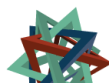




BVHG/BASL

Best Practice for ODN Stakeholders Meeting

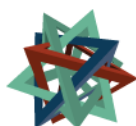


11–12 January 2018

The Britannia Country House Hotel,
Didsbury, Manchester

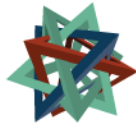
MEETING REPORT





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Foreword

The first BVHG and BASL Best Practice for ODN Stakeholders Meeting was held on the 10–11 January 2018 in Manchester. The meeting provided opportunity for stakeholders to explore the challenges faced by operational delivery networks (ODNs) since their establishment in 2015, and to share solutions and best practice examples to help achieve the goal of hepatitis C virus (HCV) elimination whilst meeting the requirements of NHS England (NHSE).

The meeting was attended by 121 individuals coming from each of the 22 ODNs across England, key stakeholder groups including patient advocacy groups (Hepatitis C Trust and Change, Grow, Live(CGL)), NHSE, and the pharmaceutical industry.

This report highlights the limitations of the current HCV treatment model, and provides suggestions on how it can be modified and improved. The report describes best practice examples for eliminating HCV for ODNs to take and adapt to work in their area. The intention is that this information will provide all ODNs with a framework to develop the 5-year plans needed to meet their CQUIN requirement, and importantly to also leave them well placed to deliver on the World Health Organisations goal of HCV elimination by 2030.

We have summarised beneath the key themes that emerged from the meeting.

Matthew Cramp

(BASL President and Peninsula ODN)

Ahmed Elsharkawy

(BVHG Chair and West Midlands ODN)

Steering Committee

Andy Ustianowski (Manchester ODN)

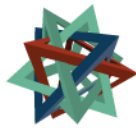
Adam Lawson (Nottingham ODN)

Sally Bufton (West Midlands ODN)

Adele Torkington (Manchester ODN)

Mark Wright (Wessex ODN)

Will Gelson (Eastern Hepatitis Network)



Key themes and recommendations

What to do with the data held by Public Health England on the identity of up to 45,000 individuals previously diagnosed with HCV infection but who are not currently engaged with treatment services was discussed. All representatives from patient groups, ODNs, and BASL/BVHG at the meeting expressed the unanimous view that these individuals should be contacted with information on their diagnosis and the curative treatment options now available. The benefits to infected individuals with this knowledge, when provided together with ready access to treatment, was unanimously agreed to significantly outweigh the concerns about information governance or confidentiality.

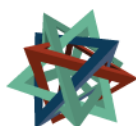
To facilitate treating greater numbers, and treatment in out-of-hospital settings, streamlining and simplification of on-treatment virological testing was strongly recommended – on the basis of the very high efficacy of current treatment options. There was consensus from all groups present that viral load testing should be mandated at baseline and at 12 weeks post-treatment only. Viral testing at other time points, based on clinical or adherence concerns, should be decided by the local treating team.

Streamlining and simplification of the ODN approval process for treatment was strongly recommended. This will shorten the patient journey from diagnosis to treatment. Routine treatment decisions should be devolved to local treating centres with full hub ODN MDT discussion reserved for complex cases. Removing the need for second ODN sign off for cases where the lowest acquisition cost treatment option is not appropriate was recommended.

The development of a unified tool to measure and monitor patient experience was welcomed by all present. The Hepatitis C Trust led by Charles Gore together with volunteers from the meeting delegates will share this with all ODNs once it is finalised (target date end of February 2018).

All present agreed that new treatment paradigms are needed for treatment outside hospitals. The news of the new NHSE tendering process to link drug procurement to case finding was welcomed as a way for ODNs to overcome the commissioning obstacles that hamper development of community treatment. A number of examples of successful treatment delivered in a variety of community settings were presented. All ODNs now need to devise simple and rapid pathways from diagnosis to treatment.

There was consensus among the delegates (but not the NHSE representatives present) that to achieve hepatitis C elimination, a national elimination plan needs to be formulated and implemented through national leadership.



Highlights and other recommendations

The majority of the challenges discussed were common across the ODNs, including meeting the Commissioning for Quality and Innovation (CQUIN) requirements, financial constraints, the current structure of hubs and spokes, engaging hard-to-reach populations, getting patients access to treatment, and the unwieldy bureaucracy of 'ODN buddying' and multi-disciplinary team (MDTs) approval. It was recognised that the fragmentation of the commissioning landscape along the HCV patient journey was a major barrier.

An insight was provided into the new tendering process for HCV medicines. Alongside the usual procurement process which aims to improve the cost of medicines, the pharmaceutical industry is being invited to work with NHS England (and potentially together) to identify and support solutions to increase case finding and achieve the HCV elimination target faster.

Best practice examples in HCV elimination efforts across England and Scotland were shared, including the 5 pillars of the Greater Manchester HCV elimination plan and integrated community models of care. It was clear that key learnings from the discussions and examples such as these can be adapted by ODNs based on local requirements.

