Location, Location, Location

An Audit of Hepatitis C Healthcare in England

An All-Party Parliamentary Hepatology Group Report

14 February 2008

2008 Audit of the Department of Health Hepatitis C Action Plan for England

An All-Party Parliamentary Hepatology Group Report

Contents ______ 2

Executive summary ______ 3

Background ______ 4

Methodology ______ 5

Primary Care Trust audit results ______ 6

NHS Hospital Trust audit results ______ 15

Appendix 1 – Letter to PCTs ______ 17

Appendix 2 – PCT audit questionnaire ______ 18

Appendix 3 – Letter to NHS Hospital Trusts ______ 21

Appendix 4 – NHS Hospital Trust audit questionnaire ______ 22

Appendix 5 – Supplementary questions sent to PCTs that scored 5 or lower ______ 24

Appendix 6 – Alphabetical list of PCT Scores 2008 (with 2006 comparison) ______ 25

Appendix 7 – PCT ranked by score ______ 32

Appendix 8 – Members of the APPHG ______ 36

Appendix 9 – APPHG secretariat and its funding ______ 36

Executive Summary

Background

In July 2004 the Department of Health published a Hepatitis C Action Plan for England, setting out required actions for Primary Care Trusts (PCTs) and NHS Hospital Trusts. Over the following 18 months the All-Party Parliamentary Hepatology Group (APPHG) became concerned by anecdotal evidence from patients and clinicians that the Action Plan was not being implemented in their area.

In spring 2006 the APPHG audited hepatitis C services in PCTs and NHS Trusts across the country. The resulting report, 'A Matter of Chance', highlighted many areas of deficiency with only 8% of PCTs implementing the Plan effectively. 18 months on, in September 2007, the APPHG decided to repeat the audit to see whether, more than 3 years after the Hepatitis C Action Plan was published, it was finally being implemented nationwide and whether patients across the country were receiving a universal standard of care.

PCT Results 2008

- Hepatitis C services across the country have improved but the improvements are patchy. Of responding PCTs still just a third are implementing the Action Plan effectively with half achieving only partial implementation.
- Unacceptably 15% of PCTs have demonstrated minimal or no implementation at all.
- Over half of PCTs have delayed treatment by more than three months, or do not monitor delays in treatment.
- 58% of PCTs used the Health Protection Agency commissioning template to estimate the prevalence of hepatitis C in their area, but only 22% of PCTs used the same template to estimate the number and cost of patients needing treatment – for which it was designed.

NHS Hospital Trusts 2008

- 37 of the 63 (59%) responding NHS trusts reported that some of their patients had their treatment delayed for more than 3 months from their first hospital consultation.
- The waiting time from referral to a patient's first appointment with a consultant varied between 3 and 20 weeks. The waiting time between a recommendation of treatment and the first injection of interferon varied between 2 and 24 weeks.
- Less than two thirds (62%) of responding NHS Trusts are confident that they will have the infrastructure in place to ensure all hepatitis C patients can start treatment within 18 weeks by the December 2008 government deadline.

Executive Conclusion and Recommendations

There has been a marked improvement in hepatitis C services compared to the audit results in 2006. However, we are still a long way from effective country-wide implementation of the Action Plan. Indeed the discrepancies between the best and worst performing PCTs within Strategic Health Authority boundaries are just as wide as before. Hepatitis C healthcare is still dependent on where you live. It is just as much 'a matter of chance' as it was in 2006.

The Action Plan was launched over 3 years ago and we feel that its limited implementation indicates a fundamental inadequacy in the effectiveness of Action Plans that do not contain budgets, targets and timetables. With targets currently out of favour, the APPHG feel that issuing an Action Plan is not a suitable or workable lever to effect improvements in the devolved National Health Service. We believe the Department of Health should introduce a reform strategy for hepatitis C which relates to current NHS reforms, sets a clear direction for services, and requires providers to implement best practice at every stage of the patient pathway. Specifically, we call on the Secretary of State for Health to:

- Introduce a 'World Class Commissioning pilot' in hepatitis C.
- Develop a good practice model for service organisation and delivery as part of a wider reform strategy for hepatitis C.
- Support the inclusion of hepatitis C case-finding in QOF (Quality & Outcomes Framework).
- Conduct a national audit of GP practice building on the model being piloted for cancer referral and diagnosis.

Background

Hepatitis C is a blood-borne virus that primarily attacks the liver. It can lead to severe and potentially fatal liver disease and to liver cancer. It represents a global health problem with more than 130 million people chronically infected worldwide[1]. In England and Wales estimates vary between 231,000 and 500,000 people infected[2][3][4].

In July 2004 the Department of Health published a Hepatitis C Action Plan, setting out required actions for Primary Care Trusts (PCTs) and NHS Hospital Trusts. The Action Plan states that:

> ***"Chief Executives of Primary Care Trusts and NHS Hospital Trusts should be able to demonstrate that there are adequate services and partnerships at local level to enable models of best clinical practice to be followed, as set out in the Hepatitis C Strategy for England."***

Concerned by anecdotal evidence from patients and clinicians that the Action Plan was not being implemented, in 2006 the All-Party Parliamentary Hepatology Group (APPHG)[5] conducted an audit of PCTs and NHS Hospital Trusts to monitor what actions they had taken to fulfil the Action Plan's requirements.

The results, published in May 2006, were extremely disappointing. Only 63% of PCTs felt able to respond to the survey and, of these, only 8% were implementing the Action Plan effectively. Almost half of the responding NHS Trusts reported significant delays for patients wanting treatment and the time from recommendation for treatment to actually starting it varied from 1 week to 1 year, indicating huge regional disparities.

In April 2007 the Roddick Foundation hosted the 'Improving Hepatitis C Healthcare Conference' bringing together 90 PCT directors of public health and senior managers from all over England to share best practice in implementing the Action Plan. Sessions covered service commissioning, implementing NICE guidance, measuring the cost effectiveness of treatment, implementing a clinical network and reaching socially excluded groups as well as an explanation of the new Health Protection Agency (HPA) costing and commissioning template.

In September 2007 the APPHG decided to repeat the audit to see what progress PCTs and NHS Trusts had made in meeting the requirements of the Hepatitis C Action Plan. We hoped that the combination of Anita Roddick's campaigning work, the government's national awareness raising *Face It* campaign, and the HPA's work on the disease would have generated significantly more awareness about hepatitis C amongst healthcare practitioners, resulting in dramatically improved services within PCTs and Hospital Trusts. We believed that, more than 3 years after its publication, the Action Plan should be fully implemented by all PCTs and Hospital Trusts.

As well as investigating what action has been taken in response to hepatitis C, the Group wanted to discover whether, in our now devolved healthcare system, issuing an 'action plan' is an effective method of combating public health threats.

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1 WHO hepatitis C fact sheet no 164, revised October 2000
2 Hepatitis C in England, Health Protection Agency Annual Report, December 2007
3 NICE Technology Assessment 075, January 2004
4 The UK vs. Europe: Losing the fight against hepatitis C, The Hepatitis C Trust/University of Southampton, 2006
5 See Appendix 8 for more details of the All-Party Parliamentary Hepatology Group

Methodology

The audit consists of a PCT questionnaire and a NHS Trust questionnaire, based on the requirements in the Action Plan. They were constructed with the help of a panel of healthcare professionals and The Hepatitis C Trust, who provide the APPHG's secretariat. Both questionnaires were kept as short as possible to minimise the time required to complete them.

The PCT questionnaire was sent to all 152 PCTs in England (the 2006 audit was conducted before the recent boundary changes and so was sent to all 305 PCTs then existing). The Hospital Trust survey was sent to the 171 Acute Hospital Trusts.

Questionnaires were sent out with accompanying letters by mail with the option of an email version on request to the respective chief executives in mid September 2007 and responses were accepted up to 1 December. Examples of the questionnaires and letters can be found in Appendix 1-4.

Once the audit forms had been returned and marked, supplementary questions were sent to PCTs who scored 5 or less out of 10 to identify what support they felt they needed in order to improve their implementation of the Action Plan (see appendix 5 for the supplementary questions).

Primary Care Trust Audit Results

Responses and overall scores

128 out of 152 PCTs took part in the audit. This response rate of 84% was a significant improvement on the 2006 rate of 63%.

