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



An Update Briefing from the All-Party Parliamentary Hepatology Group (APPHG), October 2015

In March 2014, the All-Party Parliamentary Hepatology Group (APPHG) released the report of its inquiry into outcomes in liver disease, entitled 'Liver Disease: Today's Complacency, Tomorrow's Catastrophe'. On the basis of evidence the APPHG had received from royal colleges, clinicians, charities, patients, industry and Government bodies, the report highlighted the catastrophic consequences of failing to act immediately to reverse the rising tide of liver disease, and made a number of recommendations.

Nineteen months on from the 2014 Liver Inquiry, the APPHG has taken a look at how far we have come in terms of policy action to address liver disease. For the purposes of this briefing, the APPHG consulted organisations that had submitted written evidence to the 2014 inquiry, including Public Health England (PHE), Alcohol Concern, the British Liver Trust and the Alcohol Health Alliance, to gather their perspectives on progress in addressing liver disease since March 2014.

Liver Disease Framework

A key recommendation of the APPHG's 2014 inquiry report concerned the need for clear recognition of liver disease as a priority area for action by all Government health bodies, with a taskforce initiated to coordinate a national approach to addressing liver disease and its major causes of alcohol, obesity and viral hepatitis. This call to policy action stemmed from the clear evidence received on rising premature morbidity and mortality from liver disease, in contrast to the situation in the rest of Europe, with liver disease containing the potential to become the UK's biggest killer within a generation. The 2014 report also emphasised the fact that – as a major cause of premature deaths among the most disadvantaged in society - liver disease must be addressed if we are to tackle health inequalities, as prioritised under the Health and Social Care Act of 2012. Given the clear evidence that stakeholders submitted to the inquiry regarding the patchy nature of service provision across the country, late diagnosis of patients and a lack of the necessary drive and prioritisation, the APPHG continues to view the development of an extensive and coordinated national approach to liver disease as a vital requirement. The APPHG welcomes the fact that PHE has since committed to producing a Liver Disease Framework, which it says will 'describe its activities to tackle liver disease'.

Within an update submitted to the APPHG in October 2015, PHE noted that:

"Since the launch of the All Party Parliamentary Hepatology Group Inquiry report in March 2014 Public Health England (PHE) has identified liver disease as a public health priority...'"

Public Health England, October 2015

As well as outlining some of PHE's current programmes designed to address the key risk factors for liver disease and highlighting its publication of data and intelligence on liver disease (for example its Liver Disease Profiles, to be updated in December 2015), PHE wrote:

"PHE has... committed to producing a Liver Disease Framework" which is wide in scope, covering 'cradle to grave' with specific activities including "antenatal testing of pregnant mothers for Hepatitis B with immunoglobulin treatment and vaccination for babies born to Hepatitis B virus positive mothers, through to end of life care for patients dying from liver disease. The scope also ranges from laboratory to local authority, including identification of new strains of hepatitis virus through Local Authority Liver Disease Profiles."

Public Health England, October 2015

The APPHG judges it to be essential for the upcoming Liver Disease Framework to contain concrete targets and benchmarks by which progress can be measured, as well as having the clear backing of NHS England and the Department of Health, in order to drive meaningful change in reducing liver disease deaths and place the country back in line with its European neighbours.

Evidence submitted to the APPHG in October 2015 by a number of organisations also suggests that there is a need for enhanced communication with all relevant stakeholders around the liver disease framework, with opportunities provided to review and input into drafts of the framework, and clear information given on its expected release date. Whilst it was initially promised that a Liver Disease Framework would be produced by summer 2015, a written answer to a Parliamentary Question - tabled in July 2015 by the APPHG's Co-Chair Baroness Randerson - subsequently stated that a Liver Disease Framework would be published in autumn 2015. iii Most recently, in evidence submitted to the APPHG in October 2015, PHE has suggested that the framework will be produced later this year. Concern was expressed by some of the stakeholders consulted in October 2015 that a draft has not been shared more widely to date:

"Despite any recent progress, there is currently no national strategy designed to coordinate an effective response to the growing burden of liver disease. Plans to publish a National Liver Strategy have seemingly been put on hold, and the policy with the strongest evidence of effectiveness in tackling deaths from liver disease, Minimum Unit Pricing (MUP), has been abandoned from the Government's Alcohol Strategy. The AHA still believes an overarching framework for national action on liver disease is urgently required."

