EASTERN REGION HCV ODN MEETING
TUESDAY 11 JUNE 2019
BRITISH RACING SCHOOL NEWMARKET

PRESENT: Dr Will Gelson (Chair)
Jo Brown
Paul Selby
Jaime Browne
Massey
Rachael Bates
Katie Eiloart
Amanda Innis – HMP Highpoint
Paula Roberts
Tillie Bond
Claire Watson – Health & Justice Commissioner
Mark Brunning
Sean Cox – Hep C Trust Director of Prison Service
Julia Sheehan – Hep C Trust Prison Peer Co-ordinator
Caragh Arthur – Hep C Trust Prison Peer Co-ordinator
Dr Iain Brew – Medical Director CareUK
Therese Moore
Enid Nyaumah

APOLOGIES: Dr Sambit Sen
Dr Abdul Mohsen
Tanya Chapman
Georgi Rutherford
Naomi Glover
Bridget Langstaff
Dr Anne Day

Unfortunately the meeting was not quorate as a second consultant was unable to attend at the last moment. As agreed at our ODN meeting in November 2018 in this situation the minutes would be circulated to the regional members for their perusal with a five day period given for comments. After that time the items discussed at the meeting and the minutes would be approved and closed.

Dr Will Gelson opened the meeting and welcomed the representatives from the Hep C Trust and Iain Brew from CareUK.

Sean Cox gave a presentation on the work of the HepC Trust peer to peer prison programme (slides attached). This was followed by a Q&A session.

PR asked how peers are recruited bearing in mind the stigma associated with HCV in prisons.

SC explained that during the in prison HCV education events prisoners were asked to let the team know if they would like to consider becoming a peer support worker. CA reported that once the prisoners appreciate that the members of the HepC Trust have had a lived experience they gradually become more willing to engage, consider testing and treatment and to become a peer support worker moving forward.

AI commented that have open conversations around HCV testing and treatment starts to reduce the stigma.

CW asked if prison officers were also trained about HCV.

SC explained that the HepC Trust can offer prison officer training. It is a more difficult audience to reach due to other training commitments and limited time. However they try to work with the confines of the prison and deliver training whenever possible.

IB introduced himself as the Medical Director for CareUK. Previous experience as a prison GP in HMP Leeds. There are five CareUK prisons within our ODN. CareUK are committed to increasing opt out testing. Point of care testing and treatment for remand prisoners is essential as their sentences are shorter and the risk of them spreading infection once released is higher than those in the training prison environment who tend to have longer sentences.

IB commented that the proposed intensive test and treat initiative would require close working with the prison officers and would help raise awareness and reduce stigma.

WG said that the ODN were supportive of this initiative however it would require careful planning with both the prison and with the clinical staff from the ODN. Access to pangenotypic regimes for the prison and homeless population would make treatment easier to provide.

IB commented that in his experience approximately 50% of patients have a genotype recorded somewhere in their history if they have previously tested HCV RNA positive. This should be investigated before offering a pangenotypic regime.

PR asked how SVR12 would be obtained.

IB explained that continuity of care with the IDTS programme and with the support of the HepC Trust 'Follow Me' scheme should improve ability to track prisoners once they are released.

WG clarified that the requirement for an SVR48-60 has been removed from the CQUIN however we have continued to collect this where possible to finish the patient's treatment journey and allow discharge from hepatology follow up where appropriate.

JB confirmed that the SVR12 is a metric in the new CQUIN. WG made it clear that the ability to get an SVR12 should never be a barrier to treatment.

IB said the proposed use of Cepheid machines in pharmacy settings might also be a way of getting an SVR12.

PR said that some prisoners rotate in and out of prison and therefore it was sometimes possible to get an SVR when they were readmitted.

WG thanked the HepC Trust for an interesting presentation and looks forward to working with them in the future.

WG confirmed that non ODN members were welcome to stay for the remainder of the ODN meeting.

RISK REGISTER

JB stated two new risks had been added to the register.

1. Relating to delivery of medications by Homecare to a patient at NNUH. The patient missed three days of treatment due to non-delivery because Homecare said they had no stock of drugs.
   WG said the risk should remain for six months and then be removed if no other incidents had occurred.

2. Citysprint delivery issues which seem to have been directly or indirectly responsible for blood samples being mislaid at CUH. Fortunately the samples were found, but we are investigating the issue to avoid a recurrence.
   WG said the investigation should continue and when a clear pathway has been agreed the risk can be closed.

JB reported that Homecare cannot offer a translation service which is difficult for patients who do not speak English. WG agreed this was not acceptable. The ODN will lodge a complaint about this this issue.

PR reported that if Lloyds Pharmacy cannot contact the patient to arrange delivery, they write to the patient. They only alert the CNS two weeks after this process to say that they haven't delivered medication.

PS replied that this problem has already been raised with Lloyds and he will raise it again.

