

Hep C: Fighting back

Greater Manchester has made hepatitis C a health priority by harnessing local services to work together. **Kathy Oxtoby** reports

Just three years ago, hepatitis C was not even on the health radar of the Greater Manchester area. Now it is one of the top 20 health priorities being tackled by the region's primary care trusts (PCTs), thanks to an ambitious programme that aims to improve services for an estimated 20,000 people living with the condition in the region.

The Greater Manchester hepatitis C strategy is funded by all 10 PCTs in the area, who work together to develop a collaborative and coordinated approach to developing local services. The strategy group is involved in several projects to improve services across the region, focusing on such areas as bloodborne virus prevention, testing, treatment, research, workforce development and communication.

Dr Erika Duffell, a consultant in health protection, helped to set up the hepatitis C steering group in 2005, which included representatives from the PCTs, drug services, DAATS, infectious disease services and the Health Protection Agency (HPA). Back then she recalls that while hepatitis C was a big issue for clinicians, drug services and DAATS, the condition 'hadn't hit the radar' of the PCTs and health commissioners.

'At that time, not much was known about hepatitis C and there was a lot of confusion surrounding it,' she says.

What was clear, however, was that Greater Manchester had among the highest prevalence of hepatitis C in England and Wales. A health needs assessment commissioned by the steering group in 2005 estimated that 0.8 per cent of people in the region had chronic hepatitis – higher than other areas where the prevalence is thought to be 0.5 per cent. Many of those individuals were undiagnosed and unaware of their condition.

The assessment looked at the whole remit of hepatitis C services – from testing through to treatment. For the steering group overseeing the work, 'that was when we realised we were dealing with an epidemic and a serious public health threat', says Dr Duffell.

The group realised that if action was not taken to halt this epidemic, in 20 years time the already stretched health service in the region would be unable to cope with the growing demand for resources and services to treat hepatitis C and associated conditions, such as chronic liver disease.

Based on the results of the needs assessment, a strategy was developed to address this 'hidden epidemic'. The directors of public health from all of Greater Manchester's PCTs gave the strategy the green light and financial backing – a move that Siobhan Fahey, the programme manager of the Greater Manchester hepatitis C strategy describes as 'exceptional'. 'It was the first time in England and Wales that so many PCTs had put their heads together to work on hepatitis C,' Fahey says.

One of the main thrusts of the strategy is prevention – so increasing the numbers of people being tested for the virus is seen as vital. For people with difficult venous access, which is a particular problem for substance misusers, a new dry blood spot test was developed. The test involves pricking the patient's finger and taking five drops of blood onto a special card.

The card dries for 30 minutes and then is posted to a local hospital laboratory where it is put into a solution and the liquid screened for antibodies. If this is positive, the lab will do a second test – a PCR – on the card to find out if the patient has the virus. The process, Fahey says, is simpler and easier than other testing methods and consequently means more people are being tested.

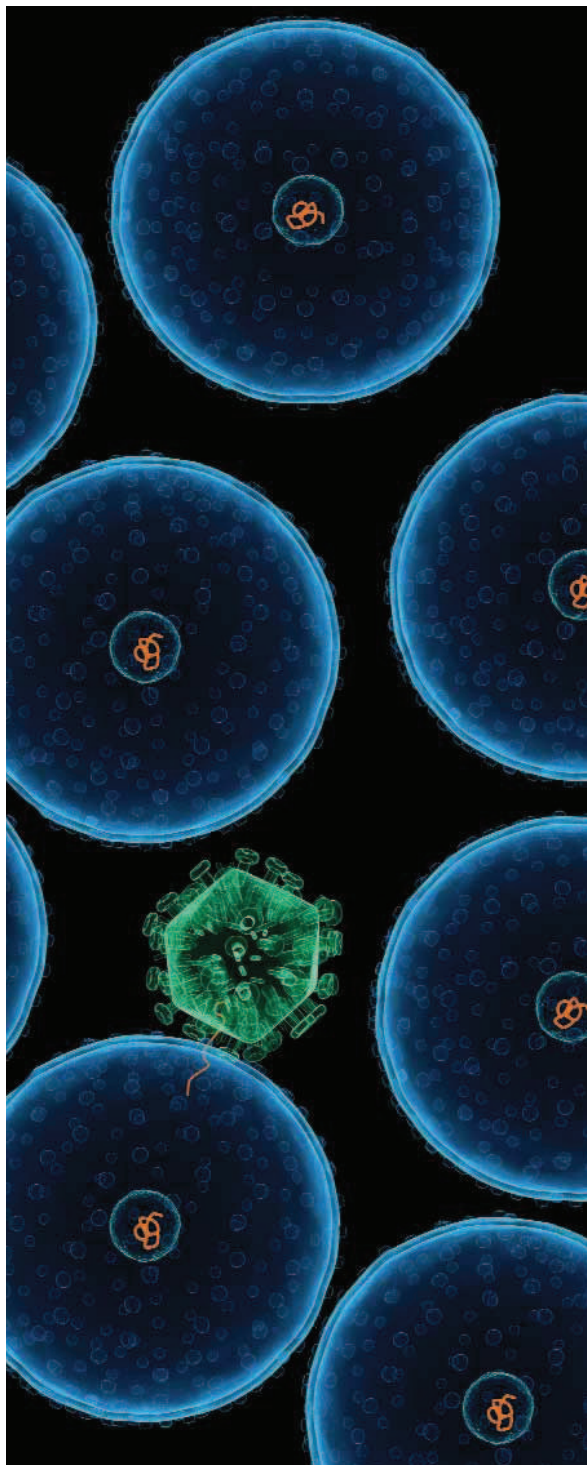
The test is now being rolled out in drug clinics across Greater Manchester, and it is hoped that by the end of March around 300 drug workers will have been trained to carry out the test, offer pre and post test counselling and give out general hepatitis C information.

