

# A MATTER OF CHANCE

## AN AUDIT OF HEPATITIS C HEALTHCARE IN ENGLAND



THE ALL-PARTY PARLIAMENTARY  
HEPATOLOGY GROUP

**AUDIT OF THE DEPARTMENT OF HEALTH 2004 HEPATITIS C  
ACTION PLAN FOR ENGLAND**

**AN ALL-PARTY PARLIAMENTARY HEPATOLOGY GROUP REPORT  
MAY 2006**

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## EXECUTIVE SUMMARY

- Out of 305 Primary Care Trusts (PCTs) 191 (63%) responded.
- **Amongst those PCTs responding, the Action Plan has been implemented effectively by just 16 PCTs (8%), to some degree by 107 PCTs (56%) and not at all or minimally by 68 PCTs (36%), meaning that hepatitis C care depends on where you live – it is a matter of chance.**
- Only 63 out of the 191 PCTs responding (33%) have made a sensible attempt to estimate the number of people with hepatitis C in their area.
- Only 64 out of the 191 PCTs responding (34%) have a protocol in place for the testing and/or screening for hepatitis C so there is clearly no concerted nationwide effort to identify the estimated 400,000 people infected with hepatitis C but still undiagnosed.
- Only 49 out of the 191 PCTs responding (26%) have a process in place to monitor treatment, such as how many are receiving it, its success rate, serious adverse events, how and where it is delivered and any delays encountered in delivery.
  
- 107 out of 165 NHS Hospital Trusts (65%) responded.
- 39 out of 85 hospitals (46%) reported significant delays for patients wanting treatment.
- The time from recommendation for treatment to actually starting it varied from 1 week to 1 year, indicating huge regional disparities.
- These delays were due to staff shortages (38%), budget or contractual problems (51%) or delays in accessing facilities such as liver biopsy (49%).
  
- Strategic Health Authorities are also failing in their oversight role.
  
- The audit was performed by means of separate surveys sent to chief executives of PCTs and Hospital Trusts. Replies from PCTs were judged against 10 criteria and scored accordingly.
- The audit was carried out by the All-Party Parliamentary Hepatology Group, which was formed in 2003 to look into all aspects of liver disease. It has 20 registered members and over 70 participants from both Houses of Parliament.

### **Executive Conclusion**

The All-Party Parliamentary Hepatology Group is extremely disappointed by the local NHS response to hepatitis C. The Department of Health's Hepatitis C Action Plan for England is not working because it is not being implemented.

Unless vastly more vigorous efforts are made now at local level by PCTs, encouraged by targets and a timetable set out nationally by the Department of Health, we predict that hepatitis C will in the future become a crushing burden to our health service and that we will look back and know that we could have prevented that happening.

## INTRODUCTION

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 170 million people chronically infected worldwide<sup>1</sup>. In England and Wales estimates vary between 200,000 and 500,000 people infected<sup>2 3 4</sup>.

In March 2001 the Department of Health commissioned a Hepatitis C Strategy for England. Due by the end of that year, it was finally released in August 2002. An accompanying Hepatitis C Action Plan, setting out required actions for Primary Care Trusts (PCTs) and NHS Hospital Trusts, was promised within months but did not eventually appear until July 2004.

The All-Party Parliamentary Hepatology Group (APPHG)<sup>5</sup> has been extremely concerned by the lack of urgency apparent in these delays in tackling this major public health threat. In particular, we were dismayed that the Action Plan contained no targets or timetable. We feared that this omission could jeopardise its full and timely implementation. We set out our concerns in our March 2005 report *The Hepatitis C Scandal*.

Since then, anecdotal evidence from patients and clinicians has suggested that our fears were justified and that implementation was at the very least patchy. We therefore decided in February 2006, more than 18 months after the launch of the Action Plan, to undertake a survey of Primary Care Trusts and NHS Hospital Trusts in order to audit what actions they have taken to fulfil the Action Plan's stated requirement 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*.'** As well as investigating what action has been taken in response to hepatitis C, we also wanted to discover whether, in our now devolved health care system, issuing an 'action plan' is an effective method of combating public health threats.

To do this we constructed 2 separate questionnaires 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 consisted of 13 questions and was sent to all 305 PCTs in England; the hospital questionnaire had just 9 questions and went out to all 179 Hospital Trusts. Some questions in each required some supplemental information.

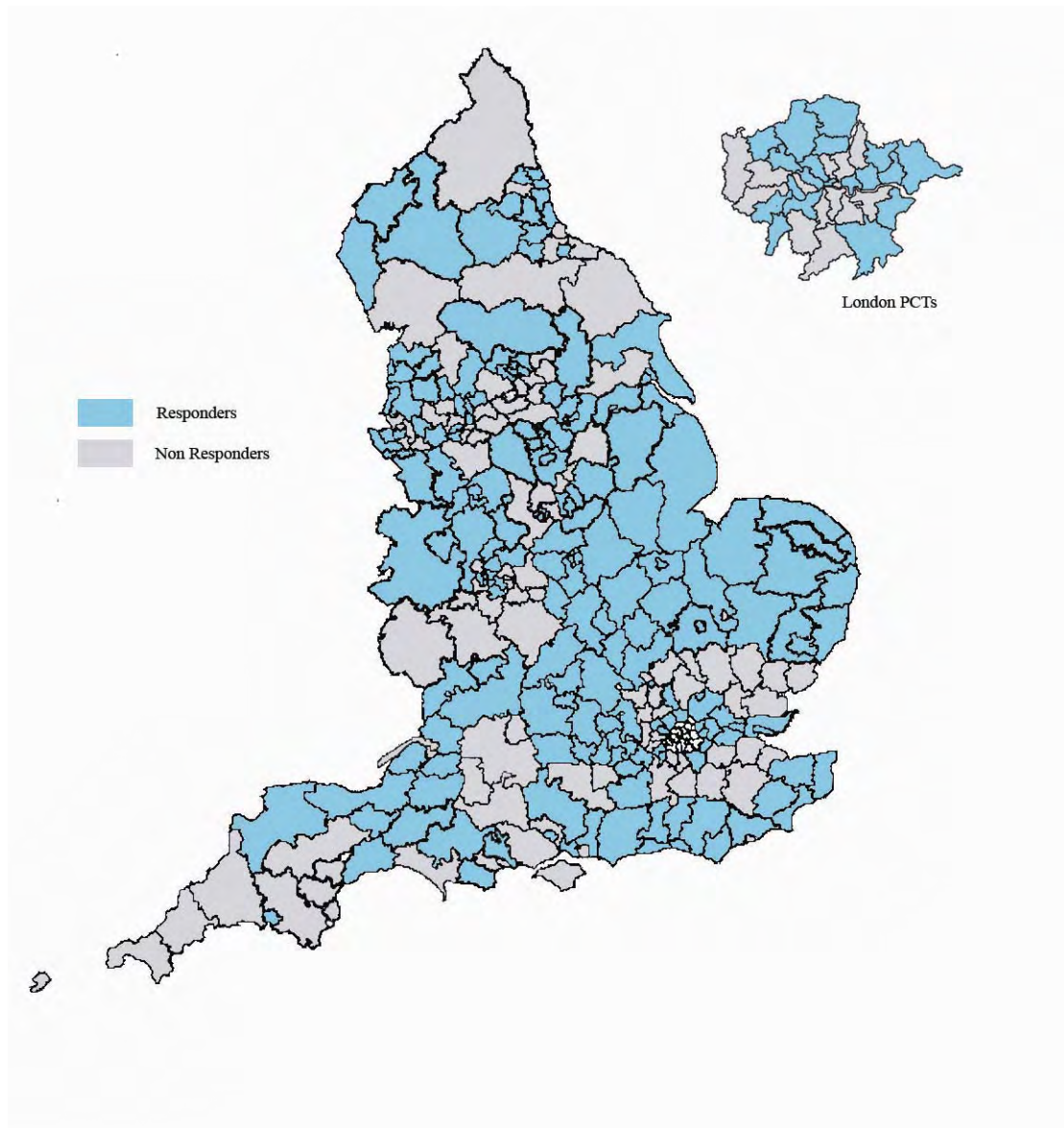
Both questionnaires were sent out with accompanying letters<sup>6</sup> by mail (with the option of an email version on request) to the respective chief executives in mid-February 2006. By the requested completion date of end March, less than half of the PCTs (133) but nearly two-thirds of the hospitals (107) had replied. Reminder letters were then sent at the start of April to all those who had not replied. Examples of the questionnaires and letters can be found in Appendix 1.

