HCVAction

HCV ACTION WEST LONDON HEPATITIS C GOOD PRACTICE ROADSHOW, 27 SEPTEMBER 2019

SUMMARY REPORT

Introduction

On Friday 27th September, HCV Action and Public Health England (PHE) held the latest in the long-running series of hepatitis C good practice roadshow events with the West London ODN. The event brought together a range of health professionals to share best practice in prevention, testing, diagnosis and treatment of hepatitis C.

The morning of the roadshow featured presentations from a variety of experts and heath professionals, including Emma Burke (Programme Manager for Alcohol, Drugs and Tobacco, Public Health England London), Hikaru Bolt (Epidemiology Scientist, PHE), Professor Ashley Brown (Clinical Lead, West London ODN), Dr Christopher Tibbs (Medical Director Commissioning, NHS England & NHS Improvement South East Region), Professor Ashley Brown (West London ODN Clinical Lead) and Lorna Harrison (Clinical Nurse Specialist, Hepatology, Imperial College Healthcare NHS Trust). From The Hepatitis C Trust, Rachel Halford (Chief Executive) chaired the event whilst Stuart Smith (Director of Community Services) spoke about the value of peer support programmes and Aidan Rylatt (Policy and Parliamentary Advisor) provided an overview of HCV Action's work and belief in sharing best practice in hepatitis C care. Former patient Billie Hands provided a patient perspective, outlining her own experience of hepatitis C and achieving cure.

Following lunch, the morning's speakers returned to answer questions and respond to points from attendees, discussing the need to test everyone accessing drug and alcohol services (rather than just clients who disclose a history of injecting), the best approach for patients who do not complete a course of hepatitis C treatment, and the importance of needle exchanges as a point of contact for supporting the healthcare needs of people who inject drugs.

Around 60 people attended the roadshow, including clinicians, nurses, drug service workers, prison health care staff and project managers. The full set of slides presented by each of the speakers can be found in the HCV Action resource library here.

Agenda

Introduction and setting the scene
Emma Burke, Programme Manager, Alcohol, Drugs and Tobacco, Public Health England – London

HCV Action: Sharing good practice
Aidan Rylatt, Policy and Parliamentary Adviser, The Hepatitis C Trust

Local epidemiology
Hikaru Bolt, Epidemiology Scientist, Public Health England

Hepatitis C elimination: the next three years
Dr Christopher Tibbs, Medical Director, Commissioning, NHS England & NHS Improvement South East Region

Treatment of hepatitis C and possibilities for elimination in London
Professor Ashley Brown, West London ODN Clinical Lead

Good practice case study presentation one: Hepatology nurse community outreach
Lorna Harrison, Clinical Nurse Specialist, Hepatology, Imperial College Healthcare NHS Trust

Good practice case study presentation two: The value of the peer
Stuart Smith, Director of Community Services, The Hepatitis C Trust

Patient perspective
Billie Hands

Panel discussion: problems and solutions for tackling hepatitis C and achieving elimination locally
Emma Burke, Hikaru Bolt, Dr Christopher Tibbs, Professor Ashley Brown, Lorna Harrison, Stuart Smith, Billie Hands

Workshop A: Identifying solutions to challenges faced by the ODN
Dr Matthew Foxton, Hepatitis C Clinical Lead, Chelsea & Westminster Hospital NHS Foundation Trust

Workshop B: Awareness and testing in drug services
Archie Christian, National Training and Volunteer Manager, The Hepatitis C Trust

Workshop C: Hepatitis C in prisons
Prof Ashley Brown, ODN Clinical Lead, West London ODN

Workshop discussions

During the afternoon, attendees split up into three separate interactive workshops. Dr Matthew Foxton, Hepatitis C Clinical Lead at Chelsea & Westminster NHS Foundation Trust, ran a breakout session specifically focused on finding solutions to challenges faced by the ODN; Archie Christian, National Training and Volunteer Manager, led a workshop focused on awareness and testing in drug services; and Professor Ashley Brown ran a session on hepatitis C in prisons. Below is a summary of the discussions and conclusions from the workshops.

