Hepatitis C: scale and impact in Britain

The sleeping giant wakes

The first attempt to plot the national dimensions of the hepatitis C epidemic provides evidence that the potentially deadly virus is a major problem for British drug users and drug services – so major that some health authorities prefer not to see it.

by
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SUMMARY

During 1994 a questionnaire on hepatitis C was sent to drug agencies and others working with drug users. Hepatitis C was found in 6 out of 10 of over 2000 tests done on injectors attending services across the country. Nearly half the drug services responding complained of difficulty in obtaining testing or further investigation and treatment. Up to 400,000 people in the UK may have contracted the virus from injecting drugs and in a decade increasing numbers will suffer serious liver disease.

HEPATITIS C IS NOW becoming recognised as an infection afflicting drug injectors often with very serious consequences and on a far greater scale than the HIV epidemic. Like HIV, it is a problem recent technical advances have allowed us to identify. Following a key discovery in 1989[1] (relating to what was then called non-A, non-B hepatitis), a specific test was developed for the newly named hepatitis C virus.[2] In 1991 second generation antibody tests made routine testing for hepatitis C reliable and widely available.

Since then evidence has been accumulating that in some parts of the United Kingdom many drug injectors test positive for hepatitis C,[3,4] reflecting similarly high figures from other Western countries,[5] though the nationwide scale of the infection remained unclear. This survey is the first attempt to establish the national prevalence of hepatitis C in British injectors attending services. It also highlights the problems these agencies experience when they try to obtain further services for infected clients. There are limitations to our survey and the findings need confirmation, but they are by far the best indication to date of the national picture.

Druglink itself was the main vehicle for distributing a questionnaire last year to drug services and other involved professionals, asking about the prevalence, investigation, and management of hepatitis C (see *How the sample was collected*). This methodology poses problems with establishing representativeness but the scope and consistency of the replies lend the findings considerable credibility. Among the respondents were a quarter – 73 – of the community drug agencies in England and Wales listed by SCODA, plus another ten not listed, five from Scotland and one from Northern Ireland.

We are grateful for financial support from Schering-Plough Ltd, without which we would have been unable to undertake this project, and for statistical help from Christine Walters of Suffolk College. We are especially grateful to all those who completed and returned our questionnaires.

The number of hepatitis C tests organised by the 131 services which responded to the survey varied from none at all to 233 at one English agency, where 73 per cent of tests were positive. The impact of such a large proportion and number of positives from one agency will have been to overstate the level of infection in England outside London. Outside England relatively few agencies responded, so these figures should be treated with special caution.

However, the large UK-wide sample and the fact that the results were relatively consistent across agencies[6] suggest they are a reliable indicator of the extent of hepatitis C infection among drug injectors attending services.

High level of infection As table 1 shows, of 2081 second generation laboratory tests done on injectors attending services, 60 per cent were positive for antibodies to hepatitis C, a figure suggestive of a major epidemic.

Looking at table 1 in more detail, the figures for Northern Ireland appear artificially low, but reflect the situation there. A psychiatrist explained they had "not been testing for hepatitis C largely due to the very small numbers of injecting drug users ... The [few] I do treat tend to be either therapeutic addicts or health workers who have become addicted to their own supplies. In neither case would sharing needles be a likelihood." The Regional Viral Laboratory in Belfast confirmed this ; only 20 cases of injection-related hepatitis C had been found in the entire province.

At over 70 per cent, the rates of hepatitis C infection in London and Scotland were higher than in the rest of the UK. Again, the chances are that this reflects the situation among drug injectors as a whole, as London and Scotland also have relatively high HIV infection rates.

Testing restricted We know some doctors believe testing for hepatitis C is an ineffective use of resources,[7] a view we have challenged.[8] We asked whether agencies were now or had in the past experienced difficulties in obtaining

Rate of hepatitis C infection in injectors

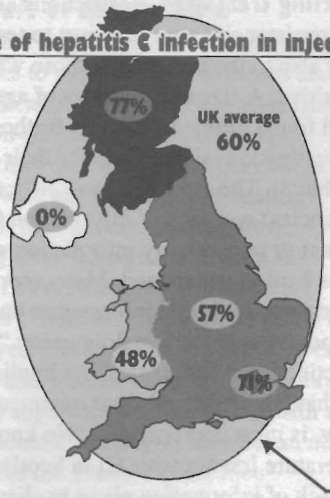

Table 1: prevalence of hepatitis C in drug injectors

	No. of replies	No. tested	No. HCV +ve	% HCV +ve
England	115	1785	1081	61%
London	28	416	295	71%
Rest of England	87	1369	786	57%
Wales	5	230	111	48%
Scotland	10	66	51	77%
N. Ireland	1	0	0	0%
UK	**131**	**2081**	**1243**	**60%**