## PRIMARY CARE TRUST SURVEY

### Responses

Although we asked for replies by 31<sup>st</sup> March at the latest, we in fact accepted them until May 8<sup>th</sup> but any after that date could not be included. By May 8<sup>th</sup> replies had been received from 191 PCTs out of a total of 305. Of the 114 who did not reply, Hillingdon PCT actually refused, first claiming that it did not have the resources and then in a later letter claiming that this was because the APPHG received funding from the pharmaceutical industry<sup>7</sup>.

### Map of PCTs responding to survey



## Table of PCT responses by Strategic Health Authority

Strategic Health Authority	No of PCTs	Replying	Not replying
Avon, Gloucestershire and Wiltshire	12	6	6
Bedfordshire and Hertfordshire	11	3	8
Birmingham and The Black Country	12	6	6
Cheshire and Merseyside	15	8	7
County Durham and Tees Valley	10	7	3
Cumbria and Lancashire	13	11	2
Dorset and Somerset	9	6	3
Essex	14	7	7
Greater Manchester	14	5	9
Hampshire and Isle Of Wight	10	4	6
Kent and Medway	9	4	5
Leicestershire, Northamptonshire and Rutland	9	9	0
London			
North Central London	5	5	0
North East London	7	5	2
North West London	8	4	4
South East London	6	2	4
South West London	5	3	2
Norfolk, Suffolk and Cambridgeshire	16	16	0
North and East Yorkshire and Northern Lincolnshire	11	6	5
Northumberland, Tyne and Wear	7	4	3
Shropshire and Staffordshire	10	10	0
South West Peninsula	11	3	8
South Yorkshire	9	8	1
Surrey and Sussex	15	13	2
Thames Valley	15	15	0
Trent	19	13	6
West Midlands South	8	1	7
West Yorkshire	15	7	8
<b>TOTALS</b>	<b>305</b>	<b>191</b>	<b>114</b>

As can be seen from the map and the table some areas had much better levels of response than others. By Strategic Health Authority (SHA) the best levels of response came from Norfolk, Suffolk and Cambridgeshire SHA, North Central London SHA, Shropshire and Staffordshire SHA and Thames Valley SHA in each of which 100% of PCTs responded. Cumbria and Lancashire SHA and Surrey and Sussex SHA each had PCT response rates above 75%. Leicester, Northamptonshire and Rutland SHA answered on behalf of all its 9 PCTs but failed to give a satisfactory answer to a single question. So, although technically they responded, their level of response was, along with that from the West Midlands South SHA, from where only 1 PCT responded, in fact the worst.

Amongst the responses there was also a marked variation in the effort put into them, the quality of answers and the way they were presented. As many as 20% of the responses were either handwritten so poorly as to be at least partially illegible, failed to answer some questions at all (such as ‘Did you have a designated budget for hepatitis C treatment and monitoring in 2005/6?’) or answered them in such a way as to make it clear the question had been misread.

### **Criteria for judging implementation performance**

The lack of specific requirements in the Action Plan made it harder to develop a set of criteria by which to judge PCTs’ efforts to implement it. Extrapolation was required: so, for example, we considered it necessary to have made at least some effort, such as 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. Again 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. 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 consult with local Drug Action Teams/Community Safety Partnerships in the development/planning of services for particular groups of patients such as prisoners and injecting drug users?
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. a scoping exercise) to estimate numbers of people with chronic hepatitis C in their area?

Response	Number of PCTs	% of responding PCTs
Yes	63	33
No	128	67

It is very worrying to see how few PCTs have made any effort to ascertain the number of people with hepatitis C in their area, the number diagnosed, the number likely to be diagnosed shortly and the number likely to remain undiagnosed in the absence of increased testing. It is hard to see how proper services and staff for testing, for hospital appointments or for treatment can be put in place without a reasonable idea of the number of people needing them. We do not consider simply multiplying the Department of Health's prevalence estimate (of 0.4%) by the number of people in the PCT area to be an adequate way of arriving at a reasonable estimate, since the Department's figure is a national estimate and there are accepted divergences between the prevalence in, for example, rural and inner city areas and, besides, the December 2005 Health Protection Agency Hepatitis C in England Report says that new prevalence modelling techniques are being developed and suggests that the 0.4% figure can no longer be relied upon.

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

Response	Number of PCTs	% of PCTs
Yes	64	34
No	127	66

Just as concerning is the lack of a protocol for testing and/or screening. Since we know from Health Protection Agency figures that less than 50,000 have ever been diagnosed with hepatitis C in England out of as many as 500,000 people infected, it means that up to 9 out of 10 people who have this virus are undiagnosed. 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.

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

Response	Number of PCTs	% of PCTs
Yes	62	32
No	129	68

We interpreted 'sensible' very broadly in order to accept almost any genuine attempt at estimating numbers. Therefore, to find that less than a third of PCTs responding could be judged to have made a sensible effort was disheartening. Since anti-viral treatment is such a major component of the staffing time and of the cost of managing hepatitis C, how are services being provisioned or budgeted for in the majority of PCTs?

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

Response	Number of PCTs	% of PCTs
No	51	27
Yes	140	73

Considering the response to question 3, it is hardly surprising that there are delays in providing treatment. It is very disturbing to note that there are already widespread delays, when so few of those infected have yet been diagnosed.

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

Response	Number of PCTs	% of PCTs
Yes	49	26
No	142	74

Crucially, treatment needs to be monitored. 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 Health Protection Agency 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	Number of PCTs	% of PCTs
Yes	140	73
No	51	27

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. 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	Number of PCTs	% of PCTs
Yes	79	41
No	112	59

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	Number of PCTs	% of PCTs
Yes	59	31
No	132	69

The action plan states that the 'adequate services and partnerships' to be put in place should include 'the development of clinical networks.'<sup>8</sup> Less than one-third of PCTs have done this, 18 months after the Action Plan's publication.

9. Does the PCT consult with local Drug Action Teams/Community Safety Partnerships in the development/planning of services for particular groups of patients such as prisoners and injecting drug users?

Response	Number of PCTs	% of PCTs
Yes	130	68
No	61	32

We are relieved that in at least one area over two-thirds of PCTs have responded positively. However, the Action Plan should be implemented in all aspects by all PCTs and it needs to be pointed out that consulting about the development and planning of services is not the same as putting them in place.

