

# HEP C U Later


May 2022

## Quarterly Newsletter

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Please let us know your thoughts, comments and suggestions for further newsletters.

- Hep C U Later is an initiative of the NHS Addictions Provider Alliance (NHS APA). 
- The NHS APA is a collective of NHS addictions service providers who are working collaboratively with service users, carers and other organisations and are committed to contributing positively to the ongoing development of the addictions field including within drug and alcohol, gambling and gaming treatment.

Hep C U Later are extremely pleased to announce that we have signed a two year extension of the joint working agreement with Gilead Life Sciences, bringing us into years 4 and 5 of the project.

This extension marks the commitment both organisations have to our continued collaboration and our efforts to micro-eliminate Hepatitis C within our NHS APA member services across the country. This arrangement is part of NHS England's ground breaking Hepatitis C elimination programme.

Reflecting back there have been some incredible achievements over the last three years and we are extremely proud to have worked with so many driven individuals and services. It has been wonderful to see member services commit to the objective of micro-eliminating Hepatitis C for service users engaged in structured treatment by 2023. Whilst highly achievable, this time-scale is short and will require a sustained and continuous effort from all over the coming and future months. This continued partnership with Gilead Life Sciences, the unprecedented level of collaboration, and the tireless work of the NHS APA services we work with have enabled us to make great strides towards our main objective, and as always, keep our service user's health at the heart of everything we do.

*Deanne Burch, Lead for Hep C U Later*

**Our friends and partners at the health shop in Nottingham have written the piece below about the launch of their preventing infection/reinfection of Hep C workshop and would like to share it with you all.**

The Health Shop team in Nottingham have recently launched some training that they have developed looking at preventing infection/reinfection of Hepatitis C. This initially has been written for staff working within the Nottingham Recovery Network, but they plan to provide this to service users as part of a workshop setting, over the next couple of months.

The session was co-facilitated by a member of staff with lived experience of both Hepatitis C infection and treatment and included an overview of Hepatitis C, a practical discussion and demonstration of how drugs are apportioned and where the transmission risks may be in the process. The aim of the training is to support staff to be able to have more informed conversations with service users about needle coverage, myths and language associated with splitting/sharing drugs and the importance of testing/re-testing. The team also devised a checklist to help staff with these discussions.



For the data leads.

The 1st of April saw the introduction of dataset Q. Although there were a large number of changes made there are 2 changes that will affect the recording of Hepatitis C data.

## 1. An additional status for HCVPCR

The HCVPCR records the data PCR(RNA) status. In dataset Q they have added a new code defined as Negative (cleared naturally). To estimate the number of clients who will be in this new category you can use their HCVAS status of Anti-body Positive and if their HCVPCR status is Negative (never infected), they would fall into this new category. There is no need to back date the data.

### 3.41 Hep C test result PCR (RNA) status – HCVPCR

Code	Text	Comments	Dataset inclusion	Sort order
1	Positive		AD	1
2	Negative (never infected)		AD	2
3	Unknown	Client has received a test but the result is unknown/ inconclusive	AD	5
4	Negative (cleared by treatment)	Client has received treatment for hep c and has subsequently tested negative for hep c.	AD	3
5	Negative (cleared naturally)		AD	4

## 2. Change in the coding for REFHEPCTX and CIRREFHEPCTX

These 2 field's record data on a client being referred for Hepatitis C treatment and have also changed. Although there are no additional codes for the data in dataset Q the code type has changed from a number to letter. If you have reports analysing these codes please be aware of this as it will cause your report to fail

Dataset Q

### 3.64 Has the client been referred for hep C treatment – REFHEPCTX

Code	Text	Comments	Dataset Inclusion	Sort order
N	No		AD	1
Y	Yes		AD	2

## Dataset P

### 3.58 Referred for hep C treatment – REFHEPCTX

Code	Text	Comments	Dataset Inclusion	Sort order
2	No		AD	1
1	Yes		AD	2

To support the new dataset, a new BBV guidance form is available and can be found here - <https://www.ndtms.net/resources/public/Event%20and%20Training%20Documentation/CDS-Q/NDTMS%20BBV%20guidance%20CDS-Q%20V1.0.pdf>