By increasing tests, it is also hoped more people will receive treatment. The health needs assessment showed that just 200 people a year were being treated for the condition and feedback from drug agency workers showed greater need than there was capacity to offer treatment.

'It was clear that the majority of people with the condition were not in contact with treatment services,' says Dr Duffell, who as chair of the Greater Manchester hepatitis C strategy continues to oversee its development.

To help address this, the strategy group is looking at embedding services in hospitals and GP surgeries and is also considering outreach provision so that hard-to-reach groups get the testing and treatment they need.

As the strategy has developed, new schemes have evolved. A prison project has been set



up, where instead of inmates having to visit hospital under guard to be treated, a hepatitis C treatment specialist nurse is now in post to treat inmates in the four prisons across the region.

A research and workforce development project is also underway, which involves conducting a more detailed healthcare needs assessment and examining the training needs of those working with people with hepatitis C to help them carry out services more effectively.

Improving both professional and public awareness of hepatitis C is a key part of the strategy. 'Professional awareness-raising involves cascading out information to key professional groups, such as GPs, to increase their knowledge base about hepatitis C. It's a huge part of our work and we hope it will smooth the care pathway for service users,' says Dr Duffell.

To make more people aware about the facts of the condition, regular newsletters are produced and a website is about to be launched. The strategy's communications project also includes research into ways that target audiences, such as ex injecting drug users, would like to be communicated with. 'We hope to gain some interesting insights that allow us to really tailor our messages and how we put them across to people, so we can raise awareness,' says Fahey.

To support and sustain local hepatitis C support groups in the region, the University of Manchester, which is involved in a research project for the strategy, has employed community development worker Steven Miles. Part of his role is to help existing support groups become better organised – for example, helping them make the most of funding opportunities – and to encourage more groups to be set up.

Support is vital for people with hepatitis C and their needs, he says, are sometimes neglected because they lack the influence and power of other patient groups. 'Hepatitis C is a chronic condition that affects every aspect of an individual's life, so it is vital to have support groups to help give them a voice,' Miles says.

Jane Bird, from Sale, South Manchester, established a support group when she was diagnosed with hepatitis C in 2007. 'I wanted more support, but there was nothing in place. So I set up a group so that others in a similar situation can meet for a chat, and share experiences.'

Jane attends the Greater Manchester hepatitis C support group forum meetings along with representatives from other support organisations, to discuss ideas. Services user representatives also attend some of the steering group meetings to air their views on what improvements might be made. These meetings, Jane says, are 'really useful because they include the service users' voice and hopefully that means we can change things'.

Already, in the three years since the health needs assessment was carried out, so much has changed. The number of patients being treated has more than doubled from 200 to well over 400, while testing for hepatitis C is expected to raise diagnosis in the region. And treatment services are being embedded in more peripheral hospitals across the region, which Dr Duffell hopes will reduce inequalities in service provision.

Having a cohesive group of PCTs working together on the strategy is one of the main reasons it has been successful Fahey believes. 'Everyone is working together, which helps it to run smoothly,' she explains. The support of different professionals – drug workers, DAAT teams, patient representatives and specialist nurses – has also been essential to making the strategy work.

One of the biggest obstacles the strategy group faces is the lack of data about hepatitis C in the region, but there are proposals for a database on the condition and an audit to establish more detailed information.

Increasing the number of hepatitis C treatment nurses in Greater Manchester, offering more peer support for service users and making sure all key professional groups are appropriately trained are priorities as the strategy moves into its next phase of development.

And while Dr Duffell says raising hepatitis C from an unknown issue to the top 20 list of health priorities for the region's PCTs 'is a fantastic achievement', she stresses the drive to improve understanding of the condition across the region must continue – or the consequences will be dire.

'Raising awareness is at the heart of our strategy. It is fundamental to prevention. And without prevention we are never going to halt this epidemic.'

For more information about the Greater Manchester hepatitis C strategy contact Siobhan Fahey, programme manager. Email: siobhan.fahey@hmrpct.nhs.uk

For more information about support groups in Greater Manchester contact Steven Miles, community development worker, University of Manchester. Email: steven.e.miles@manchester.ac

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'I was badly in need of support'

Carl Curphey, from Whalley Range, Manchester, was diagnosed with hepatitis C in 2001. He believes he contracted the condition through injecting drugs such as heroin.

At the time he recalls there was little information about chronic hepatitis. 'I didn't know anything about the condition. So I just got on with my life,' he says.

It was several years before Carl was offered treatment, when his viral load increased dramatically. After 72 weeks he has just finished treatment. That course of treatment affected him 'profoundly', he says.

'There were constant side effects. I had to stop work. I had headaches and felt so tired it was hard to reach out for a glass of water when I was thirsty. I couldn't concentrate and felt depressed.'

Living on his own Carl says he was badly in need of support when he started treatment, but that no help was available. So he invited friends who also had hepatitis C to form a support group. This led to his being invited to take part in the Greater Manchester hepatitis C support group forum to meet with other groups and share ideas.

Carl has also taken part in a steering group meeting, along with key professionals and other service user representatives, to talk about the problems those with the condition have encountered and discuss the support they need.

The strategy, he believes, has had a positive impact on the region. 'It's helping to standardise treatment around different hospitals in Greater Manchester, it's trying to inform more people about hepatitis C and it's making waiting times for treatment shorter.

'And those involved with the strategy seem to be genuinely trying very hard to sort out problems for service users.'