All services, difficulties obtaining hepatitis C tests

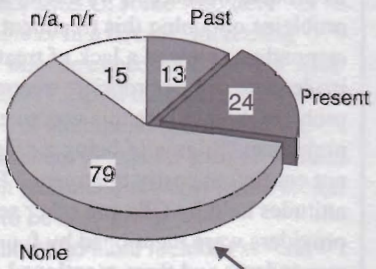

Table 2: services reporting difficulties obtaining hepatitis C tests

	No. of services	Difficulties experienced: Past	Present	None	n/a,n/r
CDTs	89	11	20	48	10
Rehabs	14	2	1	11	0
DDUs	6	0	2	4	0
Regional services	3	0	0	3	0
Inpatient units	2	0	0	2	0
Outreach/exchange	6	0	1	3	2
GPs	4	0	0	4	0
Others	7	0	0	4	3
Total	**131**	**13**	**24**	**79**	**15**
Total %	**100%**	**10%**	**18%**	**60%**	**12%**

All services, difficulties obtaining investigation/treatment for hepatitis C

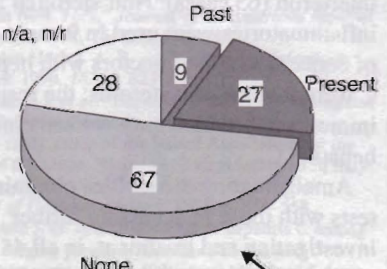

Table 3: services reporting difficulty obtaining investigation or treatment for hepatitis C

	No. of services	Difficulties experienced: Past	Present	None	n/a,n/r
CDTs	89	7	19	42	21
Rehabs	14	2	5	6	1
DDUs	6	0	1	5	0
Regional services	3	0	1	2	0
Inpatient units	2	0	0	2	0
Outreach/exchange	6	0	1	2	3
GPs	4	0	0	4	0
Others	7	0	0	4	3
Total	**131**	**9**	**27**	**67**	**28**
Total %	**100%**	**7%**	**21%**	**51%**	**21%**

tests for hepatitis C (see table 2). The answers showed that some NHS trusts are clearly attempting to limit testing, often on grounds of cost. Thirty seven drug services – over a quarter of the sample – reported past or present difficulties, including over a third of community drug teams. Twelve teams had done no testing; four of these had been prevented from testing. Two of the six drug dependency units did report problems but other medical services – GPs, inpatient units and regional drug services – did not.

Asked the reasons for these difficulties, 11 agencies cited the high cost of testing; one was funded for just 20 tests a year. GPs' reluctance to test or lack of knowledge about hepatitis C were cited by seven; another found difficulty arranging tests for clients not registered with a GP. One said "very few" Scottish GPs were testing as they considered the virus "not significant in Scotland". Another enclosed a letter from his local consultant in public health medicine advising that "testing is of little use if there is no remedy or preventive vaccine". The same would not have been said of HIV disease, indicating double standards. Two more respondents said costs might prevent testing in the future.

In three agencies testing was usually only allowed if a client showed symptoms of liver disease or had abnormal liver function tests – an ill-advised policy as serious liver disease may be developing even in the absence of symptoms; indeed, this is usually the case.

Access to tests could be particularly difficult when they were not done at the drug service. One respondent described how the "GP refused to do the test; accident & emergency refused to do test; client was passed around from agency to agency like a parcel." For three respondents tests were only available through

> Some NHS trusts are clearly attempting to limit testing on grounds of cost

infectious diseases consultants; for another four, only through the local genito-urinary clinic. Worryingly, one of these clinics had reportedly stopped testing due to the "lack of treatment to offer" to the "large percentage testing positive".

