



HCVAction

**HCV Action West Yorkshire Hepatitis C
Good Practice Roadshow
6 September 2017**

Summary report



Introduction

With hepatitis C representing a significant public health concern in the Leeds and West Yorkshire region, HCV Action and Public Health England (PHE) staged the second hepatitis C good practice roadshow of 2017 in Leeds on 6th September. The roadshows are an annual series of events aiming to bring together professionals working with hepatitis C in a variety of contexts, identify challenges and solutions for tackling hepatitis C locally, and showcase and share examples of good practice in prevention, testing, and treatment.

The roadshow brought together around 70 people, including clinicians, nurses, drug and alcohol service workers, prison health professionals, and others working around hepatitis C in West Yorkshire.

The roadshow's morning sessions included overviews of current opportunities and challenges surrounding hepatitis C and updates on the latest treatment options and data from experts, including Dr Mike Gent, Madeline Cox, Dr Mark Aldersley, and Dr Michael Gregory.

Examples of local good practice in prisons and community outreach were presented by Dr Iain Brew and Catherine Wigglesworth, with Rachel Halford sharing examples of good practice from elsewhere in the UK. Peter Griffiths shared his experience of diagnosis and treatment as a hepatitis C patient.



The afternoon workshops allowed participants to choose a focused area of interest to discuss local challenges in smaller groups. These topics included the work of Operational Delivery Networks, awareness and testing in drug services, and hepatitis C in South Asian communities.

Full slides presented by each speaker (unless omissions were requested) can be found in the HCV Action resource library [here](#).

Agenda

Introduction and setting the scene

Dr Mike Gent, Deputy Director for Health Protection, Yorkshire & the Humber, Public Health England

Local epidemiology

Madeline Cox, Information Manager, Yorkshire and Humber, Public Health England

Treatment of hepatitis C and possibilities for elimination

Dr Mark Aldersley, Operational Delivery Network Clinical Lead, West Yorkshire Hepatitis Network

Commissioning landscape for hepatitis C

Dr Michael Gregory, Clinical Director North, Specialised Commissioning, NHS England

Good practice case study presentation one: hepatitis C in prisons

Dr Iain Brew, Speciality Doctor in Viral Hepatitis, Leeds Teaching Hospitals NHS Trust

Good practice case study presentation two: community outreach

Catherine Wigglesworth, Clinical Nurse Specialist, Viral Hepatitis Leeds Teaching Hospitals NHS Trust

Patient perspective

Peter Griffiths

HCV Action: Sharing good practice

Rachel Halford, Deputy Chief Executive, The Hepatitis C Trust

Panel discussion: problems and solutions for tackling hepatitis C locally

Workshop A: Introduction to the work of the Operational Delivery Network

Dr Mark Aldersley, Operational Delivery Network Clinical Lead, West Yorkshire Hepatitis Network

Workshop B: Awareness and testing in drug services

Archie Christian, Peer Educator, The Hepatitis C Trust

Workshop C: Hepatitis C in South Asian communities

Dr Sulleman Moreea, Consultant Gastroenterologist and Hepatologist, Bradford Institute for Health Research

Workshop discussions

In the afternoon of the roadshow, three workshops were held on local issues relating to hepatitis C in the West Yorkshire area, with opportunities for attendees to discuss and contribute. The workshops are summarised below.

Workshop A: Introduction to the work of the Operational Delivery Network

Dr Mark Aldersley, Operational Delivery Network Clinical Lead, West Yorkshire Hepatitis Network

This workshop was intended to inform attendees of the structure and aims of Operational Delivery Networks, and encourage a discussion about the positives and negatives of the current system.

The workshop began with a summary of what ODNs are, reminding participants that 22 hepatitis C ODNs were established in 2015 alongside the introduction of direct acting antiviral treatments in order to co-ordinate cost effective care, data collection, and access to treatment across a region.

Each ODN has a set of specific operational requirements, and are incentivised and regulated through CQUIN indicators and payments. The operational requirements cover areas including:

- Hepatology, ID, virology and pharmacist expertise
- Administration
- Multi-disciplinary team meetings
- Access to Fibroscan
- Development of outreach
- HCV UK research membership
- Clinical trials
- Patient representative(s)

Dr Aldersley then presented the most recent local data on treatment initiations and SVR rates for the West Yorkshire ODN, broken down by provider, demographic, treatment centre, and drug regimen.