Alcohol Health Alliance, October 2015

Alcohol

In its 2014 inquiry report, the APPHG recommended that the Government implement a minimum unit price for alcohol of 50p per unit, in line with the recommendations of 70 leading alcohol and health related organisations. A number of organisations have expressed disappointment that these plans continue to be stalled in England, and the APPHG joins the Lancet Commission in its calls for evidence-based legislative measures – such as a MUP – to reduce alcohol consumption.

Looking to the devolved nations, the Scottish Government has made efforts to introduce minimum unit pricing for alcohol, though these plans have been delayed after appeals led by the Scotch Whisky Association. Despite the Alcohol (Minimum Pricing) (Scotland) Act being passed by the Scottish Parliament in June 2012, the proposals have yet to be put into practice due to ongoing legal challenges in the European Court of Justice. In Wales, as well as publishing a Liver Disease Delivery Plan in May 2015, the Government published draft legislation in July 2015 which would introduce minimum unit pricing for alcohol. The proposals, which are open for public consultation until December, follow a previous consultation on minimum alcohol pricing held as part of a wider Public Health Bill.

'There has been a 117% overall increase in alcoholic liver disease hospital admissions in England amongst the under 30 age group, rising to 400% in the north east of England, in the last decade. This is a crisis that requires urgent national action on liver disease delivered through evidence-based interventions'

Alcohol Concern, October 2015

Obesity

Several of the stakeholders who gave evidence to the APPHG's 2014 inquiry saw tackling obesity as a priority in order to prevent non-alcoholic fatty liver disease, and highlighted poor general awareness of the link between obesity and liver disease, despite a growing crisis. Many of those consulted also noted a worrying lack of clarity on what needs to be done to address the issue of obesity. The APPHG report also welcomed the creation of Public Health England as a potential opportunity to overturn this record, noting that '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 recent release by PHE of its report on 'Sugar Reduction: The evidence for action' indicates it is continuing to play an important role in providing the evidence base needed to address causes of liver disease such as obesity. Vii

The APPHG urges policy action to reduce sugar content in diet, and found in its recent consultation with stakeholders that awareness of obesity as a result of liver disease still needs to be raised, with – as in the case of alcohol-related liver disease – greater attention paid to screening and early intervention.

"Far more recognition needs to be given to liver disease being a significant result of obesity. More needs to be done around prevention and awareness, and those who are overweight or have type 2 diabetes should have their Liver Function Tests (LFTs) regularly monitored."

British Liver Trust. October 2015

Viral Hepatitis

The APPHG's 2014 inquiry report called for PHE and NHS England to set a goal of eliminating hepatitis C within the next 15 years, and to lay out joint plans for achieving this goal. As a result, a major focus of the APPHG's work since the launch of its report last year has been on calling for increased patient access in England to highly effective, curative new treatments for hepatitis C. Progress is underway in this area, with the National Institute for Health and Care Excellence (NICE) reaching a landmark decision in October 2015 to make a range of these treatments available to many more patients on the NHS.