10. Has the PCT made an estimate of the number of people requiring treatment during 2006/7?

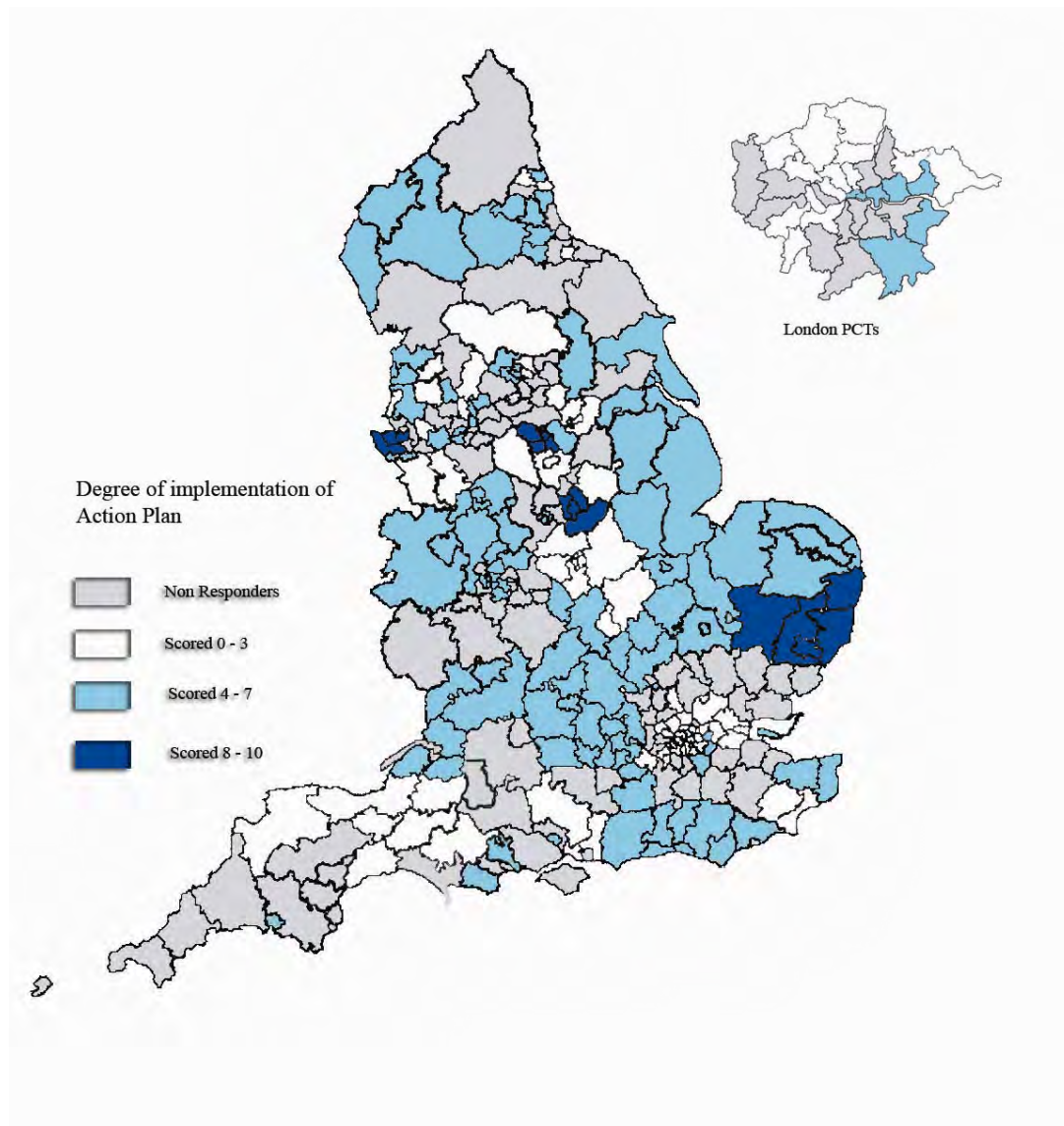
Response	Number of PCTs	% of PCTs
Yes	77	40
No	114	60

Less than half of responding PCTs had an estimate of numbers of patients requiring treatment, so how did the other 114 PCTs negotiate contracts with the hospitals to provide the treatment and how were the hospitals able to plan staffing in liver units? This lack of planning is likely to lead to the mixture of bottle-necks in some areas and overcapacity in others that the NHS cannot afford.

## Other data

We were dismayed to see that only 40 PCTs were anticipating any increase in the numbers being treated for 2006/7 over 2005/6, even though in August 2006 NICE is set to recommend treatment for everyone with hepatitis C, not just those with moderate to severe liver damage, and the Department of Health has an ongoing hepatitis C awareness campaign. Indeed, the Thames Valley Health Protection Unit, which answered the survey on behalf of the 15 PCTs in the Thames Valley SHA, wrote: ‘There is no evidence to date that the Department of Health’s current HCV awareness campaign has led to an increase in demand for tests among either the ‘general public’ or specific risk groups.’ Of the 40 anticipating an increase in treatment numbers, only 21 indicated a significant increase. Yet a forthcoming report highlights how far behind comparable European countries the UK lags in numbers receiving treatment<sup>9</sup>. In order to reach European levels and begin to reduce the pool of infection, we need to be treating at least 3 times as many patients as at present. Clearly there are no plans to do this.

## Map of PCTs by overall score



**Table of overall PCT scores by Strategic Health Authority**

<b>Strategic Health Authority</b>	<b>No of PCTs responding</b>	<b>Poor implementation</b>	<b>Partial implementation</b>	<b>Effective implementation</b>	<b>Average PCT score</b>
Avon, Gloucestershire and Wiltshire	6	0	6	0	5.17
Bedfordshire and Hertfordshire	3	1	2	0	3.67
Birmingham and The Black Country	6	0	6	0	5.67
Cheshire and Merseyside	8	5	0	3	4.63
County Durham and Tees Valley	7	1	6	0	3.71
Cumbria and Lancashire	11	3	8	0	4.91
Dorset and Somerset	6	5	1	0	2.67
Essex	7	6	1	0	2.14
Greater Manchester	5	1	4	0	4.80
Hampshire and Isle Of Wight	4	3	1	0	2.00
Kent and Medway	4	2	2	0	3.50
Leicestershire, Northamptonshire, Rutland	9	9	0	0	0.11
London					
North Central London	5	5	0	0	1.80
North East London	5	2	3	0	4.00
North West London	4	4	0	0	1.75
South East London	2	0	2	0	4.50
South West London	3	3	0	0	1.67
Norfolk, Suffolk and Cambridgeshire	16	0	11	5	5.56
N and E Yorkshire and N Lincolnshire	6	1	5	0	5.00
Northumberland, Tyne and Wear	4	2	2	0	3.50
Shropshire and Staffordshire	10	0	10	0	4.90
South West Peninsula	3	2	1	0	3.33
South Yorkshire	8	3	1	4	4.88
Surrey and Sussex	13	2	11	0	3.85
Thames Valley	15	0	15	0	5.33
Trent	13	4	5	4	5.31
West Midlands South	1	1	0	0	3.00
West Yorkshire	7	3	4	0	2.86
<b>TOTALS/OVERALL AVERAGE</b>	<b>191</b>	<b>68</b>	<b>107</b>	<b>16</b>	<b>4.05</b>

Out of the total of 191 responses 68 scored 3 or less, including 14 that scored 0, meaning they failed to fulfil a single criterion. 107 scored between 4 and 7, indicating that moves have been made to implement the Action Plan but more needs to be done and just 16 scored 8 or more<sup>10</sup>. In other words just 8% have made real progress towards implementing the Action Plan. If we then assume that those PCTs that were unable or unwilling to reply to the survey have also been unable or unwilling to tackle hepatitis C in their area – a not unreasonable assumption in general, although there will doubtless be a few exceptions – then almost two-thirds of all PCTs are failing to take the appropriate action to combat a major public health threat and a mere 5% have responded adequately. The overall average PCT score at 4.05 is indefensibly low.

Furthermore, even the best performing SHA has a PCT average of less than 6 out of 10 and in 9 out of 28 SHAs the average PCT score is 3 or less. It seems clear that SHAs are also failing in their oversight role, as set out in the Action Plan, to ‘ensure that local NHS arrangements are in place to achieve the objectives of [Action 3: High-quality health and social care services].’

## NHS HOSPITAL TRUST SURVEY

### Responses

Out of the 179 NHS Hospital Trusts 165 were eligible, after excluding those, for example, with single disease specific hospitals, such as the Moorfields Eye Hospital NHS Trust. Of the 165, we received responses from 107 (65%). Of these, 11 said they did not treat patients with hepatitis C, 11 said they only offered work-up and then referred to another hospital for treatment. 85 actually treat patients.

### Table of responders and non-responders by Strategic Health Authority

Strategic Health Authority	No of hospitals	Replying	Not replying
Avon, Gloucestershire and Wiltshire	7	4	3
Bedfordshire and Hertfordshire	4	2	2
Birmingham and The Black Country	8	3	5
Cheshire and Merseyside	14	9	5
County Durham and Tees Valley	3	3	0
Cumbria and Lancashire	4	2	2
Dorset and Somerset	5	4	1
Essex	6	3	3
Greater Manchester	9	7	2
Hampshire and Isle Of Wight	5	4	1
Kent and Medway	4	3	1
Leicestershire, Northamptonshire and Rutland	4	1	3
London			
North Central London	6	4	2
North East London	5	5	0
North West London	8	4	4
South East London	6	4	2
South West London	5	3	2
Norfolk, Suffolk and Cambridgeshire	5	4	1
North and East Yorkshire and N Lincolnshire	8	6	2
Northumberland, Tyne and Wear	5	5	0
Shropshire and Staffordshire	4	2	2
South West Peninsula	5	4	1
South Yorkshire	5	2	3
Surrey and Sussex	9	6	3
Thames Valley	5	4	1
Trent	6	5	1
West Midlands South	5	2	3
West Yorkshire	5	2	3
<b>TOTALS</b>	<b>165</b>	<b>107</b>	<b>58</b>

It is noticeable that Leicestershire, Northamptonshire and Rutland SHA had the worst response rate, just 1 hospital out of 4 replying. This is the same SHA that had the worst PCT response rate and the worst average overall PCT score, 0.11 out of 10.

