

HCV Action and Lancashire & South Cumbria ODN workshop, 11th October 2017: Summary report

About HCV Action

HCV Action is a network, co-ordinated by The Hepatitis C Trust, that brings together health professionals and others from across the patient pathway, including GPs, specialist nurses, clinicians, drug services, public health practitioners, prison healthcare staff, commissioners and industry.

It exists to highlight, promote and share good practice in the prevention, testing, and treatment of hepatitis C. By providing resources, staging events, and engaging with professionals and decision-makers, it seeks to raise professional awareness and knowledge of hepatitis C and act as a catalyst for the improvement of hepatitis C services and strategy across the UK.

Background

Operational Delivery Networks (ODNs) are the structures through which hepatitis C treatment in England is delivered. They involve regional centres that manage treatment decisions and prescribing, and which have a dispersed treatment model which aims to support partnership working and access for local patients.

There are 22 ODNs across England, with each having a 'hub' hospital responsible for leading the Network, and 'spoke' hospitals which each provide treatment with the oversight of the hub. Each ODN must adhere to a number of requirements, aimed at improving quality standards in hepatitis C care, with these standards being linked to Commissioning for Quality and Innovation (CQUIN) payments. These requirements include:

- Hepatology, virology, infectious disease and pharmacist expertise
- Administrative support
- Multi-disciplinary team meetings
- Access to Fibroscan
- Development of outreach treatment services
- HCV UK research membership
- Involvement of patient representative(s)

This workshop brought together a range of stakeholders working across the hepatitis C pathway in the Lancashire & South Cumbria ODN region, with the aim of discussing some of the barriers faced by the ODN, as well as providing a forum in which to develop solutions to some of these challenges.

Workshop summary

Challenges and opportunities for the ODN, Dr Ioannis Gkikas (ODN Clinical Lead)

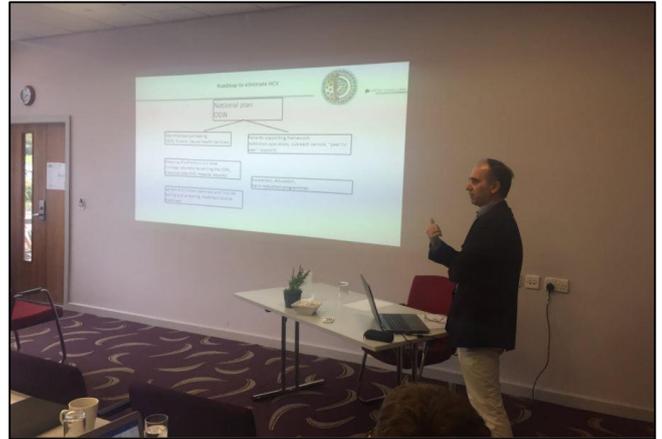
The workshop began with Dr Ioannis Gkikas providing an overview of key challenges and opportunities surrounding hepatitis C both locally and across the UK.

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Dr Gkikas summarised the hepatitis C care pathway, giving an overview of transmission routes, estimated prevalence globally, and developments in treatment over the last few decades, culminating in the revolutionary clinical benefits provided by new direct-acting antiviral treatments.

He provided an overview of the World Health Organisation hepatitis C elimination targets, and the linked efforts in treatment, prevention, and awareness-raising that will be required to achieve these targets in the UK.

He reminded 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. Since the establishment of ODNs, we have seen positive early data suggesting a reduction in liver disease-related deaths and a 50% reduction in the need for HCV-related liver transplants.



Since its establishment in September 2016, 402 patients have been treated for hepatitis C in the Lancashire and South Cumbria ODN. Over the last year, positive developments for the ODN have included the addition of a number of key staff members, including an additional consultant, two new liver clinical nurse specialists, an ODN co-ordinator, and an ODN pharmacist. Two new outpatient clinics have also been established.

Proposals for a new outreach clinic within the premises of substance misuse services have been progressing over the last six months, and await final approval. The ODN also operates a system of direct referrals of HCV patients from substance misuse services, with 80 referrals through this route since February 2017.

Dr Gkikas emphasised the importance of effective treatment pathways for active drug users, pointing to clinical trials of treatment for those on opioid replacement therapy, which show relatively low reinfection rates and significant benefits in reducing transmission.