The group discussed positive and negative features of the current ODN system.

Positive reflections on the ODN system included:

- Participants felt that the multi-disciplinary team (MDT) process for treatment allocation worked relatively well, and effectively ensured suitable treatments were allocated to each patient.

- The run rate system was seen to drive outreach and participants felt it had supported an overall increase in treatment numbers, though some CQUIN penalties were regarded as being too severe.
- As long as service providers were interested and engaged, participants felt the processes within each network worked relatively well.

Features of the ODN system which participants felt to be challenging included:

- The fact that the creation of the ODN system did not come with any additional funding.
- Run rates create a lack of autonomy and clinical freedom.
- Some CQUIN requirements, like conducting follow-up tests 48 weeks after the start of treatment, were felt to be difficult to comply with.

The group collectively emphasised the overarching need to increase political pressure for a national elimination strategy in order to hold the government to account on delivering universal access to treatment.

Workshop B: Awareness and testing in drug services

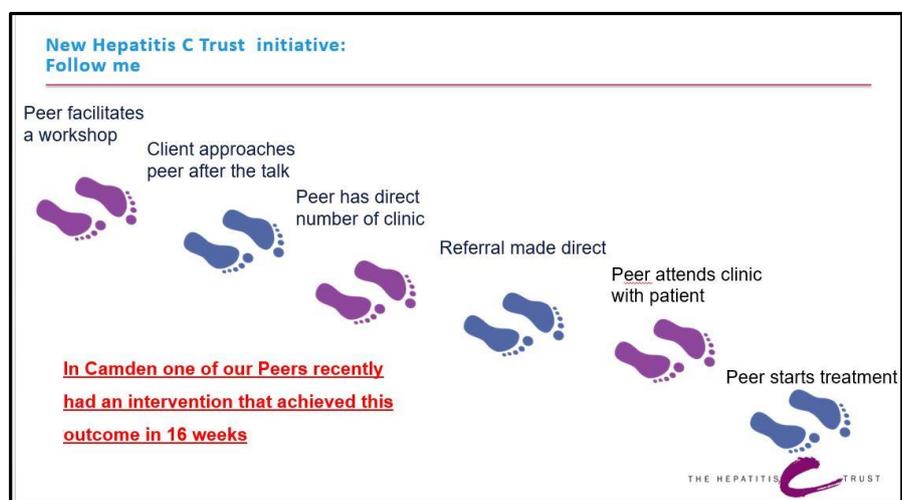
Archie Christian, Peer Educator, The Hepatitis C Trust

In this workshop, Archie Christian emphasised the importance of continuing to increase levels of testing among groups at high risk of infection, with over 50% of the estimated population infected with hepatitis C remaining undiagnosed. It was noted that many patients with known diagnoses have now been treated, creating an urgent impetus to find those who remain undiagnosed. With high prevalence for hepatitis C among people who inject drugs (PWIDs), drug services are an important setting to find undiagnosed patients.

The workshop introduced participants to the Hepatitis C Trust's peer support work. The Trust trains peers to deliver one hour workshops comprising their story and key messages related to

transmission, prevention, testing, pathways and treatment. These workshops are delivered in a variety of environments like rehabs, detox clinics, hostels, and prisons. A new peer initiative called *Follow Me* has

recently been piloted in Camden, with peers making direct referrals into treatment for



workshop attendees, and supporting them through the process of attending appointments. One peer recently initiated an intervention that achieved an SVR outcome for a patient just 16 weeks after their first attendance at a workshop.