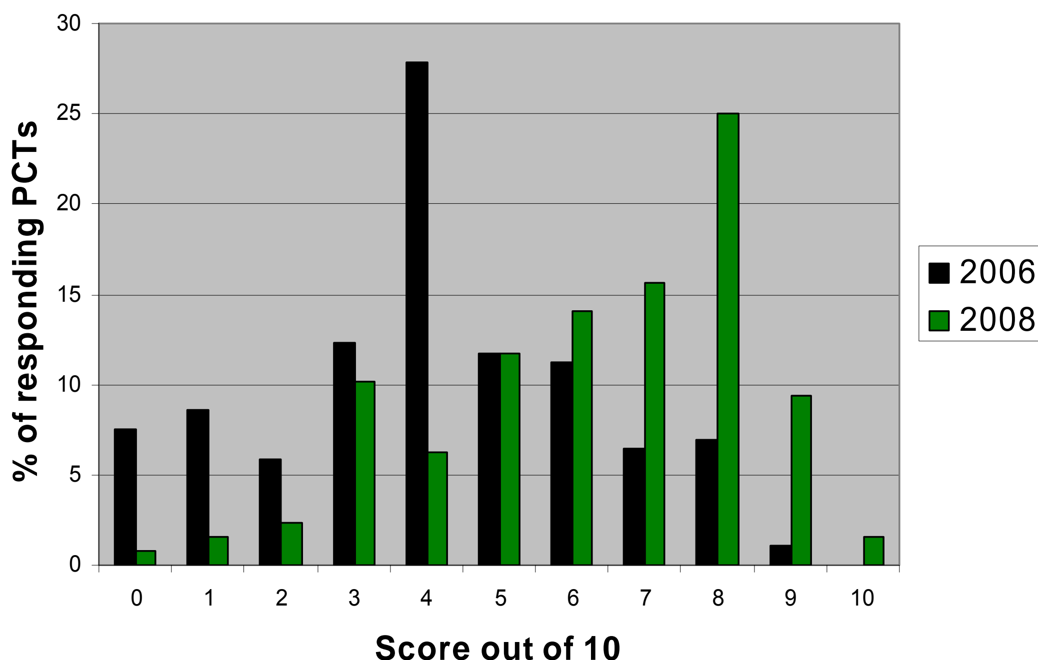
The last 18 months have seen an improvement in hepatitis C services in most PCTs. Just over one third of PCTs are now implementing the Action Plan effectively. However, 15% of PCTs are still implementing the Action Plan minimally or not at all. This is dismaying. Hepatitis C remains a priority for the Department of Health with its requirement that the HPA produce an annual report just on this disease, yet it is clearly not a priority for a significant number of PCTs. For how long will the 19 PCTs that scored 3 or less out of 10 continue to ignore this major public health issue?

Score out of 10	2006	2008
Score 0-3 (minimal implementation)	36% (68 out of 191)	**15%** (19 out of 128)
Score 4-7 (partial implementation)	56% (107 out of 191)	**49%** (63 out of 128)
Score 8-10 (effective implementation)	8% (16 out of 191)	**36%** (46 out of 128)

Despite the overall increase in audit scores there is still a huge spread of results, from 0 to 10, highlighting the massive differences in services available to hepatitis C patients across the country. 18 months after the publication of the first audit, we are disappointed that these discrepancies are not decreasing.

Similarly, within Strategic Health Authority regions there continues to be vast differences in service provision which in many cases are growing. This is of particular concern as SHAs are responsible for ensuring consistency and standards of service provision across their areas. This is made explicit for hepatitis C in the action points of the 2004 Action Plan. For example, in the East of England, scores ranged from 0 (Mid Essex) to 9 (Cambridgeshire). In the North East region, scores ranged from 2 (Newcastle) to 10 (County Durham).

Bar chart to show the percentage of PCTs with each score in 2006 and 2008:



Criteria for judging implementation performance

The same criteria, based on the Hepatitis C Action Plan for England, were used to judge the 2008 audit as the 2006 audit, allowing us to compare performance.

The lack of specific requirements in the Action Plan required some extrapolation in establishing the criteria. For example, we considered it necessary to have made at least a realistic attempt, such as using the HPA commissioning template or conducting a scoping exercise, to estimate the number of people with hepatitis C in a given PCT area in order to 'be able to demonstrate that there are adequate services' as stipulated in the Action Plan.

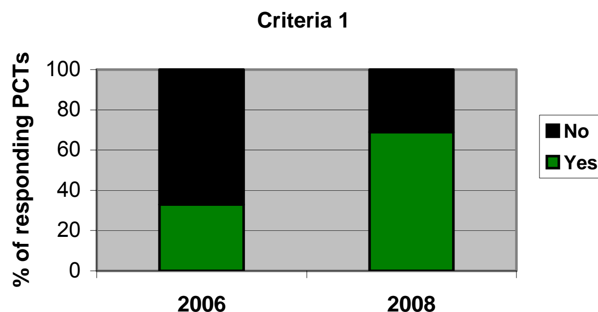
With help and advice from a panel of healthcare professionals and The Hepatitis C Trust, we chose 10 criteria, gave equal weight to each and scored each PCT out of 10, depending on whether or not they had fulfilled each of the criteria. We expect that certain PCTs will object to particular criteria leading to the score we have given them and their consequent ranking. What we believe to be clear, however, is that any PCT that scores 8 or more out of 10 has made a major effort and significant progress in implementing the Action Plan, whilst a PCT that scores 3 or less has not done nearly enough or at the very least has not let us know about it.

The 10 criteria are:

1. Has the PCT demonstrated that they have used a sensible method (e.g. the HPA commissioning template or a scoping exercise) to estimate numbers of people with chronic hepatitis C in their area?
2. Does the PCT have an agreed protocol for hepatitis C testing/screening?
3. Has the PCT used a sensible method of estimating the numbers of patients to be treated?
4. Has there been a delay of more than 3 months or deferment to the next financial year in providing treatment?
5. Does the PCT have a system for monitoring hepatitis C treatment, e.g. success rates?
6. Does the PCT know where anonymous testing facilities for hepatitis C are available?
7. Does the PCT have a hepatitis C lead?
8. Does the PCT have a hepatitis C clinical network?
9. Does the PCT provide services for particular groups of patients such as prisoners, injecting drug users and children?
10. Has the PCT made an estimate of the number of people requiring treatment during 2006/7?

Individual Criteria

1. Has the PCT demonstrated that they have used a sensible method (e.g. the HPA commissioning template or a scoping exercise) to estimate numbers of people with chronic hepatitis C in their area?

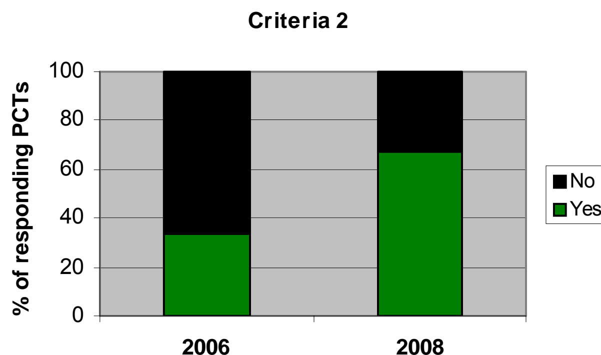


Response	2006: % of responding PCTs	**2008: % of responding PCTs**
Yes	33	**69**
No	67	**31**

It is encouraging that the number of PCTs scoring on this criterion has doubled but it is very worrying that almost a third of PCTs have still not made an effort to ascertain the number of people with hepatitis C in their area. A reasoned estimate of local prevalence is the starting point for ensuring adequate funding, services and staff for testing and for timely hospital appointments and treatment.

The Health Protection Agency (HPA) have produced a commissioning template to help PCTs with estimating the prevalence of HCV in their local population in recognition of the fact that simply multiplying the Department of Health's national prevalence estimate (of 0.4%) by the number of people in the PCT area is an inadequate way of arriving at a reasonable estimate of local prevalence.

2. Does the PCT have an agreed protocol for hepatitis C testing / screening?



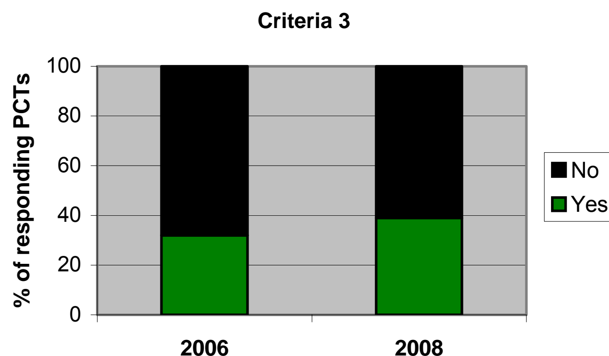
Response	2006: % of responding PCTs	**2008: % of responding PCTs**
Yes	34	**67**
No	66	**33**

It is unacceptable that one third of PCTs still do not have a protocol for hepatitis C testing and screening. Developing such a protocol is essential if PCTs are to be able to offer treatment and care to the tens of thousands of people with hepatitis C who are still undiagnosed. HPA figures show that only around 63,000 people in England with hepatitis C have been diagnosed, yet they estimate that 231,000[6] are infected. Other estimates put this figure as high as 466,000.[7] Testing these people must be a priority because they are the ones most at risk of serious and potentially fatal liver damage and liver cancer.