To conclude the workshop, Dr Gkikas summarised areas where the ODN must make improvements in order to achieve hepatitis C elimination:

- Maximising opt-out testing (in substance misuse services, prisons, and sexual health services)
- Mapping of patients in the area (through virology laboratories serving the ODN, historical data from PHE, hospital records)
- Agreement and funding for pathways for testing and re-testing, treatment and re-treatment
- Patient support frameworks (addiction specialists, outreach services, peer-to-peer support)
- Awareness, education, and harm reduction programmes

Peer to Peer Support, Stuart Smith (Head of Drug Services, The Hepatitis C Trust)

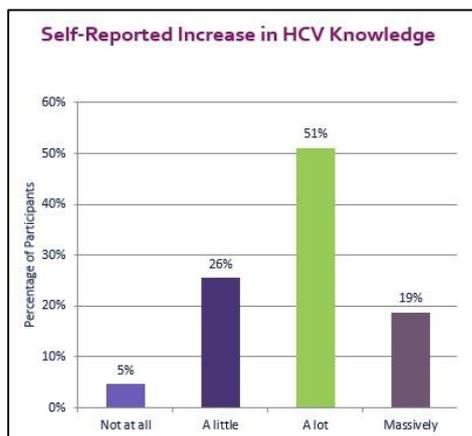
In this portion of the workshop, Stuart Smith of The Hepatitis C Trust introduced participants to The Hepatitis C Trust's peer-to-peer support programmes, one solution to the challenge of engaging more individuals in the care pathway.

The talk began with an overview of the World Health Organisation hepatitis C elimination targets and the opportunities presented by the new treatments for hepatitis C. The key challenge for achieving elimination is finding the undiagnosed and re-engaging those who have been diagnosed in the past but have not been treated.

As a strategy towards engaging people into care, The Hepatitis C Trust trains peers to deliver one hour workshops telling their story and conveying key messages about hepatitis C transmission, prevention, testing, pathways and treatment. These workshops are delivered in a variety of environments like rehabs, detox clinics, hostels, and prisons. The key objectives of these talks are:

- Improving awareness of hepatitis C amongst PWIDs, including key messages on prevention and sharing
- Motivating people at risk to access testing
- Motivating people already diagnosed to access specialist services to get treatment
- Improving understanding of hepatitis C amongst staff in drug services, particularly on testing and appropriate pathways
- Changing attitudes toward hepatitis C amongst PWIDs and the wider community

Peer-to-peer sessions usually begin with the peer's personal story and their experiences of injecting drug use, hepatitis C diagnosis and treatment, followed by a discussion of the issues with workshop attendees. Following the discussion, participants complete a quiz to establish their understanding of key messages.



The talk also covered key outcomes from the peer support programme, with quantitative and qualitative analysis showing the intervention is effective at embedding key messages and increasing the numbers of individuals tested and accessing care. 70% of workshop attendees reported that their knowledge of hepatitis C increased "a lot" or "massively" as a result of the workshop.

Interviews with some participants were also conducted months after they attended a workshop, with the vast majority recalling key messages on prevention and treatment. Some interviewees relayed

that after learning about transmission risks at a peer workshop, they had changed their behaviours to minimise risk. Others also indicated that they had passed on messages from the sessions to their peers, demonstrating the value of the peer-to-peer model in embedding key messages among at-risk groups.

An innovation introduced in Birmingham was the provision of testing at the end of peer talks, known as 'Talk and Test'. During the period from April 2016 to October 2016, 25 workshops were delivered in Birmingham with 195 attendees. 18 of these workshops adopted the 'Talk

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and Test' model. Following the workshops, 72 clients (51% of participants) received a test for hepatitis C.

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. 'Follow Me' demonstrates the benefits of empowering peers with the ability to directly signpost people into care and ensure they complete the treatment pathway.

Delivery Date	Number attending session	Test complete on day	
April	8	6	75%
May	18	10	55%
June	21	10	47%
July	18	8	44%
August	28	16	57%
September	25	9	36%
October	26	13	50%
Total	144	72	50%

The talk concluded with a summary of the key outcomes of successful peer-to-peer support programmes, highlighting the benefits to clients and volunteers alike:

- Decreased transmission of hepatitis C.
- Increased numbers of drug users tested, diagnosed, undergoing treatment and cured.
- Behavioural change amongst PWIDs – decreased sharing of equipment and syringes.
- Key messages embedded into the drug using community.
- Increased volunteer empowerment.
- Increased numbers of volunteers finding employment.

