



THE ALL-PARTY PARLIAMENTARY
HEPATOLOGY GROUP

Commissioning for better outcomes in hepatitis C

July 2011

FOREWARD

The All-Party Parliamentary Hepatology Group (APPHG) has worked since 2005 to raise awareness of hepatitis C and its patients' needs amongst politicians, the media and the public. Our pioneering campaign with The Hepatitis C Trust led the former government to announce that they would introduce a national liver strategy to improve services and outcomes in England. The Department of Health is now developing this strategy, with the support of the Coalition Government and we hope that this report will help to inform its development.

Hepatitis C is a preventable and curable cancer-causing, blood-borne virus. However, poor awareness and stigma have meant that it has been overlooked and misunderstood by many health professionals as well as by the general public since its discovery in 1989. It is therefore imperative that the planning, organising, purchasing, management and evaluation of services (commissioning) for hepatitis C is undertaken by those who fully understand the virus and the implications of ineffective co-ordination between public health, the NHS and adult social care services.

We hope this report usefully sets out the challenges to improved outcomes for liver disease presented by poor hepatitis C service commissioning and the opportunities presented by changes to public health, NHS and social care systems for building robust, responsive services that improve outcomes for patients and reduce unnecessary deaths from liver disease.

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SUMMARY OF RECOMMENDATIONS

Recommendation 1: The Department of Health should publically reaffirm its commitment to developing a national liver strategy and should urgently set out the revised timescales for publication.

Recommendation 2: The Department of Health should consult with senior representatives from the hepatitis C clinical community on the definition of ‘complex’ hepatitis C treatment within the Specialised Services National Definitions Set and should issue clear guidance on this definition.

Recommendation 3: As part of the National Liver Strategy, the Department of Health should publish advice to commissioners setting out at what population level it would be appropriate to commission different hepatitis C services.

Recommendation 4: The Department of Health should work with pathfinder clinical commissioning groups to explore the most appropriate models for collaborative commissioning.

Recommendation 5: The NHS Commissioning Board should develop and host liver clinical networks to support the effective commissioning of hepatitis C services.

Recommendation 6: The national liver strategy should set out how liver clinical networks, hosted by the NHS Commissioning Board, will support the delivery of high quality, coordinated commissioning.

Recommendation 7: The core duties for liver clinical networks should be to promote coordination in the commissioning of liver services, enable integration where it makes sense and ensure that patients are offered choice where this is appropriate.

Recommendation 8: The National Clinical Director for Liver Services should be tasked with developing the model for liver clinical networks, working in partnership with secondary and tertiary care clinicians, clinical commissioning groups, local authorities, patients and other stakeholders.

Recommendation 9: All commissioners should be reminded of their legal responsibility to fund treatments recommended by NICE.

Recommendation 10: The NHS Commissioning Board should develop a benchmarking toolkit to enable commissioners to assess how many patients in their population should be receiving treatment and to plan resource and capacity accordingly.

Recommendation 11: The National Clinical Director for Liver Services should lead work to further explore the reasons for low levels of treatment, building on the data published in *The extent and causes of international variations in drug usage*.

Recommendation 12: Public Health England should set out at the earliest possible opportunity its plans for strengthening data collection on hepatitis C, including designating a lead public health observatory to take responsibility for improving the quality and timeliness of information available, as well as linking relevant datasets to encourage fresh analyses.

Recommendation 13: The NHS Commissioning Board should encourage the development of a national clinical audit for hepatology, providing information on the number of patients treated, their co morbidities, the interventions performed and the outcomes achieved. This should be used to generate information on case mix adjusted clinical outcomes at provider level.

Recommendation 14: The Department of Health should commission a national liver patient experience survey, based on the successful model used in cancer. Results should be made available at provider level to inform commissioning and to support patient choice.

Recommendation 15: The NHS Commissioning Board should make available a commissioning support pack for liver services, setting out the data sources which should be used to inform commissioning, the quality standards which should be used to assess the quality of services, the incentives which could be used to drive improvements in quality and the metrics which should be used to assess the effectiveness of commissioning.

Recommendation 16: Liver clinical networks should be tasked with leading hepatitis C-specific user involvement initiatives.

BACKGROUND

Liver disease is the fifth biggest killer in the UK. Its incidence is rising and unlike the other of the five biggest killers, more people are dying each year, and people are dying younger than ever before. There are a variety of different causes of liver disease, the most common of which include alcohol, viral hepatitis and obesity.