## Responses to questions

1(a). Within the Hospital Trust have patients had treatment delayed for more than 3 months or had it deferred to the next financial year?

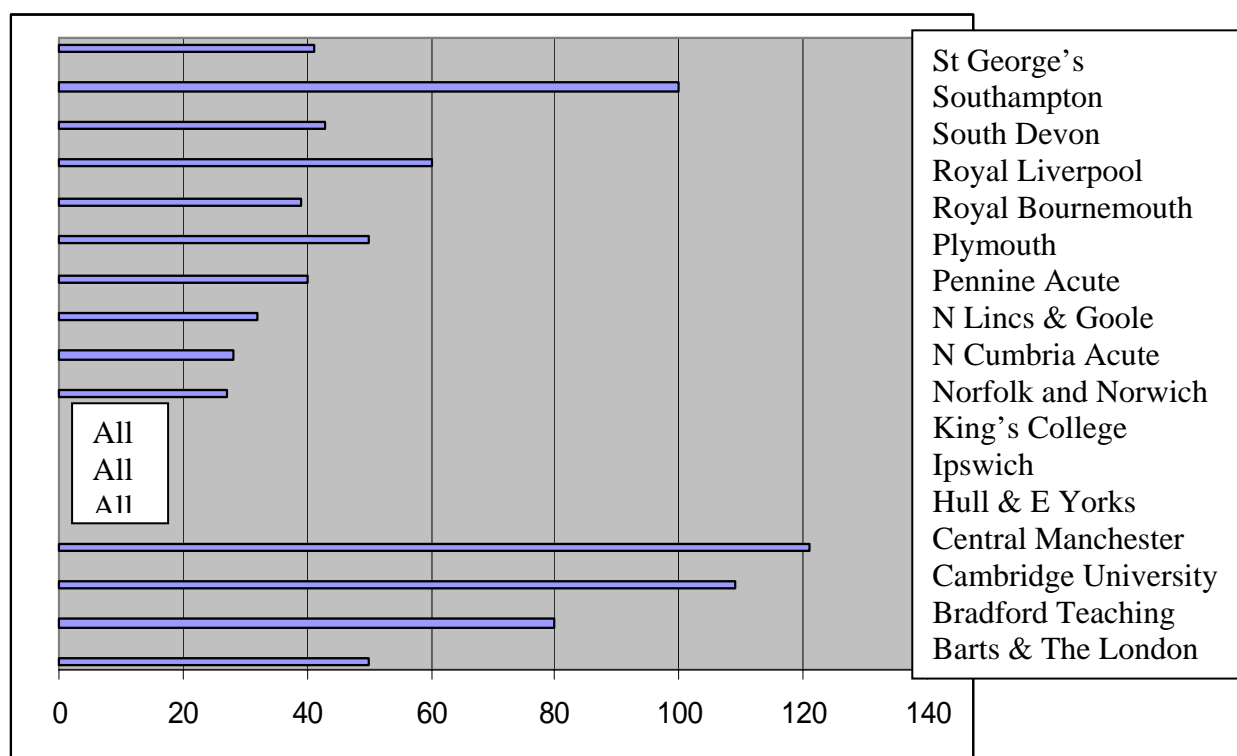
Response	Number of Hospital Trusts	% of number responding (85)
Yes	39	46
No	46	54

1(b). What was the reason for the delay/deferment?

	Budget	Contractual problems	Staff shortages	Access to biopsy	Other
No of responses	11	9	15	19	18

Even though up to 5 times more hepatitis C patients are treated annually in comparably sized European countries<sup>11</sup>, services are clearly already stretched with patients having their treatment significantly delayed or deferred in almost half of the treating Hospital Trusts responding. Of the reasons given, budget and contractual problems suggest there has not been proper PCT commissioning of services; staff shortages suggest that the NHS is not ensuring adequate staffing levels; and lack of access to biopsy suggests inadequate provision of histopathology services, although all these are requirements clearly set out in the Action Plan.

## Number of patients waiting more than 3 months for treatment in the NHS Hospital Trusts with longest waiting lists



2. What are the waiting times: from referral to first consultant appointment; for biopsy; and from recommendation to start of treatment?

	Number of responses	Shortest (weeks)	Longest (weeks)	Average (weeks)
Time from referral to 1 <sup>st</sup> consultant appointment	89	2	16	10
Waiting time for biopsy	87	0	36	7
Time from recommendation to start of treatment	67	1	52	8

The patient journey for a newly diagnosed hepatitis C patient often involves a referral by a GP, then a hospital appointment with a consultant, then a biopsy, then a recommendation for treatment and finally the start of treatment. Other investigations such as further blood tests (e.g. for genotype) and ultrasound scans may also lengthen the process. It is not unreasonable to add together the 3 columns in the table above to give an overall time from GP referral to start of treatment. The shortest time of 3 weeks is excellent, although hard to achieve in practice. The average wait of 25 weeks, or almost half a year, is too long and the longest time of 104 weeks, or 2 years, is unacceptable. It is more than possible in that time for a patient to progress from vital-to-treat cirrhosis to too-late-to-treat decompensated liver disease or liver cancer. If we are going to tackle hepatitis C effectively, we need to have clear, expeditious care pathways, as set out in the Action Plan. The requirement for biopsy before treatment will shortly disappear<sup>12</sup> but nevertheless patients may still wish to have a biopsy to see whether they need treatment immediately.

3. How many Hospital Trusts have hepatitis nurse specialists and how are they funded?

Trusts with nurse specialists	Funded by Trust	Funded by PCT(s)	Funded by industry	Funded by a mixture
63	36	6	10	11

We are concerned about the continuing high proportion of nurses being funded by the pharmaceutical industry. This is not because we are suggesting that nurses are in any way influenced by where their funding originates. On the contrary, from anecdotal evidence from patients it is clear that hepatitis nurse specialists are entirely impartial and devoted to patient care and, in fact, the importance of nurses in hepatitis C treatment in the UK is one area of advantage over other European countries.<sup>13</sup> Rather, we believe that industry funding is another way that permits Hospital Trusts and PCTs to cut corners and provide services in a piecemeal fashion instead of being forced to address the whole of hepatitis C service provision in a proper, co-ordinated, long-term manner.



## CONCLUSION

The All-Party Parliamentary Hepatology Group is saddened to find that its pessimism about the implementation of the Department of Health's Hepatitis C Action Plan for England was fully justified. With just 8% of responding PCTs implementing the Action Plan in what we consider to be an effective manner and significant delays in almost half of responding NHS Hospital Trusts, we have to conclude that, more than 18 months since its publication, the Action Plan is failing to deliver the services that hepatitis C patients have a right to expect.

Indeed, the situation may be even worse. The questionnaires were short and hardly onerous to complete for those trusts engaged in tackling hepatitis C. Inevitably, however, they would have been more time-consuming to answer, the less the action taken to put services in place. There must therefore be the suspicion that it is precisely those trusts that have done the least to implement the Action Plan that are the most likely not to have responded.

We have voiced our concern in the past that the Action Plan had no budget, no targets and no timetable and that without them it would fail. We accept that in the current environment there will be no ring-fenced budget for hepatitis C, much as we still think it necessary. We are also aware that in our devolved healthcare system it is much harder for the Department of Health to be prescriptive and that targets are unpopular, capable as they are of causing unforeseen distortions. This, however, is a major public health issue and we believe that the Department could and should define targets and a timetable and do so as a matter of urgency. This audit clearly demonstrates that, as things now stand, the Action Plan is failing.

