# HEPATITIS C ODN MEETING
# THURSDAY 29 NOVEMBER 2018

PRESENT:
Dr Will Gelson
Bridget Langstaff (PHE)
Iain Roddick (PHE)
Tanya Chapman
Jo Brown
Kirsty McKibben
Wendy Smeeton
Rachael Bates
Katie Eiloart
Paul Selby
Mark Brunning

APOLOGIES:
Dr Anne Day
Dr Sambit Sen
Sarah Fairclough
Therese Moore
Naomi Glover
Tracy Woodall
Liz Read
Georgi Rutherford

Unfortunately the meeting was not quorate as Dr Mohsen was unable to attend at the last moment. It was agreed at the start of the meeting that 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.

PHE Data

IR explained to the meeting that he has been writing to GPs in our region who have had patients who have previously tested positive for HCV Ab. There are some discrepancies between the data sent by the national PHE team and the data that is local. IR will provide details of GPs who have responded to state that the patients are no longer in the area. IR suggested writing a further letter to all GPs in the region to alert them to the fact that CUH will be contacting them about historical HCV Ab positive patients as part of the NHSE commitment to eradicate HCV by 2025.

KMcK gave details about the processes that have to be followed now that the historic HCV Ab positive data has arrived from PHE. The Eastern region ODN have received the details of 3813 people who have previously tested positive HCV Ab positive. We have been sent details of approximately 249 people who aren't within our ODN. WS will forward these details on to the correct ODNs. MB asked whether it is possible that other ODNs have been sent details of people in our area. WS confirmed that that is possible. The onus is on each ODN to check their own data and to forward on people to other ODNs if they don't belong to them.

As the data was released to the Clinical Lead for the ODN, processes have been started with teams at CUH for the handling of the data. The Caldicott Guardian has given approval to contact patients directly with approval of the enclosed letter (copy also circulated prior to the meeting). A few typos have been highlighted and these will be actioned (KMcK). WG and KMcK have meetings planned on the 5th and 7th December with the CUH directors and members of the CCG to notify them that the data has arrived and to discuss ways of using the data. KMcK explained that we need to seek regional CCG approval for self referral.

Discussion around how to approach the process of recalling people followed. It was agreed that the initial letter to people would be sent from CUH with an information leaflet. Routes for further testing/referral would be detailed in the letter.

MB commented that many people who receive the letter may have mental health issues and therefore wording and sign posting to support is vital. BL suggested sending letters to be received at the start of the week (Mon-Wed) so that people would not be receiving news at a weekend when access to help is limited.

RB commented that the letter needs to be clear that people can contact their local centres and not just the HCV trust.

MB commented that it is important to emphasise that there are new treatments for HCV. It is important to destroy the myths about the continued need for interferon.

Discussion followed on whether a telephone help line could be established locally.

Discussion around how and when to send out letters to patients followed. The Caldicott Guardian at CUH has agreed that we can write directly to people copying in the GP. Positive HCV Ab results have been sent from 1996 to 2017. WG suggested picking people from the 1996-2009 list and also people from the 2009 to 2017 list. BF suggested perhaps a 60/40 split between the old list and the new list. This approach could be reviewed after a few months when an indication of response would be available.

Capacity to see and treat people who respond needs to be considered when deciding when to send letters. Clinics at both Basildon and Peterborough are general hepatology clinics and therefore do not always have capacity for HCV patients.

MB commented that people should not be contacted unless there is capacity for them to attend clinic and get ready access to treatment.

BL suggested writing a document detailing the rationale for the decision process taken to order the recall.

KMcK asked whether we should communicate to local MPs about the recall process so that they are aware of it in the event they receive complaints from constituents. BL thought this was a sensible idea. WG said we should be guided by the CUH communications team regarding this.

KMcK stated that the letters would not be sent before 1st April 2019 for spokes. CUH might start contacting GPs with high prevalence rates earlier than this to maintain the run rate.

WG confirmed that patients can be sent blood forms to get their HCV RNA checked locally. He suggested liaising with the LTX team at CUH who already have a process in place for patients to have bloods checked locally and results being forwarded to CUH. KMcK suggested that the Eastern Liver website lists places where people can get their blood tests taken.

WS has checked the details of the 953 people who are listed as being under CUH. 33% of these are HCV RNA negative; 10% HCV RNA positive; 56% have no results available.

WS has divided the data into spoke sites. This data will be circulated to spokes along with detailed guidelines on how to validate the data. Data will only be sent via nhs.net email addresses. The importance of confidentiality will be reiterated at all stages. Once the data has been validated at the spoke sites it will be returned to WS.

WG suggested that we could think about the Nottingham model where treatment is provided locally via pharmacies. Is there a role for pharmacies to test for HCV RNA, man telephone help lines?