[6] Hepatitis C in England, Health Protection Agency Annual Report, 2007

[7] The UK vs. Europe, 2006

3. Has the PCT used a sensible method of estimating the numbers of patients to be treated in this financial year?

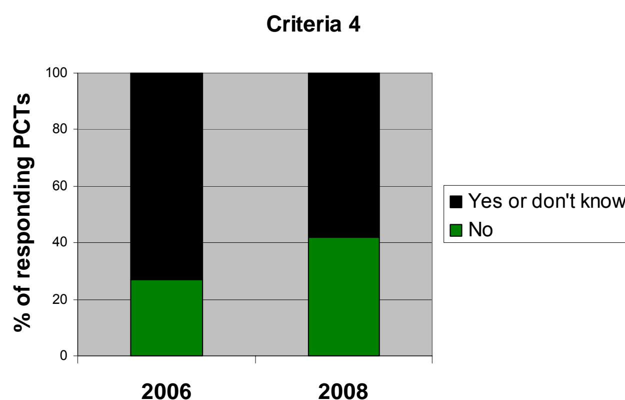


Response	2006: % of responding PCTs	**2008: % of responding PCTs**
Yes	32	**39**
No	68	**61**

Anti-viral treatment is a major component of the staffing time and of the cost of managing hepatitis C. Therefore it is concerning that almost two thirds of PCTs do not have an estimate of how many patients will be treated in this financial year.

The HPA put a considerable amount of time into designing a template to help PCTs estimate the cost of treating their hepatitis C population. It was made available to all PCTs and showcased at the Roddick Foundation/Hepatitis C Trust conference. We are mystified that, whilst 74 PCTs used the HPA template to estimate the prevalence in their community, only 28 used the same template to estimate the number of patients that would need treatment and the associated costs of this. This shows a misunderstanding of the template's function and a unfortunate failure to make proper use of an excellent resource.

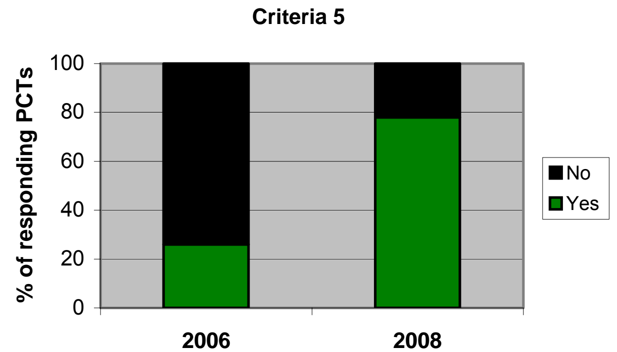
4. Has there been a delay of more than 3 months or deferment to the next financial year in providing treatment?



Response	2006: % of responding PCTs	**2008: % of responding PCTs**
No	27	**42**
Yes or don't know	73	**58**

We find it unacceptable that over half of PCTs have delayed treatment by more than three months, or do not monitor delays in treatment. We only included administrative delays, not delays due to patient request, medical issues, mental health issues or lifestyle issues. Once patients have been recommended for treatment, a process often subject to too many delays, they should not have to wait another 3 months or more to start it. The cause of this delay is frequently budgetary and the result of poor financial planning. We believe this could be avoided by making proper use of the HPA template referred to above, the purpose for which it was designed.

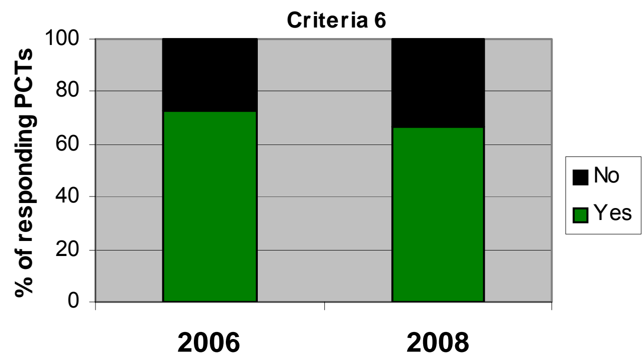
5. Does the PCT have a system for monitoring hepatitis C treatment, e.g. success rates?



Response	2006: % of responding PCTs	**2008: % of responding PCTs**
Yes	26	**78**
No	74	**22**

Crucially, treatment needs to be monitored and we are happy to see a significant improvement in the numbers of PCTs monitoring some aspect of treatment. It is imperative to know how many people have been treated and for how many of those it has been successful, information that we asked the HPA to include in its Hepatitis C in England Report but which it was unable to do. Without this information it is impossible to know, from a public health perspective, just what inroads, if any, we are making into the pool of infection. This applies just as much at local PCT level as at national level. Furthermore, if PCTs are not monitoring treatment success rates, they cannot tell whether the rates quoted in trials actually apply to real-life, clinical settings and therefore how best to allocate resources.

6. Does the PCT know where anonymous testing facilities for hepatitis C are available?

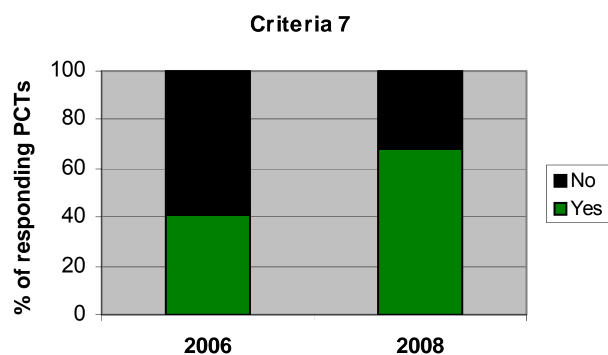


Response	2006: % of responding PCTs	**2008: % of responding PCTs**
Yes	73	**67**
No	27	**33**

Hepatitis C remains a highly stigmatised disease in England and a positive diagnosis can have significant financial implications, for example in obtaining insurance or a mortgage. Many people, therefore, may be deterred from seeking a test, unless it can be done anonymously.

Given the importance of increasing diagnosis and making testing as accessible as possible, we are both disturbed and surprised that not all PCTs know about anonymous testing facilities in their area. In fact, the proportion of PCTs that are aware that they provide anonymous testing services has actually decreased in the last 2 years. Some PCTs showed very little awareness of the issue by simply answering ‘GUM clinics’, when in fact some GUM clinics will not test for hepatitis C on the grounds that it is not a sexually transmitted disease.

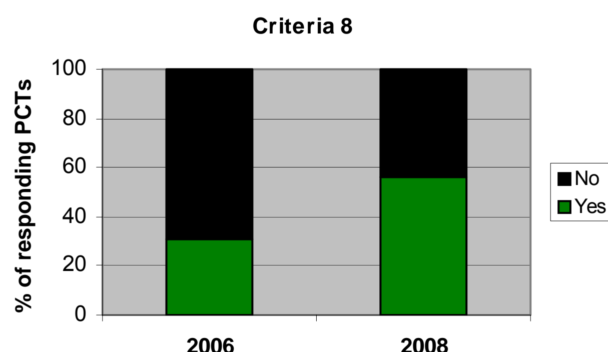
7. Does the PCT have a hepatitis C lead?



Response	2006: % of responding PCTs	**2008: % of responding PCTs**
Yes	41	**68**
No	59	**32**

It is not a requirement of the Action Plan for each PCT to have a hepatitis C lead but nonetheless the appointment of such a person indicates a willingness to approach hepatitis C with the purpose required to ensure adequate services and is likely to be a first step in establishing a managed clinical network.

8. Does the PCT have a hepatitis C clinical network?

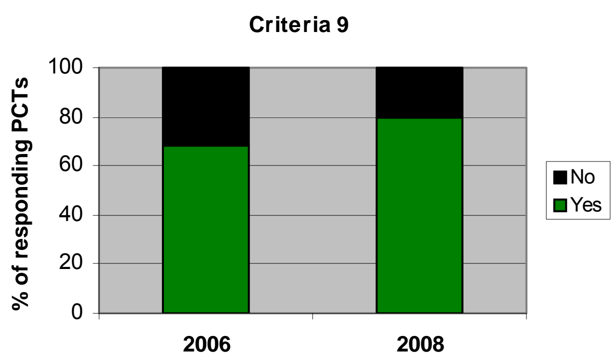


Response	2006: % of responding PCTs	**2008: % of responding PCTs**
Yes	31	**56**
No	69	**44**

The Action Plan states that the 'adequate services and partnerships' to be put in place should include 'the development of clinical networks.'[8] Barely half of PCTs have done this more than 3 years after the Action Plan was published. This is not acceptable. Anecdotally, it appears that a managed clinical network requires leadership to get off the ground, in other words the appointment of a hepatitis C lead and we urge all PCTs to ensure they have such a person in place immediately.

28 PCTs have a hepatitis C lead, but have not established a hepatitis C clinical network, and 14 have a clinical network in place but with no hepatitis C lead. We urge all PCTs to establish both a hepatitis C lead and clinical network to coordinate and improve services to patients.