The situation in the UK is in sharp contrast to the rest of Europe where mortality rates are decreasing. The UK will soon have higher death rates from liver disease than any similar EU country. The importance of improving outcomes from liver disease has been recognised in the NHS Outcomes Framework, with mortality from liver disease designated as an improvement area in Domain 1 of the NHS Outcomes Framework.

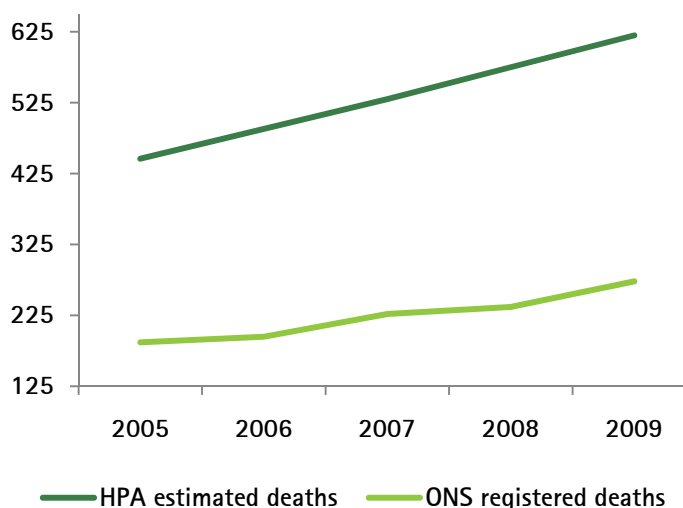
The UK's poor record on liver disease has been caused by a range of factors, including:

- Inadequate prevention strategies, with too many people adopting behaviours which put them at increased risk of liver disease
- Delayed diagnosis, resulting in liver disease only being identified at a stage when it has developed significantly, making management or cure more challenging
- Low treatment rates, resulting in people not being offered timely access to interventions
- Poor support, with patients not being provided with the appropriate care

Poor quality commissioning, often undertaken without access to the appropriate evidence, data or expertise, lies at the heart of all these problems. Put simply, unless services are planned, purchased, monitored and rewarded appropriately, it will be difficult to achieve the improvement in outcomes which is required to address the rising trend of mortality from liver disease.

This report focuses on hepatitis C, the blood-borne infectious virus that can cause cirrhosis and liver cancer. However the APPHG considers that the approach outlined in this report is equally applicable to other forms of liver disease. Mortality from hepatitis C has risen by between 39% and 45% since 2005, depending on whether Health Protection Agency estimates or Office of National Statistics registrations are used, as set out in Figure 1¹. This is particularly frustrating as there is a range of clinically and cost effective treatments available which can cure the disease and which have been recommended by NICE².

Figure 1: deaths from hepatitis C-related end stage liver disease or hepatocellular cancer in England



THE IMPORTANCE OF EFFECTIVE COMMISSIONING

Effective strategies to tackle hepatitis C need coordinated working by public health, NHS and adult social care services. Achieving this will require strong commissioning (the planning, organising, purchasing, management and evaluation of services). Despite this, successive audits of the commissioning, provision and management of liver services have revealed stark variations in service performance:

- *Location, Location, Location*ⁱⁱⁱ, an All Party Parliamentary Hepatology Group report on implementation of the Department of Health's *Action Plan for Hepatitis C*, found that four years after publication more than one third of PCTs had no protocol for hepatitis C testing and screening, and that patients faced treatment delays of more than three months (or delays were not monitored) at more than half of PCTs
- A 2009 audit of Strategic Health Authority (SHA) performance on hepatitis C^{iv} revealed that, despite being charged with this responsibility in the Action Plan, 70% of SHAs were failing to oversee implementation. Significantly, six out of ten SHAs had not conducted any assessment of hepatitis C provision or the needs of their populations
- In 2010, an audit of hospitals providing hepatitis C services^v showed that a third of hepatitis C patients referred to hospitals are not being offered treatment despite the fact that it is shown to clear the virus in around half of patients. Treatment levels vary considerably between hospitals - from 20% of new patients to 100%^{vi}. Around 10 hospitals refuse NICE approved treatment to all injecting drug users, despite the lack of any convincing evidence of compliance problems in IDUs^{vii} and NICE's clear direction on the subject. Thus, the NICE Appraisal Committee concluded that, with respect to those continuing to use intravenous drugs in naturalistic settings, the rate of discontinuation of treatment would not be so great as to prevent the treatment being cost effective (TA106). Moreover, studies of re-infection rates have shown a very low re-infection rates in people in whom the virus has been eliminated^{viii}.