This failure to address hepatitis C is not acceptable. It is not acceptable in individual human terms, because patients' lives are at stake; it is not acceptable in public health terms, because this is an infectious disease with already a very large pool of infection; and it is not acceptable in NHS resource terms, because a failure to act now will inevitably create for the future huge numbers requiring enormously costly treatments for advanced liver disease.

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<sup>1</sup> WHO hepatitis C fact sheet no 164, revised October 2000

<sup>2</sup> Health Protection Agency Hepatitis C in England December 2005

<sup>3</sup> NICE Technology Assessment 075 January 2004

<sup>4</sup> The Hepatitis C Trust/University of Southampton Comparative HCV Service Provision in Europe – in print

<sup>5</sup> See Appendix 3 for more details of the APPHG

<sup>6</sup> See Appendix 1 for questionnaires and letters in full

<sup>7</sup> See Appendix 4 for details about funding

<sup>8</sup> Department of Health Hepatitis C Action Plan for England August 2002, Chapter 5

<sup>9</sup> The Hepatitis C Trust/University of Southampton Report (footnote 4 above)

<sup>10</sup> See Appendix 2 for full ranking of PCTs

<sup>11</sup> The Hepatitis C Trust/University of Southampton Report (footnote 4 above)

<sup>12</sup> NICE FAD Peginterferon alfa and ribavirin for the treatment of mild chronic hepatitis C, May 2006

<sup>13</sup> The Hepatitis C Trust/University of Southampton Report (footnote 4 above)

## APPENDIX 1

### PCT survey, NHS Hospital Trust survey and accompanying letters

#### ALL-PARTY PARLIAMENTARY HEPATOLOGY GROUP

Chair – Mr David Amess, MP; Vice Chair – Mr Bob Laxton, MP

Secretariat Contact: Dr Rebecca Moses,

The Hepatitis C Trust, 27 Crosby Row, London SE1 3YD

Tel: 020 7089 6220, Fax: 020 7089 6201,

e-mail: rebecca.moses@hepctrust.org.uk

Chief Executives  
Primary Care Trusts

8th February 2006

Dear Sir,

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 more than 18 months ago in July 2004. This audit will form part of a report to the Government.

In Chapter 5, Action 3, 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.***’

To help us with the audit would you be kind enough to 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.

**I would be grateful if you could return your completed questionnaire by 30<sup>th</sup> March 2006 to our secretariat contact –**

**Dr. Rebecca Moses, The Hepatitis C Trust, 27 Crosby Row, London SE1 3YD**

Yours faithfully

David Amess MP  
Chair, All-Party Parliamentary Hepatology Group.

**ENCL:** APPHG PCT Survey 2006

**All-Party Parliamentary Hepatology Group**  
**PCT Survey 2006**

- For the sake of clarity please use a separate sheet for your reply, numbering your answers in the same manner used in the questionnaire.
- Any names supplied in your answers will not be published and will only be used to aid the APPHG with mapping hepatitis C services.

**Please return completed questionnaires to – Dr. Rebecca Moses, The Hepatitis C Trust, 27 Crosby Row, London SE1 3YD by 30<sup>th</sup> March 2006**

**Questions**

- 1 What is the population of your PCT area?
- 2 How many people do you estimate have chronic hepatitis C in your PCT area?
  - a. How did you arrive at this estimate? (E.g. what scoping exercises have you carried out?)
  - b. Is this information routinely shared with the local Drug Action Team / Community Safety Partnership?
- 3 Does your PCT have an agreed protocol for hepatitis C testing / screening?
- 4 How many people did you estimate would need anti-viral treatment for chronic hepatitis C in the financial year 2005/6?
  - a. How did you arrive at this figure?
- 5 In practice, how many people have needed anti-viral treatment so far in 2005/6?
  - a. If this was more than your estimate, how many, if any,:
    - i. had their treatment delayed for more than three months after their first hospital consultation?
    - ii. had their treatment deferred to the next financial year?
- 6 Did you have a designated budget for hepatitis C treatment and monitoring in 2005/6?
  - a. If yes:
    - i. What was the total amount?

- ii. What percentage was for anti-viral drugs?
    - iii. What percentage was for staff (e.g. specialist hepatitis C nurses)?
    - iv. What percentage was for diagnostics, including biopsy?
    - v. What percentage for other budgetary categories? (Please specify).
  - b. If no:
    - i. From what budgetary area did you fund hepatitis C treatment and monitoring?
    - ii. How much was allocated for hepatitis C treatment and monitoring?
- 7 What monitoring of hepatitis C treatment is ongoing in your region?
- 8 Please list the hospitals you have contracts with for the treatment and monitoring of hepatitis C?
- a. For each please indicate whether the contract is a block contract or on a per patient basis.
  - b. For each please give the number of consultants treating and monitoring hepatitis C.
- 9 Please list where people in your area can be tested for hepatitis C anonymously? (E.g. which GUM clinics are willing to test for hepatitis C).
- 10 Does your PCT have a hepatitis C lead? If so please provide their name, job title and affiliation.
- 11 Does your PCT have a hepatitis C clinical network? If so please provide the names, job titles and affiliations of those involved.
- 12 Does your PCT include or consult with the local Drug Action Team/Community Safety Partnership in the development/planning of clinical networks for the assessment and treatment of patients with hepatitis C, including the provision of services for particular groups of patients, such as prisoners and injecting drug users?
- 13 In the light of the Department of Health's current hepatitis C public awareness campaign and NICE's anti-viral drug guidance review due out in August 2006, which may extend the indication for treatment to those with mild disease,
- a. What is your estimate of the number needing treatment for Hepatitis C, in your area, in the financial year 2006/7?
  - b. What is your total budget for this estimate?

**ALL-PARTY PARLIAMENTARY HEPATOLOGY GROUP**  
Chair – Mr David Amess, MP; Vice Chair – Mr Bob Laxton, MP  
Secretariat Contact: Dr Rebecca Moses,  
The Hepatitis C Trust, 27 Crosby Row, London SE1 3YD  
Tel: 020 7089 6220, Fax: 020 7089 6201,  
e-mail: rebecca.moses@hepctrust.org.uk

Chief Executive Officers  
Acute Hospital Trusts

8<sup>th</sup> February 2006

Dear Sir,

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 more than 18 months ago in July 2004. This audit will form part of a report to Government.

In Chapter 5, Action 3, 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*.’**

To help us with the audit would you be kind enough to 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.

**I would be grateful if you could return your completed questionnaire by 30<sup>th</sup> March 2006 to our secretariat contact –**

**Dr. Rebecca Moses, The Hepatitis C Trust, 27 Crosby Row, London SE1 3YD**

Yours faithfully

David Amess MP  
Chair, All-Party Parliamentary Hepatology Group

**ENCL:** APPHG NHS Hospital Trust Survey 2006

**All-Party Parliamentary Hepatology Group**  
**NHS Hospital Trust Survey 2006**

- For the sake of clarity please use a separate sheet for your reply, numbering your answers in the same manner used in the questionnaire.
- Any names supplied in your answers will not be published and will only be used to aid the APPHG with mapping hepatitis C services.

**Please return completed questionnaires to – Dr. Rebecca Moses, The Hepatitis C Trust, 27 Crosby Row, London SE1 3YD by 30<sup>th</sup> March 2006.**

**Questions**

- 1 How many patients in 2005/6, if any, had their treatment for hepatitis C (interferon with or without ribavirin):
  - a. delayed for more than three months from their first hospital consultation?
  - b. deferred to the next financial year?
- 2 If this happened was the reason for this:
  - a. Budget?
  - b. Contractual difficulties?
  - c. Staff shortage?
  - d. Biopsy access?
  - e. Other? (please specify)
- 3 Please give the names of the hospitals in your Trust which treat hepatitis C?