### So what does this mean?

The changes in dataset allows us to accurately represent when someone has spontaneously cleared the Hepatitis C virus also known as cleared naturally. This is estimated to happen in around 20-25% of cases, however the data is limited so it is great news that NTMDS is starting to collect this in a robust way. Through the dedicated and meticulous work of our Data Analyst Rob, we will also be able to track those people (anonymously) and see whether they get reinfected, which is another good point about Dataset Q. We should now be able to see when people get reinfected and act quickly, subsequently seeing when there are second or even third referrals for specialist treatment. So, for example if we take Alan's story (which shall feature later in the newsletter) just by looking at his NDTMS data we would have a good understanding of his patient journey.

### British Journal of Nursing – Hepatology Team of the Year 2022



We were exceptionally pleased that the Hepatology nurses from the Queen Alexandra Hepatology unit we work with won this award. They were nominated by staff and patients for their commitment and non-judgemental approach to hep C care. They were incredibly responsive during the Covid 19 pandemic and led the way for the up-scaling of the Wessex Clinical Van service, being the first to adapt their clinics and utilise the van during the pandemic.

Karen Gamble, Hepatology Nurse Specialist, said: *"We were really excited to win this award, particularly having heard the fantastic work of other nominees."*



We are happy to announce the Hep C U Later team and the Wessex Clinical Van have been joined by Clare Skaife, the new Hep C Mental Health Engagement worker. She has written the piece below to give us all a summary of this new exciting role.

The Hep C Mental Health Engagement worker role aimed to engage clients sitting under mental health services across Dorset around their Hep C status. Research shows an increased risk of risky behaviour associated with substance misuse in groups of individuals with significant mental illness. Based on this risk, the role of Hep C mental health engagement worker was piloted as part of the nationwide Hep C elimination program to identify mental health service users who fell into this group, test them for Hep C and refer any positive diagnoses into the local treatment pathways. The expectation was that the mental health engagement worker would build relationships with county-wide mental health services (especially Community Mental Health Teams), assist these teams with identifying clients on their caseloads who were at risk of having Hep C, and implement BBV testing clinics for these teams to refer any of their at-risk clients into.

Retrospectively, most of the barriers that were encountered in this process were to be expected. Community mental health teams are busy and complex services, and despite all best efforts, it was difficult to make significant headway without clear communication and awareness of the collaboration within the mental health teams across Dorset - after all, how can a service accommodate a Hep C testing resource if they don't know it exists? Throughout the duration of this role, a continued effort was made to try and link in with CMHT leads across the area, but eventually sending constant introductory emails without response felt like throwing pebbles at Goliath.

There was success booking a fortnightly spot in a clinic room at a Bournemouth-based building that houses multiple mental health services. This dedicated clinic space ran for 8 months, and in that time a total of just 4 mental health clients were referred for Hep C engagement. The teams were aware of the service offered, because of the presence of the mental health engagement worker on their team meetings - so either awareness of the testing service was lost and forgotten, or there just weren't that many service users to flag as at-risk.



Despite this low turnout, 2 of the 4 people tested came up positive for hepatitis C - the (very) small sample size aside, that's still a prevalence of 50%. These individuals have since been referred to treatment and are now under the care of the Dorset hepatology team. Importantly, these were service users who likely wouldn't have otherwise been tested for Hep C. This is an encouraging sign that the rationale behind offering Hep C testing in mental health services is a very reasonable one - it is just perhaps the implementation of this service that needs revising. A stronger emphasis on multi-agency collaboration and a realistic communication of expectations across all teams involved would have gone a long way to increase awareness, and likely would have also increased the efficacy of the mental health engagement resource.