Counselling opportunities missed When tests are allowed, clients are often sent to genito-urinary clinics rather than tests being done at the drug service. This is inappropriate because sexual spread of the virus occurs rarely, and because the worker already helping the drug user with his or her drug problem is also the best person to counsel about risktaking and how to prevent or slow progress to cirrhosis.

Often tests are done without any counselling. Opportunities are missed to advise against heavy drinking (common in drug users, this further damages infected livers), to stress the importance of being immunised against hepatitis B (co-infection worsens the prognosis in patients infected with hepatitis C), or to discuss how to stop the virus spreading.

Coupling such counselling with hepatitis C tests can have a marked impact on HIV/hepatitis C risk behaviour. Our service noted a four to five fold increase in syringe exchange uptake by drug injectors in the two years after starting widespread testing;[9] knowing they harbour the hepatitis C virus can (but not always) be an important incentive to positive behaviour change. Many drug users ask to be tested and feel they have a right to know whether they are infected.

Getting treatment Restrictions and inconsistencies apply not just to testing but also to the response to those who test positive. A sizeable minority of agencies had found problems gaining further investigation or treatment for their clients (table 3). The most common difficulty (12 agencies) was lack of information for the client or poor quality information which was hard to understand. Many services said there was little information on what to advise seropositive drug users: "Conflicting information as to the implications of having hep C and what treatment, if any, is most appropriate"; "No known literature [on hepatitis C] in Scotland"; "Lack of information given to client on [test] result and no further help offered."

Of the 1243 injectors testing positive for hepatitis C, just 84 – below 7 per cent – were known by the drug service to have received treatment. An unknown extra percentage may have been waiting to see a specialist or have been treated without the service being told.

Alpha interferon, the drug mainly used to treat hepatitis C infection, is expensive and at the time of the survey was awaiting its product licence, so we anticipated problems obtaining this treatment. Six respondents viewed a lack of treatment or inadequate or inappropriate treatment as a problem. Sometimes this was seen as prejudice: "Stigma of being a drug user – not entitled to costly treatment." Poor attitudes held by GPs and other service providers were mentioned by four respondents and three mentioned cost.

Seven respondents said GPs would not refer infected clients to specialist help. For four agencies, long waiting times to see a specialist were a problem. When it occurs, onward referral is most often to one of Britain's few specialist hepatologists; long waiting times suggest these specialists are already overloaded. In some cases hepatologists may have been selected in order to access interferon treatment trials. Four agencies referred clients to a genito-urinary clinic, perhaps because the tests had been done there.

When treatment was known to have been given, overwhelmingly it involved interferon (63 cases). Non-steroidal anti-inflammatories were used in 9 cases. It is of concern that six injectors with hepatitis C were treated with steroids; the resultant immunosuppression may worsen chronic hepatitis C.

Amalgamating difficulties obtaining tests with those in accessing further investigation and treatment, in all 45 per cent of respondents, including half the community drug teams, reported difficulties of one kind or another.

HOW THE SAMPLE WAS COLLECTED

A questionnaire on the prevalence, investigation, and management of hepatitis C by drug services and other professionals was circulated during 1994 with two consecutive issues of ***Druglink***. Further questionnaires were sent to agencies where there were geographical gaps in the responses. Finally a round of questionnaires reminders were sent out by direct mailing to those who normally receive ***Druglink*** with invitations to a national conference on hepatitis C. A single complementary place at the conference was offered to participating agencies.

131 questionnaires were returned, 120 from drug services. 89 were from community drug teams, six from drug dependence units, 14 from rehabilitation houses, three from regional drug services, four from needle exchanges, two from outreach workers, two from specialist inpatient units, four from GPs. The remaining seven included a community psychiatric nursing unit, a community and social services department, a prison doctor, a NACRO housing association, two genito-urinary clinics, and a private clinical pathology laboratory (which had not done any testing).

The inducement of the conference place may have introduced an element of bias into the sample. A further 63 questionnaires followed the offer, giving 784 test results of which 421 (54 per cent) were positive, compared with the 68 questionnaires returned earlier of which 822 (63 per cent) were positive. If the lower percentage after the offer is due to bias (as opposed to geographical or other reasons) its effect will have been to *under-* rather than *over-*state the overall UK prevalence rate.

The scale of the problem

With what we already know, our survey allows us to make some predictions about the medical need which could arise from injection-related hepatitis C infection.

