LONDON JOINT WORKING GROUP ON SUBSTANCE USE + HEPATITIS C

Overview of the London Joint Working Group on Substance Use and Hepatitis C Annual Conference

3 December 2018, London Guildhall

SEVEN YEARS TO HCV ELIMINATION: THE ROAD TO 2025

A summary report including key points from the workshops

Full speaker slides and videos are available at www.ljwg.org.uk/events

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1. Key themes from the day

The London Joint Working Group on Substance Use and Hepatitis C (LJWG) 2018 conference brought together more than 250 hepatologists, specialist nurses, commissioners, public health experts, drugs service staff, patient representatives, peer support workers and pharmacists from across London to discuss what more needs to be done across services in order to reach the shared goal of eliminating hepatitis C in the capital by 2025.

The key themes from the plenary speakers were:

Proactive case finding needs to be prioritised

- There are estimated to be around 100,000 people in England who have hepatitis C and need to be treated
- In 2016, London accounted for over a third (36%) of new laboratory confirmed HCV reports in England.
- It is estimated that almost two-thirds of people who inject drugs (PWID) in London had hepatitis C (63%) infection in 2016 and that 34% of PWID are unaware of their infection.
- PHE have launched a patient re-engagement exercise that aims to re-engage patients already diagnosed but lost to follow-up through their GPs
- Testing should be easy, normalised and regular re-testing should be encouraged for those at risk
- Proactive case finding interventions for PWIDs are cost effective

We need increased awareness in communities that there is now an interferon-free cure for hepatitis C

- The national SVR rate is 95.16%
- Phase 1 of the LJWG pharmacy HCV testing showed that 57% of clients did not know that hepatitis C treatment was now interferon-free
- There is a positive message on hepatitis C that needs to be promoted across all at-risk communities. This has not yet been achieved.

Treatment needs to be easily accessible in the community as well as in hospitals

- All ODNs have out-reach into drug services and therapy outside hospitals is growing
- Treatment availability in prison is patchy and poor in many areas
- Peer support can be critical in encouraging people to get tested, and then to go on to get treated
- There are still barriers than need to be overcome in order to enable people to access treatment in community pharmacies.

2. Workshop summary: What more needs to happen in drugs services

Chaired by LJWG co-chair Dr Emily Finch, this workshop began with introductory remarks from an expert panel: Jackie Howe, Regional Hepatitis C Coordinator, CGL; Helen Hampton, Lead Clinical Nurse for BBVs, Addaction; John Jolly, Chief Executive, Blenheim CDP; and Stuart Smith, Director of Community Services, The Hepatitis C Trust.

Following this, attendees split into group to discuss the current situation and what needs to happen in three areas: awareness & engagement; increasing testing; and increasing treatment.

A common theme of attendees' assessment of the current situation was the broader challenges facing drug services, with financial and staffing cuts affecting services' capacity to take action on hepatitis C. It was reported that time constraints are affecting the amount of awareness-raising and testing activity taking place in some services. The disruptive impact of re-tendering of service contracts was also raised in both workshops, with data often being lost and time consumed by the process.

Stigma was highlighted as still being an issue that prevented some clients coming forward for testing. It was also said that testing in drug services is often dependent on the personal commitment of individual staff members, rather than being an integral part of the whole service. Some delegates felt that there were insufficient links between drug services and secondary care treatment services, which caused issues with referring clients for treatment.

However, there were examples of good practice in drug services that were highlighted by participants. Some services operate in-house treatment clinics, offering a 'one stop shop' treatment service. Good practice in supporting clients to engage with treatment was also shared, with some services providing vouchers and other incentives to support engagement and many using peers to provide support.

A number of common themes also emerged in relation to what drug services can do to improve their approach to hepatitis C. **Increasing the availability of peer support** was repeatedly highlighted as a measure that would deliver improvements in client awareness of hepatitis C and engagement with testing and treatment. **Regular staff training** was also felt to be essential, with some staff members not confident in delivering messaging and/or testing for hepatitis C. Another point raised by participants was the need for **consistent hepatitis C-related Key Performance Indicators (KPIs) for staff** across all services, rather than them being dependent on the individual commissioner.

Specific measures cited to improve drug services' approach to testing included the introduction of **'opt-out' testing** in drug services, **better guidance for service staff** on delivering testing and the introduction of **incentives** for clients to refer friends and associates for testing (to assist with 'network tracing'). It was also felt that **all clients should be offered hepatitis C testing and re-testing**, rather than the current approach in some services, whereby only those deemed 'high risk' are offered a test.

Participants also identified measures that would support drug services to increase treatment rates, including **appointing more specialist nurses**, securing the 'buy in' of service managers and commissioners and developing better links with other services, such as needle exchanges, to deliver treatment. The need to tailor treatment services to clients' needs was also highlighted (with different treatment settings better suited to different clients). More widespread availability of pan-genotypic treatments was also identified as a positive prospect, with consequent reductions in the number of appointments needed.

