



ALL-PARTY PARLIAMENTARY HEPATOLOGY GROUP

**Divided Nations:
Tackling the hepatitis C challenge across the UK**

*A report of a meeting of the All-Party Parliamentary Hepatology Group,
18 November 2008, House of Commons*

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1. Abbreviations

APPHG	All-Party Parliamentary Hepatology Group
BBV	Blood Borne Virus
DH	Department of Health
DNA	Did Not Attend (appointment)
GP	General Practitioner
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HPA	Health Protection Agency
HPS	Health Protection Scotland
IDU	Injecting Drug User
MCN	Managed Care Network
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NPHSW	National Public Health Service for Wales
NTA	National Treatment Agency
PCT	Primary Care Trust
QIS	NHS Quality Improvement Scotland

2. Acknowledgements

The All-Party Parliamentary Hepatology Group would like to thank Professor Goldberg, Dr Lyons and Professor Thomas for coming to the Palace of Westminster to present to the APPHG the approach to tackling hepatitis C taken by their respective countries, Scotland, Wales and England. The APPHG would like to extend thanks to Nicola Hill for chairing the meeting and to the hepatology stakeholders from around the country who joined the meeting and contributed to the discussion.

3. Executive summary

Hepatitis C is a public health time bomb, a cancer-causing infectious virus that is undiagnosed in the majority of the 250,000 to 466,000 people infected in the UK.ⁱ Health services in England, Scotland and Wales are all facing similar threats: increasing numbers of hospital episodes, increasing numbers of liver transplants required and increasing numbers of deaths. The virus can be successfully treated and cured in around half of patients, averting these complicated and costly health interventions and avoiding premature death. However, this requires that infections are diagnosed promptly and patients are given the option of treatment. England, Scotland and Wales have taken very different approaches to tackling this urgent public health challenge.

The Department of Health was first to respond to this challenge but the actions taken have not yielded the necessary results. The DH issued a Strategy for England in 2002 and then published an Action Plan for England in 2004. However, in previous research, the All-Party Parliamentary Hepatology Group found that most PCTs have only partially implemented the Plan and some have not implemented the Plan at all.ⁱⁱ Further, only 3% of patients are receiving treatment each year, GP awareness remains low despite a limited professional awareness campaign and infrastructure inadequacy is a major constraint.

The Scottish Government has responded to the public health challenge with the most comprehensive approach in the form of a two-phase Action Plan. Phase I (2006-8) largely focused on gathering evidence to inform and plan actions in Phase II. This research showed that the numbers of deaths from hepatitis C overtook deaths from HIV in the mid-1990s and that a step change in the numbers of people being diagnosed and treated was needed if Scotland was to flatten the mortality curve caused by the virus. To do this, Phase II of the Action Plan promises investment of £43 million in testing, treatment, care and support; prevention; information generating initiatives; and co-ordination. The intention is to increase the numbers of patients receiving treatment each year from less than 500 per year currently to 1,500 per year in 2011 and 2,000 per year thereafter. A strong governance structure has been established to ensure that the Action Plan is implemented and the necessary health outcomes are realised.

An Action Plan for Wales has been drafted but has not yet been published. Extensive research was conducted between 2004 and 2006 to inform this draft Blood Borne Viral Hepatitis Action Plan for Wales. It will tackle both hepatitis B and C through awareness raising and harm reduction; initiate developments to improve the number of diagnoses; and drive improvements in treatment and care pathways through nurse-led clinical networks. The Blood Borne Viral Hepatitis Action Plan for Wales was submitted to the Welsh Assembly Government in 2007 and the APPHG wishes to express its concern at the continuing failure to launch the Plan.

Analyses of the Action Plans and the presentations and discussion in the meeting have led the APPHG to make the following recommendations:

1. *Detailed planning*: Action Plans should include detailed, step by step actions, timelines and dedicated funding.
2. *Accountability*: Clear measures of performance – such as targets or benchmarks – are vital for effective implementation.
3. *Governance*: A robust governance structure is needed to ensure that organisations are in fact accountable for their performance. This should include regularly published progress reports.
4. *Managed Care Networks*: MCNs should be mandatory at a local NHS level to improve the patient pathway.
5. *Improved infrastructure*: Improvements in specialised hepatitis C and liver service infrastructure are required to meet the growing demand from hepatitis C and other liver patients.
6. *Addressing blood borne hepatitis viruses together*: There should be a co-ordinated approach to tackling hepatitis B and C as the same liver units provide treatment and care to these patients.

Therefore the APPHG calls for the following:

1. **The Welsh Assembly Government to publish its Action Plan at once.**
2. **The Department of Health in England to launch a new strategy for hepatitis C as part of a comprehensive liver strategy, taking into account the recommendations above.**
3. **The Scottish Government to continue with the implementation of its Action Plan, to include hepatitis B in the future and to look at the English public awareness campaign.**

4. Background to the meeting

Hepatitis C is a public health time bomb with up to 466,000 people infected with the virus across the UK.ⁱⁱⁱ This is a serious national health problem, often referred to as a 'silent killer', as the disease primarily attacks the liver and can lead to severe and potentially fatal liver disease and cancer, yet is very often asymptomatic. As a result most infected people are undiagnosed at present. Hepatitis C disproportionately affects disadvantaged, vulnerable and socially excluded groups. Research in Scotland shows that 75% of diagnosed patients are from the two most deprived socio-economic quintiles.