9. Does the PCT provide services for particular groups of patients such as prisoners, injecting drug users and children?



Response	2006: % of responding PCTs	**2008: % of responding PCTs**
Yes	68	**80**
No	32	**20**

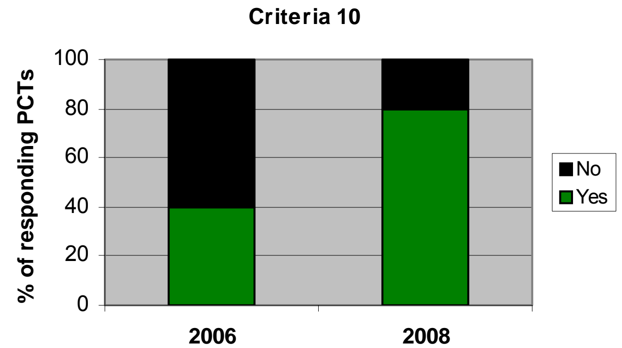
The Action Plan for England instructs that PCTs should make provision for particular groups of patients. It is encouraging that four out of five PCTs do have special provision for at least one particular group, but we would like to see all

[8] Hepatitis C Action Plan for England, Department of Health, August 2004, Chapter 5

PCTs make provision for all the groups specified in the Action Plan. 95 PCTs make special provision for injecting drug users, 68 PCTs make special provision for prisoners and 26 PCTs have special provision for children. The range of extra support for certain groups indicates that many PCTs would benefit from more coordinated dissemination of best practice.

10. Has the PCT made an estimate of the number of people requiring treatment during 2008/9?

Response	2006: % of responding PCTs	**2008: % of responding PCTs**
Yes	40	**80**
No	60	**20**



We are pleased that 80% of PCTs have a rough estimate of how many patients they will treat in the next financial year. This will allow PCTs to negotiate contracts with the hospitals that provide treatment, allow the hospitals to plan staffing in liver units and will help to avoid bottle-necks or over capacity.

Other data

Treatment figures

59% of PCTs do not have a designated budget for hepatitis C services for this financial year. This often results in delays in treatment. Only 3,607 people were treated for hepatitis C in the responding PCTs last year and over 10 % of these patients (308) had their treatment delayed.

Meeting the government's 18 week target

Worryingly, only 71% of the responding PCTs expect to have the funding arrangements in place to allow hepatitis C patients to start treatment within 18 weeks by the December 2008 deadline. A quarter of PCTs do not know whether they will be able to meet this prominent target and 4% know that they will not meet the target.

Supplementary questions: What support do PCTs need to deliver the Action Plan?

Once the audit forms had been marked, the All-Party Parliamentary Hepatology Group decided to write to the 42 PCTs that scored 5 or lower in the audit to find out what additional support they required in order to improve the hepatitis C patient experience in their area (see appendix 5 for the supplementary questions). Of the 19 PCTs that replied:

- 17 PCTs felt that more detailed guidance on commissioning would help them to improve their hepatitis C services.
- 17 PCTs felt that national best practice guidelines on hepatitis C service delivery would help them to improve their hepatitis C services.
- 13 PCTs thought that including hepatitis C in QOF would help to improve local diagnosis rates.
- 13 PCTs said that they required additional budget in order to provide the services required in the Action Plan.

Alarmingly, one PCT Director of Commissioning replied to the supplementary questions saying:

> *"The majority of people currently being tested for hepatitis C have no treatment or intervention options open to them. This raises questions about why testing happens. National initiatives aimed at delivering testing only to those that can benefit should be considered."*

This response exemplifies the lack of understanding about hepatitis C amongst many medical professionals at all levels of the industry. Diagnosing all hepatitis C patients should be a public health priority so they can be offered treatment, thereby saving lives and saving the NHS money in the long term.

All hepatitis C patients should be offered treatment as recommended by NICE. If the patient chooses not to undertake treatment, or if treatment is unsuccessful, it is still imperative that the patient is aware of their diagnosis so they can make appropriate lifestyle adaptations, such as giving up alcohol which is a powerful accelerant for liver damage for people with hepatitis C. It also allows them to take appropriate precautions to make sure that they do not put other people at risk of infection.

The All-Party Parliamentary Hepatology Group believes that hepatitis C training for GPs and nurses should be addressed as a matter of urgency.

Based on the findings of these supplementary questions, the APPHG recommends that the Department of Health provides PCTs with more detailed guidance on commissioning hepatitis C services and national best practice guidelines on hepatitis C service delivery. Further, hepatitis C case-finding should be added to QOF to incentivise doctors to improve diagnosis rates.

Regional analysis of PCT scores

The regional breakdown of PCT scores highlights the disparity in hepatitis C services across the country. Strategic Health Authority average scores varied between 5.5 and 8 out of 10.

Areas that performed the best tended to be those where there were strong, coordinated links between the PCTs in tackling the disease. For example, in the South East Coast region there is a well established clinical network and the Kent Health Protection Unit have published management guidelines for local services.

Strategic Health Authority boundaries have changed so that the 28 SHAs in 2006 are now 10, therefore the results for the equivalent 2006 areas are listed below.

Ranking 2008	SHA 2008	Average score	Equivalent SHA(s) 2006	Average score of SHAs in 2006
1	South East Coast	**8**	Surrey and Sussex	**3.8**
			Kent and Medway	
2	South Central	**7**	Thames Valley	**3.7**
			Hampshire and Isle of White	
3	North West	**6.6**	Cumbria and Lancashire	**4.8**
			Cheshire and Merseyside	
			Greater Manchester	
3	Yorkshire and Humber	**6.6**	North and East Yorkshire and Northern Lincolnshire	**4.3**
			West Yorkshire	
			South Yorkshire	
4	East Midlands	**6.5**	Trent	**2.7**
			Leicestershire, Northamptonshire and Rutland	
5	North East	**6.4**	Northumberland, Tyne and Wear	**3.6**
			County Durham and Tees Valley	
6	South West	**5.8**	Avon, Gloucestershire and Wiltshire	**3.7**
			Dorset and Somerset	
			South West Peninsula	
7	East of England	**5.7**	Norfolk, Suffolk and Cambridgeshire	**3.8**
			Essex	
			Bedfordshire and Hertfordshire	
7	London	**5.7**	North Central London	**2.7**
			North East London	
			North West London	
			South East London	
			South West London	
8	West Midlands	**5.5**	Birmingham and the Black Country	**4.5**
			Shropshire and Staffordshire	
			West Midlands South	

Within each SHA region the audit results show that hepatitis C services vary hugely. For example, in the East of England, scores ranged from 0 (Mid Essex) to 9 (Cambridgeshire). In the North East region, scores ranged from 2 (Newcastle) to 10 (County Durham). In the South Central region, scores ranged from 1 (Southampton) to 8 (where there is a coordinated approach across the Thames Valley region and as a consequence Milton Keynes, Berkshire East, Berkshire West, Oxfordshire, Buckinghamshire and Hampshire all scored 8).

NHS Hospital Trust Audit Results

Responses

Of the 171 Hospital Trusts, 141 were eligible after excluding those with single disease focus and those which do not treat hepatitis C patients. Of these, only 45% of the Trusts responded (63 responded and 78 did not respond). This is a shocking and disappointing decrease in response rate from the 2006 audit where 65% of Hospital Trusts responded. We are concerned that this poor response rate to a simple 12 question survey may indicate that the Trusts would not want their results published and made public.

Delays to treatment

37 of the 63 (59%) of the responding Hospital Trusts reported that some of their patients had their treatment delayed for more than 3 months from their first hospital consultation. This was due to a variety of administrative reasons; staffing shortages in 16 Trusts, biopsy delays in 14, budget constraints in 9 and contract difficulties in 4 of the Trusts.

The responding 63 NHS Hospital Trusts treated a cumulative total of 2087 patients in 2005/6. At least 470 of these patients had their treatment delayed by 3 months from their first hospital consultation. Many of the Trusts do not measure the numbers who had to wait for treatment and simply responded 'unknown' or 'most' when asked how many hepatitis C patients had their treatment delayed for more than 3 months.

Waiting times

The average waiting time from referral to a patient's first appointment with a consultant was 7.2 weeks. However, this masks a huge variation in waiting times between 3 and 20 weeks.

The average waiting time between a recommendation of treatment and the first injection of interferon for hepatitis C patients was 6.9 weeks, although again this covers a wide range of waiting times from 2 weeks to 24 weeks.

Staffing issues

The number of consultants dealing with hepatitis C patients and specialist nurses has risen steadily over the last 3 years. The total number of consultants and specialist nurses in the 63 responding Trusts is as follows:

Year	No. of consultants	No. of specialist nurses
2005/6	99	51
2006/7	107	57
2007/8	124	68

Specialist nurses are an imperative part of the hepatitis C patient pathway and they can make all the difference to the success of a patient's treatment. Every hepatitis C patient should have access to a specialist nurse.