The group discussed several hypothetical patient case studies, aiming to identify reasons why some people might remain undiagnosed for so long. Reasons discussed included:

- Old or inaccurate information, particularly amongst older people
- People who injected drugs only several times in their youth being unaware they were at risk
- Misdiagnosis of other conditions
- Lack of symptoms leading people to believe they do not need to get tested
- People who do not see themselves as part of a risk group
- People unwilling to talk to their GP due to stigma
- Isolation from any healthcare services
- People who are unaware of having been exposed to risk

Participants in the workshop were asked to discuss ideas for increased outreach in testing and diagnosis. Ideas included:

- Involving pharmacies in engaging PWIDs who are not in drug treatment services
- A 'reducing stigma' campaign – peers/visitors with experience of hepatitis C encouraging others to get tested
- Lobbying for NHS England to take the cap off the number of patients that can be treated
- A public campaign to educate and dispel myths
- Inviting a Hepatitis C Trust peer educator to visit local services
- Event ideas for World Hepatitis Day: Fundraisers, oral fluid swab testing in public settings
- Universal screening in A&E
- Universal screening for pregnant mothers
- Home visits for dry blood spot (DBS) testing
- More targeted, brief hepatitis C educational interventions for nurses
- Radical hepatitis C postal drive – send out swab tests to large parts of the population
- Continuing conversations with NHS England about the disincentives in the current CQUIN structure
- Big media campaign (Facebook, Instagram, TV) encouraging people to go to pharmacy for a DBS test
- Get a hepatology outreach worker to do DBS tests, get people to appointments, assertively engage
- Testing clinics in places of worship

- Monetary incentives for getting tested in at-risk populations
- Remove the 48 week re-test CQUIN requirement to allow medical staff to concentrate on treatment completion

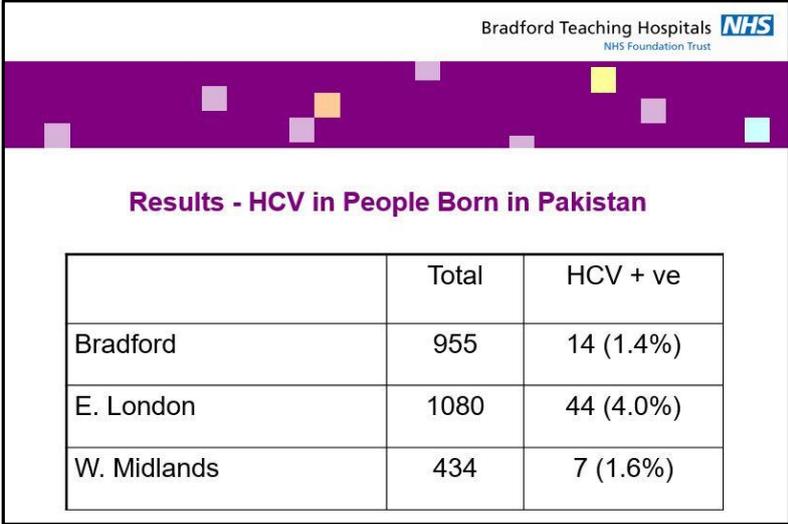
In discussion with other group members, participants often realised that other services were running similar initiatives to theirs, and many group members felt that improved joint working between services to avoid duplication was essential.

Workshop C: Hepatitis C in South Asian communities

Dr Sulleman Moreea, Consultant Gastroenterologist and Hepatologist, Bradford Institute for Health Research

Dr Moreea introduced the workshop by summarising the lack of accurate data on the prevalence of hepatitis C among the South Asian community globally, then shifting the focus of the workshop to local initiatives in Bradford. There has been a significant increase in the South Asian population in Bradford in recent years, with the proportion of South Asian residents rising from 14.5% in 2001 to 26.8% in 2011.

Dr Moreea presented three key hepatitis C testing and research initiatives in Bradford which aimed to clearly establish the level of HCV prevalence among South Asians, while also contributing to increased testing and treatment numbers.



	Total	HCV + ve
Bradford	955	14 (1.4%)
E. London	1080	44 (4.0%)
W. Midlands	434	7 (1.6%)

The first was an informal pilot in 2004 to universally screen expectant mothers for hepatitis C. This was discontinued after a year, but found that prevalence of HCV in African mothers was 3% and 1.1% in Asian mothers, compared to 0.4% in White Caucasian mothers.