Treatment is available that can eradicate the virus in around half of patients but only a very small proportion of individuals who could benefit from the treatment are receiving it. If left untreated, chronic hepatitis C can lead to complex liver diseases that require expensive and complicated interventions such as liver transplants. If nothing is done to diagnose and treat patients, the future burden of the disease on UK-wide health care services is estimated to be between £4 and £8 billion.^{iv}

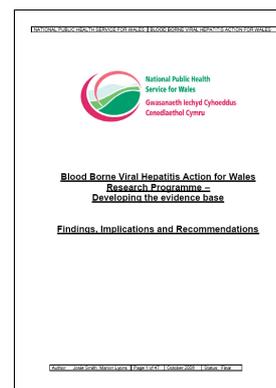
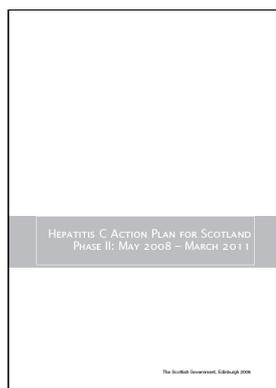
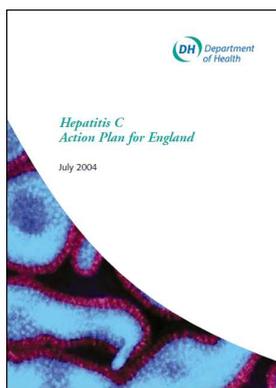
In response to this public health challenge, national Governments in England, Scotland and Wales have all taken radically different approaches. The All-Party Parliamentary Hepatology Group convened a meeting to explore the impact of the different national strategies. The meeting provided an opportunity for Parliamentarians, experts and stakeholders to compare and contrast the effectiveness of each approach and identify areas of best practice, which can be shared across national borders.

The APPHG heard from speakers from England, Scotland and Wales who described the strategy that each country had taken, the reasons why they had taken their approach and their plans for the future:

England: Professor Howard Thomas, Consultant Hepatologist at St Mary's Hospital London and Chairman of the Department of Health Steering Group on Hepatitis C National Strategy (2000-2004)

Scotland: Professor David Goldberg, Consultant in Public Health at Health Protection Scotland and Chair of the Scotland Hepatitis C Action Plan Governance Board

Wales: Dr Marion Lyons, Lead Consultant in Communicable Disease Control at the National Public Health Service for Wales and lead for the Blood Borne Viral Hepatitis Programme



5. Comparing the different approaches:

a. The context

Hepatitis C was discovered in the 1980s when it became apparent that there was a new virus causing liver damage that was neither hepatitis A nor hepatitis B. It was therefore known as non-A non-B hepatitis until it was properly identified in 1989. A screening process was developed in 1991 that made it possible to detect it in blood samples. It is thus a relatively newly identified disease and there are still many aspects of it that are little or poorly understood.

Prevalence differs between England, Scotland and Wales and also between areas within each country. In government estimates Scotland has the highest prevalence rate of chronic hepatitis C of 0.8%; England has an estimated prevalence of 0.5%; and Wales has an estimated prevalence of 0.4%. Other estimates have put the prevalence in England closer to that of Scotland.^v Whatever the correct prevalence, all three countries are facing similar disease trends: increasing numbers of HCV-related liver failure, increasing numbers of hospital bed days associated with HCV-related liver failure and increasing numbers of deaths from hepatitis C. They all report low public and professional awareness about the disease and the majority of infected people in each country have not yet been diagnosed.

No country has made a confident estimation of the current incidence rate of hepatitis C. However, the Health Protection Agency has undertaken back-calculations from the observed trends in severe HCV related liver disease that suggests that there was an increase in incidence in England until the late 1980s, peaking at around 14,900, and then plateauing at around 12,000 in the mid-1990s. This back-calculation method does not allow for more recent incidence estimates. Estimates of more recent incidence amongst IDUs have varied widely, with the lowest estimate suggesting that only 3 per cent, and the highest suggesting that almost 42 per cent, of susceptible injectors become infected each year.^{vi}

b. Research

Health Protection Scotland and the National Public Health Service for Wales both spent two years conducting research in order to develop an evidence base to inform the actions in their respective Action Plans.

The focus of Phase I of the Scottish Action Plan (2006-8) was on evidence generation and, as part of this, HPS engaged service providers through questionnaires and focus groups, analysed existing laboratory and clinical databases and reviewed scientific literature. The individual actions of Phase II of the Action Plan are therefore based on evidence of effectiveness.

Between 2004 and 2006, NPHSW conducted extensive research into drug service users and providers which included a needs assessment of substance misuse services across Wales and questionnaires and interviews conducted with GPs, community drug teams, clinical nurse specialists and consultants.