Almost 1 in 5 of the specialist nurses are funded by pharmaceutical companies. We are concerned that PCTs may be relying on this funding which is not secure in the long term.

Psychiatric services
Psychiatric side effects are a significant risk during anti-viral treatment for hepatitis C and pre-existing psychiatric co-morbidities may be a contra-indication. Psychiatric services are important in assessing patients for treatment and psychiatric support may be crucial in enabling patients to adhere to the often challenging treatment regime. So it is concerning to report that psychiatric services are only available in 35% of NHS Trusts. 65% of NHS Trusts do not integrate psychiatric services into the care pathway, which is likely to result in less successful treatment outcomes.

Meeting the government's 18 week target
Less than two thirds (62%) of responding NHS Trusts are confident that they will have the infrastructure in place to ensure all hepatitis C patients will start treatment within 18 weeks by the December 2008 government deadline. 28% of NHS Trusts do not know if they will be able to meet the target and 10% expect not to meet the target.

Appendix 1: Letter to PCTs

ALL-PARTY PARLIAMENTARY HEPATOLOGY GROUP
Co-chairs – Mr David Amess MP, Mr Bob Laxton MP
Secretariat Contact: Jane Allen, Parliamentary Officer,
The Hepatitis C Trust, 27 Crosby Row, London SE1 3YD
Tel: 020 7089 6220, Fax: 020 7089 6201,
e-mail: jane.allen@hepctrust.org.uk

PCT address

20 September 2007

Dear Chief Executive,

Last year the All-Party Parliamentary Hepatology Group conducted an audit of the implementation of the Department of Health Hepatitis C Action Plan for England.

We were extremely disappointed to find that the Department of Health Action Plan was being implemented effectively by just 8% of PCTs. We were also disappointed that only two thirds of PCTs felt able to respond. Your PCT scored as follows:

PCT	Score	Level of implementation
PCT		

The full report, 'A Matter of Chance', can be found at The Hepatitis C Trust website: www.hepctrust.org.uk

We are hopeful that, as three years have passed since the release of the Action Plan, there will now be a more acceptable level of implementation across the UK, and so are repeating the audit. The results will form part of a report to the Government and so it is vital that we receive responses from all PCTs. A prize will be awarded to the PCT with the highest score at the launch of the report in honour of Dame Anita Roddick, who spent the last months of her life working so tirelessly to raise awareness about the disease. We feel that this audit will be a timely and important addition to her achievements in this field.

We have directed this audit to you as chapter 5, action 3 of the Action Plan states that:

> 'Chief Executives of Primary Care Trusts … should be able to demonstrate that there are adequate services and partnerships at local level to enable models of best clinical practice to be followed, as set out in the *Hepatitis C Strategy for England*.'

We would be grateful if you could take the time to complete the attached short questionnaire and return it to our secretariat. Any names supplied in your answers will not be published and will only be used to aid the APPHG with mapping hepatitis C services.

If you would prefer to receive the questionnaire in electronic form, please email jane.allen@hepctrust.org.uk. Please post or email your completed questionnaire by **19 October 2007** to our secretariat:

Jane Allen, The Hepatitis C Trust, 27 Crosby Row, London, SE1 3YD
jane.allen@hepctrust.org.uk

Thank you for your help with this important audit.

Yours sincerely,

David Amess MP

Bob Laxton MP

Joint Chairs, All-Party Parliamentary Hepatology Group

Appendix 2: PCT audit questionnaire

All-Party Parliamentary Hepatology Group

PCT Audit 2007

Name of PCT ____

1. How many people in your PCT area do you estimate have chronic hepatitis C?

____

2. How did you arrive at this estimate?

a. ï Extrapolated from national prevalence estimates
b. ï Used HPA commissioning template
c. ï Carried out your own scoping exercise
d. ï Other, please explain ____________________________________

____

____

3. Does your PCT have an agreed protocol for hepatitis C testing?

ï Yes ï No

4. On what basis did you estimate how many people you would need to treat (or how much money you would need to spend on treatment) for chronic hepatitis C in the financial year 2006/7?

a. ï Number treated in 2005/6
b. ï Available budget
c. ï Used HPA commissioning template
d. ï Other, please explain ____________________________________

____

____

5. How many people in your PCT area actually received anti-viral treatment for hepatitis C in 2006/7?

____

6. How many patients had their treatment delayed for more than three months after their first hospital consultation in 2006/7?

____

7. What is your designated budget for hepatitis C treatment for the financial year 2007/08?

a. ï No designated budget
b. ï < £50,000
c. ï £50,000 - £100,000
d. ï > £100,000

8. What aspects of hepatitis C treatment do you as a PCT monitor?

a. ï Number receiving treatment
b. ï Number achieving sustained virological responses by genotype
c. ï Number of treatment discontinuations

d. ï Number of patients receiving re-treatment
e. ï None
f. ï Other (please specify) ____

____

9. Please specify where people in your area can be *anonymously* tested for hepatitis C*?* [i.e. Name(s) of Clinic(s)]

____

____

____

10. Does your PCT have a hepatitis C lead? If so please provide their name, job title and the name of the organisation/hospital they report to

ï No hepatitis C lead

Name: ____

Job Title: ____

Organisation: ____

11. Does your PCT have a hepatitis C clinical network? If so please provide the names, job titles and organisation of the key members.

ï No hepatitis C clinical network

Name: ____

Job Title: ____

Organisation: ____

Name: ____

Job Title: ____

Organisation: ____

Name: ____

Job Title: ____

Organisation: ____

Name: ____

Job Title: ____

Organisation: ____

12. Please give details of any special provision your PCT is making for services for particular groups of hepatitis C patients?

Prisoners: ____

____

Injecting drug users: ____

____

Children: ____

____

13. In comparison to 2006/7, do you expect to treat more or fewer hepatitis C patients in 2007/8?

a.ï 25% More
b.ï 50% More
c.ï 100% More
d.ï Fewer
e. ï About the same
f. ï Don't know

14. In comparison to 2007/8, do you expect to treat more or fewer hepatitis C patients in 2008/9?

a.ï 25% More
b.ï 50% More
c.ï 100% More
d.ï Fewer
e. ï About the same
f. ï Don't know

15. Will your funding arrangements with hospital trusts ensure that all hepatitis C patients will start treatment within 18 weeks by the December 2008 deadline?

ï Yes ï No ï Don't know

Appendix 3: Letter to NHS Hospital Trusts

ALL-PARTY PARLIAMENTARY HEPATOLOGY GROUP
Co-Chairs – Mr David Amess MP, Mr Bob Laxton MP
Secretariat Contact: Jane Allen, Parliamentary Officer
The Hepatitis C Trust, 27 Crosby Row, London SE1 3YD
Tel: 020 7089 6220, Fax: 020 7089 6201,
e-mail: jane.allen@hepctrust.org.uk

NHS Trust address

20 September 2007

Dear Chief Executive,

The All-Party Parliamentary Hepatology Group is conducting an audit of the implementation of the Department of Health Hepatitis C Action Plan for England, launched in July 2004.

Last year we conducted a similar audit and we are keen to see how services have progressed. The results will form part of a report to the Government.

You will be aware that chapter 5, action 3 of the Action Plan states that:

> 'Chief Executives of NHS Hospital Trusts… should be able to demonstrate that there are adequate services and partnerships at local level to enable models of best clinical practice to be followed, as set out in the *Hepatitis C Strategy for England*.'

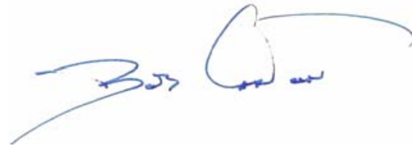
We would be grateful if you could take the time to complete the attached short questionnaire and return it to our secretariat. Any names supplied in your answers will not be published and will only be used to aid the APPHG with mapping hepatitis C services.

If you would prefer to receive the questionnaire in electronic form, please email jane.allen@hepctrust.org.uk. Please post or email your completed questionnaire by **19 October 2007** to our secretariat:

Jane Allen, The Hepatitis C Trust, 27 Crosby Row, London, SE1 3YD
jane.allen@hepctrust.org.uk

Thank you for your help with this important audit.

Yours sincerely,



David Amess MP Bob Laxton MP

Joint Chairs, All-Party Parliamentary Hepatology Group

ENCL: APPHG NHS Hospital Trust Audit 2007

Appendix 4: NHS Hospital Trust audit questionnaire

All-Party Parliamentary Hepatology Group

NHS Hospital Trust Audit 2007

Name of Hospital trust ____

1 **How many patients did you treat for hepatitis C with interferon and ribavirin in:**

a. 2005/6 ______________________________________

2. How many do you expect to treat in:

b. 2006/7 ______________________________________

c. 2007/8 ______________________________________

3. How many patients had their treatment for hepatitis C delayed for more than three months from their first hospital consultation in 2005/6?