An illustration of the challenges facing hepatitis C services was provided in the recently published *Extent and causes of international variation in drug usage* which found that usage of hepatitis C drugs in the UK was significantly lower than in comparable countries, with the UK ranking 13th of 14 countries studied. This is particularly concerning because the drugs considered have strong NICE approval. The report identified poor service organisation, capacity and planning as potential explanations^{ix}. The development of a national liver strategy was highlighted as being the primary mechanism for addressing these challenges.

IMPROVING COMMISSIONING

The APPHG believes that, unless the quality of commissioning for hepatitis C improves, efforts to improve outcomes for liver disease will fail:

- Efforts to prevent infection will remain fragmented
- Programmes to encourage early diagnosis will remain sporadic
- Treatment will remain under-resourced and of variable quality, with insufficient capacity available to address the rising burden of disease
- The care offered to patients will remain inconsistent

The APPHG has already undertaken a number of audits which have exposed the unacceptable variations in the quality of commissioning. We are clear that the existing system has failed to deliver the improvements required and therefore that reform is necessary. However, we are also concerned that the reforms being undertaken could disrupt and destabilise services, damaging patient outcomes rather than improving them. The recommendations made in this report are intended to prevent this from happening and ensure that hepatitis C services are able to benefit from the opportunities created by the reforms.

The APPHG believes that commissioning should be:

- Based on the needs of the whole population and undertaken at a sufficient population level to enable effective service redesign
- Informed by disease-specific expertise from every part of the patient pathway, enabling integration and joined up delivery and ensuring that quality is placed at the heart of all decisions
- Clear about the interventions which should be available to all patients providing they are clinically appropriate, irrespective of their personal circumstances or where they live
- Supported by the use of appropriate and relevant data to benchmark performance
- Underpinned by involvement from people affected by hepatitis C, drawing on their expertise and insights, and accountable to patients, the public and policymakers

Our starting point is that national leadership is required to support improvement in outcomes. We welcome the personal commitment of the Prime Minister to improving outcomes for hepatitis C:

“Perhaps the most shocking rise in modern disease has been Hepatitis C - since 1997 the number of cases reported each year has almost trebled. While the latest official figures show that 60,000 people in England have been infected, the Department of Health estimates that the real figure is more like 200,000. But the Hepatitis C Trust believes that you can double that number - with nearer 400,000 people in England being infected”.^x

We also warmly welcome the appointment of the National Clinical Director for Liver Disease and the continued commitment of the Department of Health to develop a national liver disease strategy, which we believe should set out the national framework for how liver outcomes will be improved, as well as describing how the health reforms should be applied to driving improvements in liver outcomes. We are, however, concerned that the development of the strategy is now behind schedule.

Recommendation 1: *The Department of Health should publically reaffirm its commitment to developing a national liver strategy and should urgently set out the revised timescales for publication.*

PLANNING SERVICES AT AN APPROPRIATE POPULATION LEVEL

Health services are commissioned at a variety of different levels and this will continue once the current health reforms have taken effect. Table 1 sets out the different population sizes covered by different commissioning organisations.

Table 1: different populations covered by commissioning organisations

Population level	Current commissioning body	New commissioning body
c200,000		Clinical Commissioning Group
c350,000	Primary Care Trust	
c1-2 million	Clinical networks	Clinical networks
c4.5-8 million	Regional specialised commissioning	NHS Commissioning Board
c51 million	Advisory Group for National Specialised Services (AGNSS)	NHS Commissioning Board

The statutory commissioners of most services are primary care trusts (PCTs), which will change to clinical commissioning groups subject to the successful passage of the Health and Social Care Bill. Many aspects of hepatitis C services are best planned and commissioned at a local level where the specific needs of the local population can be taken into account and addressed. These include prevention initiatives, such as needle exchanges, and care interventions, such as visits by community nurses.