Furthermore, PHE is working on a Caldicott Guardian process that will allow ODNs to receive information regarding the 45,000 individuals who have been diagnosed with HCV but were subsequently lost to follow-up. It is imperative that all stakeholders work together to ensure that these patients are found, re-engaged in services and treated. There was widespread support from the ODNs for this process (see above) and an agreement that nationally provided template letters to be sent to general practitioners (GPs) and patients would help reduce anxieties around the information governance compliance issues raised as part of this.

It was agreed that there needs to be a national map of hepatitis C services available to both healthcare professionals and patients.

Recommendations

Testing and treatment

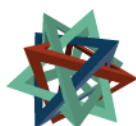
- Multi-agency collaboration to establish community testing and treatment for HCV should be encouraged by the ODNs and other stakeholders; if more patients can be identified, more patients can be treated and elimination achieved
- Testing for HCV should be increased and simplified through the use of near-patient testing (including novel point of care PCR and antigen testing technologies), use of dry blood spot testing (DBST), self-testing kits, and the use of incentivisation schemes to increase case finding
- NHSE should explore reducing community pharmacy restrictions to allow dispensing and supervision of high-cost hepatitis C treatments where many marginalised patients access their healthcare currently

Education, communication and engagement

- ODNs should increase the level of peer support available in their locality and consider patient incentivisation to increase the number of patients linking to care and completing therapy
- A named PHE representative should be assigned to each ODN to collaborate on HCV elimination activities
- Through local and national programmes, ODNs, PHE, the Hepatitis C Trust and NHSE should aim to educate all stakeholders in order to remove stigma and debunk myths about HCV and treatments
- A 'Clear and Cure' national campaign to increase HCV awareness, reduce stigma and increase testing should be actively explored by BVHG, the Hepatitis C Trust and appropriate stakeholders
- BVHG, BASL and NHSE should consider increasing networking opportunities amongst the multidisciplinary ODN team members through similar events such as this one

Management and administration

- NHSE is strongly urged to re-evaluate the CQUIN model especially in the light of the new proposed procurement model and the reduction in drug costs. The current model is sub-optimal for achieving elimination goals
- Collaboration among ODNs should occur to provide a comprehensive map of services freely available to all, to make hepatitis C services easier to locate
- ODN hub sites need to review their processes for allowing greater independence to appropriately staffed and experienced partner sites



Appendix 1: Summary of presentations from day 1

Background: State of the nation

Graham Foster

In the last few years, considerable progress has been made in the treatment of HCV in England as a result of the efforts of key stakeholders, including ODNs. However, in order to meet the WHO-endorsed Global Health Sector Strategy (GHSS) target for the elimination of hepatitis C as a public health threat by 2030 (reducing new infections by 90% and mortality by 65%), more work needs to be done.

Presently, there are several areas where improvements need to be implemented to allow progress in the drive for HCV elimination. Information sharing is important for progress; this encompasses data which is critical to eliminating HCV. Knowledge of who the patients are and where resources are needed is crucial and the Hepatitis C Registry data will be key to moving forward. Approval has been received from every Trust in England, and a website containing the Hepatitis C Registry information is currently in development. It is anticipated that the website will go live during Q1 2018. The Hepatitis C Registry data will provide information on the number of HCV patients, as well as providing insight on the efficacy of HCV treatments. PHE are working on a Caldicott Guardian process that will allow ODNs to receive information regarding the 45,000 individuals on their database who have been diagnosed with HCV but subsequently lost to follow-up. It is hoped that this information will be released in Q1 of 2018 and ODNs can start following up these patients.

In order to achieve the elimination goal, it will be important to treat 'high risk' transmitters, such as people who inject drugs (PWIDs), and ODNs will need to move into an era of unlimited HCV treatment numbers.

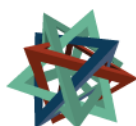
Trusts have links to people who commission drug and alcohol services in many places; therefore, ODNs have been tasked with encouraging the appropriate personnel in their Trusts to ensure there is a proviso for linking patients to care when the time comes for renewing drug contracts at a local authority level.

Although useful, drug choice was identified as a non-critical factor for HCV elimination. In the absence of interferon (IFN) and ribavirin (RBV), it is not critical what blend of drugs is administered to patients for HCV treatment. The experience has been that consistent use of lowest acquisition cost drug choices helps drive down drug prices therefore, limited drug choice may be a price worth paying in order to get more patients treated, as there will be more cost savings. Negotiations are currently ongoing with the pharmaceutical companies to slightly expand the limited options of drugs, whilst keeping prices as low as possible.

NHS England update

Claire Foreman

On 9 January 2018, the Under-Secretary of State for Health, Lord O'Shaughnessy, launched the first step of the new HCV procurement process, with an invitation extended to the pharmaceutical industry to show support. The aim of the procurement process is to eliminate HCV with long-term partnership with the pharmaceutical industry. The idea is that funding will continue at the current level, with the amount from the reductions in drug prices ploughed back into the system for treating more people. The hope is that the final negotiated settlement will incentivise finding more people with HCV and giving ODNs access to more patients to treat. Support is contingent upon the pharmaceutical industry working with NHSE on a new deal. ODNs are encouraged to find out the requirements for eliminating HCV locally and engage and collaborate with pharma. There will be pushbacks; however, it is imperative that the focus remains on the ultimate goal of HCV elimination. The proposed start time for the new process is September 2018, but in the interim, a 'bridging tender' in which pharma will be invited to deliver a combined procurement package that demonstrates value for money from both drug costs and screening and linkage to care initiatives is being considered.



