

*Measuring the impact of
the recommendations of
the London Joint Working
Group on Substance
Use and Hepatitis C –
learning from the pilots*

Overview

The aim of the London Joint Working Group on Substance Use and Hepatitis C (LJWG) Pilot Project was to assess the impact of the LJWG's recommendations on improving care pathways in hepatitis C. The intention was to measure the number of people being tested for blood-borne viruses (BBV), along with rates of diagnosis and onward referral for specialist assessment. The findings highlight the fact that the current infrastructure is not set up in a way that supports measuring improvements in the provision of integrated care for people with hepatitis C and a history of using drugs. The participants in the pilot sites found it very onerous to collect the data on top of the routine data sets that are currently required by Public Health England (PHE) and commissioners. In anticipation of NHS England's Hepatitis C Improvement Framework later this year, more needs to be done to ensure that the right data is being collected routinely in order to assess improvements in care provision for this vulnerable cohort. Data collection needs to be made easy for teams to do in the course of normal practice.

Aim

In 2011 the LJWG published *Tackling the Problem of Hepatitis C, Substance Misuse and Health Inequalities: a Consensus for London*. The document set out a number of recommendations to improve the integration of services in London for people with hepatitis C and a history of using drugs. In 2013 the group aimed to assess the impact of its recommendations by setting up a pilot project in four London boroughs. By establishing goals and enabling the pilot teams to set out their own plans to achieve them, it was hoped that it would be possible to identify specific measures that most effectively led to increased rates of testing and referral, as well as identifying gaps and blocks in the care pathway.

Objectives

The pilot project was designed to align with the aims of the Policy Outcomes Framework for the NHS and Drug Services. The outcomes to be measured were:

1. Improved rates of access to assessment for hepatitis C treatment for people who have a history of drug use
2. Clear patient pathways (informed by best practice) in place
3. Improved workforce and service user awareness of hepatitis C and the patient pathway
4. Development of patient-focused services

Commissioners and providers of drug treatment and specialist hepatitis treatment services should note that the LJWG had no additional funding to run this project. The LJWG Pilot Project Team was able to identify existing resource – e.g. training and testing – that could be provided to support the pilot sites.

Site selection process

The LJWG Pilot Project Team presented to the Joint Commissioning Meeting for London, hosted by the National Treatment Agency, in November 2012. A project outline, inviting expressions of interest, was circulated to all London Commissioners. The outline included the following supporting documentation:

1. LJWG pilot outcomes document¹ - to enable commissioners to assess their ability to provide the necessary data
2. The LJWG pilot offering (see fig 1 below): a set of resources to support the pilot sites
3. An example of local borough prevalence data, provided by a tool offered by Roche Products Ltd.
4. Patient information leaflet: '5 Things you need to know about hepatitis C' – and example of best practice from Lambeth
5. Details of a project that had helped improve rates of attendance for appointments in general practice
6. An example of a stakeholder mapping process
7. A leaflet about The Hepatitis C Trust testing van and pharmacy training service.

Seven expressions of interest were received by the LJWG Scientific Steering Committee. Five boroughs were chosen; one subsequently withdrew, as they considered the data collation aspect of the project to be too onerous.

Pilot project process

Croydon, Haringey, Islington and Lambeth started the pilot in early 2013. The LJWG Pilot Project Team aimed to have the project

¹ Appendix 1

completed by mid-year, and present preliminary outcomes at an LJWG conference in September 2013, where the practical next steps would also be explored.

The borough teams participating in the pilot project selected different elements of the support offering and the Pilot Project Manager arranged for them to access the resources they requested. All offerings were considered but some (e.g. The Hepatitis C Trust testing van) were taken up more than others.