WG wondered if it would be worth combing with another ODN to facilitate a help line.

RUN RATES

KMcK reported that the previous concerns about meeting the Q4 run rate are now alleviated. Out reach is starting in seven new locations in Essex in the next month. TC mentioned the lack of referrals from CGL. BL and KMcK confirmed that many discussions have taken place with commissioners and senior staff at CGL to improve referral rates. KMcK asked BL if there are clauses within their contracts about continuing partnerships. BL thought there should be.

WG has a meeting with Ben Jones lead CGL nurse for Cambridgeshire on 11th December. Neither Lisa Gould nor Jackie Howe can attend. Lindsay Morris hasn’t responded to the invitation.

CASE FINDING

WS explained how case finding can start from your chair. Using data from the waiting list on the HCV registry she has contacted patients who aren’t engaging. 76 letters were sent to patients who aren’t engaging. Seven responses have been received. Two patients have been seen in clinic. One of whom has now been to MDT and is ready to start treatment. A further letter was sent to patients who have been to MDT then defaulted from follow up. Three responses have been returned stating that the patients have moved away. These patients will now be removed from the waiting list.

WS has tidied the WL for Ipswich, removing patients who are RIP and those who have moved out of area. This makes the WL a more realistic. The Ipswich team plan to send a recall letter out to their non engaging patients. She is happy to do this for all spokes once they have put comments in the comment box on the home page of the registry.

REGISTRY

WS asked for agreement on a new prioritisation code for patients starting treatment. As WL are reducing and access to treatment is getting quicker it was agreed that the term ‘According to Waiting List’ (ATWL) would be introduced as a new code for prioritisation.

WS again highlighted the need for complete data entry for all patients on the HCV registry who are on treatment. All mandatory fields should be completed. WS monitors data completeness on a monthly basis and will alert spokes where their data compliance is poor.

LAB DATA

WG wanted to know which centres are liaising with local labs to get notification of HCV RNA positive patients. TC confirmed they are working with the lab at NNUH. WS performs a weekly check of HCV RNA positive results at CUH. L&D, Bedford and Peterborough aren'tworking with their labs.

TC said that the labs at NNUH are performing resistance testing with all genotyping requests. WG confirmed that there is no necessity to do this. TC will discuss this issue with the NNUH laboratory.

SOP FIBROSCAN

WS gave details of an SOP for Fibroscan which has been forwarded by the central HCV team. The SOP sent is two years old and for another ODN. There were also Fibroscan guidelines drawn up by the BASL nurse group. KMcK will write an SOP for Fibroscan in out reach as part of the SOP for nurse led clinics.

PHARMACY

PS updated the meeting regarding the SOP for medicine storage at DAS. The committee agreed this SOP.

PS presented details of a community pharmacy plan to test/engage/treat patients. A pharmacy in Huntingdon attached to a GP practice has agreed to be a pilot for this in the event that funding is agreed.

KMcK hopes that working with pharmacies will be something that is included in the new procurement deal.

TC asked who would fund the testing kits? PS said the ODN would. WS told the meeting about an approach made by Matrix Diagnostics. They are willing to provide 50-100 HCV Ab testing kits free of charge. The kits retail at £5 which is cheaper than the Ora-quick swabs. The kits work with a finger prick test and give an instant result.

PS asked about the experience of homecare delivery. TC said that her experience has been sub optimal. It seems that there can be poor communication with patients from Lloyds. There have been drug errors and labelling errors. These experiences are not isolated to the NNUH.

Gilead fund Lloyds Homecare so it is free to the NHS. PS had had a tele-conference with Gilead and Lloyds Homecare which had seemed positive. Homecare doesn't fit well with our patient cohort.

WG suggested that an audit is carried out of 20 patients who are using homecare.

PS asked that the next patient experience questionnaire includes experience of medication delivery etc. WS confirmed that would be included. MB is also consulted on questions to be included.

ANY OTHER BUSINESS

WG alerted the meeting to the new HCV guidelines that WS circulated this week. The changes are around paediatric treatment. NHSE are not supporting treatment with sof alone for children under 12 years of age. Over 12s can have sof/led. There are no other treatment options until after puberty except within the clinical trials setting.

WG stated that there is a variation in practice across the ODN with regards to consultant led clinics. The committee did not feel that there was a need for consultants to review all new patients but that they should be discussed as part of the MDT process. An SOP will be written to offer protection to consultants who aren't seeing all new patients (Action KMcK). TC confirmed that she discusses new patients with Dr Alam rather than him seeing them face to face when she's back at the NNUH. KE confirmed that she discusses patients with WG through the hepatitis MDT.

Meeting closed.