One of the four key action areas in the Action Plan for England was improved surveillance and research so that trends in hepatitis C infection and the effectiveness of prevention measures can be monitored. This epidemiological research has been published annually by the HPA since December 2005. Whilst the HPA provides robust epidemiological data for England, it is evident that there has been less qualitative research conducted into the views and needs of service providers and users in England than in Scotland and Wales.

c. Care pathways and Managed Care Networks (MCNs)

The care pathway for hepatitis C patients has, in the past, been unclear and many patients have been lost after their diagnosis. For example, research in Nottingham between 2000 and 2002 showed that, of 256 anti-HCV positive patients, only 125 were referred appropriately for further management. Of these 68 attended clinic, 45 underwent liver biopsy, and only 26 began treatment.^{vii}

The Action Plan for England states that Chief Executives of PCTs and NHS Hospital Trusts 'should be able to demonstrate that there are adequate services and partnerships at a local level to enable models of best clinical practice to be followed', including the development of clinical networks and local protocols between primary and secondary care centres to ensure complete patient pathways that encompass testing, referral and treatment services. However, an audit of PCTs published by the APPHG in 2008

showed that 44% of responding PCTs did not have a hepatitis C clinical network and a third of responding PCTs did not have a protocol for hepatitis C testing or screening.

The Action Plan for Scotland takes a multi-disciplinary approach to tackling hepatitis C, establishing several local and national networks comprising representatives from all relevant disciplines and organisations. Each NHS Board will have, or be affiliated to, a MCN comprising of representatives from a wide range of stakeholder groups and organisations, including the Prison Service, the Local Authority, social work, the voluntary sector, mental health, addiction services and patients, to ensure a smooth patient pathway. To support the development of patient pathways and to allow effective audit, NHS Quality Improvement Scotland will develop standards for the treatment, care and social support of persons with hepatitis C infection.

Although the Welsh Action Plan has not yet been published, Dr Lyons explained that the draft contains plans for the development of nurse led clinical networks and clearly defined referral and care pathways for primary care. The development of testing and treatment in community settings, where appropriate, will help more patients to access testing, treatment and care.

d. Resources and infrastructure

The Action Plan for England does not contain direct investment in hepatology infrastructure. Professor Thomas explained that hepatology networks are not adequately structured and resourced: many do not have a formal link with hepatology commissioners; anti-viral nurses are in short supply; and delivery of care to injecting drug users and ethnic minority groups needs attention.

The Scottish Government announced serious investment of £43 million over the next three years for the implementation of Phase II of their Action Plan. This will support a three to four fold increase in the numbers of patients receiving treatment per year by 2011, paying for the development of infrastructure and the treatment required.

The details of the plans for infrastructure development and investment in the Action Plan for Wales have not yet been published.

e. Treatment and commissioning

All three speakers at the meeting identified the low proportion of patients accessing treatment as a problem for their national health services.

There are no targets for treatment in the Action Plan for England. Since the publication of the Action Plan in 2004, commissioning has become an increasingly important part of service delivery and management for local health services. Professor Thomas recommended that the commissioning of liver services should be improved. Similarly, in the 2008 APPHG audit of hepatitis C services, most low scoring PCTs felt that more detailed guidance on hepatitis C commissioning would help them to improve their services.^{viii}

The Action Plan for Scotland has set a national target for numbers of people receiving treatment per year to rise from the current rate of around 450 per year to 1000 in 2009/10, 1,500 in 2010/2011 and at least 2,000 per year thereafter. It requires NHS Boards to commission services accordingly.

f. Prevention and public awareness

Prevention is a key plank of the Action Plans for Scotland and England and of the draft Action Plan for Wales. Efforts to improve the quality and quantity of needle exchange services are emphasised in all three countries. Similarly, although to different extents, all three Action Plans provide for educational interventions aimed at vulnerable individuals such as people entering young offenders' establishments.

In addition, the Action Plan for England contained actions for the Department of Health to develop information about avoiding hepatitis C infection abroad and for the NTA to carry out a national audit of needle exchanges.

The Action Plan for Scotland mandates each NHS Board to have, or be affiliated to, a network covering the prevention of hepatitis C. National guidance for services providing injection equipment to IDUs will

be developed and services will be improved in line with these. The plans for preventing more infections include a pioneering pilot of an in-prison needle/syringe exchange initiative.

The Department of Health has been running a public awareness campaign in England since 2003 and has recently committed to a new three-year awareness campaign to encourage people who have been at risk to get tested. Governments in Scotland and Wales, who have not yet started public awareness work, can learn from the experiences and successes of the English awareness campaign.

g. Other Blood Borne Viruses

Only the Welsh Government is taking a holistic approach to tackling blood borne hepatitis viruses in their Action Plan: they are planning to publish a Blood Borne Viral Hepatitis Action Plan for Wales that will tackle both hepatitis B and C.

Whilst hepatitis B and C are very different viruses that present different challenges for the NHS, they share many routes of transmission and cause similar liver disease so there are many overlapping issues that could be most efficiently tackled together. These include prison health, transmission through injecting drug use and infrastructure since, crucially, it is the same liver units in hospitals that provide the care, monitoring and treatment for both.

h. Monitoring, evaluation and governance

The governance structure in the Action Plan for England is simply that 'Strategic Health Authorities will ensure that local NHS arrangements are in place to achieve the objectives of this action area.'^{ix} There are no further formal monitoring or evaluation measures of the implementation of the Action Plan at either national or local level. Indeed, following anecdotal evidence from clinicians and patients that the Action Plan was not being implemented, the APPHG conducted an audit of PCTs in 2006 and found that only 8% of responding PCTs were effectively implementing the Action Plan.^x

The lack of monitoring and governance arrangements for the Action Plan for England emerged as a key problem in the meeting. Professor Thomas held that, as there are no targets in the Action Plan, strong monitoring and governance of implementation action is vital.

