

## HCV Action and North East & Cumbria ODN workshop, 3<sup>rd</sup> May 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 North East & 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.

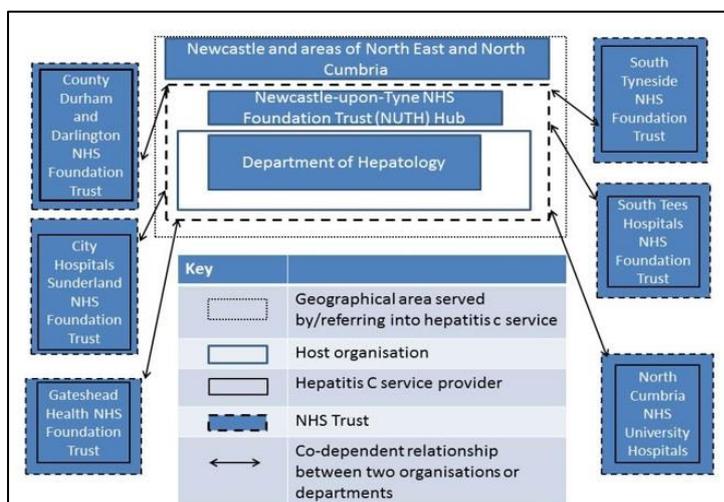
### **Workshop summary**

*Challenges and opportunities for the ODN, Dr Stuart McPherson (ODN Clinical Lead) and Dr Sarah Morey (Hepatitis C Network Manager)*

The workshop began with an overview of some of the significant successes achieved by the ODN since its establishment. This included the development of a more structured referral

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pathway (see diagram below), greater joint working across the region, and the development of outreach treatment provision in drug treatment centres and in two prisons in the region (HMP Acklington and HMP Durham). The ODN also met its treatment target, with 398 patients treated in 2016/17.



One of the most significant challenges faced by the ODN was said to be the need to meet the increased treatment run rate in the coming year, which for 2017/18 will be 624. This increased number, while welcome, was said to represent a test of the ODN's ability to increase the numbers of people tested, diagnosed and referred into the treatment pathway.

This was reported to be particularly challenging given the fact that many of the people who are yet to be diagnosed may either find it difficult to access services or are unaware that they may be at risk. A third cohort who remain difficult to engage in services were said to be people who have previously been diagnosed but who have been lost to follow up. While an exercise could be undertaken to identify and contact these people, this would be time-intensive and would require additional resources to be made available to the ODN.

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

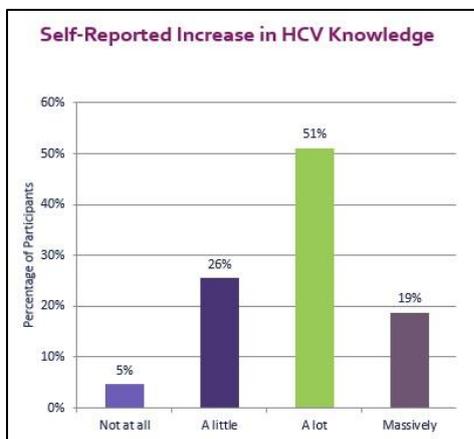
After some of the challenges faced by the ODN had been outlined, Stuart Smith of The Hepatitis C Trust presented one of the possible solutions to the challenge of increasing the engagement of individuals in the care pathway; the establishment of peer-to-peer support programmes in the region.

The talk began with a step-by-step overview of how a peer support programme could be established, as outlined below:

- 1) Establish existing volunteer network within local service provider
- 2) Recruit peers with personal experience of hepatitis C
- 3) Provide 2 days training (1<sup>st</sup> day is also open to staff)
  - Optional 3<sup>rd</sup> day, with a level 2 qualification made available to peers
  - Assist peers with initial bookings for workshops
- 4) Review peer educator(s)
- 5) Offer new recruit training when appropriate

Once peers are trained, their main role is to deliver 1 hour workshops in rehabs/detox units/day programmes and prisons. These workshops include 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. The workshop is delivered within a framework that includes five key messages around:

- Transmission (transmission routes and risks)
- Prevention
- Testing
- Pathways
- Treatment (availability of treatment and how to access treatment services)



Outcomes from the peer support programme were detailed, with the intervention already proving that it can embed its key messages and increase the numbers of individual tested and accessing care, with 51% of workshop attendees reporting that their hepatitis C increased “a lot” as a result of the workshop, with another 19% reporting that it had increased “massively”.

As part of the peer support programme, a ‘Talk and Test’ model was adopted in Birmingham through the period April 2016 to October 2016. Overall, 25 workshops were delivered in Birmingham with 195 attendees. 18 of these workshops adopted the ‘Talk and Test’ model, whereby 72 clients received a test for hepatitis C following a peer talk.

Talk and Test, ensuring that testing was available following sessions, led to significant increases in the numbers of people tested in participating services.

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%
<b>Total</b>	<b>144</b>	<b>72</b>	<b>50%</b>

### *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, identify potential actions to address these barriers or gaps, and identify who should own that particular action (i.e. who is actually responsible for ensuring change).

Suggestions and proposals included:

#### **1) Hepatitis C training for frontline services**

It was agreed that the skills and knowledge of most professionals working in the hepatitis C pathway in the region were of a high standard. However, it was suggested by workshop participants that additional training could be provided (and co-ordinated by the ODN hub) to further increase the skills, knowledge and confidence of some, to enable them to more effectively play a part in the success of the ODN.