Action: PS to contact Lloyds

CASE FINDING/WAITING LIST

WS thanked the teams for their continued work on their waiting list on the HCV registry. WS will continue to send round a copy of each spokes waiting list during the first week of the month. Most of the patients on the waiting list are patients who are known to services but who don't engage. WS suggested that time could be spent trying to re-engage with these patients. This could be via a letter or telephone call. WS has written to patients on the CUH WL and has found a 10% response rate of patients who are now willing to engage. WG said that WS could help spoke sites with the letter approach if required. WS asked spokes to continue to use the WL codes which had been circulated. There are many HMP patients on the WL and these names could be targeted during the intensive treat period.

WS explained the 'testing event' spread sheet that she'd circulated on the 10th June. WS would like to gather data around testing events as evidence that the ODN is actively trying to case find.

WG suggested that 'case finding from your chair' is an importance exercise in trying to find patients. WG said that WS would be able to assist spokes with this exercise.

Action: Spokes to contact WS if they would like assistance

PHE DATA UPDATE

WS gave a brief update on the situation with the PHE historic HCV Ab positive data. So far 240 letters have been sent with only 19 responses. Of those only three people needed to be seen in clinic at CUH. Over the next few weeks WS will send out letters to the remaining people on the list. A deceased check will be performed within 24 hours of the letters being sent. Totals at the moment are:
Basildon 362
Ipswich 251
Luton & Bedford 116
NNUH 270 (109 HCV RNA positive and not being treated)
Peterborough 161
CUH 366

Initial response to the letter will be via the helpline at CUH. Any necessary work up will be arranged by the team at CUH before the patient is referred on to the spoke centre.

It was agreed that for those people who are in prison, WS will write to the Head of Healthcare at the respective prison. WG and WS will devise a letter for this population.

Action: WG and WS to create letter to healthcare departments

No letters have been sent to paediatric names that appear on the list at this stage.

Action: WG to chase a response from the central HCV team about letters to paediatric patients.

REGISTRY

WS thanked the teams for their continued hard work entering patients on the HCV treatment registry. WS stressed the importance of completing all fields and limiting the use of the answer 'not known'. WS will be auditing data completeness each month and alerting spokes to gaps that they need to complete.

WS asked that SVR12 are recorded wherever possible. The ODN needs to achieve 85% SVR for patients treated in a hospital setting and 60% for patients treated in prisons, DAS etc.

NEW RATE CARD

The new rate has previously been circulated and is now in use. The meeting confirmed that the new rate card is understood and being implemented. Clinical decisions should be made to choose which treatment to use for genotype 1a and 1b. We should be mindful of not using the shorter durations of treatment for too many patients as we may be penalised later in the year for doing so.
WG suggested choosing the shorter duration and less pill burden treatments for those patients who are most chaotic.

PROCUREMENT DEAL

A meeting with the pharmaceutical companies (Gilead, MSD and Abbvie), ODN representatives and representatives from partner organisations is being held on 25th June to discuss how we would like to work with the pharmaceutical companies. WG is keen that we lead the discussions. The following seven aims were ratified at the meeting:

1. Prisons. Rapid on site testing of HCV antibody and RNA. Health care professionals and peer to peer support to ensure all prisoners are screened and treated rapidly when positive, often with pangenotypic regimens.
2. Drug and alcohol services. Rapid on site testing of HCV antibody and RNA. Health care professionals and peer to peer support to ensure high screening rates and rapid treatment access, ideally with pangenotypic regimens.
3. GPs. Facilitation of GP database interrogation to identify HCV positive and "at risk" patients for testing, and for linkage to care.
4. Pharmacies. PS to provide summary of this, but is essentially the ability to dispense from pharmacies. On site pharmacy testing and treatment.
5. Facilitate a public health awareness campaign across our region, perhaps as part of a national campaign.
6. DBST kits for community usage.
7. Incentives and support to attend clinic appointments and undertake screening. Ideally incentives would be provided for all clinic visits, but if not then first clinic appointment and SVR12 appointment should be prioritised.

WG explained that initiatives have been agreed between the pharmaceutical companies and NHSE. JB gave a brief overview of the types of initiatives that have been agreed.

JB explained that all initiatives have dependencies. For the prison scheme the ODN would need approximately 12 weeks' notice to allow sufficient time to plan appropriately.

The initiatives have been prioritised for the ODN and returned to NHSE. We await the outcome of their decision.

ANY OTHER BUSINESS

WG raised Mary Ninkovic's question around HCV screening for ante natal women. It is likely not cost effective to test all ante natal women for HCV. WG and JB have met with the CUH BBV midwife and have agreed a list of risk factors which should be used to assess whether a woman should be screened for HCV. The CUH BBV midwives can share this information with the other BBV midwifes in the region. We would be happy to provide the list to anyone who wishes to pursue such a screening programme locally.

Action: JB to contact CUH BBV midwife for update

SC asked whether we receive any HCV referrals from private fertility clinics. WG said that he could only recollect HBV cases.

Matrix Diagnostics WS asked for feedback from any of the team who have been using the Matrix Diagnostics HCV testing kits. PR has been using the mouth swab but not the finger prick test. TM hasn't used the kits yet. No real feedback.

JB gave out dates of interest: BBV training day organised by PHE in Chelmsford on 27/6/19.
World hepatitis day 28/7/2019
Prison Event 31/10/19 at the British Racing School.

20:00 Meeting closed.