Where there were fall backs, there were also real strengths to be found. Multiple individuals with complex mental health needs and a positive Hep C diagnosis were seen on the Wessex and Dorset Clinical Van - and due to the presence of the mental health engagement worker, they received targeted, mental health centred support during the referral and treatment process. Having a specialised worker present on outreach to form understanding relationships with these clients meant that we could implement a support plan tailored to the client's specific needs, and consequently remove barriers that would have prevented them from accessing treatment for Hep C. Supporting these individuals on their journey to clearing Hep C was definitely a highlight of my time in post.

## Alan's story

Alan was first diagnosed with hep C in 2013 and referred to Portsmouth Hepatology; he waited for the new Direct Acting Antivirals and started his first course in 2017. Alan achieved his SVR however, during a routine appointment in 2018, he advised the service he had put himself at risk, Alan was retested and found to be reinfected. At that time the guidance was he could not be immediately retreated and Alan spent many months frustrated until later that year he was able to commence his second course of treatment. Alan achieved his SVR and then another routine test a year later showed he had been reinfected, he has since been treated for a third time and 18 months later he is still not detected. Alan spoke to us, as he believes reinfection is an issue and he is determined not to have another one.

Alan says "I have had 2 reinfections and 3 courses of treatment, each time I took my medication as prescribed bar one or two days here and there and each treatment was successful. I was told about the risks of getting reinfected and always supported to get clean needles. However I do think equipment needs to be more readily available and accessible with more chemists signing up to the needle exchange programmes though.

The first time I was reinfected, I was really angry, as I knew I only had one chance at treatment, thankfully the guidance changed and I was allowed to be re-treated. However, this meant that I got complacent and became lazy around clean equipment. I took it for granted that I could get re-treatment. Also the fact the treatment was really easy meant that this wasn't a deterrent as heard horror stories about the previous treatment

I have had incredible support from my drug service Inclusion and Hep C Hants P2P. Portsmouth Hepatology have gone above and beyond in supporting me. I have always been greeted warmly and not once have I felt judged for putting myself at risk. The nurses in particular have been very supportive and have always managed to get my blood. I am thankful they now have a Cepheid machine though and don't need to get venous bloods!"

Karen Gamble Hepatology Nurse Specialist from Queen Alexandra Hospital in Cosham, Portsmouth says

"Alan had been known to the Portsmouth Hepatology nurse led service since 2013 when he first presented with Hepatitis C infection. Alan has so far accessed treatment 3 times for hepatitis c infection. His hepatitis C has been successfully cleared on each of these occasions.

Alan is engaged with needle exchange and is fully aware of the risks for viral transmission. It is his awareness of these risks that means that on the occasions when Alan feels that he may have not used safe injecting practices, that he contacts the Hepatitis C recovery teams for support and re testing- protecting not only Alan from the physical consequences of re-infection but also those around him. Being treated promptly and encouraging those who are also at risk to access testing and treatment reduces the potential pool of infection and moves us one step closer to the WHO target of Hepatitis C elimination.

Information about reducing the risks for hepatitis C and offering and engaging with re-testing for Hepatitis C in those have ongoing risk factors is really important. We have access to very effective treatments for Chronic Hepatitis C these days and these will always be given without judgement".



# Upcoming Events & Contacts

## Hep C U Later Awards

We are thrilled to announce the launch of the Hep C U Later awards.

We have now sent an e form around which you can use to nominate people and teams for the three different award categories. The nominations are open until 15/06/22, and the nominees must be a member of a NHS APA service, or someone who has worked alongside one of these services, which has contributed to the elimination of Hep C.

If you haven't received the nomination form then please email us and we can send you across a copy.



To find out more about Hep C U Later please visit us at [www.hepculater.com](http://www.hepculater.com) and follow us on social media  @HepC\_U\_Later  Hep C U Later

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The work of the Hep C U Later co-ordinators is supported by a great team which includes **Candie Lincoln** (Project Manager), **Rob Fair** (Data Analyst), **Edward Taylor** (Marketing and Communications Assistant) and **Grace Masinuka** (Programmes and Communications Lead).