Perspectives on key challenges in the treatment and management of HCV

Key challenges in the treatment and management of HCV were described and discussed from the perspective of representatives of key stakeholder groups. A summary is provided below and details of the presentations are provided in the supplementary meeting information which can be accessed on the BVHG webpage:

<https://www.basl.org.uk/index.cfm/content/page/cid/3>.

Hub perspective: key challenges

Mark Aldersley

Several challenges were highlighted from a hub perspective, including: HCV elimination strategy with limited funding other than for drugs; limited ability to provide resources to spokes or community-based programmes; access to patients and lack of clarity as to who has ownership and responsibility for the increased testing services; interaction with other secondary centres and recruitment of gastroenterologists; competition with Genitourinary (GU) medicine team; integration of services when private companies win tenders to deliver care; community drug treatment centres (staff turnover, lack of training, competing services, etc); financial constraints – CQUIN seen as a ‘fine’; and most ODN leads lack public health training and may not have the required support/expertise to lead the drive for elimination, which is a public health challenge.

Spoke perspective: key challenges

Adam Lawson

Several challenges were highlighted from a spoke perspective, including: the need for spokes to have more independence from hubs; bureaucracy relating to MDTs, particularly in cases where the treatment is not first line and when there is a delay in receiving feedback via the ‘buddying’ system, which impacts on run rates; more transparency around CQUIN; delivery times of patient medication in rural areas; and retention of patients to treat for a sufficient amount of time once identified.

Nursing perspective: Treating an increasingly challenging population

Janet Catt

A key challenge is finding hard-to-reach patients and it is critical to establish novel ways of finding and treating these patients. There are several innovative projects ongoing in the fight to eradicate HCV from a nursing perspective; the “Follow me” South Thames project is one of these projects and details were provided. The project commenced in October 2017 and involves a small number of patients. The aim of the project is to reach the community of PWIDs in the South Thames area. Peers buddying systems are proving critical to the success of this project. This hard-to-reach population is challenging to engage; however, they are being engaged and are on treatment as part of this project.

Pharmacy perspective: current challenges in HCV treatment

Adele Torkington

The current challenges, current community pharmacy model, current opportunities and future community model were highlighted. The current challenges include: bureaucracy around ODNs and pharmacy teams doing similar work instead of collaborative working; the cost of regimens – there is still room to bring these costs down; locating patients, especially in the prison services; run rates; and logistics around transportation of medicines. Current opportunities include CQUIN funding for pharmacists, finding undiagnosed patients and eradication. The current community pharmacy model has some limitations; however, the preferred future community pharmacy model will be more beneficial (Figure 1).

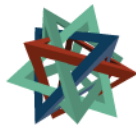
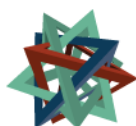


Figure 1: Preferred community pharmacy model

Drug and alcohol services perspective: barriers to HCV delivery

Stacey Smith

The treatment landscape has significantly improved for PWIDs infected with HCV. A holistic approach is employed in treating substance misuse and there is a strong drive to lower the mortality rate. Some of the critical challenges and barriers faced by the drug and alcohol services include: disparity on the role of the services in HCV treatment; funding for DBST and the need to retest; historical data – service users that have been registered with services for a long time; ineffective models and dysfunctional pathways; cultures within services not seeing HCV as a crucial intervention; and service users being unaware of new, all-oral treatments and, therefore, still holding fears and concerns around previous treatment with IFN.



Viral hepatitis elimination and best practice sharing

Best practice examples in elimination of HCV across England and Scotland were provided, with an aim of attendees going away with key points that can be implemented in their ODNs. A summary is provided below and details of the presentations are provided in the supplementary meeting information which can be accessed on the BVHG webpage: <https://www.basl.org.uk/index.cfm/content/page/cid/3>.

PWIDs in Scotland

Jan Tait

The background and overview were provided on the Scottish Hepatitis C Action Plan, the work currently being done with PWIDs in Tayside and progress with HCV elimination in Tayside. The key learnings include:

- Treat everyone, including re-infections
- Have easy diagnostic tests
 - DBST kits, oral swabs, etc
- Find the patients
 - Embed routine HCV testing within all drug services (opioid substitution treatment clinics, needle exchanges and community pharmacies)
 - Opt-out testing for prisoners
- Develop easy pathways of care
 - Stop doing unnecessary tests and investigations
- Make treatment uncomplicated
 - Provide treatment daily in pharmacies with opioid substitution treatment
 - Provide treatment in needle exchange centres
 - Provide treatment in prisons

Engaging the “lost”, hepatitis C-positive patients in treatment

Stuart McPherson

The background and overview of the HCV burden and elimination efforts in North East England were provided. The key learnings in engaging the “lost”, HCV-positive patients and eliminating HCV in North East England include:

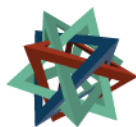
- Mapping untreated HCV can help to strategically design treatment services
- Tracking known HCV-positive individuals to engage them in treatment using PHE records is likely to be a cost-effective method for increasing treatment rates
- Collaboration with PHE is beneficial in finding “lost”, HCV-positive patients and in efforts to eliminate HCV

Community HCV models: Engaging the Disengaged

Sumita Verma

An overview was provided on the community effort to eliminate HCV in vulnerable adults, including PWIDs and homeless adults. The key learnings in engaging this hard-to-reach population and eliminating HCV include:

- PWIDs represent a hard-to-reach population who find it difficult to access traditional models of care. A service that relies on a traditional, secondary-care model of care for these groups will fail, with high levels of “did not attend”
- Not “one size fits all” but **ALL** aspects of care provided at **ONE** site
- Easy access should be provided, e.g. mobile phone, flexible drop-in clinics
- Offer a non-judgemental service: stigma and shame are huge barriers – injecting drug use and alcohol use should not be a barrier to HCV treatment
- Unrestricted access to pan-genotypic, 8-week, non-ribavirin direct-acting-antiviral (DAA) regimens



Towards the elimination of hepatitis C on the Isle of Wight

Ryan Buchanan

An overview was provided on the community effort of eliminating HCV in the Isle of Wight. The key learnings include:

- Finding innovative ways of raising awareness of HCV and encouraging testing
- Develop novel means of engaging hard-to-reach populations
- Involve community pharmacies in testing efforts
- Critical to define the disease burden in an area to be able to monitor progress of elimination effort
- Peer-to-peer referral is important in ensuring hard-to-reach patients receive access to treatment

Greater Manchester elimination plans

Andy Ustianowski

An overview was provided on the HCV elimination plans for Greater Manchester. The key learnings from the Greater Manchester elimination plan include:

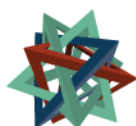
- To achieve elimination, there is a need to scale up in order to find, engage, and treat more patients
- Community pharmacies are a vital resource; chaotic patients such as PWIDs would usually access these services to pick up prescriptions, etc, and are easily accessible
- Network treating following diagnosis; this involves incentivising patients to bring other individuals within their social network along to services, enabling case finding with the aim of treating the infected person's whole network. This will reduce the chances of re-infection
- Interrogation of records; this involves joining up different records (eg primary- and secondary-care records) and using markers to develop algorithms to predict who may be more likely to have HCV
- Rapid diagnosis and treatment in prisons
- Unselected testing in A&E and GP settings; although very expensive for the small number of patients, it is a pillar worth considering if the right returns are not received from the other pillars
- Informatics and data generation on different levels, including generation of data on current HCV prevalence in the UK. This will provide an understanding of the current situation, as well as how much progress is required to achieve the elimination goal in the future

Measuring patient outcomes and experience

Charles Gore

The ODN service specifications states that service providers should use a patient questionnaire, developed and validated with appropriate patient representative groups, to record patient feedback on outpatient services

In light of the service specification, the group recognised the importance of having a standardised tool for assessing patient outcomes and experience, and reached a consensus to develop a standardised questionnaire for use across all ODNs. A working group led by Charles Gore (CEO, Hepatitis C Trust) was commissioned to develop this standardised form with a timeline of delivery of February 2018.



Appendix 2: Summary of workstream discussions from day 2

On Day 2 of the meeting, the group was divided into 4 workstreams to discuss key topics aimed at HCV elimination and best practice in the management and treatment of HCV. The workstreams provided an opportunity for attendees to identify and discuss current challenges, and proffer actionable solutions to the challenges identified, with an aim for the outputs to feed into the 5-year plan, as well as the development of tools that can be adapted for use by the ODNs. Each workstream had a different topic and sets of key objectives. The workstreams had a 2-part structure; the first part focused on the discussion of current challenges, limitations and solutions, and the second part focused on the practical implementation of the solutions to overcome the problems identified.

Is the present ODN model the best means of achieving HCV elimination?

Facilitators: Mark Wright and Sally Bufton

It is widely accepted among key stakeholders that the current ODN model has several limitations and challenges which impact on the goal of achieving HCV elimination in England. These limitations and challenges include:

- Lack of integrated resources, especially from the spoke (hub- and spoke-model) perspective
- The impact of ODN treatment run rates, which can act as a barrier to scaling up treatment numbers and HCV elimination efforts
- Challenges with accessing data
- Limited or non-existent engagement with important stakeholders, including teams from public health and primary care
- Limitations of the current hospital model of HCV treatment delivery
- Bureaucracy, especially with MDT meetings and unnecessary virological testing

Some improvements identified by the workstream include:

- Removing the treatment run rates and incentivising ODNs who treat more patients
- Funding which is currently from the CQUIN needs to be invested in broader hepatitis services and not absorbed into the hub Trust bottom line
- Empowering and incentivising spokes to make HCV a priority
- Minimise bureaucracy – eliminate the need for all cases to go through ODN MDTs before treatment (MDTs to be for complex cases only), provide spokes with more independence, and eliminate the need for frequent on-treatment virological testing
- Increased funding and involvement of PHE in ODNs
- National leadership and accountability for substance misuse services, health and justice, etc
- Empowering non-specialists to deliver HCV treatment

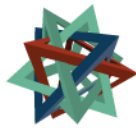
Following the consideration of the limitations and potential improvements that could be made to the current ODN model, some key questions were considered. These key questions, if addressed appropriately, could become a catalyst for improving the current ODN model, moving closer to the goal of eliminating HCV in England.