We know that in up to 80 per cent of people who test positive for hepatitis C the virus may persist, causing slow, ongoing liver damage. Following an infected blood transfusion, chronic hepatitis C normally has a latent phase of 25–30 years, after which cirrhosis, liver failure, and sometimes liver cancer may become apparent. We are dealing with a new epidemic which probably began at the end of the 1960s. Before then injecting drug use was rare. On this time scale, most UK injectors have not been infected long enough for serious disease to appear, and among injectors the time scale may be even longer as sharing syringes and needles typically passes on much smaller amounts of the virus than transfusions. This could explain why liver biopsies so far suggest some drug users may take longer to develop liver disease.[10]

Nevertheless, we are beginning to see a few injectors with liver disease from chronic hepatitis C, some who only injected once. In a decade, increasing numbers may be expected to present with liver failure. Despite the unknowns, it is important to attempt an estimate of the sort of numbers to expect; with or without interferon treatment, the cost to the nation is likely to be very great.

Information to hand includes several small-scale general population surveys. These have come up with infection rates ranging from 0.1 to 1 per cent[11] but are liable to under represent drug users by, for example, excluding the homeless or those in institutions.

KEY POINTS

- **Sharing contaminated injecting equipment is by far the most common mode of spread of hepatitis C in the UK.**
- **Six out of ten drug injectors attending UK drug services have been infected with hepatitis C.**
- **Up to 400,000 people in the United Kingdom may have been infected through sharing injecting equipment.**
- **Nearly half the professionals responding to our survey reported difficulty in either obtaining tests for hepatitis C or arranging further investigation and treatment for clients**
- **Lack of information, poor understanding of the disease process, and financial and other restraints are leading to poor quality care.**

Further evidence that the infection rate may be at the higher end this range comes from organ donors, where the prevalence of hepatitis C has been shown to be 1.08 per cent.[12] Organ donors are not necessarily representative of the general population, but we and others believe this figure is the closest we have to the overall prevalence of hepatitis C.[13] If this is the case, it means up to 615,000 people in the UK harbour the disease. The true figure is likely to be lower, perhaps 400,000, as the very young and the very old are not usually selected for organ donation.

From this 400,000 we need to subtract the number who may have become infected through blood products or in ways other than shared injecting equipment. It's estimated that 2000 haemophiliacs[14] have received blood products infected with hepatitis C and 3000 people have contracted the virus through blood transfusions.[15]

About 1 in 2,000 blood donors carry the virus.[16] Drug users and those who have received blood or blood products are asked not to donate blood. This means most infected blood donors should have contracted the virus through sexual or household contact, tattooing or mother to baby transmission (though some who have not admitted to injecting drug use may remain among this group). This suggests that 28,000 UK citizens have become infected via these routes – confirming that such spread occurs rarely.[17]

So the total number who became infected by means other then injecting is probably just 33,000, meaning nearly all the 400,000 people who may have hepatitis C became infected by sharing injecting equipment – a result which fits with our survey finding that hepatitis C is very common in injecting drug users.

But this estimate is far higher than the 1990–91 survey finding that 175,000 people in England and Wales have ever injected an illicit drug.[18] How can we explain this discrepancy? For several reasons, the survey's authors cautioned that their estimate was a minimum. In the face-to-face interviews, many respondents may not have answered truthfully. A relatively high proportion of those aged 16–24 were not asked about injecting drug use. The homeless were excluded (and with them large numbers of drug users) as were drug users in institutions such as rehabilitation centres and prisons.

Taking these difficulties into account, and adjusting the figure to include Scotland and Northern Ireland and the increase in injecting since the early '90s, the real number of injectors could be several times greater than 175,000, making it not so unthinkable that 400,000 of the UK population have been infected with hepatitis C through injecting drug use. Further research is urgently needed to test this conjecture.

THIS SURVEY SHOWS that the hitherto hidden epidemic of hepatitis C has taken UK drug services by surprise and that their response is being hampered by patchy health service limitations on testing and further investigation or treatment. There is an urgent need for these limitations to be subjected to detailed ethical and medicolegal scrutiny. Overall the picture is one of confusion, lack of information, unequal service provision, and some possible mismanagement. Clear guidelines are needed to ensure a high quality, standardised approach to drug users infected with the virus. Above all, efforts must be intensified to prevent any further spread of hepatitis C. ❍

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