However, whilst recent treatment access decisions represent a very welcome development, the elimination of hepatitis C as a serious public health concern will not be possible without increased testing, awareness and joined-up working locally to improve pathways to treatment on the ground, facilitated by national strategic policy direction. To the disappointment of the APPHG and members of the Hepatitis C Coalition, there remains a notable lack of such a strategy for hepatitis C. The improvement framework for hepatitis C, which was first drafted in summer 2014, officially announced in July 2014 within PHE's 'Hepatitis C in the UK report' and subsequently promised for release in spring 2015,**xi* is still to be published. A recent written answer to a Parliamentary Question tabled by Liz McInnes MP, Vice-Chair of the APPHG, suggests that no new timeframe has been committed to for the framework's release: 'a publication date for the hepatitis C framework has not yet been confirmed...'*Xiii

In contrast, important policy lessons can be taken on board from Scotland, as an internationally recognised exemplar of good practice in efforts to tackle hepatitis C.xiiixiv In September 2015, the Scottish Government launched its Sexual Health and Blood Borne Virus Framework to drive viral hepatitis strategy in Scotland up to 2020.xv The report builds on the country's highly acclaimed hepatitis C action plan of 2014, and makes an over-arching pledge to eliminate hepatitis C as a public health concern. Other commitments include:

- To increase by 20% the numbers of people being treated for hepatitis C each year for the next five years.
- To evaluate the potential and cost-effectiveness of a "population-based case-finding approach", i.e. screening based on age cohorts and/or areas of high hepatitis C prevalence.
- To deliver hepatitis C treatment to most people in a community setting.
- To introduce an 'opt-out' approach to blood borne virus testing in Scottish prisons.
- Achieve a 75% reduction in the annual number of people developing hepatitis C-related liver failure and/or liver cancer by 2020.

"With far more effective curative treatments now available to many more patients, there exists a landmark opportunity to eliminate hepatitis C as a serious public health concern in England. This opportunity must be seized by Government health bodies to avert future costs to the NHS and to prevent morbidity - as much as mortality - among some of the most disadvantaged in our society. We have the Operational Delivery Networks now in place to deliver treatment, but we urgently need the long promised national improvement framework for hepatitis C to ensure that patients are diagnosed and supported into the ODNs to get that treatment. The Hepatitis C Trust calls for the release of the framework immediately."

Charles Gore, Chief Executive, The Hepatitis C Trust, October 2015

Another area of viral hepatitis in which the APPHG continues to call for faster progress is in introducing a universal hepatitis B vaccination for infants, as recommended by the World Health Organisation. However, whilst the Department of Health's Joint Committee for Vaccination and Immunisation (JCVI) has recommended that hepatitis B be included in the UK infant vaccination programme subject to procurement at a cost-effective price, xvi the consensus from the organisations consulted by the APPHG is that progress has been slow in terms of implementing this, and the group hopes that the Liver Disease Framework due to be published soon will drive action forwards in this area.

"As Chairs of the All-Party Parliamentary Hepatology Group, we will continue to raise awareness in Parliament of the urgent need to fast-forward policy action to address all major causes of liver disease: alcohol, viral hepatitis and obesity. As our report of 2014 showed, we cannot afford to be complacent about its continued rise if we are to address health inequalities and reduce premature mortality."

Baroness Randerson,

Sir David Amess MP

Baroness Masham of Ilton

Co-chairs, All-Party Parliamentary Hepatology Group



The All-Party Parliamentary Hepatology Group is a group of MPs and Peers focused on tackling the growing problem of liver disease, by promoting discussion of hepatology including viral hepatitis and related public health issues - and raising matters of concern with government and policymakers. To join the APPHG as a member, please contact the secretariat at The Hepatitis C Trust, via grace.everest@hepctrust.org.uk.

