



THE ALL-PARTY PARLIAMENTARY
HEPATOLOGY GROUP

In The Dark

An audit of hospital hepatitis C services across England

August 2010

FOREWORD

The All-Party Parliamentary Hepatology Group (APPHG) and *The Hepatitis C Trust* have worked together since 2005 to raise awareness amongst politicians, the media and the public of the virus and hepatitis C patients' needs. In publishing this audit we aim to provide a unique insight into the state of hepatitis C services in hospitals in England.

Hepatitis C is a preventable and curable cancer-causing, blood-borne virus but stigma and poor awareness have meant that it has been overlooked and misunderstood by many health professionals as well as the general public since its discovery in 1989.

This is the first time that the quality and outcomes of hospital hepatitis C services have been publicly audited at a national level and the responses have uncovered an alarming shortage of data being collected. Where hospitals were able to provide information, the audit reveals stark differences in services and care available to patients in different parts of the country.

Our previous audits of hepatitis C services in Primary Care Trusts (2006 and 2008) revealed a postcode lottery of care, with patchy and slow implementation of the Department of Health's 2004 Action Plan for Hepatitis C. By 2008, four years after the publication of the Action Plan, only a third of Primary Care Trusts were effectively implementing the Plan. This prompted our call for a new approach to hepatitis C services through a National Liver Strategy, which is now being developed and is due for publication in autumn 2011.ⁱ

The UK's use of hepatitis C drugs was found to be the second lowest out of 14 comparable countries surveyed by Professor Sir Mike Richards in a report for the Secretary of State, *Extent and causes of international variations in drug usage*, published in July 2010. This audit offers insight into why we are failing in comparison to other countries: it shows that around a third of patients referred to hospitals last year were not offered treatment and hospitals have widely differing informal and formal policies on who should receive treatment. This is contrary to NICE guidance which recommends treatment for all hepatitis C patients except where it is contraindicated. Further, there are significant differences between hospitals in the level of specialist support and care available.

The NHS White Paper, *Equity and Excellence: Liberating the NHS*, proposes an 'information revolution' to put patients at the heart of the NHS with greater choice and control. This audit has exposed an urgent need for an information revolution in hepatitis C services. Many hospitals were unable to answer the audit as they do not routinely collect even basic hepatitis C-specific data on patient referrals, treatment numbers and treatment outcomes.

We hope this report will usefully inform national and local service developments, particularly as the NHS is reformed. Ultimately, we hope that this audit will help towards our overarching aim: to eradicate hepatitis C in the next 30 to 40 years by diagnosing all patients, preventing further transmissions and ensuring high quality care and treatment for all.

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ABBREVIATIONS

APPHG	All-Party Parliamentary Hepatology Group
BBV	Blood Borne Virus
DAAT	Drug and Alcohol Action Team
DH	Department of Health
HCV	Hepatitis C Virus
HPA	Health Protection Agency
IDU	Injecting Drug User
MCN	Managed Care Network
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
PCT	Primary Care Trust
SVR	Sustained Viral Response

ACKNOWLEDGEMENTS

The All-Party Parliamentary Hepatology Group and The Hepatitis C Trust would like to thank all of the consultants, nurses and staff who responded to the questionnaire on behalf of their hospitals. The Group and Trust would also like to thank the hepatitis team at the Health Protection Agency for their time.

EXECUTIVE SUMMARY

In The Dark is based on the findings of a national audit of hepatitis C hospital services conducted by the All-Party Parliamentary Hepatology Group and The Hepatitis C Trust. It presents data from 69 hospitals delivering hepatitis C services in England. Hepatitis C is a blood-borne cancer-causing infectious virus that is undiagnosed in the majority of the 250,000 to 466,000 people infected in the UK.