How can we change the current treatment model to facilitate getting more people to treatment?

The current HCV treatment model is seen as suboptimal and has several barriers to getting more people to treatment. These barriers and the actions to overcome them are described below:

Multidisciplinary team meetings: These meetings are a barrier to getting people with HCV to treatment. It is recommended that where the treatment of a HCV patient is deemed straightforward by a clinician, the clinician can prescribe or refer them for treatment immediately. This removes the need for MDT meetings for non-complex cases, saving time and resources.

Virological testing: There was a unanimous consensus (121 attendees) that on-treatment virological testing should not be mandated as part of the reporting requirements. On-treatment virological testing is not a cost-effective means of identifying on-treatment breakthrough, non-adherence or relapse, and therefore adds to bureaucracy and contributes to resource wasting.



ODN 'buddying system': Identified as unnecessary and bureaucratic. It acts as a barrier to patients getting treatment and leading to wasted time and resources. It is recommended that the buddying system be reviewed or removed.

Support from Public Health England: It is recommended that a named PHE representative is assigned to each ODN. It was agreed that more engagement between public health experts and ODNs will contribute to successful HCV elimination initiatives.

How can we change the CQUIN in a way that incentivises for treatment, rather than punishing?

The current CQUIN model means that ODNs feel like they are being penalised for treating HCV patients. In order to change the current CQUIN model, it is recommended that hubs and spokes be incentivised for over-treating. The ODN's 5-year plan should consider frameworks for incentivisation, as well as improving the relationship between hubs and spokes with regard to treating more HCV patients.

How can we change the relationship between hubs and spokes for more functional ODNs?

Unnecessary bureaucracy was identified in the relationship between hubs and spokes. It is recommended that the spokes become more independent and rely less on the hubs. The 5-year plan should consider methods of improving the relationship between the hubs and the spokes, with an aim of increasing the number of HCV patients treated.

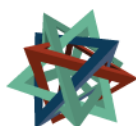
How can we get more public health involvement in ODNs?

Public health professionals are trained in the treatment of infectious diseases and can assist in the elimination of HCV. It was noted that not all clinicians have received public health training and may have some limitations with regard to the public health aspect of HCV elimination. Therefore, it is recommended that a named PHE professional is assigned to each ODN. Although the group recognised the challenge of involving public health colleagues in the task of eliminating HCVs by ODNs, it was identified as a critical success factor for HCV elimination. The 5-year plan should consider a framework for continuous and sustainable collaboration with public health professionals.

It was also recommended that there should be a multi-agency effort in community testing for HCV. If more patients can be identified, more patients can be treated and elimination achieved.

Recommendations

- *On-treatment virological testing should NOT be mandated as part of the reporting requirements*
- *Multi-agency effort in community testing for HCV. If more patients can be identified, more patients can be treated and elimination achieved*
- *End the ODN buddying system, as it is bureaucratic and contributes to wasting resources*
- *Eliminate the need for an MDT decision on all cases before treatment, it should be reserved for the discussion of complex patients only*
- *Public health professionals are trained in the treatment of infectious diseases and can assist in the elimination of HCV; therefore, a named PHE representative should be assigned to each ODN to collaborate on HCV elimination activities*
- *Hubs and spokes should be incentivised for over-treating*
- *Facilitate more independence of spokes, ensuring they rely less on the hubs*



Prioritising hepatitis C management in prisons, and drug and alcohol services

Facilitators: Andy Ustianowski and Stacey Smith

Prioritising and optimising HCV management in prisons, and drug and alcohol services was seen as a challenging endeavour but a much-needed approach, especially in diagnosing the undiagnosed, improving linkage to care, and ultimately eliminating HCV. Some of the key limitations, challenges and concerns included:

- Testing chaotic groups with current re-testing is seen as too costly
- Staff shortage within prisons and in drug and alcohol services; no time to focus on health and case finding
- Myths associated with treatments; patients do not want to receive interferon-based treatment
- Lack of continuity; patients change prisons and treatment too often
- No national database
- Lack of funding for community services
- Outdated treatment policy, Fibrosan diagnosis required before starting treatment
- Behaviour and culture around HCV has inhibited best practice

Some improvements identified by the workstream include:

- Hand back ownership to chaotic groups for self-testing or group-testing (DBST)
- Create incentives and streamline testing process
- Develop peer support, innovative testing methods, and increase community care to reduce hospital visits
- Create a national database to reduce re-testing, improve linkage to care, and tackle issues with patients changing prisons or losing interest
- Create an educational programme to debug myths around HCV, increase awareness, and spur behaviour change of staff and healthcare workers
- Assessment and services to be mobilised and allowed in prisons
- Ensure skill mix and staff support in prisons or drug and alcohol services is appropriate

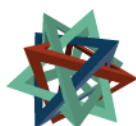
Following the consideration of the limitations and potential improvements that could be made to prioritise HCV management in prisons and drug and alcohol services, some key actions were discussed and consensus achieved on high-impact and easily implementable actions. These key actions, if applied appropriately, would help optimise HCV care in a chaotic setting, moving closer to the goal of eliminating HCV in England.