However, other aspects of hepatitis C services are likely to require commissioning at a higher population level due to their relative rarity and high unit cost. Some interventions, such as liver transplants and ‘complex’ treatment, are designated as national specialised services within the Specialised Services National Definitions Set^{xi}. Specialised services are those “*with low patient numbers but which need a critical mass of patients to make treatment centres clinically and cost effective, usually catering for rare diseases and other complex conditions. This means that the catchment or planning population needed to commission the service will be over one million. Consequently, there will be relatively few centres offering treatment and there will not be a specialist centre in every local hospital.*”^{xii}

The Transition Oversight Group (TOG) responsible for the transition of responsibility for specialised services to the NHS Commissioning Board must consult with senior hepatitis C clinicians on which parts of hepatitis C treatment are defined as ‘complex’. There are a number of important issues to be considered in defining ‘complex’ treatment that should be commissioned by the Board and expert advice will be critical to getting it right. For instance, new treatments for hepatitis C, with increased rates of cure, are becoming available. These treatments are over 30% more effective than current treatment, increasing the chances of successful treatment to 80%. The new treatments are two to three times more effective on patients for whom treatment has previously failed. Furthermore in many cases patients will benefit from a reduction in treatment duration, from 48 to 24 weeks.

However no clinicians in this country have experience with one of these new drugs and only around seven centres have experience with the other treatments. These new drugs require complex algorithms and have potential drug to drug interactions with drugs commonly used by people with HCV - e.g. with methadone and citalopram and ‘may require close monitoring’^{xiii}. Increasing access to treatment by encouraging it to be offered closer to patients in the community (out of specialist centres and hospitals) is essential if enough patients are to be treated in order to reverse the increasing mortality from hepatitis C. However, patient safety must be paramount. It is vital that the TOG seeks advice from senior hepatologists from the British Association for the Study of the Liver and British Society of Gastroenterology as to the appropriate definition of ‘complex’ hepatitis C treatment to be commissioned by the NHS Commissioning Board.

Many other hepatitis C services are not likely to be designated as specialised services, but will still require commissioning at a higher population level in order to ensure that commissioners have sufficient purchasing and coordinating power to work with providers to redesign services in the interests of patients (a commissioner who only expects to have a few patients requiring the intervention in question is unlikely to be able to achieve this alone).

Recommendation 2: The Department of Health should consult with senior representatives from the hepatitis C clinical community on the definition of ‘complex’ hepatitis C treatment within the Specialised Services National Definitions Set and should issue clear guidance on this definition.

Recommendation 3: As part of the National Liver Strategy, the Department of Health should publish advice to commissioners setting out at what population level it would be appropriate to commission different hepatitis C services.

Recommendation 4: The Department of Health should work with pathfinder clinical commissioning groups to explore the most appropriate models for collaborative commissioning.

ENSURING COMMISSIONING SUPPORTS INTEGRATION AND IS INFORMED BY APPROPRIATE EXPERTISE

Given the nature of hepatitis C services, a range of different commissioners are likely to be involved, including:

- Public health commissioners (Public Health England and local authorities), for the prevention and early diagnosis of hepatitis C
- NHS commissioners (the NHS Commissioning Board and clinical commissioning groups), for the treatment and care of hepatitis C
- Social care commissioners (local authorities), for ongoing care requirements for people affected by hepatitis C

Figure 2 sets out in some more detail how different commissioners will be involved in commissioning services at different points in the patient pathway.

Figure 2: expected responsibility for the commissioning of hepatitis C services

Liver services			
	Public health	NHS	Social care
Prevention and early diagnosis	Alcohol harm reduction	Hepatitis C screening	Supportive care
	Drug harm reduction	Hepatitis C treatment (which	during treatment
	including replacement	reduces the prevalent pool and	(enabling)
	and needle exchange	therefore minimises the risk of	Drug harm
	Viral hepatitis awareness	onward infection)	reduction
	programmes		
	Hepatitis C screening		

Diagnosis and referral	<p>‘Routine’ testing for viral hepatitis</p> <ul style="list-style-type: none"> - Liver function testing - Blood spot testing - BMI assessment <p>Referral to a specialist</p>	
Treatment	<p>Viral hepatitis treatment (drugs)</p> <p>Non-routine treatment</p> <p>Alcohol dependency treatment</p> <p>Alcohol interventions</p> <p>Treatment for pre-transplant cirrhosis</p> <p>Liver transplant</p> <p>Supportive care in the community</p> <p>Long term condition management</p> <p>Access to clinical trials</p>	
After care	<p>Follow-up to treatment</p> <p>Supportive care</p> <p>Back to work services (GP referral)</p> <p>Palliation</p> <p>Long term condition management</p> <p>Advice on self-management</p> <p>Transplant maintenance</p>	<p>Back to work services</p>
End of life care	<p>Palliation</p> <p>Place of death</p>	<p>End of life care</p>

Given the number of different commissioners involved in the hepatitis C pathway, and without effective coordination, there is a danger that services will become fragmented or that the actions of one commissioner may have consequences for another which, if not planned for, could impact on patient care and the quality of services. Figure 3 sets out an example of how commissioning one intervention could have knock-on implications for other services and will therefore require coordination.