KEY FINDINGS:

- There are huge variations in hepatitis C services available to patients across the country through internal hospital policies, both formal and informal. For example, 10 hospitals refuse NICE approved treatment to all injecting drug users; 12 hospitals do not offer re-treatment to any patients, 55 offer it to some patients but with varying criteria; and two hospitals refuse treatment to anyone continuing to consume alcohol
- Around a third of hepatitis C patients referred to hospitals are not being offered treatment
- Less than half of hospitals are part of a hepatitis C Managed Care Network (MCN)
- Less than one third of hospital hepatitis C services measure patient satisfaction
- There is a worrying shortage of basic monitoring in hepatitis C services, such as numbers of patients referred, numbers offered treatment, numbers initiating treatment and treatment results, which inevitably hampers local and national planning and efficient commissioning of services

SUMMARY OF RECOMMENDATIONS
An information revolution:

- A national reporting requirement for hospitals offering hepatitis C services should be introduced immediately, based on an agreed standard national dataset, so the NHS Information Centre can collate data on hepatitis C referrals, treatment and outcomes. This should be available to the public, alongside treatment policies, as part of the NHS information revolution
- National clinical audits should be extended to cover liver services, including hepatitis C, to enable more effective monitoring and choice for patients between services as set out in the NHS White Paper, *Equity and Excellence: Liberating the NHS*
- Outcomes measures, including Patient Reported Outcomes Measures (PROMS) and Patient Reported Experience Measures (PREMS), should be developed on diagnosis, successful treatment and completed courses of treatment for patients with hepatitis C and should be used as a key part of service performance management

Supporting patients:

- Patients should be at the centre of hepatitis C care, and services should be configured and sited to meet their needs
- There should be greater integration between NHS, Public Health and Social Care providers to enable patients with hepatitis C to access all the support they need and prevent them losing contact with services

Successful commissioning for the whole patient pathway:

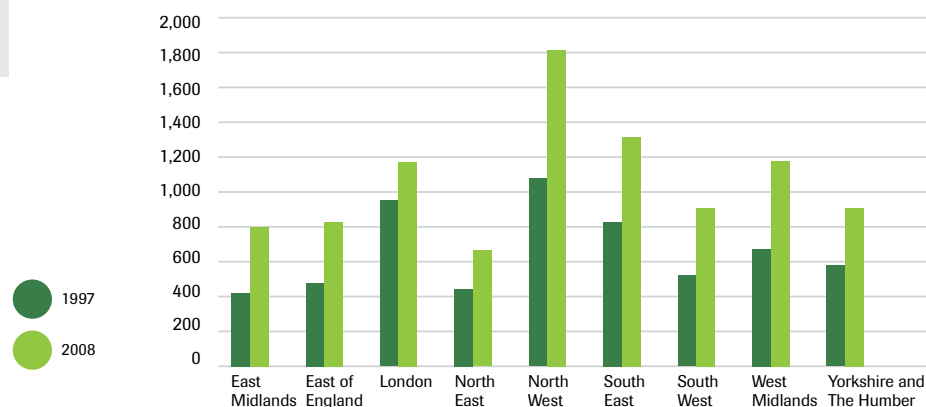
- Good practice should be identified and shared with commissioners
- Interim Quality Standards for liver services, including hepatitis C, should be developed at an early stage to support the development of commissioning outcomes for hepatitis C (to be superseded by NICE Quality Standards once developed)
- Commissioners should consider the additional support required by patients with hepatitis C to help them access treatment and to support them along the patient pathway
- Commissioners should work closely with NHS, Public Health and Social Care colleagues in the planning of services for patients with hepatitis C to ensure a seamless patient pathway