Treating and incentivisation

- Bring-a-friend initiative should be rolled out in drug and alcohol services to increase diagnosing the undiagnosed
 - DBST should be used in these cases as a cheap and effective testing method
- Pay-to-play scheme has been very successful for some centres. In one centre, the Clinical Commissioning Group (CCG) funded a food voucher for patients who bring a friend for testing
- The process of incentivisation can be used to create peer-support programmes and improve education among chaotic groups
- Centres, prisons and key healthcare workers should be incentivised towards case finding

Cure campaign

- Local educational programmes to be created in order to capture the interest of potential patients and to spread the correct information to these populations
 - These programmes were identified as easily implementable, with significant impact early on if staff and patients could act as 'champions'
 - Reduce the myths about treatments for HCV and communicate that treatments are no longer interferon-based
- Development of wider educational schemes should be considered for GPs and other healthcare workers to increase awareness that HCV is curable and to reduce associated stigma
 - Messages should not be focused on the affected population (ie drug users) as that would perpetuate the stigma. Instead, materials should be generic and informative
 - Success could be measured by the increase in number of referrals
 - Reinforce NHSE messages about the importance of testing



- National HCV 'Clear and Cure' campaign was recognised as the action with the greatest impact, but would require additional work to be effectively implemented
 - Charles Gore noted that this was something that the Hepatitis C Trust would collaborate on; however, for a nationalised programme, this should be funded by pharmaceutical companies with agency involvement to properly manage the campaign
 - Campaign roll out should be run in conjunction with ODNs reaching out to their long-term follow-up patients, as an awareness campaign would help increase response rate
 - A national campaign should help and incentivise GPs to send out response letters to reconnect with long-term follow-up patients

Funding and simplification of care/treatment

- Self-testing kits using DBST to increase case finding
 - Anxiety from positive result can be undone by clear messaging that HCV is curable
 - Simplified linkage-to-care schemes are critical to begin treatment immediately
- Simplified testing regimens should be created for patients under direct supervision
 - Improved policy would reduce the requirements to test at certain points of care, which often prevents treatment
 - Create a better structure for improved access to treatment
- Reduce the unnecessary costs of re-testing, through better data sharing
 - Once tested, results should come back to a central database
 - Minimise the number of Polymerase chain reaction(PCR) tests and associated administration, and move towards DBST to identify at the first level
 - Money saved through better management and prioritisation should be reinvested back into the community, perhaps to hire additional nurses
- Remove the requirement for a Fibroscan or other liver fibrosis assessment before beginning treatment
- Optimise facilities through better management of capabilities and shortcomings by allocation of skilled staff at the appropriate level

National elimination plan and policy

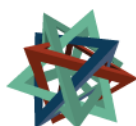
- Create a national best practice plan for how HCV elimination could be achieved
 - A national plan exists for the treatment of HCV, but not how this should be implemented or supported for best outcomes
- NHSE to develop an elimination plan and CQUIN scheme which could be achieved by ODNs and not lead to penalisation
- PHE messages should align with NHSE messages
- Enforce testing in the plan and policy; testing should be a priority
 - Develop league tables and write to lenders and commissions to put pressure back on the community services and prisons

National procurement

- National procurement of swabs and testing kits would reduce costs for individual centres
 - Some ODNs already bulk-buy kits/swabs, which is highly effective at minimising costs
 - This would be a high-impact action, but would need considerable effort to implement
- Neighbouring ODNs should work together to develop a deal for procuring swabs/kits
- Money saved should be reinvested back into the ODNs or individual centres

Recommendations

- *Testing simplification through DBST, self-testing kits, and incentivisation schemes to increase case finding*
- *Create a national database to record test results and increase linkage to care*
- *Through local and national programmes, educate all stakeholders to remove stigma and debunk myths about HCV and treatments*
- *'Clear and Cure' national campaign to increase HCV awareness, reduce stigma and increase testing*
- *National procurement of swabs and kits to save money that should be reinvested into centres*



Models for hepatitis C treatment in the community

Facilitators: Adele Torkington and Jan Tait

The workstream discussed the current limitations to providing and delivering HCV treatment in the community setting (defined as minority groups, community pharmacy, drug and alcohol services, general practice, etc) and what needed to change to address these limitations. Following consideration of these, the workstream identified actions that could be taken to improve the delivery of hepatitis C treatment in the community setting.