For each hospital that treats hepatitis C please indicate (questions 4-9):

- 4 How many consultants in total do you have treating and monitoring people with hepatitis C?
  - a. Of these, how many are in each of the following specialist areas:

- 1 Infectious Diseases?
  - 2 Hepatology?
  - 3 Gastroenterology?
  - 4 General Medicine?
  - 5 Other? (Please specify).
- 5 How many specialist nurses are treating people with hepatitis C?
  - 6 How is each specialist nurse being funded?
    - 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).
  - 7 What is the average waiting time from referral to 1<sup>st</sup> appointment with consultant for hepatitis C patients?
  - 8 What is the average waiting time from recommendation of treatment to 1<sup>st</sup> injection of interferon for hepatitis C patients?
  - 9 What is the average waiting time for a liver biopsy for hepatitis C patients?

## APPENDIX 2

### Alphabetical list of PCTs with scores (DNR = did not respond)

Adur, Arun & Worthing Teaching Primary Care Trust	4
Airedale Primary Care Trust	4
Amber Valley Primary Care Trust	DNR
Ashfield Primary Care Trust	DNR
Ashford Primary Care Trust	3
Ashton, Leigh & Wigan Primary Care Trust	DNR
Barking and Dagenham Primary Care Trust	6
Barnet Primary Care Trust	0
Barnsley Primary Care Trust	DNR
Basildon Primary Care Trust	1
Bassetlaw Primary Care Trust	DNR
Bath & North East Somerset Primary Care Trust	7
Bebington & West Wirral Primary Care Trust	9
Bedford Primary Care Trust	4
Bedfordshire Heartlands Primary Care Trust	4
Bexhill & Rother Primary Care Trust	4
Bexley Care Trust	5
Billericay Brentwood & Wickford Primary Care Trust	1
Birkenhead & Wallasey Primary Care Trust	9
Blackburn with Darwen Primary Care Trust	4
Blackpool Primary Care Trust	5
Blackwater Valley & Hart Primary Care Trust	DNR
Bolton Primary Care Trust	DNR
Bournemouth Teaching Primary Care Trust	DNR
Bracknell Forest Primary Care Trust	6
Bradford City Teaching Primary Care Trust	4
Bradford South & West Primary Care Trust	4
Brent Teaching Primary Care Trust	3
Brighton & Hove City Primary Care Trust	4
Bristol North Primary Care Trust	DNR
Bristol South & West Primary Care Trust	DNR
Broadland Primary Care Trust	4
Bromley Primary Care Trust	4
Broxtowe & Hucknall Primary Care Trust	8
Burnley, Pendle and Rossendale Primary Care Trust	2
Burntwood Lichfield & Tamworth Primary Care Trust	4
Bury Primary Care Trust	0
Calderdale Primary Care Trust	DNR
Cambridge City Primary Care Trust	4
Camden Primary Care Trust	3
Cannock Chase Primary Care Trust	4
Canterbury and Coastal Primary Care Trust	4
Carlisle & District Primary Care Trust	7
Castle Point & Rochford Primary Care Trust	3



Central Cheshire Primary Care Trust	3
Central Cornwall Primary Care Trust	DNR
Central Derby Primary Care Trust	4
Central Liverpool Primary Care Trust	DNR
Central Manchester Primary Care Trust	DNR
Central Suffolk Primary Care Trust	8
Charnwood & North West Leicestershire PCT	0
Chelmsford Primary Care Trust	DNR
Cheltenham & Tewkesbury Primary Care Trust	4
Cheshire West Primary Care Trust	3
Chesterfield Primary Care Trust	3
Chiltern and South Bucks Primary Care Trust	4
Chorley & South Ribble Primary Care Trust	3
City and Hackney Teaching Primary Care Trust	DNR
Colchester Primary Care Trust	DNR
Cotswold & Vale Primary Care Trust	4
Coventry Teaching Primary Care Trust	DNR
Craven, Harrogate & Rural District PCT	2
Crawley Primary Care Trust	4
Croydon Primary Care Trust	DNR
Dacorum Primary Care Trust	DNR
Darlington Primary Care Trust	4
Dartford, Gravesham & Swanley Primary Care Trust	DNR
Daventry & South Northants Primary Care Trust	1
Derbyshire Dales & South Derbyshire PCT	DNR
Derwentside Primary Care Trust	4
Doncaster Central Primary Care Trust	1
Doncaster East Primary Care Trust	1
Doncaster West Primary Care Trust	1
Dudley South Primary Care Trust	DNR
Dudley: Beacon & Castle Primary Care Trust	DNR
Durham & Chester Le Street Primary Care Trust	5
Durham Dales Primary Care Trust	4
Ealing Primary Care Trust	DNR
Easington Primary Care Trust	4
East Cambridgeshire & Fenland Primary Care Trust	5
East Devon Primary Care Trust	3
East Elmbridge and Mid Surrey Primary Care Trust	DNR
East Hampshire Primary Care Trust	1
East Kent Coastal Teaching Primary Care Trust	4
East Leeds Primary Care Trust	DNR
East Lincolnshire Primary Care Trust	6
East Staffordshire Primary Care Trust	4
East Surrey Primary Care Trust	DNR
East Yorkshire Primary Care Trust	DNR
East Yorkshire Primary Care Trust	DNR
Eastbourne Downs Primary Care Trust	4
Eastern Birmingham Primary Care Trust	DNR

Eastern Cheshire Primary Care Trust	DNR
Eastern Hull Primary Care Trust	DNR
Eastern Leicester Primary Care Trust	0
Eastern Wakefield Primary Care Trust	2
Eden Valley Primary Care Trust	7
Ellesmere Port and Neston Primary Care Trust	3
Enfield Primary Care Trust	3
Epping Forest Primary Care Trust	0
Erewash Primary Care Trust	DNR
Exeter Primary Care Trust	DNR
Fareham & Gosport Primary Care Trust	1
Fylde Primary Care Trust	6
Gateshead Primary Care Trust	DNR
Gedling Primary Care Trust	8
Great Yarmouth Teaching Primary Care Trust	4
Greater Derby Primary Care Trust	4
Greater Peterborough Primary Care P'ship-South PCT	6
Greenwich Teaching Primary Care Trust	DNR
Guildford & Waverley Primary Care Trust	4
Halton Primary Care Trust	DNR
Hambleton & Richmondshire Primary Care Trust	DNR
Hammersmith and Fulham Primary Care Trust	2
Haringey Teaching Primary Care Trust	1
Harlow Primary Care Trust	0
Harrow Primary Care Trust	1
Hartlepool Primary Care Trust	DNR
Hastings & St Leonards Primary Care Trust	4
Havering Primary Care Trust	2
Heart of Birmingham Teaching Primary Care Trust	4
Herefordshire Primary Care Trust	DNR
Hertsmere Primary Care Trust	DNR
Heywood & Middleton Primary Care Trust	5
High Peak & Dales Primary Care Trust	3
Hillingdon Primary Care Trust	DNR
Hinckley and Bosworth Primary Care Trust	0
Horsham and Chanctonbury Primary Care Trust	4
Hounslow Primary Care Trust	DNR
Huddersfield Central Primary Care Trust	DNR
Huntingdonshire Primary Care Trust	5
Hyndburn & Ribble Valley Primary Care Trust	DNR
Ipswich Primary Care Trust	8
Isle of Wight Primary Care Trust	DNR
Islington Primary Care Trust	2
Kennet and North Wiltshire Primary Care Trust	DNR
Kensington & Chelsea Primary Care Trust	DNR
Kingston Primary Care Trust	3
Knowsley Primary Care Trust	DNR
Lambeth Primary Care Trust	DNR