3. Workshop summary: What more needs to happen in pharmacies

Chaired by LJWG co-chair Dr Suman Verma, this workshop focused on challenges and solutions to tackling hepatitis C in a pharmacy setting. Attendees heard from speakers who made the case for expanding hepatitis C case-finding and testing in pharmacies, as well as highlighting best practice and improving data-sharing.

Dr Zoe Ward of the University of Bristol presented on several studies evaluating the cost-effectiveness of case-finding initiatives in the community, all of which were proven to be cost-effective, and would even become cost-saving as the cost of hepatitis C drugs declines. Most of these included some form of one-stop hepatitis C service in the community, whether in a drug treatment centre or on a mobile van, which aimed to minimise the number of appointments for patients and facilitate the smoothest and quickest possible care pathway. The presentation made the case for increased community case-finding interventions and demonstrated that many such interventions have been **proven to improve quality of life, avert deaths, and save money**.

Rekha Shah from the Kensington, Chelsea and Westminster Local Pharmaceutical Committee made the case for why testing in pharmacies makes sense, highlighting that community pharmacies which provide a needle exchange service already have direct access to the highest-risk population for hepatitis C who might not be in touch with other health services. People who inject drugs face many barriers to accessing testing and treatment, often including complex needs, sometimes having no stable home. Needle exchange pharmacy teams offer an opportunity for regular contact with these patients, and **pharmacy staff often have a pre-existing positive rapport with regular clients.** This also provides opportunities to provide educational interventions regarding safe injecting practices and re-infection.

Michael O'Sullivan, who administers hepatitis C tests in a Brixton pharmacy, presented a practical best practice guide to pharmacy testing. He noted challenges to getting clients to accept a hepatitis C test, including exacerbating stigma, difficulty in getting hold of clients, low awareness of new treatments and fear of interferon treatments, and non-English speaking clients. He also mentioned some **interventions which have produced positive results in encouraging testing in a pharmacy setting,** including cash or voucher incentives, pamphlets for non-English speakers, and persevering with friendly and engaging personal contact.

Pritpal Thind from Sonar Informatics presented an example of how data from pharmacy HCV testing – hopefully soon to be treatment as well - can be **linked across health services to ensure appropriate delivery, follow-up, tracking, and monitoring.**

Participants then discussed challenges and potential solutions to awareness-raising, testing, and treatment in pharmacies within small groups. Key points raised included:

- Pharmacies are a good place to raise awareness about hepatitis C, transmission routes, testing and new treatments, but awareness-raising advertising, including the availability of testing could be improved
- Fear of old interferon treatments continues, there is a need to persistently spread the message about new treatments
- There are differing opinions on whether testing should be limited to only pharmacies which also have a needle exchange service, or whether testing could be mainstreamed to all pharmacies
- Securing funding for a new pharmacy-based service can be a challenge. There was an expressed desire for instant testing facilities like Cepheid.
- Participants expressed a desire for greater partnership working with Local Authorities and Local Pharmacy Committees, but an acknowledgment that this can be challenging due to resource pressures
- Regulatory challenges that are currently preventing pharmacies from delivering treatment must be addressed urgently at a policy level.

4. Workshop summary: What more needs to happen in prisons

Chaired by Sean Cox from The Hepatitis C Trust, the expert panel gave introductory remarks to stimulate group discussion on what more needs to be done to increase testing and treatment in prisons.

Professor Peter Vickerman, Bristol University:

- Given that 72% of people who have ever injected drugs have been incarcerated and over 32% within the last year, prison can be a good place for case finding.
- New economic analysis suggests that it is **now cost effective to treat in prisons**. In 2012 it wasn't cost effective due to uptake of treatment was low, and treatment took longer to deliver. Now treatment is likely to be cost effective, however the **cascade of care is important**.

Janet Catt, Nurse Consultant, Kings College Hospital:

- Kings was one of the last hospitals to go into local prisons but now goes into 4 prisons and 75 patients started treatment so far this year.
- Treatment should be led within the prison and hopefully soon a protocol for **starting treatment on the same day as the test, or within 24 hours will be possible.** Having a streamlined pathway shared pathway in all prisons would help movement in this direction.
- **Engaging with probation services is vital** – the prisoners Kings' work with get released with medication but some are released before this can happen.

Dr Mike Kelleher, Consultant Psychiatrist, Lambeth Drug and Alcohol Service:

- **Supporting prisoners on release is very important.** Prisoners have to attend a large number of appointments on the day they are released, making attending appointment regarding hepatitis C treatment/prescriptions difficult. Work needs to be done to make this transition more effective e.g. being able to leave prison with a prescription rather than having to pick it up.
- **Peer work has been crucial** to the success of prison testing and treatment.
- It is important to take the service to the patient – where **clinics have been held on the wings** rather than in healthcare they can be better attended as they do not need guards to accompany prisoners to healthcare.