Figure 3: an example of how the commissioning of one liver service can affect another

CASE STUDY: SCREENING

With local authorities taking on responsibility for commissioning public awareness campaigns and screening, coordination with NHS liver services will be very important.

Hepatitis C can be used as an example. Hepatitis C is undiagnosed in the majority of the 250,000 to 466,000 infected with the virus in the UK^{xiv}. Greater awareness among the at risk population, as well as proactive testing campaigns are needed to ensure that those currently undiagnosed get access to treatment and support to manage their condition. If the UK manages to improve uptake of treatments for hepatitis C, it will be reducing the patient pool in the longer term. However, a successful public health awareness and screening programme would identify more patients requiring treatment, with consequences for planning and delivery of services in secondary care.

The proposed role for local authorities in bringing together NHS, public health and social care commissioners, will be crucial to ensuring that NHS commissioners are prepared for the increased capacity required in terms of treatment and support for newly diagnosed patients. If this coordination is not well managed, there is high risk of blockages in the system which could result in patients waiting too long for treatment or dropping out of the system altogether. It would also make it more difficult to reduce costs and operate efficiently.

A situation like that described above could lead to reluctance on the part of local authorities to commission awareness campaigns in the future, even though well-planned awareness and screening programmes could have long term benefits for the health of the local population.

Screening is far from an isolated example. There are many other parts of the pathway which will require coordination between different commissioners, as set out in Figure 4.

Figure 4: areas of hepatitis C services where coordination of commissioning will be required

Need for coordination between public health and NHS commissioning	Need for coordination between NHS and adult social care commissioning
<p>Prevention Campaigns and programmes encouraging at risk groups to get tested will lead to an increased demand on diagnostics and treatment services.</p>	<p>Drug and alcohol abuse Coordination between Drug and Alcohol Action Teams (DAAT) and NHS services should ensure that all service users are assessed for viral hepatitis and liver disease. Patients from these vulnerable groups should be supported throughout their care pathway. There should be shared accountability for successful outcomes for these patients.</p>
<p>Screening As outlined in Figure 3, coordination is required when public awareness campaigns and screening programmes are commissioned, to ensure liver services are prepared for increased capacity.</p>	<p>End of life care Where a patient reaches the end of their life, there should be seamless and coordinated transition from NHS care into a social care setting, according to the patient’s wishes.</p>
	<p>Back to work As part of their care pathway, and where appropriate, patients should be supported to return to work. Coordination and information sharing between NHS and social care services is essential to facilitating this.</p>

It will of course also be necessary to ensure coordination between different providers of services. For example, a patient may be diagnosed following testing at a community pharmacy, referred to a specialist by a GP, started on treatment by one provider and managed on treatment by another. This is before ongoing support in the community is considered.

It will therefore be imperative that mechanisms are established to ensure the coordination of care, as well as the input of specialists from across the pathway into commissioning decisions. One potential mechanism for ensuring coordination would be to develop clinical networks for liver disease. Such an approach would be consistent with the direction of travel for the reforms. *Equity and excellence: Liberating the NHS* set out that one of the key functions of the NHS Commissioning Board will be: “hosting some clinical commissioning networks... to pool specialist expertise.”^{xv}

The Government has subsequently reaffirmed this in its response to the NHS Future Forum report, stating that: “[the NHS will] retain and strengthen... networks so that they cover many more areas of specialist care. And we will give them a stronger role in commissioning, in support of the NHS Commissioning Board and local clinical commissioning groups^{xvi}.”

The intention is that such networks will have an explicit focus on commissioning, helping: “the NHS Commissioning Board and clinical commissioning groups to improve the design and delivery of better patient care. For example, the NHS Commissioning Board and national clinical networks will work together to develop the best pathways of care^{xvii}.”