____.

4. If this happened was the reason for this:

a. ï Budget
b. ï Contractual difficulties
c. ï Staff shortage
d. ï Biopsy access
e. ï Other (please specify) ____

____

____

5. How many fulltime equivalent *consultants* do you have in all the hospitals treating people with hepatitis C in your Trust?

For: 2005/6 ___ 2006/7 ___ 2007/8 ___

6. How many fulltime equivalent *specialist nurses* do you have in all the hospitals treating people with hepatitis C in your Trust?

For: 2005/6 ___ 2006/7 ___ 2007/8 ___

7. **How is each specialist nurse being funded?**
   (Please indicate number for each method)
   a. By your trust ___
   b. Explicitly by one or more PCTs ___
   c. By a pharmaceutical company ___
   d. By a mixture of these (please specify the full time equivalent funded by each)

____

____

____

8. **What is the average waiting time from referral to 1st appointment with consultant for hepatitis C patients?**

   ______________________________ weeks

9. **What is the average waiting time from recommendation of treatment to 1st injection of interferon for hepatitis C patients?**

   ______________________________ weeks

10. **Are psychiatry services integrated into the care pathway for hepatitis C patients?**

    ï Yes ï No

11. **What policy or protocols exist to test for hepatitis C?**

____

____

12. **Do you have the infrastructure in place to ensure all hepatitis C patients will start treatment within 18 weeks by the December 2008 deadline?**

    ï Yes ï No ï Don’t know

Appendix 5: Supplementary questions to PCTs that scored 5 or lower

All-Party Parliamentary Hepatology Group Audit of Hepatitis C Services

Supplementary questions to improve the patient experience

1. Would more detailed guidance on commissioning help you to improve your hepatitis C services?

☐ Yes ☐ No

2. Would national best practice guidance on hepatitis C service delivery help you to improve your services?

☐ Yes ☐ No

3. Would you like to see hepatitis C included in QOF in order to improve diagnosis rates?

☐ Yes ☐ No

If you answered no, please give details of why you feel this would not be beneficial:

……………………………………………………………………………………….

………………………………………………………………………………………

4. Do you feel that you require extra funding to deliver the full range of services as set out in the Hepatitis C Action Plan for England?

☐ Yes ☐ No

Please give an estimation of how much extra this would cost your PCT per year:

……………………………………………………………………………………

5. Are there any other initiatives that would help you to deliver improved hepatitis C services in your area?

……………………………………………………………………………………

……………………………………………………………………………………

……………………………………………………………………………………

……………………………………………………………………………………

Please return your answers by 25 January 2008 by post or email to:
Jane Allen, The Hepatitis C Trust, 27 Crosby Row, London, SE1 3YD
jane.allen@hepctrust.org.uk

Appendix 6: Alphabetical list of PCTs with scores (with 2006 comparison)

PCT 2008	Score	Previous PCT	2006 Audit Score	Difference
Ashton, Leigh and Wigan PCT	7	Ashton, Leigh and Wigan PCT	DNR	N/A
Barking and Dagenham PCT	6	Barking and Dagenham PCT	6	0
Barnet PCT	DNR	Barnet PCT	0	N/A
Barnsley PCT	3	Barnsley PCT	DNR	N/A
Bassetlaw PCT	9	Bassetlaw PCT	DNR	N/A
Bath and North East Somerset PCT	DNR	Bath and North East Somerset PCT	7	N/A
Bedfordshire PCT	7	Bedford	4	3
Berkshire East PCT	8	Bracknell Forest	6	2
		Windsor, Ascot and Maidenhead	6	2
		Slough Teaching	6	2
Berkshire West PCT	8	Newbury and Community	6	2
		Reading	6	2
		Wokingham	6	2
Bexley Care Trust	4	Bexley Care Trust	5	-1
Birmingham East and North PCT	5	North Birmingham	DNR	N/A
		East Birmingham	DNR	N/A
Blackburn With Darwen PCT	4	Blackburn With Darwen PCT	4	0
Blackpool PCT	7	Blackpool PCT	5	2
Bolton PCT	9	Bolton PCT	DNR	N/A
Bournemouth and Poole PCT	3	Poole	DNR	N/A
		Bournemouth Teaching	DNR	N/A
Bradford and Airedale Teaching PCT	9	Airedale	4	5
		Bradford South and West	4	5
		Bradford City Teaching	4	5
		North Bradford	4	5
Brent Teaching PCT	8	Brent Teaching PCT	3	5
Brighton and Hove City PCT	8	Brighton and Hove City PCT	4	4
Bristol PCT	8	Bristol North Teaching	DNR	N/A
		Bristol South and West Teaching	DNR	N/A
Bromley PCT	7	Bromley PCT	4	3
Buckinghamshire PCT	8	Vale of Aylesbury	5	3
		Wycombe	5	3
		Chiltern and South Bucks	4	4
Bury PCT	DNR	Bury PCT	0	N/A
Calderdale PCT	DNR	Calderdale PCT	DNR	N/A
Cambridgeshire PCT	9	Huntingdonshire	5	4
		South Cambridgeshire	4	5
		East Cambridge and Fenland	5	4
		Cambridge City	4	5
Camden PCT	3	Camden PCT	3	0
Central and Eastern Cheshire PCT	5	Central Cheshire	3	2
		Eastern Cheshire	DNR	N/A
Central Lancashire PCT	8	Preston	1	7
		Chorley and South Ribble	3	5

		West Lancashire	7	1
City and Hackney Teaching PCT	7	City and Hackney Teaching PCT	DNR	N/A
Cornwall and Isles Of Scilly PCT	8	West of Cornwall	DNR	N/A
		Central Cornwall	DNR	N/A
		North and East Cornwall	DNR	N/A
County Durham PCT	10	Durham Dales	4	6
		Sedgefield	4	6
		Easington	4	6
		Derwentside	4	6
		Durham and Chester-le-Street	5	5
Coventry Teaching PCT	DNR	Coventry Teaching PCT	DNR	N/A
Croydon PCT	7	Croydon PCT	DNR	N/A
Cumbria PCT	6	Carlisle and District	7	-1
		Eden Valley	7	-1
		Morecombe Bay (South Lakeland)	DNR	N/A
		West Cumbria	7	-1
Darlington PCT	7	Darlington PCT	4	3
Derby City PCT	6	Central Derby	4	2
		Greater Derby	4	2
Derbyshire County PCT	6	High Peak and Dales	3	3
		Chesterfield	3	3
		Amber Valley	DNR	N/A
		Erewash	DNR	N/A
		Derbyshire Dales and South Derbyshire	DNR	N/A
		North Eastern Derbyshire	3	3
Devon PCT	8	North Devon	2	6
		Mid Devon	DNR	N/A
		Exeter	DNR	N/A
		East Devon	3	5
		Teignbridge	DNR	N/A
		South Hams and West Devon	DNR	N/A
Doncaster PCT	8	Doncaster West	1	7
		Doncaster Central	DNR	N/A
		Doncaster East	1	7
Dorset PCT	4	North Dorset	0	4
		South West Dorset	DNR	N/A
		South and East Dorset	4	0
Dudley PCT	1	Dudley Beacon and Castle	DNR	N/A
		Dudley South	DNR	N/A
Ealing PCT	DNR	Ealing PCT	DNR	N/A
East and North Hertfordshire PCT	8	North Hertfordshire and Stevenage	DNR	N/A
		Royston, Buntingford and Bishop's Stortford	DNR	N/A
		Welwyn Hatfield	3	5
		South East Hertfordshire	DNR	N/A
East Lancashire Teaching PCT	5	Hyndburn and Ribble Valley	DNR	N/A
		Burnley, Pendle and Rossendale	2	3
East Riding Of Yorkshire PCT	9	Yorkshire Wolds and Coast	5	4