Langbaugh Primary Care Trust	DNR
Leeds North East Primary Care Trust	DNR
Leeds North West Primary Care Trust	1
Leeds West Primary Care Trust	1
Leicester City West Primary Care Trust	0
Lewisham Primary Care Trust	DNR
Lincolnshire South West Teaching PCT	6
Luton Teaching Primary Care Trust	DNR
Maidstone Weald Primary Care Trust	DNR
Maldon & South Chelmsford Primary Care Trust	DNR
Mansfield District Primary Care Trust	DNR
Medway Primary Care Trust	DNR
Melton, Rutland & Harborough Primary Care Trust	0
Mendip Primary Care Trust	3
Mid Devon Primary Care Trust	DNR
Mid Hampshire Primary Care Trust	2
Mid Sussex Primary Care Trust	4
Middlesbrough Primary Care Trust	1
Milton Keynes Primary Care Trust	5
Morecambe Bay Primary Care Trust	DNR
Newark & Sherwood Primary Care Trust	2
Newbury and Community Primary Care Trust	6
Newcastle Primary Care Trust	3
Newcastle-under-Lyme Primary Care Trust	4
Newham Primary Care Trust	5
North & East Cornwall Primary Care Trust	DNR
North Birmingham Primary Care Trust	DNR
North Bradford Primary Care Trust	4
North Devon Primary Care Trust	2
North East Lincolnshire Primary Care Trust	7
North Eastern Derbyshire Primary Care Trust	3
North Hampshire Primary Care Trust	DNR
North Herts & Stevenage Primary Care Trust	DNR
North Kirklees Primary Care Trust	DNR
North Lincolnshire Primary Care Trust	6
North Liverpool Primary Care Trust	DNR
North Manchester Primary Care Trust	DNR
North Norfolk Primary Care Trust	4
North Oxfordshire PCT Partnership - Cherwell Vale	5
North Oxfordshire PCT Partnership - NE Oxford	5
North Sheffield Primary Care Trust	8
North Somerset Primary Care Trust	5
North Stoke Primary Care Trust	6
North Surrey Primary Care Trust	3
North Tees Primary Care Trust	DNR
North Tyneside Primary Care Trust	4
North Warwickshire Primary Care Trust	DNR
Northampton Primary Care Trust	0

Northamptonshire Heartlands Primary Care Trust	0
Northumberland Care Trust	DNR
Northumberland Care Trust	DNR
Norwich Primary Care Trust	4
Nottingham City Primary Care Trust	8
Oldham Primary Care Trust	DNR
Oxford City Primary Care Trust	5
Plymouth Teaching Primary Care Trust	5
Poole Primary Care Trust	DNR
Portsmouth City Teaching Primary Care Trust	DNR
Preston Primary Care Trust	1
Reading Primary Care Trust	6
Redbridge Primary Care Trust	2
Redditch and Bromsgrove Primary Care Trust	DNR
Richmond & Twickenham Primary Care Trust	0
Rochdale Primary Care Trust	5
Rotherham Primary Care Trust	4
Royston, Buntingford & Bishops Stortford PCT	DNR
Rugby Primary Care Trust	3
Rushcliffe Primary Care Trust	8
Salford Primary Care Trust	DNR
Sandwell PCTs - Oldbury & Smethwick	6
Sandwell PCTs - Rowley Regis & Tipton	6
Sandwell PCTs - Wednesbury & West Bromwich	6
Scarborough, Whitby & Ryedale Primary Care Trust	DNR
Sedgefield Primary Care Trust	4
Selby & York Primary Care Trust	4
Sheffield South West Primary Care Trust	8
Sheffield West Primary Care Trust	8
Shepway Primary Care Trust	3
Shropshire County Primary Care Trust	6
Slough Primary Care Trust	6
Solihull Primary Care Trust	DNR
Somerset Coast Primary Care Trust	3
South and East Dorset Primary Care Trust	4
South Birmingham Primary Care Trust	5
South Cambridgeshire Primary Care Trust	4
South East Hertfordshire Primary Care Trust	DNR
South East Sheffield Primary Care Trust	8
South Gloucestershire Primary Care Trust	7
South Hams and West Devon Primary Care Trust	DNR
South Huddersfield Primary Care Trust	DNR
South Leeds Primary Care Trust	DNR
South Leicestershire Primary Care Trust	0
South Liverpool Primary Care Trust	DNR
South Manchester Primary Care Trust	DNR
South Oxfordshire PCTs - South East	5
South Oxfordshire PCTs - South West	5

South Sefton Primary Care Trust	DNR
South Somerset Primary Care Trust	3
South Stoke Primary Care Trust	6
South Tyneside Primary Care Trust	3
South Warwickshire Primary Care Trust	DNR
South West Dorset Primary Care Trust	DNR
South West Hampshire PCTs - Eastleigh	DNR
South West Hampshire PCTs - New Forest	DNR
South West Kent Primary Care Trust	DNR
South Western Staffordshire Primary Care Trust	4
South Wiltshire Primary Care Trust	DNR
South Worcestershire Primary Care Trust	DNR
Southampton City Primary Care Trust	4
Southend Primary Care Trust	7
Southern Norfolk Primary Care Trust	4
Southport & Formby Primary Care Trust	1
Southwark Primary Care Trust	DNR
St Albans and Harpenden Primary Care Trust	DNR
St Helens Primary Care Trust	1
Staffordshire Moorlands Primary Care Trust	5
Stockport Primary Care Trust	DNR
Suffolk Coastal Primary Care Trust	8
Suffolk West Primary Care Trust	8
Sunderland Teaching Primary Care Trust	4
Surrey Heath & Woking Primary Care Trust	3
Sussex Downs & Weald Primary Care Trust	4
Sutton & Merton Primary Care Trust	DNR
Swale Primary Care Trust	DNR
Swindon Primary Care Trust	DNR
Tameside & Glossop Primary Care Trust	DNR
Taunton Deane Primary Care Trust	3
Teignbridge Primary Care Trust	DNR
Telford & Wrekin Primary Care Trust	6
Tendring Primary Care Trust	DNR
The North Dorset Primary Care Trust	0
Thurrock Primary Care Trust	3
Torbay Care Trust	DNR
Tower Hamlets Primary Care Trust	5
Trafford North Primary Care Trust	7
Trafford South Primary Care Trust	7
Uttlesford Primary Care Trust	DNR
Vale of Aylesbury Primary Care Trust	5
Vausedale Primary Care Trust	DNR
Wakefield West Primary Care Trust	DNR
Walsall Teaching Primary Care Trust	7
Waltham Forest Primary Care Trust	DNR
Wandsworth Primary Care Trust	2
Warrington Primary Care Trust	8

Watford & Three Rivers Primary Care Trust	DNR
Waveney Primary Care Trust	9
Welwyn Hatfield Primary Care Trust	3
West Cumbria Primary Care Trust	7
West Gloucestershire Primary Care Trust	4
West Hull Primary Care Trust	6
West Lancashire Primary Care Trust	7
West Lincolnshire Primary Care Trust	6
West Norfolk Primary Care Trust	4
West of Cornwall Primary Care Trust	DNR
West Wiltshire Primary Care Trust	DNR
Western Sussex Primary Care Trust	4
Westminster Primary Care Trust	1
Windsor, Ascot and Maidenhead Primary Care Trust	6
Witham, Braintree & Halstead Care Trust	DNR
Wokingham Primary Care Trust	6
Wolverhampton City Primary Care Trust	DNR
Wycombe Primary Care Trust	5
Wyre Forest Primary Care Trust	DNR
Wyre Primary Care Trust	5
Yorkshire Wolds & Coast Primary Care Trust	5

### PCTs ranked by score

<b>PRIMARY CARE TRUST</b>	<b>Score</b>
Barnet Primary Care Trust	0
Bury Primary Care Trust	0
Charnwood & North West Leicestershire PCT	0
Eastern Leicester Primary Care Trust	0
Epping Forest Primary Care Trust	0
Harlow Primary Care Trust	0
Hinckley and Bosworth Primary Care Trust	0
Leicester City West Primary Care Trust	0
Melton, Rutland & Harborough Primary Care Trust	0
Northampton Primary Care Trust	0
Northamptonshire Heartlands Primary Care Trust	0
Richmond & Twickenham Primary Care Trust	0
South Leicestershire Primary Care Trust	0
The North Dorset Primary Care Trust	0
Basildon Primary Care Trust	1
Billericay Brentwood & Wickford Primary Care Trust	1
Daventry & South Northants Primary Care Trust	1
Doncaster Central Primary Care Trust	1
Doncaster East Primary Care Trust	1
Doncaster West Primary Care Trust	1
East Hampshire Primary Care Trust	1