Clinical liver networks could be based on the successful model used in cancer and stroke. The function of the networks would be to:

- Promote coordination in the commissioning of liver services across public health, NHS and adult social care
- Enable integration of services where this is appropriate
- Ensure effective working between different tiers of liver service commissioning
- Assist the NHS Commissioning Board by advising on whether clinical commissioning groups are sufficiently developed to be authorised
- Support clinical commissioning groups in undertaking effective population planning
- Deliver the commissioning of some liver services on behalf of clinical commissioning groups
- Plan capacity to ensure that patients can be treated in a safe and effective way
- Advise on the appropriate level of specialisation required to deliver effective treatment
- Develop ‘hub and spoke’ models of care where these are appropriate
- Champion the availability of choice within liver services
- Facilitate the effective sharing of financial risk between commissioners
- Benchmark the performance of liver service commissioners on behalf of the NHS Commissioning Board and support continuous improvement
- Identify challenges and areas for improvement to clinical commissioning groups, local authorities and the NHS Commissioning Board
- Champion and spread good practice, promoting high quality and efficient care

Although the exact number and population coverage of liver clinical networks would have to be determined, it is envisaged that they would cover a sufficiently large population to enable effective planning of specialist services, as well as promoting choice and contestability in provision, but at the same time would be located close enough to patients to be able to reflect their needs in providing GP consortia and local authorities with effective support in commissioning high volume public health, NHS and social care interventions.

It is vital that hepatitis C services are commissioned appropriately in order to address the rising mortality from liver disease caused by hepatitis C. The APPHG has concerns that if clinical liver disease networks are not formed or if they are not sufficiently robust, they will fail to ensure that hepatitis C patients are not disadvantaged and the prevalence of hepatitis C does not rise unnecessarily. We look forward to receiving greater clarity on the role of clinical liver networks in the coming months. The NHS Commissioning Board should have an oversight role in ensuring that clinical liver networks are driving much needed improvement to hepatitis C services.

Recommendation 5: *The NHS Commissioning Board should develop and host liver clinical networks to support the effective commissioning of hepatitis C services.*

Recommendation 6: *The national liver strategy should set out how liver clinical networks, hosted by the NHS Commissioning Board, will support the delivery of high quality, coordinated commissioning.*

Recommendation 7: *The core duties for liver clinical networks should be to promote coordination in the commissioning of liver services, enable integration where it makes sense and ensure that patients are offered choice where this is appropriate.*

Recommendation 8: *The National Clinical Director for Liver Services should be tasked with developing the model for liver clinical networks, working in partnership with secondary and tertiary care clinicians, clinical commissioning groups, local authorities, patients and other stakeholders.*

ENSURING ALL PATIENTS BENEFIT FROM APPROPRIATE INTERVENTIONS

Treatments for hepatitis C have been recommended by NICE as clinically and cost effective and as such they should be available to all patients who need them^{xviii}. However, evidence suggests that the utilisation of treatment is significantly below the levels projected by NICE, or indeed the levels required to begin to address the rising curve of hepatitis C incidence, prevalence and mortality. As a result, the UK is amongst the lowest users of hepatitis C treatments^{xix}.

A critical part of effective commissioning should be to ensure that all patients have access to appropriate interventions. We therefore welcome the Government's commitment to ensure that the funding of treatments recommended through technology appraisals remains mandatory:

“Through a funding direction, we currently require NHS commissioners in England to fund drugs and treatments in line with NICE’s recommendations. We have committed to maintain this funding direction (translated into new regulations under the Bill) until January 2014, when we plan to introduce a system of value-based pricing for new drugs...A key aim of value-based pricing will be to ensure that NHS patients have consistently good access to effective, clinically appropriate drugs – which the current funding direction is also designed to achieve. We therefore intend to maintain the effect of the funding direction in the new value-based pricing arrangements to ensure that the NHS in England consistently funds medicines with a value-based price. The NHS will be required to fund drugs already recommended by NICE, as well as drug treatments subject to the value-based pricing regime. This means patients will continue to have the legal right to clinically appropriate, cost-effective drugs and treatments as set out in the NHS Constitution and accompanying handbook^{xx}.”

However, the experience of hepatitis C suggests that the existence of the funding direction alone is not sufficient to ensure implementation and that other factors – such as capacity, the effectiveness of patient pathways and the availability of support for patients, all of which are functions of effective commissioning - have a major impact on the uptake of appropriate treatment.

The low uptake of treatments in the UK is not simply a function of low levels of diagnosis. Even when this is taken into account, many patients are either not referred for treatment, not initiated on treatment or do not complete their course of treatment. All of these explanations are symptoms of fragmented pathways or gaps in care. A key task for commissioning – and a key measure of its effectiveness – will therefore be improving treatment rates.