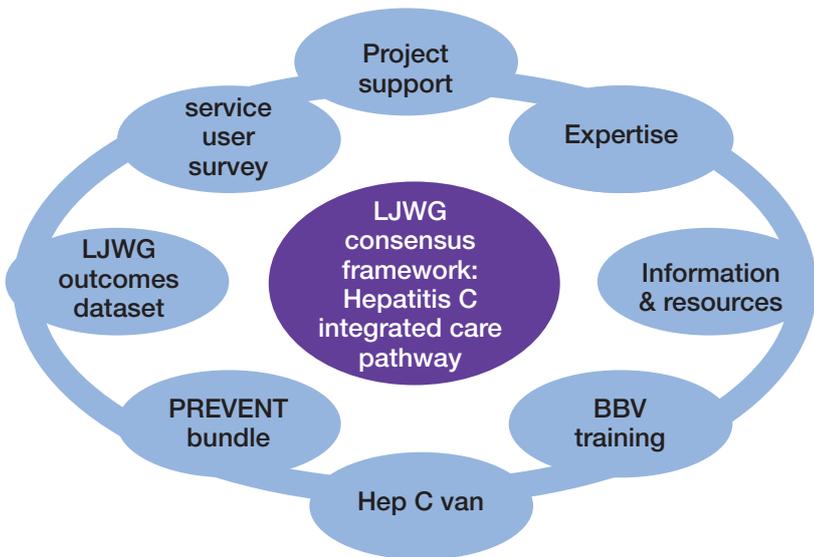


Fig 1. Elements of Support offered to LJWG Pilot Sites

The lead in each pilot area – usually the BBV nurse in the drug treatment service – was asked to collect data on the indicators set out in Table 1.

Indicator (output)
<ol style="list-style-type: none"> 1. Number of antibody tests offered 2. Number of antibody tests performed 3. Number of HCV-RNA tests offered 4. Number of HCV-RNA tests performed 5. Number of positive results 6. Number referred for specialist assessment 7. Number attending specialist care for assessment 8. Number of suitable patients offered treatment 9. Number of patients starting treatment 10. Proportion of patients taking opiate replacement treatment (ORT) referred to specialist assessment
<ol style="list-style-type: none"> 1. Easily identified pathway for hepatitis C treatment from testing to treatment in place in the pilot area 2. Evidence that the pathway is aligned to best practice models 3. Data is captured at each stage in the pathway
<ol style="list-style-type: none"> 1. Number of staff in the treatment pathway who have received relevant training (e.g. local specialist care training; Hepatitis C Trust training; RCGP Certificate in Detection, Diagnosis and Management of Hepatitis B and C in primary care; or an equivalent current qualification from Hep C Trust) 2. Number of service users and workforce displaying awareness of hepatitis C
<ol style="list-style-type: none"> 1. Number of service users from the drug treatment, screening & assessment services included in a satisfaction survey 2. Recorded levels of service user satisfaction e.g. staff engagement, access to specialist services. 3. Inclusion of a service user representative in pilot planning group

Table 1. Pilot indicators

Early on in the project it became apparent that not all services were routinely collecting the data fields requested, and that the additional workload of double data entry would be unfeasible for staff to manage on top of their existing duties.

Results from Islington for Q1 2013 are summarised in Table 2.

Pathway & outcome findings : Islington (Q1)