The second initiative was a community study which screened 1500 people from the South Asian Community in Bradford during 2007-2008. Oral swab tests were conducted across 20 community centres and mosques. The study found a prevalence of 1.4% among people born in Pakistan living in Bradford, and 4% among people born in Pakistan living in East London. This variation might be explained by the significant difference in prevalence when broken down by Pakistani region of origin, with a 3.6% prevalence among those from Punjab, and only .03% among those from Sindh.

A larger 'HepFree' study funded by the National Institute for Health Research in 2012-14 recruited 20,000 South Asian participants via invitation letters sent to home

addresses and approaches made to patients who were attending the practice for another reason. Testing was conducted across Bradford, East London, and South London.

The HepFree study found an overall prevalence of HCV of 0.9% in the South Asian test population, rising to 1.2% among first generation immigrants. Higher rates of positive tests were identified in males, non-English speaking immigrants, and older people. Applying this prevalence rate to the South Asian community in Bradford, the number of individuals potentially infected with HCV in Bradford could be as high as 2,500. Thus far, around 700 patients from this population have been treated.

There was a discussion in the workshop group about why there is a greater prevalence of hepatitis C in the South Asian community. Dr Moreea confirmed that the biggest risk factor is re-use of needles during medical procedures, and also suggested there may be an element of cultural belief that treatments which involve injections are more 'legitimate' than others, leading to many people receiving injections when they could have been avoided. Other potential sites of infection include barbers and dentists.

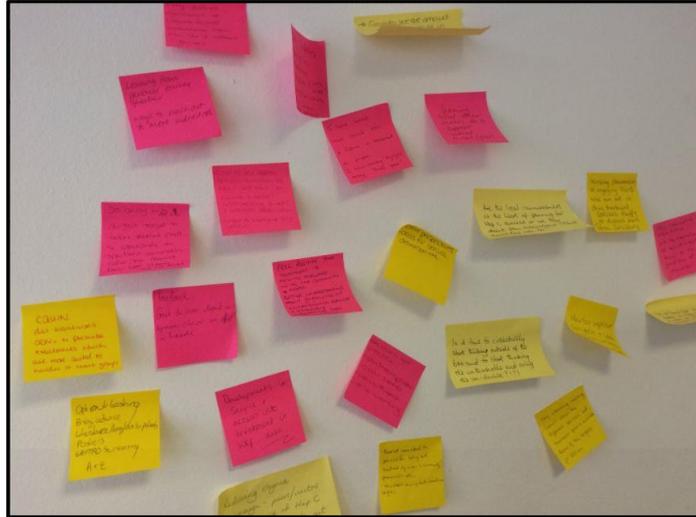
The group had a discussion on creative methods of outreach to the South Asian community. Several group members were enthused about the idea of a mail-out campaign of oral swab tests. While there was acknowledgement that this would have a high overhead cost and would risk a low return rate, it would have the potential to reach populations which are otherwise unengaged with any services.

There was agreement across the group that increasing GP awareness to a level where GPs would routinely and pro-actively offer tests to at-risk groups, including South Asians, was crucial. There was agreement that it is challenging to step out of existing infrastructures and reach a population which may be otherwise healthy and not engaged with services. Participants agreed that a national shift to approaching hepatitis C as a public health issue was key.

Attendee reflections

Before leaving, attendees were asked to write down what they would take away from the day. Some of the attendees' pledges to take action and reflections on the day are below.

- *“Invest in pilot projects to reach new people”*
- *“Meet regularly with staff “on the ground” to better commission services”*
- *“Peter Griffiths sharing his patient experience was excellent and very brave”*
- *“Learning from personal journey of speaker. Ways to reach out to more individuals”*
- *“Learned that CQUINs disincentivise ODNs to prescribe treatments which are more suited to harder to treat groups”*
- *“Frustrated with of lack of budget to back up the grand plan of HCV elimination”*
- *“Feel positive that treatment is moving forward into the community areas. Better understanding about difficulties of commissioning services & CQUINs. Informative and enjoyable day”*
- *“Great to hear about new dynamic clinics on offer in Leeds”*



Acknowledgements

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Dr Mark Aldersley – Operational Delivery Network Clinical Lead, West Yorkshire Hepatitis Network

Dr Suzanne Coles – Consultant in Communicable Disease Control, Yorkshire & the Humber Health Protection Team, Public Health England