Remove the unnecessary burden of baseline liver assessment before treatment and ongoing monitoring

- The current requirements for baseline liver assessments before treatment and ongoing monitoring are a barrier to treatment; this can, and should, be simplified to something more pragmatic that can be achieved in the community setting
- The recommendation is for BASL/BVHG to provide guidance on basic monitoring, linking into the treatment algorithm
 - This would identify patients who can be managed in the community versus those who need referral/additional follow-up
 - This would need to be applicable nationally
- For this to work, pan-genotypic HCV treatments need to be widely available
- The Blueteq form or process also needs to change to enable flexibility to adjust treatment if the liver assessment (after treatment has begun) suggests that a switch in therapy is appropriate
- The need for an MDT decision on treatment should be reserved for the discussion of complex patients only
- A 'blue-sky thinking' option was identified; this is where assessment and treatment would take place in 'one-stop shop' community settings such as homeless shelters, and drug and alcohol services. These services would be GP-led and Quality and Outcomes Framework (QOF) funded, delivering all care (not just HCV) and with access to services such as mobile ultrasound and Fibroscan, and dispensing

A need for a national awareness campaign

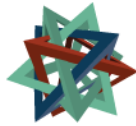
- The group felt that the time is right for a national 'cure' campaign, to engage those truly at risk
- Funding for such a campaign could come from the pharmaceutical industry as part of recently launched, new HCV procurement process
- It would need to include celebrity endorsement to break the stigma of hepatitis C
- It would need to target different groups, for example:
 - Gyms – not just today's bodybuilders, but also the middle-aged, middle-classes who may have injected drugs in the 1970s
 - Black and Minority Ethnic (BME) community – eg screening programmes using trained community workers such as driving instructors, beauticians
- A storyline on *EastEnders* would be a great way to launch the campaign

A need to change the funding streams to encourage treatment in the community setting

- The need for clear funding streams for HCV treatment in the community was recognised
- It is recommended that BVHG and NHSE work with CCGs and sustainability and transformation plans (STPs) to review funding, given the potential for community treatment to save money for secondary care. Ideally, CQUIN-derived revenue will 'follow the patient'
- There is also a need for national procurement of DBST kits
- A review of block contracts for hepatitis C by CCGs and STPs would also be desirable

A reduction in community pharmacy restrictions

- Strict rules regarding community pharmacy operation was identified as a barrier to hepatitis C treatment in the community
- HCV therapies are regarded as high-cost drugs; as such, there are restrictions that need to be removed for community dispensing to be possible



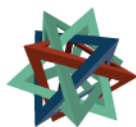
- There is also a need for transparency on contract processes and the costs of therapies
- Any changes will need to be made in consultation with the Chief Pharmacist and NHSE. It is recommended that the BVHG Pharmacy Group take this on as an action
 - It is important that the system is simplified and that further layers of administration are not added

A need for real-time informatics

- Whilst recognising the difficulties involved, the group's most impactful action to ensure implementation of optimal models of HCV treatment in the community setting is a real-time informatics system that 'does everything', can be accessed by all involved in a patient's care, and encompasses 'everything we could possibly need' to treat a patient

Recommendations

- *Remove the unnecessary burden of baseline liver assessments before treatment and ongoing monitoring; develop an algorithm to show how community treatment can fit in with other services*
- *A need for a national awareness campaign targeted to different patient groups, aiming to remove stigma and focusing on cure*
- *A need to change the funding streams to encourage treatment in the community setting*
- *A reduction in community pharmacy restrictions, to allow dispensing of high-cost hepatitis C treatments*
- *A need for real-time informatics to facilitate patient care in all settings*



Improving patient health through hepatitis C engagement

Facilitators: Will Gelson and Charles Gore

It was acknowledged that the current mindset – of both patients and healthcare professionals – needs to change when considering approaches to improving patient health through HCV engagement. The majority of patients with advanced liver disease are already known to HCV treatment services, and it is likely that, by now, most of them have been treated or are undergoing treatment. Therefore, the patients who remain untreated, and who are most important to engage with, are: undiagnosed; or not currently accessing services of any kind; and/or asymptomatic; and/or those for whom treatment for HCV is not a priority; or all of the above.

The questions outlined below were considered during discussions.

What are the key challenges to improving patient health through HCV engagement?

- Current perception and culture or mindset – both in healthcare and for patients (eg stigma of disease); or, for example, the belief among patients that interferon is the only HCV treatment option available; and, among healthcare professionals, the belief that HCV treatment must be within the remit of secondary care services, instead of community (eg drug and alcohol services)
- Lack of communication or education about HCV – for example, among commissioners, between primary and secondary care services, or at the point of patients engaging with services of some description, such as drug and alcohol services. It was noted that the lack of awareness and urgency at the public health level can have a detrimental impact on patient engagement
- Existing paths to HCV treatment and models of care – as an example, it was reported that some patients find the hospital environment inflexible, uncomfortable and formal, and often do not keep appointments with hospital services
- ODN run rates, which are widely acknowledged to present difficulties and limitations to freely treating patients regardless of the severity of their disease status
- Lack of continuity in data gathering

What best practice can be followed to improve patient health through HCV engagement?