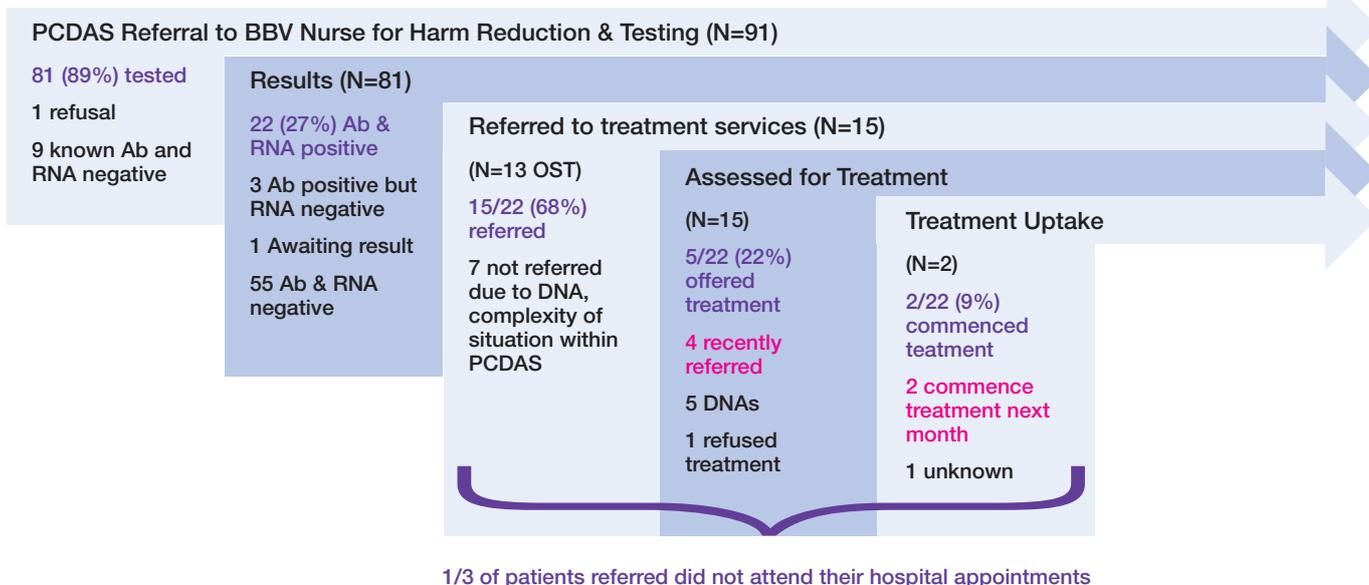


Table 2. Pathway and outcome findings from Islington.

Discussion

The LWJG had hoped to replicate this level of data in all four sites. Levels varied, however, and the sites fed back that they experienced a number of challenges in collecting the information. The pilot sites were all at different stages in the development of a local pathway from testing to treatment as summarised in the table below.

	Croydon	Haringey	Islington	Lambeth
Pathway	In development	Informal pathway	Informal pathway	Formal pathway

Table 3. Pathway development stages in pilot sites

Not all the sites had the infrastructure to be able to collect this data routinely and this highlighted an important gap in the system with serious implications for service improvement. Existing service reports do not routinely capture the number of people tested for BBVs, diagnosed with hepatitis C, referred to specialist care, or started on treatment.

If basic data is not easily available, clearly the quality of services cannot be assessed and improved. It is widely acknowledged that more needs to be done to increase the number of people who are at risk of having hepatitis C that are tested, diagnosed and referred for assessment by specialists. If services are not able to easily monitor numbers then it will be impossible to measure the effectiveness of policy implementation and service interventions.

Another barrier identified was a lack of clarity on the sharing of patient-identifiable data between the different services that patients may access along the pathway, such as community drug and alcohol services, primary care, mental health, hospitals and outreach services.

LJWG is conducting a project in 2015-16 to research and identify the key barriers to effective data collection in two boroughs in London.

Other outcomes

During the project, the Deputy Mayor of London, Councillor Victoria Borwick, accepted an invitation to visit two of the pilot sites. Not only did this help to raise awareness, but the Deputy Mayor subsequently became a strong advocate and has supported the LJWG by participating in two conferences and an international symposium.

“Many Londoners are not receiving the services and treatment they deserve and need to beat hepatitis C. Health and Wellbeing Boards, Clinical Commissioning Groups and service providers can, and must, work together more effectively to deliver better outcomes for individuals, their families and all our communities” Councillor Victoria Borwick, Deputy Mayor of London

Following the LJWG pilot project, the Islington team made changes to smooth the patient pathway and make their outreach clinic more accessible to patients. The hepatitis C outreach clinic is now scheduled to coincide with the drug clinic so that service users collecting prescriptions can access hepatitis C treatment services at the same time.

Changes have been made to laboratory services so that all hepatitis C antibody positive samples are tested for RNA at the same time to reduce the number of steps to diagnosis. The next aim is for the laboratory to also identify the genotype.

Previously, all patients were routinely seen by a hepatology consultant before starting treatment. New arrangements mean that all cases are reviewed by the multi-disciplinary team (MDT) and non-complex patients can be treated in the outreach clinic by the nurse specialist.

A mobile testing unit was provided by The Hepatitis C Trust. The van was staffed by one outreach worker from the Hepatitis C Trust, with or without support from local staff. This offering was taken up by three of the four pilot sites, suggesting that help with additional testing is perceived as a need by drug treatment services in London.

The van carried out six visits to five sites and offered testing to a diverse range of service users. The data collected from each visit provides useful insights to inform future projects.