Workshop A: Identifying solutions to challenges faced by the ODN

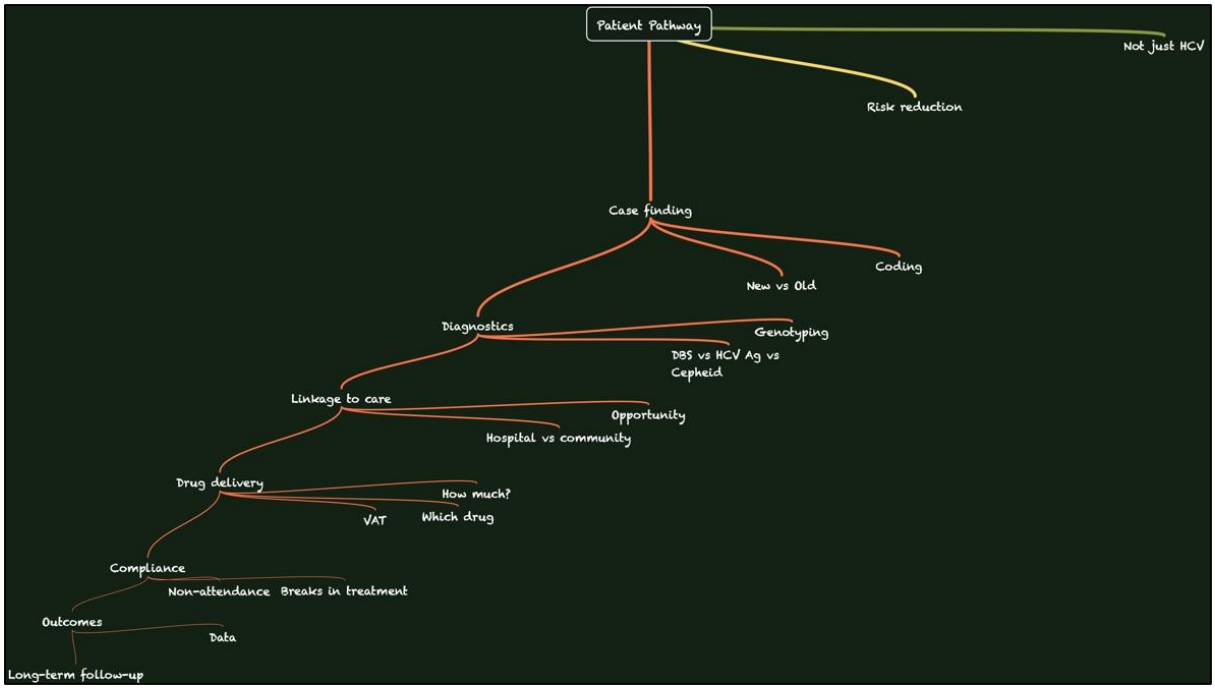
Dr Matthew Foxton, Hepatitis C Clinical Lead, Chelsea & Westminster Hospital NHS Foundation Trust

Dr Matthew Foxton began by outlining Chelsea & Westminster Hospital NHS Foundation Trust's role as a 'spoke' in the West London ODN (with Imperial College Healthcare Trust acting as the ODN 'hub'). Chelsea & Westminster Hospital treats a significant proportion of the ODN's patients each year.

Dr Foxton ran through the CQUIN (Commissioning for Quality and Innovation) scheme. Part of the CQUIN payments ODNs receive are for meeting minimum targets for patients treated. The lack of reward under the CQUIN scheme for overperformance in treating patients was highlighted as a concern, although this has been somewhat mitigated by the new arrangements whereby ODNs receive £500 per patient treated.

Payments for ODNs under the CQUIN scheme are also contingent on meeting data requirements, including recording the SVR12 outcomes for 85% of patients treated in secondary care and 60% of patients treated in outreach settings. It was felt to be a sensible approach to have less stringent data requirements for patients treated in the community, given the increased difficulty of gathering such data.

Dr Foxton outlined the main stages of the patient pathway, encompassing case finding, diagnostics, linkage to care, drug delivery, compliance and outcomes, as below:



Following the introduction, attendees discussed the specific challenges facing the ODN and potential solutions along each stage of the patient pathway.