BACKGROUND

a. Liver disease and hepatitis C in the UK

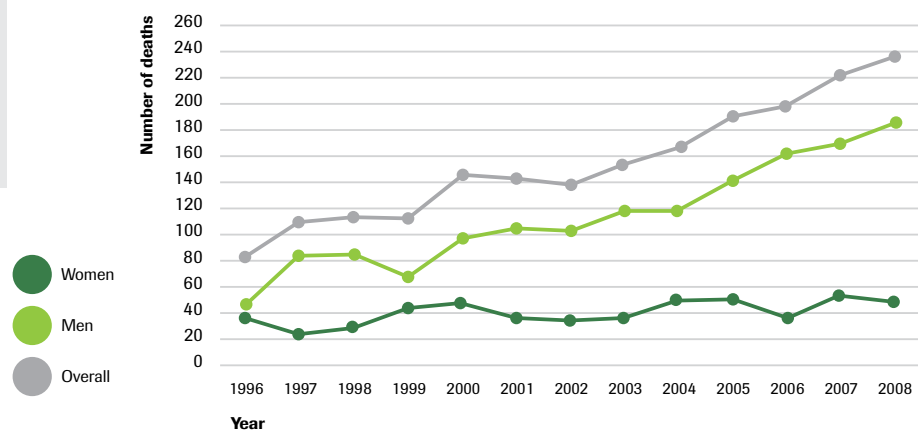
The number of deaths from liver cancer and liver disease in England increased by 60% between 1997 and 2008, from 6,058 to 9,719 per year. There is a significant regional variation in the increase in mortality – the East Midlands saw the highest rate of increase (87%) over this period – from 440 to 824. London saw the lowest rate of increase (23%) from 968 to 1,190 (see figure 1).ⁱⁱ

Figure 1: Deaths from liver cancer and liver disease by region in 1997 and 2008



Hepatitis C is a blood-borne infectious virus that can cause cirrhosis and liver cancer. It is an important contributor to this rising liver mortality. The extent of the contribution is unclear but certainly underestimated: cirrhosis and liver cancer are generally the actual cause of death and alcohol is a major contributor to hepatitis C disease progression. Consequently, cirrhosis, liver cancer or alcohol are often listed as the cause of death, with no mention of hepatitis C, and this is exacerbated by the fact that the majority of the 250,000 to 466,000 people infected with hepatitis C in the UK are undiagnosed.ⁱⁱⁱ Regardless of this, the increasing mortality trend is clear from reported deaths where hepatitis C is mentioned on the death certificate (see figure 2).

Figure 2: Deaths from End-Stage Liver Disease or Hepatocellular Carcinoma in those with HCV mentioned on their death certificate in England: 1996-2008 (Health Protection Agency, 2009)



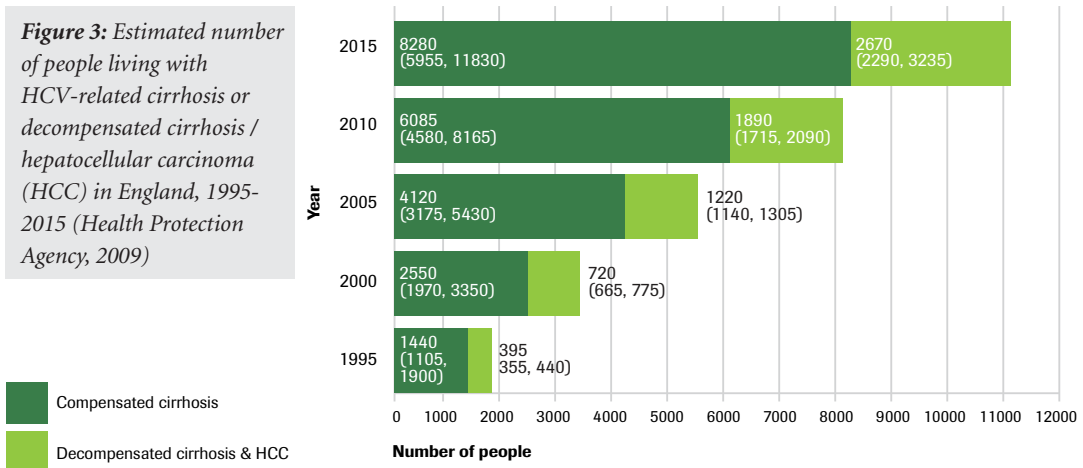
BACKGROUND

a. Liver disease and hepatitis C in the UK

The increasing numbers of deaths from hepatitis C are due in part to the relatively low numbers of patients accessing NICE approved treatment for the virus which can cure hepatitis C in around half of patients. The UK ranked 13th out of 14 countries on the usage of drugs for hepatitis C in a recent report by Professor Sir Mike Richards for the Secretary of State, Extent and causes of international variations in drug usage.^{iv}

Hepatitis C is an escalating problem: around 13,000 people are newly infected every year^v but less than 5,000 are receiving treatment that cures the virus in around half of patients. The number of people living with hepatitis C related cirrhosis is expected to increase by over a third to 10,960 by 2015 unless treatment increases (see figure 3).^{vi}