DATE	PCT	LOCATION	TOTAL HOURS	SERVICE TYPE	CLIENT GROUP	SERVICE USERS	EXPEGETED NUMBER OF TESTS	TESTING ON SITE	INCENTIVES USED	PROMOTIONS USED	TOTAL TESTS OFFERED	TOTAL TESTS DONE	+VE TESTS
14/05/13	Croydon	Lantern Hill	5.5	Drug service	Drug users	150	15-30	YES	NO	YES	21	11	3
15/05/13	Croydon	Palmer House YMCA	3.5	Hostel	Homeless complex needs	40	10	NO	NO	YES	10	6	0
15/05/13	Croydon	PLUG	2.0	Gathering place	Ex-drug users	30	10	NO	NO	YES	7	7	0
21/05/13	Islington	Cranstoun City Roads	3.0	Detox	Drug users	18	18	NO	NO	YES	9	3	1
22/05/13	Haringey	DASH, St Anne's Hospital (Day 1)	5.5	Drug service	Drug users	400	15-20	YES	YES	YES	20	14	2
23/05/13	Haringey	DASH, St Anne's Hospital (Day 1)	5.0	Drug service	Drug users	400	15-20	YES	YES	YES	13	10	4

Table 4. Data from van visits

Different methods were used to encourage attendance; activities that worked particularly well were posters, and positive encouragement from the local BBV nurses and other staff. Where staff awareness was high and there was good signposting, the van had higher usage. The key lessons from the six visits included:

- The van provides an opportunity to reach ‘hard-to-reach’ communities of hard-core drinkers and clients who may be suspicious of healthcare services

- Testing provision by the van on two consecutive days enabled word-of-mouth recommendation by clients, boosting attendance on the second day
- The use of supermarket vouchers encouraged clients to attend

Achievements, identified by the mobile testing unit staff, were:

- Enthusiasm from the van and site staff
- Clients wanted to engage with the van staff
- Identifying positive cases and engaging clients who had been lost to follow up
- Giving a negative result to a client who assumed he was positive as he lived with someone who has hepatitis C

Opportunities to reach even more clients were identified. For example, there was a need for services to share information about events and meetings that clients were likely to attend. One visit coincided with a Narcotics Anonymous meeting, which, had they known about it, might have provided an opportunity for the mobile unit staff member to talk to the group about BBV testing and harm reduction.

BBV training

During the Pilot, BBV training for keyworkers and drug service staff was provided by Addaction and The Hepatitis C Trust. This offering was taken up by all four localities and 72 members of service staff were trained in total. Feedback was very positive and attendees reported having increased confidence about their knowledge of hepatitis C and how to engage with and support service users. Clearly, if key workers lack knowledge and confidence they are less likely to initiate a conversation about hepatitis C.