Adrian Perks, Health and Justice Clinical Programme Manager, NHS England:

- Variable picture on the ground but **there is excellent practice that needs to be shared**.
- Workforce issue pose problems – prisons are finding it very difficult to recruit and retain staff at the moment.
- The work of peers in supporting prisoners through testing and treatment is very valuable.
- There has been an **evidenced based script produced for optimal results in achieving acceptance of testing** - – has been distributed to regional commissioners who are happy to send it out if people contact him (email address in slide deck).

The following key issues were raised through the group discussion and feedback:

- Good practice in this area is less to do with geography or prison category and almost entirely down to **passionate and committed individuals making it work**.
- Differences in how treatment is delivered were uncovered with connections made between delegates to follow up and streamline treatment delivery- it was highlighted how training on working with the new drugs is vital for consultants, nurses and other healthcare staff.

- It was agreed by many attendees that there are still a number of barriers to patients agreeing to a test – for instance a belief that the regime is still the same as the previous drugs and therefore would be difficult to undergo, rather than the daily pill that is now available; or, linked to the difficulties of older drug regimes, or an experience of having been tested positive before but not being started on treatment. **Education about the new treatments would help.**
- **Stigma** was also mentioned as a barrier to testing, particularly from prison guards. Awareness training of hepatitis C and what the transmission routes actually are for all staff within the prison is needed. Sean Cox mentioned that The Hepatitis C Trust is developing training for prison guards which could be delivered in a short space of time if necessary.
- The **importance of how the offer of a test is made** was mentioned several times, in particular how to optimise that contact to encourage people to accept a test. Adrian Perks encouraged people to get in touch to obtain the 'evidence-based testing offer' script. It was also mentioned that the length of the form to fill in on refusing a test may be encouraging people to accept the test.

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5. Workshop summary: What more needs to happen to find the undiagnosed who are not in touch with services

Chaired by Charles Gore, former CEO of The Hepatitis C Trust, the expert panel gave introductory remarks to stimulate group discussion on potential tools and messages to raise awareness amongst people who have been at risk in the past, or are currently at risk, but are not in touch with drugs services.

David Mackintosh, Policy Director at the London Drug and Alcohol Policy Forum gave an overview of approaches used in different countries to raise awareness of hepatitis C, such as:

- The CDC recommendation in America that people born between 1945 and 1965 are tested for hepatitis C.
- Ukraine's 'Know It, Test It, Treat It' campaign
- Australia's 'Live hepatitis C free' campaign

Kate Pogson, Head of Health from MHP gave an overview of what research and studies can tell us about how people make choices about their health and what influences them. This includes people being influenced by **social norms;** people being more likely to take action if the **message is delivered by someone similar to them**; people are more likely to take action for positive reasons and rewards rather than fear; and people value choices they make themselves rather than that are selected for them.

Diarmaid Crean, Digital Deputy Director at Public Health England, described **digital hyper-marketing techniques** that are used by businesses to target potential customers, and how these can be used to help support people at risk of mental health conditions, or other health issues. He explained how anonymized digital footprints that people have from their social media posts and browsing can give useful information to health campaigns so that **messages that an individual receives online will be relevant and will resonate.**

Fraser Woodward, Head of Communications, Engagement and Partnerships, Specialised Commissioning at NHS England described the government processes to get approval for **public awareness health campaigns** and the value of running **pilots that can be evaluated** in order to make the case for a wide-reaching campaign. Fraser emphasized the importance of working with **service users to develop campaigns**.

Groups of delegates then discussed what is needed to raise awareness with, and encourage testing amongst, people who have been at risk of contracting hepatitis C in the past (maybe a very long time ago), or who are at-risk now but not in touch with services. Suggestions included:

For people at risk now but not in touch with services:

- Testing vans and opportunistic testing in pharmacies
- Train outreach workers to offer testing in hostels and soup kitchens
- 'Bring a friend along' incentives
- More peer educators
- Destigmatise and normalise testing
- Skill up GPs so they are more aware
- Ensure pathways are clear and easy and in the community so people can start treatment soon
- Clear awareness messages – there is an interferon-free cure
- Hyper-targeted digital advertising

For people who were at risk many years ago and are not in touch with services:

- Hyper targeted digital campaigns
- Positive messaging around a new cure
- Awareness posters and info in GP surgeries; potentially test all new registrations
- Tag to other tests and screens, e.g. pilot adding to health checks
- Destigmatise and normalise testing
- Consider screening people born between 1945 and 1965 (like USA)