Figure 3: Estimated number of people living with HCV-related cirrhosis or decompensated cirrhosis / hepatocellular carcinoma (HCC) in England, 1995-2015 (Health Protection Agency, 2009)



The rising liver mortality rates and local variations in these increases, coupled with anecdotal reports from clinicians, nurses and patients that hospital services for hepatitis C patients varied widely across the country, prompted the All-Party Parliamentary Hepatology Group (APPHG) to seek to create a broad picture of hepatitis C hospital services in England and the quality of these services.

BACKGROUND

b. The optimal patient pathway

The optimal hepatitis C patient pathway starts with early diagnosis, prompt pre-referral investigations and then referral to a specialist team, who will ensure the patient is fully informed of the virus, their individual condition and treatments available. They should be offered information, treatment, care and support tailored to their individually-assessed needs. Where the patient chooses to undertake treatment and achieves a sustained viral response (SVR), they should receive ongoing management and support from their GP once they have been discharged from secondary care. Where the patient chooses not to undertake treatment, or a SVR is not achieved, the patient should continue to be monitored on a regular basis in secondary care and offered re-treatment or new therapies as appropriate. The audit questionnaire was designed with this optimal patient pathway in mind:

Hepatitis C diagnosis

Patients should be diagnosed promptly (by their GP or at other community and outreach testing facilities) as soon as possible after infection to improve their chances of cure through treatment and so they can adapt their lifestyle to avoid co-morbidities such as alcohol and obesity. Between 100,000 and 300,000 people are currently undiagnosed in England.

They should be given a confirmation test and any appropriate pre-referral investigations. They should receive their PCR test results and genotype and then be immediately referred on to a specialist secondary care team.

Referral

Patients should be referred to an experienced hepatology team (including a clinical lead in viral hepatitis, a specialist nurse and pharmacist with knowledge of the relevant medications) who will provide full information about hepatitis C and treatments available so that the patient can make a decision on whether to initiate anti-viral therapy (treatment). All patients have a right to high quality care regardless of lifestyle.

Care should be provided in a setting most appropriate for the patients' needs, including community settings, and should be of the same standard as that in specialist centres. Many hepatitis C patients are from disadvantaged, vulnerable groups (such as injecting drug users and ethnic minorities for whom English language and literacy skills might be limited) so multiple opportunities to access hepatitis C services should be put in place for patients who do not attend their initial consultation.

Patient-centred care plan

Patients should be at the centre of hepatitis C care. They should be well informed so they can make their own decision about treatment, provider and consultant-led team.

The hepatology team should identify any extra support needs the patient might have for treatment, including a mental health assessment, and services should be configured to address their needs.

Patients should receive high quality care from the specialist clinician and specialist nurse when receiving treatment and should have 24-hour access to support. Access to other support services should be immediately available when required, for example psychological, psychiatric, social and dietary support.

Post-treatment ongoing care

Patients who have an SVR should be discharged from secondary care but should be referred back to their GP for management of any symptoms caused by the treatment that persist.

Patients who do not have an SVR should continue to be monitored on a regular basis in secondary care and offered re-treatment or new therapies as appropriate. It is imperative not to lose contact with these patients.

Managed care networks

Local networks should link services together and ensure high quality care is available to all.

Monitoring and audit

Outcome measures and care quality should be benchmarked and regularly audited, for example, diagnosis rates, referral and attendance rates, treatment success rates and patient experience.

Patient information

Hospital data on hepatitis C services should be available to patients to enable them to make an informed choice.

METHODOLOGY

To build a national picture of the scale and quality of hepatitis C services in England, a questionnaire was sent to the Chief Executives of 107 hospitals that were known by The Hepatitis C Trust to offer hepatitis C treatment in November 2009. 69 (64%) of these responded and this report is based on their replies.