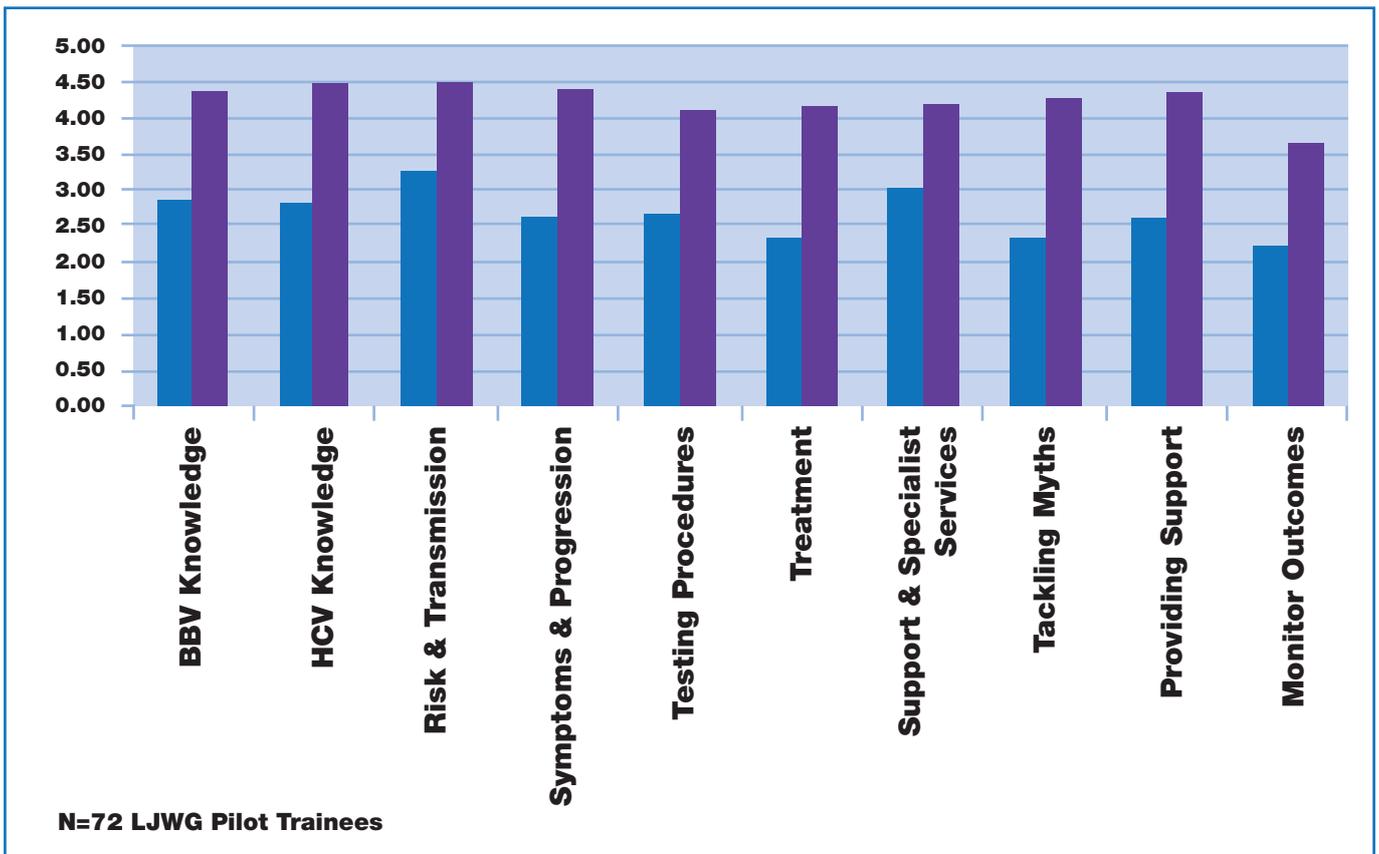


Table 5. Levels of awareness before and after training

Opiate substitution

The role of opiate substitution therapy (OST) in helping people to manage antiviral treatment has been observed and reported anecdotally. During the pilot, the Lambeth team collected data on OST in patients undergoing hepatitis C treatment, and provided the information below as an example. This template could be used to track the impact of OST prescribing on outcomes, and

provides another example of the sort of data fields commissioners and providers might consider when developing their data sets to inform treatment and service provision.

Treatment Status	Opiate Substitute	Response/Reason for discontinuation
12 patients on treatment	7 on methadone 1 on Suboxone 3 on diamorphine and methadone (RIOTT) 1 on no substitutes	
5 patients completed treatment	3 on methadone	1 sustained virological response (SVR) 1 responder relapser 1 SVR 12
	1 on Suboxone	Awaiting outcome
	1 on no substitutes	Awaiting outcome
4 early discontinuations	1 on diamorphine and methadone	SVR 12
	1 on diamorphine and methadone	Stopped after one week due to bereavement
	1 on methadone	Stopped after 2 months drinking/disengaged
	1 on no substitutes	Stopped after 12 weeks due to poor tolerance

Conclusions

Figures from Public Health England suggest that only around 3% of people with hepatitis C are treated². Models have demonstrated that a combination of new treatments and a significant increase in numbers treated could have a dramatic impact on the prevalence of the disease, effectively eliminating it as a public health issue³. More needs to be done to identify people with hepatitis C. As many of these people are engaged with drug treatment services, these provide an important contact point for people to be offered testing and access to treatment pathways.

Changes can be made to services that require minimal additional funding, which will have a significant impact, for example changing the time of the clinic, or up-skilling the staff through training sessions on blood borne viruses and harm reduction.