Case finding

On case finding, it was felt that more could be done to target ethnic minority populations with higher prevalence, particularly in the Hounslow and Harrow area. Users of image and performance enhancing drugs were also identified as a key group to target. Needle exchanges and sexual health services were highlighted as important settings for reaching this group. It was also suggested that work could be done into finding gyms where steroid use is more prevalent so that outreach testing could take place.

There was also a discussion around identifying patients with a long-term undiagnosed infection. There were issues with Public Health England data provided to ODNs, with many patients no longer contactable or even, in one case, now dead. The yield of patients on the list successfully being contacted and enrolled onto treatment is roughly around 15%. It was agreed that a national data system of diagnosed patients that ODNs could access would be extremely useful.

Diagnostics

A discussion took place on A&E as a location for diagnosing new patients. A project in the A&E department at Chelsea & Westminster Hospital resulted in around 1.6% antibody positive rates and was found to be cost-effective. It was agreed that implementing A&E testing in other hospitals within the ODN, such as Charing Cross Hospital, would be a welcome development.

Certain GP clinics were also felt to be useful locations for diagnosing patients. For example, a GP surgery in Pimlico operates a policy of screening all patients in its homeless clinic for blood-borne viruses.

Finally, antenatal screening was highlighted as an opportunity. Whilst it has not been found to be cost effective across the country, in an area like West London, with a higher proportion of migrants from high-prevalence countries, it is more likely to be so.

Linkage to care

A discussion took place around the current pathways into treatment. Lots of testing takes place in community settings within the ODN but it can be challenging to get people who test positive to then attend appointments to receive treatment. It was felt that peers would be a crucial source of support here, and The Hepatitis C Trust will soon be hiring a Peer Support Lead to work in the West London ODN area.

Further community outreach was also highlighted as being vital, with outreach among the Lithuanian community identified as an important next step, with community centres and churches key locations for reaching this group.

There have been discussions about a National Testing Registry, which is hopefully forthcoming. ODN Clinical Lead Prof Ashley Brown has advocated the development of a pan-London database at the least, given the high amount of patient transition between London ODN areas.

Drug delivery

It was noted that there is now a greater degree of clinical freedom in the prescription of treatments. There was a brief discussion regarding whether a no-deal Brexit departure would have an impact on the supply of hepatitis C treatments. It was noted that pharmaceutical companies have stockpiled four to six months' worth of medicine supplies in preparation.

A discussion also took place on how much of a treatment course should be provided in one go in drug services. At the moment, the maximum is normally four weeks' worth but it was agreed that it would be nice to have greater flexibility, with some patients given the full 12 weeks' medicines at once.

Compliance

A short discussion took place regarding the effect of patients not complying fully with the course of treatment. Normally, there is not a problem in relation to patients sticking to their prescribed treatment duration. It was noted that patients often achieve cure earlier then 12 weeks into treatment regardless and there have also been cases where it has been known that a patient has taken the medicines intermittently and still achieved cure.

Outcomes

Securing outcomes data is a challenge, particularly recording patients' SVR12 outcomes, which often require a lot of calling and chasing. Also challenging is long-term follow-up to check whether patients have developed liver cirrhosis.

It was generally felt that the ODN model had been successful and that there was a possibility, as recently suggested by the Operational Delivery Network Lead Prof Graham Foster, that the model may be expanded to cover all aspects of liver care, rather than just hepatitis C.

Workshop B: Awareness and testing in drug services

Archie Christian, National Training and Volunteer Manager, The Hepatitis C Trust

Archie Christian began by outlining the main challenges drug services face in relation to hepatitis C – identifying the undiagnosed; supporting those who have been diagnosed into treatment; and reducing 'did not attend' rates.

A number of factors preventing drug service clients from engaging were identified, including:

- Stigma
- Fear
- Myths
- Low priority
- Lack of awareness
- Bad past experiences
- Rebellion
- Lack of self-worth

Attendees then took part in an exercise identifying barriers and solutions to substance misuse clients engaging with specialist care. Barriers under four different categories were identified, with some of the solutions suggested by attendees outlined below.