		East Yorkshire	DNR	N/A
East Sussex Downs and Weald PCT	8	Sussex Downs and Weald	4	4
		Eastbourne Downs	4	4
Eastern and Coastal Kent PCT	8	Swale Teaching	DNR	N/A
		Shepway	3	5
		East Kent Coastal Teaching	4	4
		Canterbury and Coastal	4	4
		Ashford	3	5
Enfield PCT	3	Enfield PCT	3	0
Gateshead PCT	7	Gateshead PCT	DNR	N/A
Gloucestershire PCT	7	West Gloucestershire	4	3
		Cotswold and Vale	4	3
		Cheltenham and Tewkesbury	4	3
Great Yarmouth and Waveney PCT	3	Great Yarmouth Teaching	4	-1
		Waveney	9	-6
Greenwich Teaching PCT	7	Greenwich Teaching PCT	DNR	N/A
Halton and St Helens PCT	7	St. Helens	1	6
		Halton	DNR	N/A
Hammersmith and Fulham PCT	3	Hammersmith and Fulham PCT	2	1
Hampshire PCT	8	Blackwater Valley and Hart	DNR	N/A
		Mid-Hampshire	2	6
		New Forest	DNR	N/A
		Eastleigh and Test Valley South	DNR	N/A
		East Hampshire	1	7
		North Hampshire	DNR	N/A
Haringey Teaching PCT	7	Haringey Teaching PCT	1	6
Harrow PCT	5	Harrow PCT	1	4
Hartlepool PCT	DNR	Hartlepool PCT	DNR	N/A
Hastings and Rother PCT	8	Bexhill and Rother	4	4
		Hastings and St Leonards	4	4
Havering PCT	5	Havering PCT	2	3
Heart Of Birmingham Teaching PCT	6	Heart Of Birmingham Teaching PCT	4	2
Herefordshire PCT	6	Herefordshire PCT	DNR	N/A
Heywood, Middleton and Rochdale PCT	5	Heywood, Middleton and Rochdale PCT	5	0
Hillingdon PCT	4	Hillingdon PCT	DNR	N/A
Hounslow PCT	3	Hounslow PCT	DNR	N/A
Hull Teaching PCT	9	Western Hull Teaching	6	3
		Eastern Hull Teaching	DNR	N/A
Isle Of Wight NHS PCT	6	Isle Of Wight NHS PCT	DNR	N/A
Islington PCT	4	Islington PCT	2	2
Kensington and Chelsea PCT	3	Kensington and Chelsea PCT	DNR	N/A
Kingston PCT	3	Kingston PCT	3	0
Kirklees PCT	5	Huddersfield Central	DNR	N/A
		South Huddersfield	DNR	N/A
		North Kirklees	DNR	N/A
Knowsley PCT	8	Knowsley PCT	DNR	N/A
Lambeth PCT	7	Lambeth PCT	DNR	N/A
Leeds PCT	5	Leeds North West	1	4

		South Leeds	DNR	N/A
		East Leeds	DNR	N/A
		Leeds North East	1	4
		Leeds West	1	4
Leicester City PCT	5	Leicester City West	0	5
		Eastern Leicester Teaching	0	5
Leicestershire County and Rutland PCT	5	Charnwood and North West Leicestershire	0	5
		South Leicestershire	0	5
		Hinckley and Bosworth	0	5
		Melton, Rutland and Harborough	0	5
Lewisham PCT	7	Lewisham PCT	DNR	N/A
Lincolnshire Teaching PCT	2	West Lincolnshire	6	-4
		Lincolnshire South West Teaching	6	-4
		East Lincolnshire	7	-5
Liverpool PCT	7	North Liverpool	DNR	N/A
		Central Liverpool	DNR	N/A
		South Liverpool	DNR	N/A
Luton PCT	DNR	Luton PCT	DNR	N/A
Manchester PCT	8	North Manchester	DNR	N/A
		South Manchester	DNR	N/A
		Central Manchester	DNR	N/A
Medway PCT	8	Medway PCT	DNR	N/A
Mid Essex PCT	0	Witham, Braintree and Halstead Care Trust	DNR	N/A
		Maldon and South Chelmsford	DNR	N/A
		Chelmsford	DNR	N/A
Middlesbrough PCT	DNR	Middlesbrough PCT	1	N/A
Milton Keynes PCT	8	Milton Keynes PCT	5	3
Newcastle PCT	2	Newcastle PCT	3	-1
Newham PCT	9	Newham PCT	5	4
Norfolk PCT	DNR	West Norfolk	4	N/A
		Broadland	4	N/A
		Norwich	4	N/A
		Southern Norfolk	4	N/A
		North Norfolk	4	N/A
North East Essex PCT	5	Colchester	DNR	N/A
		Tendring	DNR	N/A
North East Lincolnshire PCT	8	North East Lincolnshire PCT	7	1
North Lancashire Teaching PCT	5	Morecombe Bay (Lancaster)	DNR	N/A
		Fylde	6	-1
		Wyre	5	0
North Lincolnshire PCT	8	North Lincolnshire PCT	6	2
North Somerset PCT	3	North Somerset PCT	5	-2
North Staffordshire PCT	6	Newcastle-under-Lyme	4	2
		Staffordshire Moorlands	5	1
North Tees PCT	DNR	North Tees PCT	DNR	N/A
North Tyneside PCT	4	North Tyneside PCT	4	0
North Yorkshire and York PCT	2	Hambleton and Richmondshire	DNR	N/A

		Craven, Harrogate and Rural District	2	0
		Selby and York	4	-2
		Scarborough, Whitby and Ryedale	DNR	N/A
Northamptonshire Teaching PCT	DNR	Northamptonshire Heartlands	0	N/A
		Northampton Teaching	0	N/A
		Daventry and South Northamptonshire	1	N/A
Northumberland Care Trust	DNR	Northumberland Care Trust	DNR	N/A
Nottingham City PCT	9	Nottingham City PCT	8	1
Nottinghamshire County Teaching PCT	10	Rushcliffe	8	2
		Ashfield	DNR	N/A
		Newark and Sherwood	2	8
		Mansfield District	DNR	N/A
		Gedling	8	2
		Broxtowe and Hucknall	8	2
Oldham PCT	6	Oldham PCT	DNR	N/A
Oxfordshire PCT	8	Cherwell Vale	5	3
		South West Oxfordshire	5	3
		South East Oxfordshire	5	3
		Oxford City	5	3
		North East Oxfordshire	5	3
Peterborough PCT	7	South Peterborough	6	1
		North Peterborough	6	0
Plymouth Teaching PCT	9	Plymouth Teaching PCT	5	4
Portsmouth City Teaching PCT	7	Portsmouth City Teaching PCT	DNR	N/A
Redbridge PCT	7	Redbridge PCT	2	5
Redcar and Cleveland PCT	DNR	Langbaurgh	DNR	N/A
Richmond and Twickenham PCT	5	Richmond and Twickenham PCT	0	5
Rotherham PCT	7	Rotherham PCT	4	3
Salford PCT	DNR	Salford PCT	DNR	N/A
Sandwell PCT	8	Wednesbury and West Bromwich	6	2
		Oldbury and Smethwick	6	2
		Rowley Regis and Tipton	6	2
Sefton PCT	7	Southport and Formby	1	6
		South Sefton	DNR	N/A
Sheffield PCT	6	Sheffield West	8	-2
		South East Sheffield	8	-2
		Sheffield South West	8	-2
		North Sheffield	8	-2
Shropshire County PCT	DNR	Shropshire County PCT	6	N/A
Solihull PCT	DNR	Solihull PCT	DNR	N/A
Somerset PCT	6	Somerset Coast	3	3
		South Somerset	3	3
		Taunton Deane	3	3
		Mendip	3	3
South Birmingham PCT	8	South Birmingham PCT	5	3
South East Essex PCT	6	Castle Point and Rochford	4	2
		Southend Teaching	7	-1

South Gloucestershire PCT	4	South Gloucestershire PCT	7	-3
South Staffordshire PCT	6	South Western Staffordshire	4	2
		Burntwood, Lichfield and Tamworth	4	2
		Cannock Chase	4	2
		East Staffordshire	4	2
South Tyneside PCT	6	South Tyneside PCT	3	3
South West Essex PCT	1	Billericay, Brentwood and Wickford	1	0
		Basildon Teaching	1	0
		Thurrock Teaching	3	-2
Southampton City PCT	5	Southampton City PCT	4	1
Southwark PCT	7	Southwark PCT	DNR	N/A
Stockport PCT	DNR	Stockport PCT	DNR	N/A
Stoke On Trent PCT	3	South Stoke Teaching	6	-3
		North Stoke Teaching	6	-3
Suffolk PCT	9	Suffolk Coastal	8	1
		Suffolk West	8	1
		Central Suffolk	8	1
		Ipswich	8	1
Sunderland Teaching PCT	6	Sunderland Teaching PCT	4	N/A
Surrey PCT	8	North Surrey	3	5
		East Surrey	DNR	N/A
		Guildford and Waverley	4	4
		East Elmbridge and Mid Surrey	DNR	N/A
		Surrey Heath and Woking	3	5
Sutton and Merton PCT	5	Sutton and Merton PCT	DNR	N/A
Swindon PCT	8	Swindon PCT	DNR	N/A
Tameside and Glossop PCT	DNR	Tameside and Glossop PCT	DNR	N/A
Telford and Wrekin PCT	DNR	Telford and Wrekin PCT	6	N/A
Torbay Care Trust	9	Torbay Care Trust	DNR	N/A
Tower Hamlets PCT	7	Tower Hamlets PCT	5	2
Trafford PCT	8	Trafford North	7	1
		Trafford South	7	1
Wakefield District PCT	DNR	Wakefield West	DNR	N/A
		Eastern Walkefield	2	N/A
Walsall Teaching PCT	DNR	Walsall Teaching PCT	7	N/A
Waltham Forest PCT	8	Waltham Forest PCT	DNR	N/A
Wandsworth PCT	8	Wandsworth PCT	2	6
Warrington PCT	6	Warrington PCT	8	-2
Warwickshire PCT	DNR	South Warwickshire	DNR	N/A
		North Warwickshire	DNR	N/A
		Rugby	3	N/A
West Essex PCT	DNR	Uttlesford	DNR	N/A
		Harlow	0	N/A
		Epping Forest	0	N/A
West Hertfordshire PCT	8	St. Albans and Harpenden	DNR	N/A
		Hertsmere	DNR	N/A
		Watford and Three Rivers	DNR	N/A
		Dacorum	DNR	N/A
West Kent PCT	8	Dartford, Gravesham and	DNR	N/A