In contrast, the implementation of the Action Plan for Scotland will be monitored locally and information will be fed into HPS. This will be supported by the Action Plan Information Generating Initiatives Network and the Hepatitis C Clinical Database Monitoring Group. Further, the governance structure set out in the Action Plan for Scotland is robust:

"An Action Plan Governance Board, comprising all Hepatitis C Executive Leads and the Leads of each National Network will be established to ensure that the Action Plan is being implemented in a timely, effective and efficient manner by monitoring operational progress (including spend) and the performance of actions, and identifying and addressing potential and evolving high level problems.

The Board will be presided over by HPS and will report its findings to the Scottish Government, representatives of which will attend in an observer capacity."^{xi}

Progress and available NHS Board data will be published in Annual reports starting in May 2009.

Whilst the detail of the Action Plan for Wales has not been published, Dr Lyons explained that there should be monitoring and evaluation at all stages of the process and a comprehensive surveillance system will be established.

6. Summary of presentations

Introduction from Bob Laxton MP, Co-Chair of the All-Party Parliamentary Hepatology Group

Bob Laxton MP welcomed MPs, Peers, speakers and stakeholders and explained that the APPHG has been prodding and prompting the Department of Health for more action on hepatitis C and liver disease since 2005. He explained that it is vital that hepatitis C is tackled in the most effective way possible and he hoped that the meeting and following report would stimulate a constructive debate about how policy can be improved in every nation in the UK.

a. Presentation by Professor Howard Thomas on the implementation of the Hepatitis C Action Plan for England: current position and future needs

Professor Thomas was Chairman of the Department of Health Steering Group on Hepatitis C National Strategy (2000-4) that developed the Action Plan for England (2004) alongside the Department.

The Action Plan has four main action areas: surveillance and research; increasing awareness; managed clinical networks (MCNs) to deliver NICE recommended anti-viral therapy; and prevention. It is devoid of targets except for the soft target to identify an increasing number of hepatitis C cases each year.

Surveillance and research

The Health Protection Agency produce an annual report on hepatitis C in England covering the current and projected burden of disease. It shows that the numbers of people tested and the numbers of cases identified each year have generally increased since the publication of the Action Plan. Now, around 80,000 of the estimated people infected with hepatitis C have been diagnosed. The prevalence of the virus differs around the country and is highest in the North West and London.

Increasing awareness

The Action Plan aims to improve public and professional awareness of the virus. A survey of GPs showed that some confused hepatitis C and HIV and many didn't know the difference between hepatitis A, B and C. As a result, in 2004 the Department of Health ran an awareness campaign involving 6 events around the country. This made some improvements but there is still a long way to go.

The pool of infection is increasing, and while drug treatment centres are getting better at finding cases, people who may have become infected through dabbling with drugs in the past or through other routes are still not being successfully identified.

Managed Clinical Networks to deliver NICE recommended anti-viral therapy

The delivery of NICE recommended treatment relies on three things: improved diagnosis rates, infrastructure to support patients through treatment and the availability of the anti-viral drugs.

NICE recommends that treatment for mild, moderate and severe hepatitis C is cost-effective and should be given to all patients. However, implementation is not monitored at a PCT level. Indeed, only around 3% of diagnosed patients are receiving antiviral treatment each year. Patients often have other health, social and emotional problems so may need customised treatment and support.

Infrastructure, rather than availability of the anti-viral drugs, often limits treatment numbers. For example, at St Mary's hospital in London a new liver unit has been built, funded by charitable donations, and the number of specialist hepatology nurses has increased from 2 to 8 but the demand is still there for them to increase service provision further. The new generic 18-week (from referral to treatment) target will be useful in ensuring patients are treated in a suitable timeframe.

Prevention

The most at-risk population group is injecting drug users. These people are hard to access although many will, at some point in their lives, go through the prison service. Therefore prisons present an excellent opportunity to diagnose and educate current patients and prevent at-risk people from becoming infected in the future.

The first generation South Asian migrant population have a relatively high prevalence rate due to healthcare in their home countries. The DH is therefore working on raising awareness amongst this population group and is considering a proposal to screen migrants from all countries where there is an indigenous prevalence of 2% or more.

As the Action Plan was published over four years ago, new developments and actions are needed:

- Specialist commissioning for liver services should be introduced, as is already in place for cardiology, oncology and renal services.
- Managed clinical networks should be better structured and resourced; many do not have a formal link with hepatology commissioners; anti-viral nurses are in short supply and the networks need to be better financed and quality controlled.
- Managed clinical networks should cover all hepatology issues as there are important inter-relationships between hepatitis C, alcohol and obesity.
- Strategic Health Authorities and the Health Care Commission must audit the results and volume of care delivered to patients through PCTs and managed clinical networks.
- Managed clinical networks should be linked nationwide for audit and research purposes.
- Hepatitis C disproportionately affects socially disadvantaged groups and ethnic minorities. If the Healthcare Commission is looking at any disease area, it should be this one.

b. Presentation by Professor David Goldberg on the Hepatitis C Action Plan for Scotland

There have been two phases to the Hepatitis C Action Plan for Scotland so far and the second of these phases was launched in May 2008. Both phases aim to improve the diagnosis and care of current patients and to prevent further infections.