The questions sought to find out what services were available and the quality of these services by asking for information on:

- Numbers of hepatitis C patients referred to each hospital
- Numbers of hepatitis C patients offered treatment
- Numbers of patients receiving treatment each year
- Sustained Viral Response rates of treatment (success rates)
- The availability of outreach services (e.g. in prisons, GP surgeries, drug and alcohol services)
- Policies and protocols on treating patients using drugs or alcohol
- Patient support and access to psychiatric services
- The availability of re-treatment
- Numbers of specialist staff employed by each hospital

The questions requested information for the financial year 2008-9 although some hospitals recorded data by calendar year and so gave data for 2009. As some of the information returned was incomplete or estimated, the statistics drawn from the audit give an indication rather than an exact reflection of the national picture of hepatitis C hospital services over the course of a year.

FINDINGS AND RECOMMENDATIONS

a. Building a national picture of hepatitis C services

NUMBERS OF PATIENTS REFERRED AND TREATED

The hospital audit aimed to create a broad picture of where hepatitis C treatment and specialist care is available in England and the extent and quality of these services. 69 of the 107 hospitals responded to the audit questionnaire but much of the information returned was incomplete or estimated. This, in itself, is an important finding and highlights the pressing need for consistent and accurate data collection on hepatitis C services. For example, of the 69 hospitals, 14 did not know how many hepatitis C patients were referred to them in the year, 12 did not know how many patients had been offered treatment and 3 did not know how many patients had been treated at their hospital in the year. Of the figures given, many were estimates rather than absolute.

Of the responding hospitals for 2008-9:

- 5210 hepatitis C patients were referred to specialist hospital services (data from 55 hospitals)
- 3386 hepatitis C patients were offered a course of treatment (data from 57 hospitals)
- 3356 hepatitis C patients started a course of treatment (data from 66 hospitals)

It is worrying that many hospitals do not record the numbers of patients referred, offered treatment and receiving treatment. This basic monitoring should be a national requirement so the quality of services can be monitored, adequate staff can be employed and improvements can be measured across the country. It is also essential for monitoring gaps in the patient pathway.

The shortage of high quality hepatitis C epidemiology and service quality information is currently hampering local and national planning and commissioning, leading to inefficiencies and unnecessary costs, to the detriment of patients and attempts to reduce the prevalent pool of infection.

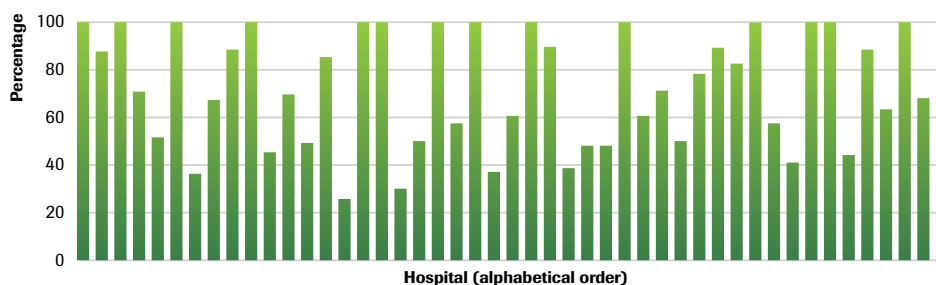
PROPORTION OF PATIENTS OFFERED TREATMENT

Hepatitis C is curable in around half of patients so it is a matter of concern that, on average, around a third of new patients are not being offered treatment. The audit found that there are huge variations in the proportion of new patients being offered treatment in each hospital area (from 20% of new patients to 100%). To flatten and reverse the rising mortality curve from the virus, all patients should be offered treatment and the support they need to have the best chance of achieving a sustained viral response. The only exceptions should be those patients for whom treatment would be highly likely to be unsuccessful because their lifestyle is too chaotic or where treatment is contraindicated. In these instances services should be available to help patients manage the virus and, where appropriate, support them in making treatment viable.

It is extremely concerning that 12 hospitals (almost one fifth) offered treatment to less than 50% of the number of patients referred to them. *Figure 4* shows the variations in the proportion of patients being offered treatment in different hospitals across the country.