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For example, it was said that hepatitis C awareness and knowledge among pharmacists and primary care staff was often low. Given the crucial role they have to play (and the likelihood that pharmacy-based and primary-care based models will be increasingly utilised in the future), it was deemed to be essential that they had an up-to-date knowledge of hepatitis C.

Similarly, while most drug services staff receive BBV training as part of their induction, it was agreed that more could be done to provide regular and scheduled 'refresher' training to drug services staff in order to keep them up-to-date, both with developments around hepatitis C testing and treatment and also with the performance of the ODN (in order to foster a culture of 'shared ownership' of the ODN).



**Action: Establish formal rolling programme of training**

**Owner of action: ODN hub (in partnership with The Hepatitis C Trust)**

The Hepatitis C Trust has partnered with Changing Lives to deliver a peer-led intervention called 'Follow Me'. As this work develops, there will be various opportunities for services to attend HCV training in the North East.

## 2) 'Drop in' testing days

Levels of testing in drug services across the region are already high (with some exceptions, detailed in point 3), but it was considered that a further increase could be achieved in order



to drive up the numbers of individuals diagnosed and referred for treatment, and support the ODN in meeting its treatment run rate for 2017/18.

Participants felt that testing had to be both opportunistic (i.e. offered at specific points at which a key worker or other professional thinks that a client may be at risk) as well as routine (i.e. offered on a rolling basis, ensuring that the offer of a test was continuous and that individuals were re-tested at regular periods).

One innovative idea was for drug services to stage 'drop in' testing days that could be publicised in advance and used to engage and re-engage service users in testing. At these sessions, drug services (possibly supported by the ODN hub) would make additional staff available to offer testing, meaning that service users were not required to wait to receive a test (something that can often lead to them disengaging with the offer of a test). Peer educators could also be present to engage in conversations with service users about transmission risks, prevention, and treatment. It was felt that, as well as increasing the numbers of people tested, these days would also offer an excellent opportunity to disseminate key messages among at-risk groups.

**Action: Drug services to offer 'drop in' testing days**

**Owner of action: Local drug services (supported by the ODN hub)**

### **3) Supporting drug services to test for hepatitis C**

While, as outlined above, there are a number of examples of good practice across the region in terms of testing in drug services, participants flagged that in some areas (such as Sunderland) no DBS testing is currently being undertaken in any drug and alcohol services.

This was viewed to be of significant concern, and something that required urgent action particularly given the need to ensure equality of access to care across the region and the need to ensure sufficient numbers of people are being referred for treatment. It was felt that engagement with commissioners was required, given that these drug and alcohol services should be mandated to carry out testing.

It was also agreed by participants that more could be done to ensure that hepatitis C testing was offered on a continual basis, rather than a one-off offer when a service user initially engages with a drug service. To facilitate this, it was suggested that the offer of a hepatitis C test is linked to Treatment Outcome Profiles, which are a set of questions that key workers ask their clients every three months. These questions tend to focus on drug taking behaviours, crime and home-life issues, but also include a focus on health and wellbeing; a focus that could and should, it was felt, include the offer of a hepatitis C test.

**Action: Engage with commissioners regarding ongoing absence of testing in some services**

**Owner of action: The Hepatitis C Trust and Newcastle upon Tyne Hospitals NHS Foundation Trust**

**Action: Include hepatitis C testing within Treatment Outcome Profiles**

**Owner of action: Local drug services**

### **4) Tracking those lost to follow-up**

One of the most significant challenges faced by the ODN, in common with all other ODNs across England, is re-engaging those individuals who have previously been diagnosed but who have disengaged with the care pathway and have therefore been lost to follow-up. Participants felt the need to re-engage with these individuals was made ever more urgent by the fact that the longer they remain disengaged from care, the more likely they are to develop serious liver disease.

Participants stated that the data is already available that would allow an exercise to be undertaken to identify these individuals and contact them in an effort to re-engage them in the treatment pathway. However, this exercise was considered to be a labour-intensive one that may require additional resources to be made available to the ODN by the NHS Trust, for example funding for a 0.5 FTE healthcare assistant role.

**Action: Undertake exercise to identify and engage those patients 'lost to follow up'**

**Owner of action: ODN hub and Newcastle Upon Tyne Hospitals NHS Trust**

## **5) Peer-based interventions**

Following Stuart Smith's overview of the kind of peer-based interventions facilitated by The Hepatitis C Trust, participants agreed that the provision of such interventions in the region would be of huge value, particularly in terms of engaging individuals in the care pathway and ensuring that they stayed engaged.

Of particular interest was a peer education programme that could be embedded in drug services across the region, and that could act as a vital way of improving awareness of hepatitis C among people who inject drugs; motivating people to access testing; motivating people to access specialist care, and improving understanding of hepatitis C among staff at drug services. Such a programme would involve the training of peers to provide talks in drug services about their experiences of hepatitis C; talks that could be followed by the offer of a test.

**Action: Establishment of regional peer education programme**

**Owner of action: The Hepatitis C Trust (supported by Changing Lives)**

## **6) Access to Fibroscan**

Participants identified issues around the time that patients often have to wait to access Fibroscans, which can lead to patients becoming disengaged from the care pathway. There was agreement that there existed a need to make Fibroscans more accessible, in particular by ensuring that community-based Fibroscanning was available.

**Action: Increased use of Fibroscan/portable Fibroscan in the community**

**Owner of action: ODN hub**