Phase I (September 2006 to March 2008)

Phase I of the Action Plan contained 41 actions that largely focused on gathering evidence to inform Phase II Actions and develop the Phase II Action Plan. A governance structure was established to oversee the Actions and some educational materials were produced for professionals and HCV infected people.

The evidence gathering activities involved engaging service providers through questionnaires and focus groups, analysing existing data from laboratories and clinical databases, reviewing scientific literature and undertaking analytical initiatives to estimate the current and future burden of HCV and the impact of therapy. A picture of the epidemiological landscape was developed, revealing an estimated 38,000 people living with the virus in Scotland (0.8% of the population), of whom 14,800 had been diagnosed. Only 2,000 of these people had ever received antiviral treatment.

The research showed cases of HCV related liver failure were increasing and the number of HCV related deaths overtook those from HIV in the mid 1990s. It also highlighted the relationship between deprivation and the virus: 75% of hepatitis C patients were from the two most deprived socio-economic quintiles.

Phase II (May 2008 – March 2011)

Phase II of the Action Plan was launched in May 2008 based on the extensive evidence generated in Phase I and stakeholder engagement. Proposals for Phase II were shared with 200 stakeholders who were asked to approve or disapprove actions using a digital vote.

Phase II adopts a multidisciplinary approach to tackling hepatitis C, embracing all relevant services such as schools, prisons, the voluntary sector, local authorities and NHS Boards. It is a high level plan that allows NHS Boards to take different measures according to their local needs and epidemiologies. It covers all geographical areas and settings, addresses inequalities and is supported by serious investment of £43million over the three years of its implementation. The investment is split between testing, treatment, care and support; prevention; information generating initiatives; and co-ordination. It will be performance managed through information generating and data sharing initiatives.

Phase II consists of 34 Actions that can be summarised in the 3 key areas:

- Prevention: To reduce incidence of infection to less than 10% among all IDU populations by providing guidelines for injection equipment provision and improving injection equipment services in accordance with these guidelines.^{xii}
- Diagnosis: To diagnose the great majority of the infected population by 2011 through awareness raising campaigns and innovative approaches to improve testing and referral activities by GPs and other community setting practitioners.
- Treatment and care: To increase the number of people receiving treatment per year to 1500 by 2011 (this is currently 450) through the creation of Managed Care Networks in all NHS Boards, developing and training the workforce, and developing services to treat an increased number of patients.

Robust governance arrangements lie at the heart of Phase II of the Action Plan for Scotland. There will be national networks for all of the supporting organisations so they can share best practice and develop project plan templates. These will report on progress to the Lead Organisations (NHS Boards, Health Protection Scotland, Scottish Prison Service, etc), which have been given funding to implement specific parts of the plan. The Lead Organisations are directly accountable to the Action Plan Governance Board who will report on progress directly to the Scottish Government.

c. Presentation by Dr Marion Lyons on the development of the Blood Borne Viral Hepatitis Action Plan for Wales

The Welsh Blood Borne Viral Hepatitis Action Plan is soon to be published. When the Action Plan for England was published in 2004, the National Public Health Service for Wales realised that there was very little understanding of the situation in Wales. Therefore in 2004 a Blood Borne Viral Strategy Group was convened to design and implement a research programme to inform a strategy for Wales. The research was completed in 2006 and a conference was held to discuss the findings. In 2007 a draft Action Plan was submitted to the Welsh Assembly Government.

The initial research involved questionnaires, surveys and interviews to service providers such as clinical nurse specialists, consultants, community drug teams and all GPs. This found that awareness was low, for example 30% of GPs did not think that hepatitis C was an issue for their populations. A study of current IDUs in South Wales was undertaken. A needs assessment of health and substance misuse services across Wales was carried out alongside a qualitative study on needle and syringe exchange provision and barriers to use. Research to inform prevalence estimates found a lower prevalence than in the rest of the UK of around 0.4% in Wales (around 14,000 people) compared to around 0.5% in England and 0.8% in Scotland.

The key findings of the research were:

- Three-quarters of the infected population were not diagnosed
- Homelessness increases the risk of transmission
- Substitution drug treatment service provision was inadequate
- Needle exchange services were patchy across Wales
- The coverage of specialist services needed to be improved
- The number of individuals undergoing antiviral treatment was unacceptably low (less than 100 people per year).

The research informed a Consensus Conference where the NPHSW engaged with stakeholders to prioritise where investment would be best placed. A public health approach to tackling the virus was favoured with high prioritisation given to:

- Strengthening health care services in prisons
- Developing networks of community and clinical staff to enable provision of treatment and support to patients in all community settings
- Ensuring equity of service provision in implementing the NICE guidance for treatment across Wales

Based on this research and consultation, an Action Plan was developed with three main strands:

- Awareness raising and harm reduction: targeted awareness raising and education for all at-risk groups and general awareness raising for the broader population to reach those who may have been at risk in the past. Strengthening of needle exchange services.
- Diagnosis: development and expansion of dried blood spot testing for BBVs in substance misuse services (with the aim of testing every IDU at least once a year) and encouraging awareness and diagnosis in Primary Care settings.
- Treatment and care pathways: development of nurse-led clinical networks, treatment where appropriate for the patient (such as in the community or prisons), clearly defined referral and care pathways for primary care, support staff to reduce DNAs, and increased availability of psychological and psychiatric support.