Figure 4: For full details of the numbers of hepatitis C referrals, patients offered treatment and starting treatment in each hospital, please email admin@hepctrust.org.uk

Percentage of patients offered treatment compared to numbers of patients referred



FINDINGS AND RECOMMENDATIONS

a. Building a national picture of hepatitis C services
**POLICIES AND PROTOCOLS CONCERNING THE TREATMENT OF
INTRAVENOUS DRUG USERS AND PATIENTS WITH HIGH ALCOHOL INTAKE**

One reason for the variation in the proportion of patients receiving treatment for hepatitis C is the lack of uniformity in approaches to offering treatment. For example, a patient who is injecting drugs might be offered treatment in one hospital, but refused it in a neighbouring hospital, despite NICE guidance that illicit drug use should not be a barrier to treatment and evidence showing that current injecting drug use does not affect treatment success rates if effectively managed and supported.^{vii}

Nearly all hospitals surveyed had a policy, either formal or informal, about treating injecting drug users (IDUs). For example:

- The Royal London Hospital had the most inclusive policy saying, “*If it moves we offer therapy!*”
- 18 respondents said they would consider treating IDUs but attached caveats such as “*non chaotic users only*”, “*so long as they attend all appointments*”, or if they were “*stable*” and “*accessing drug treatment services*”
- 8 respondent hospitals clearly stated they would not treat patients they knew or suspected were still injecting drugs
- 1 hospital insisted that patients were “*clean*” of drugs for more than a year
- 1 insisted patients should be “*clean*” for 6 months
- 1 hospital would not treat IDUs if they injected more than 3 times a week

Most hospitals also indicated a formal or non-formal policy on alcohol intake. The most common statement was “*we encourage patients to reduce alcohol intake during treatment*” or versions of this sentiment. Two hospitals said they insisted on the patient not consuming alcohol at all for the duration of treatment. One hospital stated it would treat people who still abused alcohol.

TREATMENT SUCCESS RATES

The percentage of people who had a sustained viral response to treatment is one indicator of the quality of services (after genotype and complex cases, such as cirrhotic or co-infected patients, are taken into account). It is expected that, on average, 40-50% of genotype 1 and 4 patients will achieve a SVR and 75-85% of genotype 2 and 3 patients will achieve a SVR.^{viii}

39 hospitals were able to give us details of numbers of patients who completed a course of treatment in the year and the numbers of patients who achieved a SVR. These figures allowed us to calculate approximate treatment success rates for responding hospitals, although these are indicative rather than exact figures as some people who finished treatment would receive their SVR in the following year, and some SVR results included would have been for patients treated the previous year. The SVR rates differed widely between hospitals for all genotypes:

- For genotype 1 the percentages of patients with a SVR ranged between 10% and 78% in different hospitals
- The average percentage of genotype 1 patients with a SVR was 43%
- For genotypes 2 and 3 the percentage of patients who achieved a SVR ranged between 15% and 100% in different hospitals
- The average percentage of genotype 2 and 3 patients with a SVR was 67%

It is worrying that many hospitals do not record SVR rates. This needs to be urgently addressed with a national data reporting requirement so that services can recognise if they have a lower than expected SVR rate and take appropriate steps to improve outcomes.

FINDINGS AND RECOMMENDATIONS

a. Building a national picture of hepatitis C services**AVAILABILITY OF RE-TREATMENT**

Re-treatment is only available to patients in all circumstances in 1 hospital. 12 hospitals stated that they do not offer re-treatment to patients and 55 hospitals stated that they offer re-treatment to patients in certain circumstances:

- 14 said they would offer re-treatment if a patient was a 'relapser' (somebody whose virus had become undetectable during treatment but then returned after treatment concluded)
- 7 hospitals said they offered re-treatment for patients who were only given mono-therapy rather than the combination therapy which is now standard
- 4 hospitals said they would re-treat and increase the length of treatment from 24 to 48 weeks for patients who were genotype 2 or 3 and had previously only been treated for the standard 24 weeks (depending on their response to treatment first time round)

RECOMMENDATIONS - AN INFORMATION REVOLUTION:

