarranted variation in liver disease outcomes across England?
6. Can you give examples of where a part of the pathway is working well in an area, or where it is not?

Appendix ii: List of written evidence submissions

1. Institute of Alcohol Studies
2. Alcohol Concern
3. Alcohol Health Alliance
4. Boehringer Ingelheim
5. Bristol-Myers Squibb (BMS)
6. British Liver Trust
7. British Society of Gastroenterology (BSG)
8. Department of Health
9. Dr Iain Brew, GP at HMP Leeds and GSPI in hepatitis C
10. Dr Ulrich Thalheimer, Consultant Gastroenterologist & Hepatologist, Royal Devon & Exeter NHS Foundation Trust
11. Dr Michael Glynn, National Clinical Director for GI & Liver Diseases
12. Dr Karen Lowton, Institute of Gerontology, Kings College London
13. Foundation for Liver Research
14. Gilead
15. MSD
16. Public Health England
17. Royal College of Physicians
18. Roche
19. The Hepatitis C Trust

See www.appghep.org.uk for the full evidence submitted.

Appendix iii: List of individuals who gave oral evidence to the Inquiry

Clinical evidence session (29 October 2013):

Professor Graham Foster, British Association for the Study for Liver Disease and consultant hepatologist at the Royal London

Dr Michael Glynn, National Clinical Director for GI and Liver Disease, NHS England and consultant hepatologist at the Royal London

Dr Mark Hudson, President of the British Association of the Study of the Liver, chair of the North East and North Cumbria Hepatology Network and consultant hepatologist in Newcastle

Professor Marsha Morgan, Institute for Alcohol Studies and consultant hepatologist at the Royal Free Hospital, London

Patient evidence session (29 October 2013):

Ms Susan McRae, hepatitis C patient and liver transplant recipient

Mr Martin Manning, auto-immune hepatitis patient

Mr Simon Marks, hepatitis B patient

Public Health England evidence session (7 November 2013):

Professor Paul Cosford, Director for Health Protection and Medical Director, Public Health England.

Rosanna O'Connor, lead for alcohol and drugs policy, Public Health England.

Dr Harry Rutter, Senior Strategic Adviser to Public Health England

Chief Medical Officer Evidence Session (11 November 2013):

Professor David Walker, Deputy Chief Medical Officer

See www.appghep.org.uk for full transcripts of the oral evidence sessions.

References

- ⁱ Clark et al., Public Health England, ‘Submission to the All Party Parliamentary Group on Hepatology Inquiry into improving outcomes from liver disease’, September 2013, p.1. Available at : www.appghep.org.uk
- ⁱⁱ NHS RightCare (2013) ‘Liver Disease: The NHS Atlas of Variation in Healthcare for People with Liver Disease’. [age-standardised deaths from chronic liver disease rose by 88% between 1993 and 2010]. Available at: <http://www.rightcare.nhs.uk/index.php/atlas/liver-disease-nhs-atlas-of-variation-in-healthcare-for-people-with-liver-disease/>
- ⁱⁱⁱ Department of Health (DH) Press release archive (20th October 2009) ‘Department of Health to develop National Liver Strategy’. Available at: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/MediaCentre/Pressreleasesarchive/DH_107304
- ⁱⁱⁱⁱ World Health Organisation: European Detailed Mortality Database ‘Mortality from Chronic Liver Disease and Cirrhosis by Age-Band 1997-2009’ in NHS RightCare (2013) ‘Liver Disease: The NHS Atlas of Variation in Healthcare for People with Liver Disease’. Available at: <http://www.rightcare.nhs.uk/index.php/atlas/liver-disease-nhs-atlas-of-variation-in-healthcare-for-people-with-liver-disease/>
- ^{iv} Dame Sally Davies at the Department of Health (DH) ‘Chief Medical Officer annual report 2011: volume 1, Chapter 2c’, p.163, November 2012. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/141773/CMO_Annual_Report_2011_Chapter_2c.pdf
- ^v Whilst NHS England has stated that it will not develop organ-specific strategies, there are already equivalent national strategies for the other ‘big killers’ of cancer and cardiovascular disease, respiratory disease and stroke:
- » Department of Health (DH) (2013) ‘Cardiovascular Disease Outcomes Strategy: Improving outcomes for people with or at risk of cardiovascular disease’. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/217118/9387-2900853-CVD-Outcomes_web1.pdf
 - » Department of Health (DH) (2011) ‘Improving Outcomes: A Strategy for Cancer’. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213785/dh_123394.pdf
 - » Department of Health (2011) ‘An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England’. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216139/dh_128428.pdf
 - » Department of Health (2007) ‘National Stroke Strategy’. Available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081059.pdf
- ^{vi} Verne, J., National end of life care intelligence network, ‘Deaths from Liver Disease: Implications for end of life care in England’, 2012. Available at: <http://www.endoflifecare-intelligence.org.uk/view?rid=245>
- ^{vii} World Health Organisation: European Detailed Mortality Database, ‘Mortality from Chronic Liver Disease and Cirrhosis by Age-Band 1997-2009’, September 2013. Available at: <http://data.euro.who.int/dmdb/>
- ^{viii} Clark et al., Public Health England, ‘Submission to the All Party Parliamentary Group on Hepatology Inquiry into improving outcomes from liver disease’, September 2013, p.1. Available at : www.appghep.org.uk
- ^{ix} Department of Health (DH) ‘Improving Outcomes and supporting transparency. Part 1: A public health outcomes framework for England, 2013 – 2016’, p.8, 2012. Available at: <https://www.rcpsych.ac.uk/pdf/The%20Public%20Health%20Outcomes%20Framework.pdf>
- ^x Clark et al., Public Health England, ‘Submission to the All Party Parliamentary Group on Hepatology Inquiry into improving outcomes from liver disease’, September 2013, p.1. Available at : www.appghep.org.uk
- ^{xi} British Society of Gastroenterology (BSG) ‘Chronic management: Management of patients with Chronic liver disease’, 2009. Available at: <http://www.bsg.org.uk/clinical/commissioning-report/management-of-patients-with-chronic-liver-diseases.html>
- ^{xii} Home Office, ‘Next steps following the consultation on delivering the Government’s alcohol strategy’, July 2013, p.5. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/223773/Alcohol_consultation_response_report_v3.pdf
- ^{xiii} Public Health England, ‘Slide sets for adult and child obesity’. Available at: http://www.noo.org.uk/slide_sets
- ^{xiv} ONS, ‘Mortality Statistics: Deaths Registered in 2012 (Series DR) Table 5’ in ‘Mortality Statistics: Deaths Registered in England and Wales