The draft Action Plan has a four-year time frame. It contains detailed actions and the necessary resources. There will be monitoring and evaluation at all stages of process and the establishment of a comprehensive surveillance system. The governance structure is accountable to the Health Minister and Chief Medical Officer. The NPHSW is looking at some innovative strategies to implement the Action Plan such as the introduction of specialist nurses who will work with the prison service and local clinical networks to ensure that the infected prison population are not lost. It is hoped that Ministerial approval to launch the Action Plan for consultation will be immediately forthcoming.

7. Question and answer session to the panel

a. Are there parts of the other countries' approaches that you would like to emulate?

Nicola Hill, chair of the meeting, asked all three panel members whether there were actions or approaches taken by the other two countries that they would like to copy.

Professor Goldberg said that the HPA had been doing some very useful work on the epidemiological front for England. He also commended the NHS in England for launching an Action Plan and starting awareness raising earlier than the other countries.

Professor Thomas thought that significant improvements were needed in England to the commissioning system and general hepatitis C infrastructure and that we could look to other countries for examples of success. He views the governance structure in the Action Plan for Scotland as vital to its success and stated that the governance structure for the Action Plan for England needs to be made stronger. Professor Thomas also identified a problem that all three countries have not yet solved: how to reach people who have used drugs in the past but now do not have any contact with drug services.

Dr Lyons emphasised the need for improved intelligence systems, surveillance and research collaboration across all three countries.

b. How will you improve professional awareness?

Dr Chris Ford, Clinical Director of Substance Misuse Management in General Practice, highlighted the common problem of poor diagnosis rates due to low professional awareness amongst GPs and proposed a RCGP Certificate Course for GPs to tackle this. She also proposed that IDUs should receive treatment as a matter of urgency as these are the people who are most likely to transmit the virus. To facilitate this she suggested that treatment should take place in GP practices in the community.

Professor Thomas agreed that the low numbers receiving treatment every year (around 4,000) mean that mortality from hepatitis C is projected to continue rising. He suggested improving involvement of addiction services to diagnose IDUs and ex-IDUs, and targeting first generation migrants. Further, diagnosis rates could be increased if GPs were remunerated for diagnosing HCV positive cases.

Professor Goldberg explained that the Action Plan for Scotland allows NHS Boards to introduce GP certificate courses and training if that is what the managed care network chooses as a way forward. A GP representative will be part of each managed care network.

c. Is the level of infectivity affected by the stage of the virus?

Baroness Masham of Ilton asked whether infectivity of the virus increased as a patient's liver disease worsened.

Professor Thomas clarified that the severity of liver disease caused by hepatitis C does not affect infectivity and that this was part of the reasoning behind NICE's recommendation that all cases of hepatitis C, including mild infections, should receive treatment.

d. What is happening to diagnosed people who are not receiving treatment?

Baroness Masham of Ilton asked what is happening to the thousands of people who have been diagnosed but who are not receiving treatment or accessing specialised services.

Professor Goldberg said that the Baroness had highlighted a huge challenge. In Scotland, managed care networks will be given funding to help get people into a care pathway where social services, drug and alcohol services, and other relevant organisations will work together to support the patient.

Professor Thomas emphasised that treatment can be very demanding for the patient (similar to chemotherapy) and that a higher positive response rate can be achieved with the help of psychiatrists and other care interventions. New drugs taken orally are being developed.. Available. within five years, they will make treatment in the community a much more viable option.

e. How is the Action Plan for England monitored and evaluated?

Charles Gore, Chief Executive of The Hepatitis C Trust, stated that monitoring and evaluation in the Action Plan for England is at best weak, containing one sentence saying that Strategic Health Authorities should ensure local NHS arrangements are in place. He asked whether governance was the key element that was missing from the Action Plan for England.

Professor Thomas agreed that monitoring of the Action Plan for England is weak. He stated that, as there are no targets in the Action Plan, the implementation should be monitored closely. Further, this monitoring should be made mandatory as most of the people that the Action Plan affects are from disadvantaged groups, such as ethnic minorities, IDUs and former IDUs, who do not have a strong collective voice.

f. Are targets the right thing?

Nicola Hill asked whether targets are the right approach to driving forward improvements in hepatitis C services.

Professor Goldberg explained that the targets in the Action Plan for Scotland are high level targets for the whole country and are not set at NHS Board level. This allows the Action Plan to be measurable while still allowing NHS boards to innovate and respond to issues locally.

Professor Thomas explained that when the Action Plan for England was being developed, he thought that targets were the right lever to effect change. However, he has since seen how targets can distort practice and priorities in the NHS. He now thinks that the NICE recommendation that treatment is cost effective, coupled with the generic 18-week NHS target (from GP referral to treatment) will be very effective at driving improvements in hepatitis C services so long as the nurse capacity and infrastructure are ready.

Charles Gore commented that, if the generic 18-week target is going to be a key driver in improving hepatitis C services in England, it shows that targets are indeed needed to ensure improvements in this area of healthcare.

g. How will you target at-risk people from disadvantaged groups?

Kate Jack, a hepatitis C nurse from the Windmill Practice in Nottingham, asked how the vulnerable disadvantaged groups, who are most at risk of having hepatitis C, will be targeted.