Fareham & Gosport Primary Care Trust	1
Haringey Teaching Primary Care Trust	1
Harrow Primary Care Trust	1
Leeds North West Primary Care Trust	1
Leeds West Primary Care Trust	1
Middlesbrough Primary Care Trust	1
Preston Primary Care Trust	1
Southport & Formby Primary Care Trust	1
St Helens Primary Care Trust	1
Westminster Primary Care Trust	1
Burnley, Pendle and Rossendale Primary Care Trust	2
Craven, Harrogate & Rural District PCT	2
Eastern Wakefield Primary Care Trust	2
Hammersmith and Fulham Primary Care Trust	2
Havering Primary Care Trust	2
Islington Primary Care Trust	2
Mid Hampshire Primary Care Trust	2
Newark & Sherwood Primary Care Trust	2
North Devon Primary Care Trust	2
Redbridge Primary Care Trust	2
Wandsworth Primary Care Trust	2
Ashford Primary Care Trust	3
Brent Teaching Primary Care Trust	3
Camden Primary Care Trust	3
Castle Point & Rochford Primary Care Trust	3
Central Cheshire Primary Care Trust	3
Cheshire West Primary Care Trust	3
Chesterfield Primary Care Trust	3
Chorley & South Ribble Primary Care Trust	3
East Devon Primary Care Trust	3
Ellesmere Port and Neston Primary Care Trust	3
Enfield Primary Care Trust	3
High Peak & Dales Primary Care Trust	3
Kingston Primary Care Trust	3
Mendip Primary Care Trust	3
Newcastle Primary Care Trust	3
North Eastern Derbyshire Primary Care Trust	3
North Surrey Primary Care Trust	3
Rugby Primary Care Trust	3
Shepway Primary Care Trust	3
Somerset Coast Primary Care Trust	3
South Somerset Primary Care Trust	3
South Tyneside Primary Care Trust	3
Surrey Heath & Woking Primary Care Trust	3
Taunton Deane Primary Care Trust	3
Thurrock Primary Care Trust	3
Welwyn Hatfield Primary Care Trust	3
Adur, Arun & Worthing Teaching Primary Care Trust	4

Airedale Primary Care Trust	4
Bedford Primary Care Trust	4
Bedfordshire Heartlands Primary Care Trust	4
Bexhill & Rother Primary Care Trust	4
Blackburn with Darwen Primary Care Trust	4
Bradford City Teaching Primary Care Trust	4
Bradford South & West Primary Care Trust	4
Brighton & Hove City Primary Care Trust	4
Broadland Primary Care Trust	4
Bromley Primary Care Trust	4
Burntwood Lichfield & Tamworth Primary Care Trust	4
Cambridge City Primary Care Trust	4
Cannock Chase Primary Care Trust	4
Canterbury and Coastal Primary Care Trust	4
Central Derby Primary Care Trust	4
Cheltenham & Tewkesbury Primary Care Trust	4
Chiltern and South Bucks Primary Care Trust	4
Cotswold & Vale Primary Care Trust	4
Crawley Primary Care Trust	4
Darlington Primary Care Trust	4
Derwentside Primary Care Trust	4
Durham Dales Primary Care Trust	4
Easington Primary Care Trust	4
East Kent Coastal Teaching Primary Care Trust	4
East Staffordshire Primary Care Trust	4
Eastbourne Downs Primary Care Trust	4
Great Yarmouth Teaching Primary Care Trust	4
Greater Derby Primary Care Trust	4
Guildford & Waverley Primary Care Trust	4
Hastings & St Leonards Primary Care Trust	4
Heart of Birmingham Teaching Primary Care Trust	4
Horsham and Chanctonbury Primary Care Trust	4
Mid Sussex Primary Care Trust	4
Newcastle-under-Lyme Primary Care Trust	4
North Bradford Primary Care Trust	4
North Norfolk Primary Care Trust	4
North Tyneside Primary Care Trust	4
Norwich Primary Care Trust	4
Rotherham Primary Care Trust	4
Sedgefield Primary Care Trust	4
Selby & York Primary Care Trust	4
South and East Dorset Primary Care Trust	4
South Cambridgeshire Primary Care Trust	4
South Western Staffordshire Primary Care Trust	4
Southampton City Primary Care Trust	4
Southern Norfolk Primary Care Trust	4
Sunderland Teaching Primary Care Trust	4
Sussex Downs & Weald Primary Care Trust	4



West Gloucestershire Primary Care Trust	4
West Norfolk Primary Care Trust	4
Western Sussex Primary Care Trust	4
Bexley Care Trust	5
Blackpool Primary Care Trust	5
Durham & Chester Le Street Primary Care Trust	5
East Cambridgeshire & Fenland Primary Care Trust	5
Heywood & Middleton Primary Care Trust	5
Huntingdonshire Primary Care Trust	5
Milton Keynes Primary Care Trust	5
Newham Primary Care Trust	5
North Oxfordshire PCT Partnership - Cherwell Vale	5
North Oxfordshire PCT Partnership - NE Oxford	5
North Somerset Primary Care Trust	5
Oxford City Primary Care Trust	5
Plymouth Teaching Primary Care Trust	5
Rochdale Primary Care Trust	5
South Birmingham Primary Care Trust	5
South Oxfordshire PCTs - South East	5
South Oxfordshire PCTs - South West	5
Staffordshire Moorlands Primary Care Trust	5
Tower Hamlets Primary Care Trust	5
Vale of Aylesbury Primary Care Trust	5
Wycombe Primary Care Trust	5
Wyre Primary Care Trust	5
Yorkshire Wolds & Coast Primary Care Trust	5
Barking and Dagenham Primary Care Trust	6
Bracknell Forest Primary Care Trust	6
East Lincolnshire Primary Care Trust	6
Fylde Primary Care Trust	6
Greater Peterborough Primary Care P'ship-South PCT	6
Lincolnshire South West Teaching PCT	6
Newbury and Community Primary Care Trust	6
North Lincolnshire Primary Care Trust	6
North Stoke Primary Care Trust	6
Reading Primary Care Trust	6
Sandwell PCTs - Oldbury & Smethwick	6
Sandwell PCTs - Rowley Regis & Tipton	6
Sandwell PCTs - Wednesbury & West Bromwich	6
Shropshire County Primary Care Trust	6
Slough Primary Care Trust	6
South Stoke Primary Care Trust	6
Telford & Wrekin Primary Care Trust	6
West Hull Primary Care Trust	6
West Lincolnshire Primary Care Trust	6
Windsor, Ascot and Maidenhead Primary Care Trust	6
Wokingham Primary Care Trust	6
Bath & North East Somerset Primary Care Trust	7

Carlisle & District Primary Care Trust	7
Eden Valley Primary Care Trust	7
North East Lincolnshire Primary Care Trust	7
South Gloucestershire Primary Care Trust	7
Southend Primary Care Trust	7
Trafford North Primary Care Trust	7
Trafford South Primary Care Trust	7
Walsall Teaching Primary Care Trust	7
West Cumbria Primary Care Trust	7
West Lancashire Primary Care Trust	7
Broxtowe & Hucknall Primary Care Trust	8
Central Suffolk Primary Care Trust	8
Gedling Primary Care Trust	8
Ipswich Primary Care Trust	8
North Sheffield Primary Care Trust	8
Nottingham City Primary Care Trust	8
Rushcliffe Primary Care Trust	8
Sheffield South West Primary Care Trust	8
Sheffield West Primary Care Trust	8
South East Sheffield Primary Care Trust	8
Suffolk Coastal Primary Care Trust	8
Suffolk West Primary Care Trust	8
Warrington Primary Care Trust	8
Bebington & West Wirral Primary Care Trust	9
Birkenhead & Wallasey Primary Care Trust	9
Waveney Primary Care Trust	9

## **APPENDIX 3**

### **Membership of APPHG**

Mr David Amess, 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 – Labour, Bolton South East

Mr Stewart Jackson – Conservative, Peterborough

Mr Bob Laxton, Vice-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 4

### APPHG secretariat and 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 but one 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 Gilead Sciences, Roche Products and Schering-Plough Ltd. 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](http://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.

#### Contact details:

The Hepatitis C Trust,  
27 Crosby Row,  
London SE1 3YD  
Tel: 020 7089 6220  
Email: [info@hepctrust.org.uk](mailto:info@hepctrust.org.uk)