(Series DR)', 2012. Available at: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-325289>

^{xv} The Hepatitis C Trust, 'The Uncomfortable Truth: Hepatitis C in England. The State of the Nation', p.5, October 2013. Available at: <http://www.hepctrust.org.uk/Resources/HepC%20New/The%20Trust/The%20Uncomfortable%20Truth.pdf>

^{xvi} Department of Health (DH) Press release archive, 'Department of Health to develop National Liver Strategy', 20th October 2009. Available at: http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/MediaCentre/Pressreleasesarchive/DH_107304

^{xvii} Hansard: Written Answers, 'Liver Diseases: Health Services', 1st November 2010. Available at: <http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm101101/text/101101w0006.htm#10110231001440>

^{xviii} Hansard: Written Answers, 'Hepatitis: Health Services', 29th November 2011. Available at: <http://www.theyworkforyou.com/wrans/?id=2011-11-29b.83366.h>

^{xiv} Prime Minister's Office: 10 Downing Street, 'PM's message of support for World Hepatitis Day', July 2011. Available at: <https://www.gov.uk/government/news/pms-message-of-support-for-world-hepatitis-day>

^{xx} Hansard: Written Answers, 'Liver Diseases: Health', 26th April 2012. Available at: <http://www.theyworkforyou.com/wrans/?id=2012-04-26a.105315.h>

^{xxi} Hansard: Written Answers, 'Liver Diseases', 4th November 2013. Available at: <http://www.publications.parliament.uk/pa/cm201314/cmhansrd/cm131104/text/131104w0003.htm>

^{xxii} NHS RightCare, 'Liver Disease: The NHS Atlas of Variation in Healthcare for People with Liver Disease'. [age-standardised deaths from chronic liver disease rose by 88% between 1993 and 2010], 2013. Available at: <http://www.rightcare.nhs.uk/index.php/atlas/liver-disease-nhs-atlas-of-variation-in-healthcare-for-people-with-liver-disease/>

^{xxiii} British Society of Gastroenterology and Bolton NHS Foundation Trust, 'Alcohol Care Teams: reducing acute hospital admissions and improving quality of care', September 2012. Available at: <http://arms.evidence.nhs.uk/resources/qipp/29420/attachment>

^{xxiv} Home Office Parliamentary Under-Secretary Response to Oral Question, 1st December 2005. Available at: c762W: http://www.publications.parliament.uk/pa/cm200506/cmhansrd/vo051201/text/51201w31.htm#51201w31.html_wqn1

» Health Protection Agency (July 2012) 'Hepatitis C in the UK: 2012 Report'. Available at: http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1317135237627

^{xxv} Clark et al., Public Health England, 'Submission to the All Party Parliamentary Group on Hepatology Inquiry into improving outcomes from liver disease', September 2013, p.1. Available at : www.appghep.org.uk

^{xxvi} National Confidential Enquiry into Patient Outcome and Death (NCEPOD), 'Measuring the Units: A review of patients who died with alcohol-related liver disease. Summary', 2013, p.14. Available at: http://www.ncepod.org.uk/2013report1/downloads/Measuring%20the%20Units_summary%20report.pdf

^{xxvii} PROMs – The King's Fund, 'Getting the most out of PROMs: Putting health outcomes at the heart of NHS decision-making', 2010. Available at: <http://www.kingsfund.org.uk/sites/files/kf/Getting-the-most-out-of-PROMs-Nancy-Devlin-John-Appleby-Kings-Fund-March-2010.pdf>

PREMs - Cornwell, J., 'Designing the future: approaches to measuring patient experience'. Available at: <http://www.kingsfund.org.uk/sites/files/kf/ISQua-poster-glenn-robert-jocelyn-cornwell.pdf>

^{xxviii} NHS North East, 'Liver – The clinical network', 2014. Available at: <http://www.cnne.org.uk/liver---the-clinical-network>

^{xxix} Cebolla, B., and Bjornberg, A., 'Euro Hepatitis Index 2012 Report'. Health Consumer Powerhouse, p.5, 2012. Available at: http://www.hepatitisscotland.org.uk/files/9713/5297/7968/Report_Hepl_HCP_121103.pdf