Professor Thomas thought that it will be difficult to access these groups for treatment until treatment can be administered orally and therefore in community settings.

Professor Goldberg explained that the fully funded multidisciplinary approach taken in the Action Plan for Scotland should allow for vulnerable and disadvantaged groups to be accessed. The governance structure will hold NHS Boards and other stakeholders to account.

Dr Lyons said she hopes that, once the Action Plan for Wales is being implemented, every IDU will be tested once a year through the development of community teams and improved investment in testing in community settings.

8. Recommendations

The All-Party Parliamentary Hepatology Group calls for the following actions:

1. The Welsh Assembly Government to publish its Action Plan at once.
2. The Department of Health in England to launch a new strategy for hepatitis C as part of a comprehensive liver strategy, taking into account the recommendations below.
3. The Scottish Government to continue with the implementation of its Action Plan, to include hepatitis B in the future and to look at the English public awareness campaign.

This first ever comparative analysis of the Action Plans for England and Scotland, and the available information on the anticipated Action Plan for Wales, has led the All-Party Parliamentary Hepatology Group to make the following detailed recommendations for action to tackle hepatitis C:

1. Detailed planning: Action Plans should include detailed, step by step actions and timelines together with clarification of who is responsible for each action in order to ensure successful implementation. The Action Plan for England is woefully short on detail and, as a result, responsibility for certain parts of the Plan are unclear. Delivery therefore often falls into gaps and becomes reliant on enthusiasm from individuals, resulting in patchy implementation. Much can be learnt from the level of detail in the Action Plan for Scotland, which assigns actions to organisations and gives clear timetables for implementation.

2. Accountability: Clear measures of accountability – such as targets or benchmarks – are vital for effective implementation. In areas of competing demand for limited resources, actions that do not have targets or clear accountability measures are often a lower priority for healthcare managers and practitioners. Targets were taken out of the Action Plan for England before publication and it is evident that, as a result, implementation has been patchy. It is hoped that the generic 18-week target from GP referral to treatment across the NHS will result in improved care for hepatitis C patients in England and it is worth noting the significance of the introduction of this target, even though it is not hepatitis C specific, in driving service delivery in this area. However, without further accountability measures, effective commissioning of hepatitis C services will be made more challenging. The Scottish target for increasing numbers of patients receiving treatment and the specific actions and targets for different organisations contained in the detail of the Plan will drive forward delivery.

3. Governance: A robust governance structure is needed to ensure that organisations are in fact accountable for their performance. This should include regularly published progress reports. It should be clear who is accountable for delivering each part of the Action Plan and this should ultimately be monitored by senior levels of government. The Action Plan for Scotland leads on this with actions for organisations set out with clear timescales which can be monitored and audited. The accountability structures set out the details of the monitoring and evaluation required from all organisations involved to the Action Plan Governance Board, which then reports to the Scottish Government.

4. Managed Care Networks: MCNs should be mandatory at a local NHS level, as they are in the Action Plan for Scotland. MCNs are key to enabling an improved care pathway for patients from primary to secondary and tertiary care. Professional awareness amongst GPs needs to be improved to increase diagnosis rates and diagnosed patients need to be promptly referred to a specialist. A co-ordinated multidisciplinary approach to patient care is vital as hepatitis C patients often have other social, emotional and psychological needs.

5. Improved infrastructure: Improvements in specialised liver service infrastructure are urgently needed to meet the growing demand from hepatitis C and other liver conditions. For example, more hepatology nurses, more consultants and more physical clinic space are needed. In Scotland, these needs will be met through dedicated investment secured in the Action Plan. In England these requirements will need to be met through world class commissioning of liver services.

6. Addressing blood borne hepatitis viruses together: The same liver units in hospitals provide the care, monitoring and treatment for both hepatitis B and hepatitis C patients. Therefore it would be more efficient for the viruses to be tackled together in an Action Plan, as is the case in the soon to be published Blood Borne Viral Hepatitis Action Plan for Wales. Similarly, in France a hepatitis C strategy was launched in 1999 but it became a blood borne viral hepatitis strategy from 2002 onwards.

Appendix 1: Speaker biographies

Nicola Hill (Chair)

Nicola Hill has been a journalist for more than 20 years. She began her career in newspapers, both local and national, before working on BBC and independent radio, and then Sky News where she became the first specialist correspondent. She has presented TV and radio programmes, and edited the health pages on Sky news online. She has been nominated for both an RTS award and a Sony award.

Professor Howard Thomas PhD FRCP FRCPath FMedSci.

Professor Howard Thomas is an Honorary Consultant General Physician and Hepatologist at St Mary's Hospital, Paddington. He was Chairman of the Department of Health Steering Group on Hepatitis C National Strategy (2000- 2004), playing a key role in the development of the Strategy and Action Plan. He now chairs the Department of Health's Advisory Group on Viral Hepatitis.

Howard is the Vice-President of the British Liver Trust, former President of the British Association of the Study of the Liver (BASL) and European Association of the Study of the Liver (EASL). He is the Editor of the textbook Viral Hepatitis, Founding Editor of the Journal of Viral Hepatitis and has published over 450 papers in the field of liver disease.