Group discussion: Pathway barriers and solutions

To conclude the workshop, participants worked in groups to identify some of the existing barriers or gaps in the hepatitis C pathway, and potential actions to address these barriers.

Suggestions and proposals included:

1) Supporting community services to deliver testing and treatment

There was enthusiastic agreement from participants that testing and treatment for hepatitis C in pharmacy settings would be an impactful, positive addition to HCV care in the ODN. Groups agreed that testing in pharmacy settings should lead to direct referrals into secondary care and treatment.

It was felt that drug services that dispense opioid substitution therapy could also be providing treatment directly, and that arrangements to deliver treatment to community pharmacies should be explored. This would ensure that treatment is still available to patients in a convenient, trusted location.



Participants also noted that there is a lack of regular testing in sexual health services. It was suggested that commissioners should contractually require drug & alcohol services to

appoint a dedicated BBV nurse, and for testing for hepatitis C to be mandated for drug & alcohol and sexual health services.

Action: Explore the potential for treatment to be delivered in community settings. Implement direct referral pathways from community services.

Owner: ODN hub, in partnership with community-based services.

2) Establishing a programme of peer interventions

Following Stuart Smith's overview of the peer-to-peer support model, participants agreed that the provision of such interventions in the region would be a valuable and effective way of engaging individuals in the care pathway and ensuring that they completed treatment. Peers are often better placed than services to reach vulnerable, at-risk groups with information on prevention, testing, and treatment.

Workshop participants highlighted the essential role that peers can have in supporting patients once they have entered the care pathway. It was noted that there is often a lack of social support for particularly vulnerable patients, a gap that could be addressed through peer support.

It was felt that an effective peer support programme - especially something similar to The Hepatitis C Trust's 'Follow Me' programme, where peers attend appointments with patients - would be a good solution to the high rates of patients missing appointments, identified as a consistent problem across the ODN. Additionally, it was felt that effective peer support groups could contribute to behavioural changes among patients, helping to reduce re-infection rates.

Action: Implement peer-to-peer support programmes across the ODN area.

Owner of action: ODN hub, with support from The Hepatitis C Trust.

3) New approaches to find the undiagnosed

In common with ODNs across the country, finding previously undiagnosed patients and engaging them into the care pathway was felt to be a key priority. Several ideas for innovative methods of testing and diagnosis were suggested.



High rates of patients not attending scheduled appointments were noted to be a problem across the ODN, and alternative methods of contacting patients for follow-up (via text message or email) were suggested.

It was noted that additional infrastructure like a testing unit operating out of a mobile van, or a portable fibroscanner for outreach clinics, would allow for more flexible testing in the community.

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There was a discussion of testing in GPs, and some groups felt that GPs would not always ask patients the right questions to elicit information about known risk factors, and may only suggest an HCV test under very particular circumstances. It was felt more work needed to be done to increase willingness among GPs to test patients, and a pilot of a universal testing project was suggested.

Participants also agreed that testing in prisons was currently sub-optimal. Increased in-reach to prisons was desirable. This would require building relationships with prison governors, and greater availability of specialist nurses.

It was also mentioned that there are not enough resources for re-testing in the way that clinicians believed would be beneficial. Particularly in needle exchanges and drug services, attendees suggested that people should be tested every 6 months, regardless of having been tested previously.

Action: Explore alternative methods for contacting those identified as at-risk or lost to follow up (text, email, phoning those identified as at risk and inviting them to test). Investigate possibility of universal testing for targeted groups in GPs.

Owner: ODN, in partnership with community-based services and primary care providers.

4) Improved hepatitis C training for service staff

There was agreement across workshop groups that continued efforts to increase awareness of hepatitis C among GPs and service staff were still necessary.

It was felt that clinical staff delivering talks and training in drug services would be useful, to increase drug service workers' awareness and knowledge of hepatitis C, and to enable them to more effectively contribute to the ODN's work.

Participants felt that some GPs' knowledge of hepatitis C was inadequate, with testing in primary care reported to be patchy. Providing further education on hepatitis C for GPs was also recommended.

Action: Arrange training sessions on hepatitis C for frontline services and GPs.

Owner of action: ODN hub, in partnership with services (e.g. already-trained staff may be able to provide training to colleagues within services).