Recommendation 9: *All commissioners should be reminded of their legal responsibility to fund treatments recommended by NICE.*

Recommendation 10: *The NHS Commissioning Board should develop a benchmarking toolkit to enable commissioners to assess how many patients in their population should be receiving treatment and to plan resource and capacity accordingly.*

Recommendation 11: *The National Clinical Director for Liver Services should lead work to further explore the reasons for low levels of treatment, building on the data published in *The extent and causes of international variations in drug usage*.*

Some patients may have particular risk factors, such as co-infection with HIV, continuing alcohol consumption or injecting drug use. These factors alone should not be a barrier to treatment, although it will be important to ensure that treatments are delivered by teams with an appropriate specialism and that support is tailored around the particular needs of patients.

INFORMING COMMISSIONING WITH APPROPRIATE DATA

The Government has rightly identified that access to high quality information on service quality is a prerequisite for effective commissioning to improve outcomes. Traditionally much of the data available on hepatitis C services have been provided by the Health Protection Agency, which will become part of Public Health England. It will be important to protect the collection of data both on infection, diagnosis and prevalence rates, as well as mortality from hepatitis C. In order to ensure that appropriate data are available to support the commissioning of hepatitis C services, a range of actions should be taken.

Recommendation 12: *Public Health England should set out at the earliest possible opportunity its plans for strengthening data collection on hepatitis C, including designating a lead public health observatory to take responsibility for improving the quality and timeliness of information available, as well as linking relevant datasets to encourage fresh analyses.*

However, it will be important that data collection is not seen as purely the domain of the public health service and the NHS Commissioning Board should take steps to improve the information available on the quality of hepatitis C services.

Recommendation 13: *The NHS Commissioning Board should encourage the development of a national clinical audit for hepatology, providing information on the number of patients treated, their co-morbidities, the interventions performed and the outcomes achieved. This should be used to generate information on case mix adjusted clinical outcomes at provider level.*

Recommendation 14: *The Department of Health should commission a national liver patient experience survey, based on the successful model used in cancer. Results should be made available at provider level to inform commissioning and to support patient choice.*

It will also be important to establish clear metrics against which the effectiveness of commissioning can be assessed.

Figure 5: *potential measures to be used in assessing the effectiveness of commissioning*

Stage of pathway	Example measure	Relevant commissioner
Prevention	Reduction in injecting drug users	Public Health Service (Local Authority)
	Percentage of injecting drug users using harm reduction techniques	Public Health Service (Local Authority) / NHS (GP consortium)
Earlier diagnosis	Viral hepatitis testing rate	Public Health Service (Local Authority) / NHS (GP consortium)
	Screening uptake among at risk groups	Public Health Service (Local Authority)
	One-year survival rate for liver cancer	NHS (NHS Commissioning Board)
	Stage of presentation with liver cancer	NHS (NHS Commissioning Board)
Diagnosis	Number of patients diagnosed with liver disease, compared to modelled expected rate	NHS (GP consortium)
	Number of patients diagnosed with hepatitis C who are found to have liver cirrhosis or liver cancer at diagnosis	NHS (GP consortium)
	Number of patients diagnosed with liver disease as an emergency	NHS (GP consortium)
Treatment	Number of referrals to specialist care	NHS (GP consortium)
	Proportion of patients with viral hepatitis offered treatment	NHS (GP consortium)
	Proportion of patients receiving active treatment	NHS (GP consortium)
	Sustained Viral Response (SVR) rate achieved	NHS (GP consortium)

	Proportion of patients on the transplant waiting list offered a transplant	NHS (NHS Commissioning Board)
	Liver transplant success rate	NHS (GP consortium / NHS Commissioning Board)
	Mortality rate from liver disease (decreasing)	NHS (GP consortium) / Public Health Service (Local Authority) /
	Number of patients taking part in clinical trials	NHS (NHS Commissioning Board)
Follow-up and after care	Proportion of patients reporting confidence in managing their condition	NHS (GP consortium)
	Proportion of patients reporting feeling supported following treatment	NHS (GP consortium)
	Proportion of working-age patients able to return to work	NHS (GP consortium) / Social Care Service (Local Authority)
End of life care	Proportion of patients dying in their place of choice	NHS (GP consortium) / Social Care Service (Local Authority)

Recommendation 15: *The NHS Commissioning Board should make available a commissioning support pack for liver services, setting out the data sources which should be used to inform commissioning, the quality standards which should be used to assess the quality of services, the incentives which could be used to drive improvements in quality and the metrics which should be used to assess the effectiveness of commissioning.*

USER INVOLVEMENT AND ACCOUNTABILITY

Service users can play a valuable role in informing commissioning, ensuring that decisions are taken on the basis of what really matters to patients. This will be particularly important given the funding challenges facing the NHS, as expenditure will need to be focused on those interventions which can deliver the biggest outcomes gain. However, given the nature of hepatitis C and the fact that many patients come from excluded groups, it can be difficult to achieve effective, meaningful and ongoing user involvement. For this reason it will be important that commissioners effectively engage with charities and patient support groups.