		Swanley		
		Maidstone Weald		N/A
		South West Kent	DNR	N/A
West Sussex PCT	8	Western Sussex	4	4
		Crawley	4	4
		Mid-Sussex	4	4
		Horsham and Chanctonbury	4	4
		Adur, Arun and Worthing Teaching	4	4
Western Cheshire PCT	3	Ellesmere Port and Neston	3	0
		Cheshire West	3	0
Westminster PCT	4	Westminster PCT	1	3
Wiltshire PCT	6	Kennet and North Wiltshire	DNR	N/A
		South Wiltshire	DNR	N/A
		West Wiltshire	DNR	N/A
Wirral PCT	9	Birkenhead and Wallasey	9	0
		Bebington and West Wirral	9	0
Wolverhampton City PCT	3	Wolverhampton City PCT	DNR	N/A
Worcestershire PCT	6	South Worcestershire	DNR	N/A
		Redditch and Bromsgrove	DNR	N/A
		Wyre Forest	DNR	N/A

DNR = Did not respond

Appendix 7: PCT ranked by score

PCT	Score
County Durham PCT	10
Nottinghamshire County Teaching PCT	10
Bassetlaw PCT	9
Bolton PCT	9
Bradford and Airedale Teaching PCT	9
Cambridgeshire PCT	9
East Riding Of Yorkshire PCT	9
Hull Teaching PCT	9
Newham PCT	9
Nottingham City PCT	9
Plymouth Teaching PCT	9
Suffolk PCT	9
Torbay Care Trust	9
Wirral PCT	9
Berkshire East PCT	8
Berkshire West PCT	8
Brent Teaching PCT	8
Brighton and Hove City PCT	8
Bristol PCT	8
Buckinghamshire PCT	8
Central Lancashire PCT	8
Cornwall and Isles Of Scilly PCT	8
Devon PCT	8
Doncaster PCT	8
East and North Hertfordshire PCT	8
East Sussex Downs and Weald PCT	8
Eastern and Coastal Kent PCT	8
Hampshire PCT	8
Hastings and Rother PCT	8
Knowsley PCT	8
Manchester PCT	8
Medway PCT	8
Milton Keynes PCT	8
North East Lincolnshire PCT	8
North Lincolnshire PCT	8
Oxfordshire PCT	8
Sandwell PCT	8
South Birmingham PCT	8
Surrey PCT	8
Swindon PCT	8
Trafford PCT	8
Waltham Forest PCT	8
Wandsworth PCT	8
West Hertfordshire PCT	8
West Kent PCT	8
West Sussex PCT	8
Ashton, Leigh and Wigan PCT	7

Bedfordshire PCT	7
Blackpool PCT	7
Bromley PCT	7
City and Hackney Teaching PCT	7
Croydon PCT	7
Darlington PCT	7
Gateshead PCT	7
Gloucestershire PCT	7
Greenwich Teaching PCT	7
Halton and St Helens PCT	7
Haringey Teaching PCT	7
Lambeth PCT	7
Lewisham PCT	7
Liverpool PCT	7
Peterborough PCT	7
Portsmouth City Teaching PCT	7
Redbridge PCT	7
Rotherham PCT	7
Sefton PCT	7
Southwark PCT	7
Tower Hamlets PCT	7
Barking and Dagenham PCT	6
Cumbria PCT	6
Derby City PCT	6
Derbyshire County PCT	6
Heart Of Birmingham Teaching PCT	6
Herefordshire PCT	6
Isle Of Wight NHS PCT	6
North Staffordshire PCT	6
Oldham PCT	6
Sheffield PCT	6
Somerset PCT	6
South East Essex PCT	6
South Staffordshire PCT	6
South Tyneside PCT	6
Sunderland Teaching PCT	6
Warrington PCT	6
Wiltshire PCT	6
Worcestershire PCT	6
Birmingham East and North PCT	5
Central and Eastern Cheshire PCT	5
East Lancashire Teaching PCT	5
Harrow PCT	5
Havering PCT	5
Heywood, Middleton and Rochdale PCT	5
Kirklees PCT	5
Leeds PCT	5
Leicester City PCT	5
Leicestershire County and Rutland PCT	5
North East Essex PCT	5
North Lancashire Teaching PCT	5

Richmond and Twickenham PCT	5
Southampton City PCT	5
Sutton and Merton PCT	5
Bexley Care Trust	4
Blackburn With Darwen PCT	4
Dorset PCT	4
Hillingdon PCT	4
Islington PCT	4
North Tyneside PCT	4
South Gloucestershire PCT	4
Westminster PCT	4
Barnsley PCT	3
Bournemouth and Poole PCT	3
Camden PCT	3
Enfield PCT	3
Great Yarmouth and Waveney PCT	3
Hammersmith and Fulham PCT	3
Hounslow PCT	3
Kensington and Chelsea PCT	3
Kingston PCT	3
North Somerset PCT	3
Stoke On Trent PCT	3
Western Cheshire PCT	3
Wolverhampton City PCT	3
Lincolnshire Teaching PCT	2
Newcastle PCT	2
North Yorkshire and York PCT	2
Dudley PCT	1
South West Essex PCT	1
Mid Essex PCT	0
Barnet PCT	DNR
Bath and North East Somerset PCT	DNR
Bury PCT	DNR
Calderdale PCT	DNR
Coventry Teaching PCT	DNR
Ealing PCT	DNR
Hartlepool PCT	DNR
Luton PCT	DNR
Middlesbrough PCT	DNR
Norfolk PCT	DNR
North Tees PCT	DNR
Northamptonshire Teaching PCT	DNR
Northumberland Care Trust	DNR
Redcar and Cleveland PCT	DNR
Salford PCT	DNR
Shropshire County PCT	DNR
Solihull PCT	DNR
Stockport PCT	DNR
Tameside and Glossop PCT	DNR
Telford and Wrekin PCT	DNR
Wakefield District PCT	DNR

Walsall Teaching PCT	DNR
Warwickshire PCT	DNR
West Essex PCT	DNR

DNR = Did not respond

Appendix 8: Membership of the APPHG

Mr David Amess, Co-chair – Conservative, Southend West
Mr Timothy Boswell – Conservative, Daventry
Mr James Brokenshire – Conservative, Hornchurch
Dr Vincent Cable – Liberal Democrat, Twickenham
Mr Jim Cousins – Labour, Newcastle upon Tyne Central
Lord De Mauley – Conservative
Mr Jim Dobbin – Labour/Cooperative, Stroud
Mr David Drew – Labour/Cooperative, Burton
Mr Neil Gerrard – Labour, Walthamstow
Mr Oliver Heald – Conservative, North East Hertfordshire
Mr Kelvin Hopkins – Labour, Luton
Hon Lindsay Hoyle – Labour, Chorley North West
Dr Brian Iddon, Vice-chair – Labour, Bolton South East
Mr Stewart Jackson – Conservative, Peterborough
Mr Bob Laxton, Co-chair – Labour, Derby North
Mr Andrew Love – Labour/Cooperative, Edmonton
Lord Mancroft – Conservative
Ms Shona McIsaac – Labour, Cleethorpes
Lord Morris of Manchester – Labour
Dr Bob Spink – Conservative, Castle Point
Mr Anthony Steen – Conservative, Totnes

Appendix 9: APPHG Secretariat and its funding

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, all of its paid staff are patients and all of its volunteer staff are patients.

The Hepatitis C Trust has received funding to support its work as the secretariat from Roche Products Ltd, Schering-Plough Ltd, Novartis UK, Bristol-Myers Squibb Company and Gilead Sciences Inc. In addition, it has used its own funds. Of these, approximately 20% derive from the pharmaceutical industry, 20% from the Department of Health and 60% from grant-making trusts and individual donations.

During the course of advocacy work on behalf of patients, the Trust was recently accused by 2 PCTs of being in the pocket of the pharmaceutical industry and promoting the sale of hepatitis C drugs. In fact, the Trust believes that treatment is appropriate for some people and not for others, depending on individual circumstances and clinical need. This is obvious from the Trust's website (www.hepctrust.org.uk). In addition, 2 of the Trust's employees, including the Chief Executive, have suffered serious, irreversible long-term side effects from treatment. However, the Trust is absolutely committed to ensuring that all patients for whom it is appropriate, and who want it, have access to the NICE recommended treatment for hepatitis C.