Pilot feedback supports the need for better understanding of funding streams in the new commissioning environment, as there can be a lack of clarity, which makes it difficult to effect improvements.

There is a clear need for relevant data to be routinely captured, for example, via the National Drug Treatment Monitoring System (NDTMS), to enable decision makers to assess future service provision needs.

Strategic leadership needs to be provided in London to direct a co-ordinated approach to monitoring and improving hepatitis C care pathways for people with a history of drug use.

² Public Health England 2014. *Hepatitis C in the UK: 2014 report*

³ Dore et al 2014. *Hepatitis C disease burden and strategies to manage the burden. Journal of Viral Hepatitis 21 (S1): 1-4*

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Appendix 1

Outcome	Indicator (output)	Objective (target)
<p>1. Improved rates of access to antiviral (HCV) assessment and treatment for people who have a history of drug use.</p>	<p>1. Number of antibody tests offered 2. Number of antibody tests performed 3. Number of HCV-RNA tests offered 4. Number of HCV-RNA tests performed 5. Number of positive results 6. Number referred for specialist assessment. -Local pilot areas to agree how the investigation of liver damage and the assessment of this will be measured with the local hepatologist. 7. Number attending specialist care for assessment 8. Number of suitable patients offered treatment 9. Number of patients starting treatment 10. Proportion of patients taking opiate replacement treatment (ORT) referred to specialist assessment</p> <p>1. Easily identified pathway for hepatitis C treatment from testing to treatment in place in the pilot area 2. Evidence that the pathway is aligned to best practice models 3. Data is captured at each stage in the pathway</p> <p>1. Number of staff in the treatment pathway who have received relevant training (e.g. Examples of training are: local specialist care training, Hepatitis C Trust training, RCGP Certificate in Detection , Diagnosis and Management of Hepatitis B and C in primary care, or an equivalent current qualification from Hep C Trust) - Generic harm reduction - Basic training to increase confidence when working with service users - Understanding the testing process - The pathway from testing to hospital - Dispelling myths to improve attendance at secondary care treatment centres 2. Number of service users and workforce displaying awareness of hep C</p> <p>1. Number of service users from the drug treatment, screening & assessment services included in a satisfaction survey 2. Recorded levels of service user satisfaction e.g. staff engagement, access to specialist services. 3. Inclusion of a service user representative in pilot planning group</p>	<p>1. 100% of relevant service users offered antibody 2. 90% of service users are tested: unless a) already tested in the last 6 months, or b) already known to have hepatitis C (HCV RNA +ve) 3. 100% of HCV antibody-positive patients offered HCV-RNA test 4. 90% of this population have HCV-RNA test performed 5. 100% recording of HCV-RNA results (to ensure data quality) 6. Every HCV-RNA positive patient should be referred for specialist assessment (NB: If assessment centres are not within the drug treatment services, support to should be provided if needed. This could include: transport, key worker accompanying the service user to the specialist assessment, phone calls and texts. A record should be kept of how service users are being encouraged to attend.) 7. 70% attendance and 100% reason for non-attendance recorded. (Clarify where the treatment assessment is held) 8. 100% of patients HCV-RNA positive patients to be offered hepatitis C treatment. 9. 100% of those who are assessed to be given informed choice so they can choose whether to receive treatment or not. (Local agreements to be put in place with hepatologist on how liver fibrosis/ damage should be assessed). 100% of appropriate patients have the extent of their liver fibrosis/damage assessed and recorded. 10. 100% of patients on ORT who are referred to specialist care for hepatitis C assessment have a recording of ORT review or adjustment</p> <p>1. 100% of areas have a documented hepatitis C treatment pathway for people with hepatitis C and a history of misusing drugs 2. 100% of areas have a best practice-based, clear patient pathway agreed by the LJWG 3. 100% of areas have a data collection at each stage in the pathway (testing, vaccination, results, referral, attendance)</p> <p>1. 100% of available staff trained, and the training documented</p> <p>2. Locally agreed proportion of service users who can name the '5 things to know'</p> <p>1. Locally agreed proportion of service users who complete the survey 2. 80% service user satisfaction 3. Every pilot site has service user representation</p>