<u>Patient psychological barriers</u>

Barriers	**Solutions**
• Shame • Fear • Anxiety • Unknowing • Denial • Low self-esteem	• Education on treatment options • Reassurance • Peer support • Contingency management plan • Carer's or family's support • Refer to specialist team

Patient physical or practical barriers

Barriers	Solutions
• Location/Transport	• Paying fares • Satellites or outreach
• Employment or personal circumstances	• Extended clinical hours
• ASBOs or other restrictions • Mental health • Gang issues • Disabilities	• Partnership working: police, The Hepatitis C Trust, social services, mental health services

Service barriers – drug and alcohol

Barriers	Solutions
• Staffing level	• Funding • Recruitment • Volunteers • Peers
• Language	• Interpreters • In-reach • Good data
• Funding/resources	• Funding • Commissioners fundraising
• Lack of awareness	• Education • Training • Peers
• Partnership working	• Clarity of roles and responsibilities
• Lack of prioritisation, other priorities	• Staff support

Service barriers – hospitals

Barriers	Solutions
• Fear of testing	• Awareness
• Patients getting to hospital	• Provide transport, reimburse travel • Mobile clinics

	• Satellite services
• Long waiting times	• Improve staff resources • Increase provision
• Patients fear of judgement and staff attitudes to patients	• Staff training • Consultations and feedback
• Confidentiality	• Increase awareness • Reduce stigma • Staff training
• Lack of funding	• More funding • Understanding of the issue
• Paying for prescriptions	• Make it free • Incentivised schemes
• Fear of accessing treatment due to immigration status issues	• Use of satellite services • Increase awareness
• Long wait times for test results or updates	• Streamlining processes, ensuring services have correct contact details

Workshop C: Testing and treatment in prisons

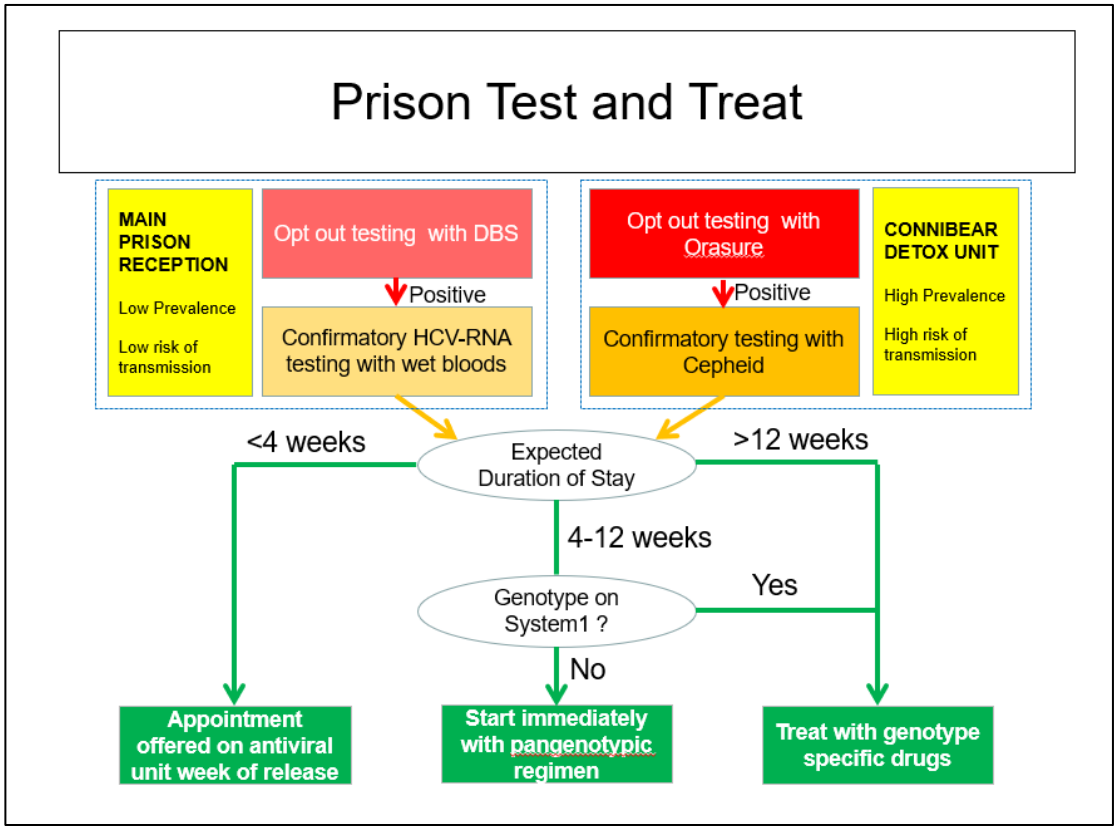
Professor Ashley Brown, ODN Clinical Lead, West London ODN

Professor Ashley Brown began the session by laying out the epidemiology of hepatitis C in prisons. Whilst the prevalence of hepatitis C in prisons has been found to be lower than some earlier estimates suggested, it is still far higher than amongst the general population.