- A national reporting requirement for hospitals offering hepatitis C services should be introduced immediately, based on an agreed standard national dataset, so the NHS Information Centre can collate data on hepatitis C referrals, treatment and outcomes. This should be available to the public, alongside treatment policies, as part of the NHS information revolution
- National clinical audits should be extended to cover liver services, including hepatitis C, to enable more effective monitoring and choice for patients between services as set out in the NHS White Paper, Equity and Excellence: Liberating the NHS
- Outcomes measures, including Patient Reported Outcomes Measures (PROMS) and Patient Reported Experience Measures (PREMS), should be developed on diagnosis, successful treatment and completed courses of treatment for patients with hepatitis C and should be used as a key part of service performance management

FINDINGS AND RECOMMENDATIONS

b. The whole patient**PATIENT SUPPORT**

Identifying support needs and meeting those needs with wrap-around care should be an integral part of the patient pathway. Ensuring a patient has adequate psychological, psychiatric, dietary, addiction and social support where required, in accessible locations, can make all the difference in determining whether a patient successfully completes their treatment course and therefore has the best possible chance of clearing the virus. Communication and shared care planning needs to be strengthened and opportunities sought for greater integration between NHS, public health and social care at both commissioner and provider level.

The majority of hospitals surveyed (61) provided support for patients outside of hospital visits. A third of hospitals (24) said that they provided 24 hour telephone support to patients. However, the quality of this support varied – in some cases it was a specialist nurses' number, in other cases a pharmaceutical company helpline.

PSYCHIATRIC NEEDS ASSESSMENT

Depression and other mental health conditions can be side effects of the treatment for hepatitis C (interferon and ribavirin). They are also prevalent among many populations at increased risk of hepatitis C, such as IDUs. In addition, they may result from stigma, discrimination and isolation associated with blood borne virus infection. Therefore it is important for patients to have good access to psychiatric services that take into account their particular needs. Some of the hospitals surveyed identified that there was a gap in service here, and that there should be closer working arrangements between psychiatric teams and their viral hepatitis colleagues. Most hospitals stated that it is only routine procedure to assess patients for psychiatric needs if they have previously accessed psychiatric support services.

EXAMPLES OF EFFECTIVE COLLABORATION WITH PSYCHIATRIC SERVICES:

“We have strong links with the psychiatrists based in hospital. We are able to refer directly and they are also willing to discuss any case with us, giving their advice on further management if required. We are able to offer increased specialist nurse support, where required, by reviewing the patient more regularly. We encourage support workers to attend the appointments, ensuring that they have our contact details and we also discuss the plan of care with them.”

Frimley Park Hospital, Surrey

“The hospital has a dedicated clinical psychologist for hepatitis C who assesses patients' mental well-being and where necessary refers them to community mental health services. The psychologist provides integrated case management of patients with severe and enduring mental illness in collaboration with secondary providers. This means people with a history of psychosis, bipolar disorder or severe personality disorder access treatment in a co-ordinated and timely fashion.”

Royal Hallamshire Hospital, Sheffield

AVAILABILITY OF SUPPORTIVE DRUGS

Supportive drugs, such as erythropoietin, can help patients manage the side effects of treatment. Almost a quarter of hospitals (23%) do not offer supportive drugs to help the side effects of treatment.

50 hospitals (77%) stated that they make supportive drugs available to patients: 36 hospitals used erythropoietin which is used to counter low haemoglobin levels. 31 of these also use granulocyte colony-stimulating factor.

FINDINGS AND RECOMMENDATIONS

b. The whole patient**OUTREACH SERVICES**

Hepatitis C patients are often from socially excluded, minority and/or vulnerable groups, such as homeless people, injecting drug users and first generation migrants, and may be hard to reach. Research undertaken by Health Protection Scotland to inform the Scottish Government's Action Plan for Hepatitis C showed that 75% of hepatitis C patients are from the two lowest socio-economic quintiles. Travel costs, low levels of literacy, low levels of engagement with services and language challenges impede awareness of the virus, diagnosis and access to hospital services. In light of this, there is a responsibility on providers of hepatitis C services to develop outreach services. However, our research shows that only a small minority are doing this:

- 18 hospitals run outreach services in local drug and alcohol teams
- 17 hospitals run outreach services in prisons
- 7 hospitals run outreach services in GP surgeries
- One hospital offers patient home visits when required

Derriford Hospital runs HCV antiviral therapy clinics in prisons and in DAAT [Drug and Alcohol Action Team] services and clinics aimed at testing and screening in homeless hostels, third sector drug units and sex worker projects.