 $\frac{http://www.appghep.org.uk/download/report/APPHG\%20Inquiry\%20into\%20Outcomes\%20in\%20Liver\%20Disease,\%20March\%202014.pdf$

^v The Scottish Government 'Minimum Pricing'. Available at: http://www.gov.scot/Topics/Health/Services/Alcohol/minimum-pricing

vi All-Party Parliamentary Hepatology Group (APPHG) (March 2014) 'Liver Disease: Today's Complacency, Tomorrow's Catastrophe: APPHG Inquiry into Outcomes in Liver Disease', p.17. Available at: http://www.appghep.org.uk/download/report/APPHG%20Inquiry%20into%20Outcomes%20in%20Liver%20Disease,%20March%202014.pdf

vii Public Health England (October 2015) 'Sugar reduction: from evidence into action'. Available at: https://www.gov.uk/government/publications/sugar-reduction-from-evidence-into-action

viii All-Party Parliamentary Hepatology Group (APPHG) (March 2014) 'Liver Disease: Today's Complacency, Tomorrow's Catastrophe: APPHG Inquiry into Outcomes in Liver Disease', p. 8, recommendation 9. Available at:

http://www.appghep.org.uk/download/report/APPHG%20Inquiry%20into%20Outcomes%20in%20Liver%20Disease,%20March%202014.pdf

ix The Hepatitis C Trust (October 2014) 'NICE announce criteria for access to Daklinza, Harvoni, Viekirax and Exviera'. Available at: http://www.hepctrust.org.uk/news/oct-2015/nice-announce-criteria-access-daklinza-harvoni-viekirax-and-exviera

x Public Health England (PHE) (July 2014) 'Hepatitis C in the UK 2014 report', p.6. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/337115/HCV_in_the_UK_2014_24_July.pdf

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xi Department of Health (March 2015) 'Living Well for Longer: One year on', p.39. Available at:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/416442/Living_Well_for_Longer
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xii Department of Health written question (tabled by Liz McInnes MP, answered by Jane Ellison MP on 12th

xii Department of Health written question (tabled by Liz McInnes MP, answered by Jane Ellison MP on 12th October 2015). Available on TheyWorkForYou at: http://www.theyworkforyou.com/wrans/?id=2015-09-17.10658.h&s=jane+ellison+hepatitis#g10658.r0

xiii Public Health England (PHE) (2014) 'Hepatitis C in the UK 2014 report', p.6. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/337115/HCV_in_the_UK_2014_24_July.pdf

xiv Health Consumer Powerhouse (2012) 'Euro Hepatitis Index: 2012 report', p.5 & p.14. Available at: http://www.healthpowerhouse.com/files/euro-hepatitis-index-2012/Report-Hepl-HCP-121104-2-w-Cover.pdf
xv Scottish Government (August 2015), 'Sexual Health and Blood Borne Virus Framework: 2015 – 2020
Update'. Available at: http://www.hcvaction.org.uk/sites/default/files/resources/SHBBV%20Framework 0.pdf

ⁱ All-Party Parliamentary Hepatology Group (APPHG) (March 2014) 'Liver Disease: Today's Complacency, Tomorrow's Catastrophe: APPHG Inquiry into Outcomes in Liver Disease', p.6. Available at: http://www.appghep.org.uk/download/report/APPHG%20Inquiry%20into%20Outcomes%20in%20Liver%20Disease,%20March%202014.pdf

ii Public Health England (October 2014) 'From evidence into action: opportunities to protect and improve the nation's health'. Available at: https://www.gov.uk/government/publications/from-evidence-into-action-opportunities-to-protect-and-improve-the-nations-health

iii Department of Health written question (tabled by Baroness Randerson, answered on 9th July 2015 by Lord Prior of Brampton). Available on TheyWorkForYou at: http://www.theyworkforyou.com/wrans/?id=2015-06-30.HL971.h&s=liver+disease+framework#gHL971.r0

iv All-Party Parliamentary Hepatology Group (APPHG) (March 2014) 'Liver Disease: Today's Complacency, Tomorrow's Catastrophe: APPHG Inquiry into Outcomes in Liver Disease', p.8, recommendation 7. Available at:

xvi Parliament.uk (written parliamentary question asked by Baroness Suttie on 15th September 2015, answered by Lord Prior of Brampton 15th September 2015), 'Hepatitis: Vaccination: Written question - HL2233'. Available at: http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Lords/2015-09-15/HL2233