Prof Brown outlined how hepatitis C in prisons is a public health issue, which prompted the need to treat cases as a form of prevention. 64% of inmates say they have used illicit drugs within a month before their admission to prison and 37% say drugs are “easily obtainable” within prison.

He also noted some important facts for HCV treatment, including the fact that those most at risk of HCV infection tend to have shorter sentences. Therefore, whilst prisons offered an opportunity to treat and reduce the risk of new transmissions, they also require specific treatment pathways.

The model for testing and treatment, divided between the Connibear detox unit and main prison reception:



He noted how care had moved from the traditional model to an outreach model to an "ideal model". Under the traditional model, in which the delivery of treatment was extremely difficult, patients would have to be taken to secondary care for treatment. In the in-reach model, care was available within the prison from hospital teams working there. In the "ideal model", wholly prison-based teams were upskilled and equipped for hepatitis C testing and treatment and delivered care with specialists able to offer advice and support when required.

Prof Brown noted that given the public health aspects of prison testing, testing at or very close to reception was vital. He also noted how the dedicated substance misuse unit (or 'Connibear') in one prison helped treatment through patients being supervised by members of the healthcare team constantly and being separate from the rest of the prison.

Attendees raised issues around staffing levels, particularly with officers not being able to unlock someone on their first night for testing. They also noted that whilst prison healthcare are seen as having a "captive audience", it is still entirely possible to "lose" a patient within a prison, especially when they are transferred to another prison.

One potential solution to issues around transfers disrupting treatment was a network of named contacts with one in each prison who could be contacted to make healthcare teams aware of new arrivals who were on the treatment pathway but yet to complete it.

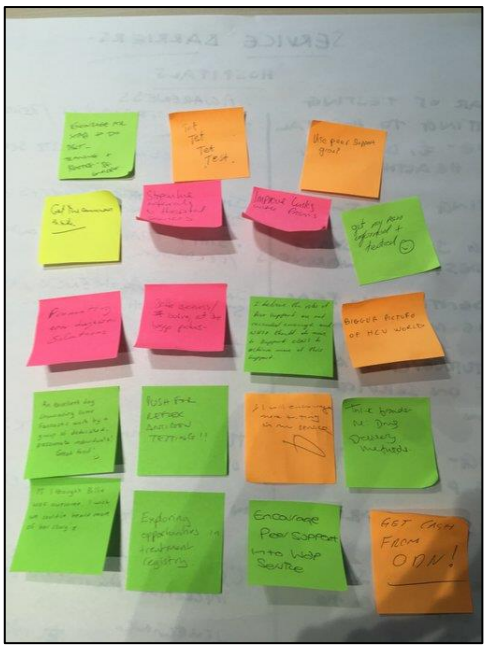
The importance of peer support work was also emphasised. Peers can build trust and relationships with patients which not only help testing and treatment in the prison but also upon release.

However, issues were raised regarding problems getting security clearance for peers given their criminal records and issues with communication between HMPPS and NHS England. It is clear that some of these issues can only be resolved through action at a national level.

Pledges by attendees

At the close of the roadshow, attendees were asked to note an action point they would take forward to their services or in their practice as a result of things they had heard discussed during the day. Contributions included:

- "Use more peer support, especially working with ethnic minorities, not just people who inject drugs"
- "Encourage all staff to do dry blood spot testing training, practice and be confident"
- "Streamline referrals to hospital services"
- "Improve links with prisons"
- "Encourage more testing in my services
- "Think broader around drug delivery methods"
- "Encourage peer support in my service
- "Push for reflex antigen testing!"



Acknowledgements

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Nigel Sanmoogan, ODN Manager, West London ODN

And, of course, thank you to all speakers and attendees.