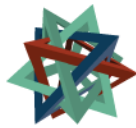
- Educational training about blood-borne viruses (BBVs) in the prison environment
- Raising awareness among ODNs – South Yorkshire are holding a hepatitis C awareness day, during which, The Hepatitis C Trust will host a round table discussion, inviting representatives from multi-disciplinary services to attend
- Peer-support programmes, where peers operate in the community, working closely with and to support HCV-infected persons, some of them with chaotic lifestyles, and some for whom management and treatment of HCV is not a priority

If there were no barriers, what would be your ideal model for engaging with HCV patients?

A model without run rates, or with run rates that prioritised 'high-risk' transmitters of the disease for treatment, would be closer to an 'ideal model'. It was suggested that tariffs could be allocated to communities, which would generate additional income and enable employment of a full-time nurse in the setting. It was further agreed that there are many innovative ways to approach and develop an ideal model, which need to be further explored by ODNs and stakeholders through MDT round table discussions or workshops, and at events such as this.

What plans or solutions can be put in place?

- Greater level of engagement with community services, eg drug and alcohol services, utilisation of BBV nurses, and prisons
- Establishing support programmes that will enable patients gain access to care
- Increase training and educational initiatives, eg for peer supporters and nominated BBV team leaders within community services
- Convene 'round table' discussions or workshops of staff representing multi-disciplinary services
- Messaging/awareness – more posters and information available to patients and staff



The following actions were proposed and rated on a scale of impact versus achievability:

- **Round table discussions with key stakeholders:** High impact and achievability – already being implemented within some ODNs
- **Improving communication with commissioning services:** Assign a dedicated coordinator to provide a link between commissioning and community services. Potentially high impact, but low achievability at present; it was suggested that network contacts could be approached to explore this further
- **National awareness campaigns:** Led by ODNs, the campaigns would be targeted for maximum impact – for example, by considering the bus route when allocating HCV awareness posters on the sides of buses. Dedicated campaigners could facilitate greater awareness of the campaign – eg operating in GP surgeries to ensure that HCV awareness posters are displayed prominently. Campaigns specifically targeted at raising public awareness could include putting posters on the back of toilet doors in areas where HCV could be a concern, eg nightclubs or gyms, or having a hepatitis C bus at a pride march. Public awareness campaigns such as this should be carefully thought through so that they address and help to remove the stigma of having hepatitis C. It was further suggested that a celebrity champion would greatly raise the profile of the campaign; however, this rated as high impact but low achievability
- **Recruitment of dedicated community workers:** Recruiting dedicated community workers with experience of operating in the community setting and who can bring connections to the role – for example, embedding and better defining the role of peers, and providing a link between primary, secondary and tertiary care services; this would achieve the objectives of improving patient engagement and, ultimately, optimising treatment programmes for them – high impact and high achievability
- **Reducing monitoring throughout treatment:** To ensure that the pathway through treatment is as easy and accessible to the patient as possible, and to maximise patient engagement throughout the course of their treatment, it was proposed to reduce the amount of times patients are monitored through blood testing – with only one blood test carried out at baseline and one post-treatment. This can be discussed with NHSE and written into CQUIN requirements. Significant cost savings of approximately £7 million could then be used to engage patients in the community setting – thus high impact, high achievability
- **Map of hepatitis C services and provisions:** Both healthcare professionals and patients should know where to access hepatitis C services. This is already in development but would benefit from further investment. It was proposed that the map would ideally have two access levels: firstly, for patients, so that they can find out where to go to get tested and/or treated, and secondly, for professionals, so that they can find out about key contacts within services. This was expected to have high impact and is highly achievable
- **Continuity and data linkage:** There is currently a disconnect between data collection and engagement with patients. Although the data are reported to be present and hospitals are collecting them (through initiatives such as HepCARE, for example), they are not being utilised to their full potential; furthermore, there is no way to connect the hospital data with, or measure, patient engagement – data are more likely to be focused on disease status, HCV genotype, etc. A ‘quick win’ to data sharing would be to enable wider access to national databases, with clear directives established as to how the data will be used. The group agreed that the achievability of this is high, but the impact is potentially lower than other solutions
- **Ensure that run rates do not delay treatment for diagnosed patients:** Explore how the commissioning of treatment could move away from run rates or provide dedicated treatment run rates for high-risk transmitters or patients who are particularly difficult to engage. It was noted that the current CQUIN model is not the best for funding access to care, and a system of ‘pay-per-treatment’ could instead be adopted – this could empower ODNs and enable more community care services

Recommendations

- *Rationalisation of blood testing so that patients do not have to repeatedly visit services throughout the course of treatment; potential for cost saving is significant, with funding put back into establishing more community services*
- *Increase the level of peer support available; consider patient incentivisation*
- *Collaboration among ODNs to provide a comprehensive map of services, to make hepatitis C services easier to locate*
- *Recruit dedicated coordinators to bridge gaps between commissioners, primary and secondary care services, and communities – eg hepatology assistants*