Professor David Goldberg DSc, FRCP (Gla, Ed & Lon), FFPH, FFTM RCPS (Gla)

Professor Goldberg is a Consultant in Public Health Medicine/Consultant Clinical Epidemiologist at Health Protection Scotland (HPS) and is an Honorary Professor of Public Health, University of Glasgow. He is administrative head of HPS's Group for Blood Borne Viruses, Sexually Transmitted Infections, Vaccine Preventable Diseases and Respiratory Infections and Lead on Hepatitis C and HIV programmes of work.

David is a former Henry Mechan Professor of Public Health, University of Glasgow and Deputy Director of Health Protection Scotland. He serves on several UK and Scottish committees and is involved in the postgraduate supervision/teaching of students affiliated to the University of Glasgow. He is the author of approximately 170 peer-reviewed articles and a holder of many grants from a wide range of funding bodies.

As Chair of Scotland's Hepatitis C Action Plan Co-ordinating Group, David led the co-ordination of Phase I of the Action Plan and will lead the co-ordination of Phase II during 2008-11 on behalf of the Scottish Government.

Dr Marion Lyons

Dr Marion Lyons is the Lead Consultant in Communicable Disease Control, leading the all Wales Health Protection Team within the health protection domain of the National Public Health Service. As well as this operational role, she also has responsibilities for leadership of two of the health protection programmes: the Blood Borne Viral Hepatitis Programme and the Sexual Health Programme.

Dr Lyons was appointed Consultant in Public Health Medicine to Sefton Health Authority in 1994, moving to Cardiff to take up her role of Consultant in Communicable Disease Control for Bro Taf Health Authority in 2000. Since 2004, Dr Lyons has been seconded part time to the Welsh Assembly Government as Director of Modernisation of HIV and Sexual Health Services.

Appendix 2: Links to the Action Plans

Hepatitis C Action Plan for England:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4084521

Hepatitis C Action Plan for Scotland, phase I:

<http://www.scotland.gov.uk/Publications/2006/09/15093626/0>

Hepatitis C Action Plan for Scotland, phase II:

<http://www.scotland.gov.uk/Publications/2008/05/13103055/0>

Blood Borne Viral hepatitis Action Plan for Wales:

www.wales.nhs.uk/sites3/page.cfm?orgid=457&pid=25483

Appendix 3 – Membership of All-Party Parliamentary Hepatology Group

David Amess MP – Joint Chair

Bob Laxton MP – Joint Chair

Dr Brian Iddon MP – Vice Chair

Tim Boswell MP

James Brokenshire MP

Dr Vincent Cable MP

Jim Cousins MP

Jim Dobbin MP

David Drew MP

Neil Gerrard MP

Oliver Heald MP

Kelvin Hopkins MP

Lindsay Hoyle MP

Stewart Jackson MP

Andrew Love MP

Lord Mancroft

Lord de Mauley

Shona Mclsaac MP

Lord Morris of Manchester

Dr Bob Spink MP

Anthony Steen MP

APPHG Secretariat

Since the 2005 General Election, the secretariat for the All-Party Parliamentary Hepatology Group has been provided by The Hepatitis C Trust, the only UK national charity for hepatitis C. It provides information, support and representation for all those affected by this disease. Started by patients, the majority of its governing Board of Trustees are patients and all of its staff, paid and volunteer, are patients.

This report has been written with the support from The Hepatitis C Trust, Roche Products, Schering-Plough Ltd, Novartis UK, Bristol-Myers Squibb Company and Your Mandate Ltd.

References

- ⁱ The HPA estimate there are around 250,000 people in the UK infected with hepatitis C (*Hepatitis C in the UK: Annual Report 2008*. London: Health Protection Agency, December 2008) although some estimates show the prevalence as much higher; up to 466,000 in the UK (*Losing the fight against hepatitis C*. London: The Hepatitis C Trust and the University of Southampton, 2005)
- ⁱⁱ *A Matter of Chance: An Audit of Hepatitis C Healthcare in England*. London: APPHG, 2006. This found that 15% of PCTs were only minimally implementing the Action Plan or not at all, and half were only implementing parts of the Action Plan.
- ⁱⁱⁱ *Losing the fight against hepatitis C*. London: The Hepatitis C Trust and the University of Southampton, 2005
- ^{iv} Adapted from Poster 487, *The Burden of Chronic Hepatitis C (CHC) from the perspective of the UK National Health Service (NHS)*; Lewis et al., Poster presentation; EASL 2004
- ^v *Losing the fight against hepatitis C*. London: The Hepatitis C Trust and the University of Southampton, 2005
- ^{vi} *Hepatitis C in the UK: Annual Report 2008*. London: Health Protection Agency, December 2008
- ^{vii} Clinical pathways for patients with newly diagnosed hepatitis C, Irving et al., *Journal of Viral Hepatology*, 2006; 13 (4):264-71
- ^{viii} *Location, Location Location: An Audit of Hepatitis C Healthcare in England*. London: APPHG, 2008
- ^{ix} *Hepatitis C Action Plan for England*. London: Department of Health, July 2004, p.13
- ^x *A Matter of Chance: An Audit of Hepatitis C Healthcare in England*. London: APPHG, 2006
- ^{xi} *Hepatitis C Action Plan for Scotland, Phase II: May 2008-March 2011*, Edinburgh: Health Protection Scotland, May 2008, p.26-27
- ^{xii} This target is provisional and is still to be approved by the Scottish Government