Again, liver clinical networks could play an invaluable role in promoting effective user involvement by:

- Ensuring that a disease-specific approach is taken to user involvement, enabling services to be shaped by those who have had or are experiencing them

- Enabling user involvement to be undertaken at a sufficiently high population level as to ensure relatively high and consistent levels of participation

Recommendation 16: *Liver clinical networks should be tasked with leading hepatitis C-specific user involvement initiatives.*

CONCLUSION

It is vital that the commissioning structure for hepatitis C encourages testing and treatment of sufficient numbers to flatten the mortality curve from this curable virus and reduce overall deaths from liver disease. To achieve this, hepatitis C services must be planned, purchased, monitored and rewarded appropriately.

The APPHG believes the formation of liver networks hosted by the National Commissioning Board to join up services and support commissioning, improved data collection including a national clinical audit of hepatitis C services, stronger implementation of NICE guidance and consultation with senior hepatitis C clinicians on the definition of 'complex' hepatitis C will be key to improving outcomes for hepatitis C and liver disease. If a robust responsive framework is not put in place to commission for improved outcomes for hepatitis C, other options to ensure effective commissioning of hepatitis C services will need to be investigated, one example being commissioning of hepatitis C treatment by the NHS Commissioning Board.

The APPHG believes the involvement of the hepatitis C clinical and patient community in advising on the new commissioning structures will be crucial to improving outcomes and calls on these groups to respond to this report.

REFERENCES

- ⁱ House of Commons Hansard, Written Answers for 28 June 2011, column 773W
- ⁱⁱ National Institute for Health and Clinical Excellence, *TA75 Hepatitis C - pegylated interferons, ribavirin and alfa interferon: guidance*, September 2010
- ⁱⁱⁱ All Party Parliamentary Hepatology Group, *Location, Location, Location*, February 2008
- ^{iv} The Hepatitis C Trust, *Hepatitis C: Out of Control*, July 2009
- ^v All Party Parliamentary Hepatology Group, *In the Dark: an audit of hospital hepatitis C services across England*, August 2010
- ^{vi} All Party Hepatology Group, *In the Dark: An audit of hospital hepatitis C services across England*, August 2010
- ^{vii} *Injecting drug users with chronic hepatitis C: should they be offered antiviral therapy?* Editorial by Professor Graham Foster in *Addiction*, 103, Society for the Study of Addiction, 2008 1412 -1413.
- ^{viii} *Treatment of hepatitis C infection in injection drug users*. Backmund M., Meyer K., Von Zielonka M., Eichenlaub D. *Hepatology* 2001; 34: 188–93.
- ^{ix} Department of Health, *Extent and Causes of international variations in drug usage: a report for the Secretary of State for Health by Professor Sir Mike Richards CBE*, 27 July 2010
- ^x David Cameron: *How the NHS can deliver rising standards of healthcare*, August 20 2009
Available at:
http://www.conservatives.com/News/Speeches/2009/08/David_Cameron_How_the_NHS_can_deliver_the_rising_standards_of_healthcare.aspx Accessed 4 July 2011
- ^{xi} Specialised Services National Definitions Set, *Specialised Services for Liver, Biliary and Pancreatic Medicine and Surgery (adult) Definition No.19*, 2010
- ^{xii} Specialised Healthcare Alliance, *What are Specialised Services?* Available at:
<http://www.shca.info/services.htm> Accessed 4 July 2011
- ^{xiii} University of Liverpool, *Drug Interactions*, <http://www.hep-druginteractions.org/LatestArticlesContent.aspx?Id=23> accessed July 2011
- ^{xiv} 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)
- ^{xv} Department of Health, *Equity and Excellence: Liberating the NHS*, July 2010
- ^{xvi} Department of Health, *Government response to NHS Future Forum Report*, June 2011, page 17
- ^{xvii} Department of Health, *Government response to NHS Future Forum Report*, June 2011, page 17
- ^{xviii} National Institute for Health and Clinical Excellence, *TA75 Hepatitis C - pegylated interferons, ribavirin and alfa interferon: guidance*, September 2010
- ^{xix} Department of Health, *Extent and Causes of international variations in drug usage*, July 2010
- ^{xx} Department of Health, *Government response to NHS Future Forum Report*, June 2011, page 26