Derriford Hospital, Plymouth

"We work closely with the local psychiatric services and have a project working with the local assertive outreach teams to actively engage, test, assess and treat patients with significant mental health problems."

Dorset wide service

PATIENT SATISFACTION

Only 20 hospitals (30%) reported that they measure patient satisfaction, predominantly through surveys or questionnaires that are handed out at appointments. Some hospitals said they also relied on feedback from patient support groups and feedback to nurses and doctors during consultations. 43 hospitals (65%) said that they do not measure patient satisfaction and did not state any plans to do so. An additional 3 hospitals were planning to launch a survey or questionnaire soon.

RECOMMENDATIONS – SUPPORTING PATIENTS

- Patients should be at the centre of hepatitis C care and services should be configured to address their needs
- There should be greater integration between NHS, Public Health and Social Care providers to enable patients with hepatitis C to access all the support they need and prevent them losing contact with services

FINDINGS AND RECOMMENDATIONS

*c. Planning for patient needs***MANAGED CARE NETWORKS**

Managed care networks (MCN) facilitate the necessary connections between professionals and organisations across the hepatitis C patient pathway. They should connect primary, secondary and tertiary services with other components of successful care, such as virology, social care, prison, social and mental health services. Worryingly, less than half of hospitals responding stated that they were part of a managed care network (29 are part of a MCN, 33 are not, 5 did not respond to this question), even though MCNs are mandated by the Department of Health's 2004 Hepatitis C Action Plan for England.

WORKFORCE

Only 29 of the responding hospitals employ one or more full-time dedicated hepatitis C nurse: 16 employ a part-time nurse while 11 do not employ a specialist nurse. This is a concern as specialist nurses are the most frequent point of care for patients and provide support to patients throughout treatment.

It is essential that every patient undergoing treatment has access to a specialist nurse for their wellbeing and to give them the best chance of successfully completing the therapy course.

44 hospitals employ at least one part-time or full-time consultant hepatologist and in 11 hospitals gastroenterologists have responsibility for treating patients with hepatitis C.

EFFECTIVE COMMISSIONING

The quality of services is variable and too often dependent on individuals. This leaves services and patients vulnerable. Commissioners have an important role to play in ensuring providers deliver coordinated and well planned care, supported by established clinical good practice and evidence based interventions.

Good practice should be identified and shared with commissioners. This can then be used to inform contracts with providers for example on treatment policies and availability of support across the patient pathway. The commissioning outcomes framework will be important in establishing a framework for performance management that will in turn inform commissioners' expectations of providers. Quality Standards on hepatitis C should be used to develop outcomes measures. However, development timelines for these are potentially long, so alternative measures need to be used in the short-term.

RECOMMENDATIONS – SUCCESSFUL COMMISSIONING FOR THE WHOLE PATIENT PATHWAY

- Good practice should be identified and shared with commissioners
- Interim Quality Standards for liver services, including hepatitis C, should be developed at an early stage to support the development of commissioning outcomes for hepatitis C (to be superseded by NICE Quality Standards once developed)
- Commissioners should consider the additional support required by patients with hepatitis C to help them access treatment and to support them along the patient pathway
- Commissioners should work closely with NHS, Public Health and Social Care colleagues in the planning of services for patients with hepatitis C to ensure a seamless patient pathway

CONCLUSION

It is unacceptable that the number of deaths from liver disease and liver cancer is rising sharply in the UK, while it is falling in the rest of Europe. Particularly unacceptable is the increasing contribution to this death toll from hepatitis C which is both preventable and treatable.

This report has revealed a serious gap in the basic monitoring of hepatitis C services across the country which is hampering local and national service planning, and allowing the prevalent pool of infection to grow. Where information is available, we found huge variations in treatment policies and care in hospitals.

In the Dark underlines the urgent need for the rapid development and implementation of a national liver strategy that has particular focus on the prevention and control of hepatitis C. This is the only way we will stop the ever increasing number of unnecessary deaths.

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