

# HEP C U Later

*November 2020*

## Quarterly Newsletter

### *In our first edition*

- Find out what Hep C U Later is
- Hear about our recent conference presentation
- Meet our team of coordinators
- Upcoming events
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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 working collaboratively with service users, carers and other organisations and are committed to contributing positively to the on-going development of the addictions field including within drug and alcohol, gambling and gaming treatment.



Hep C U Later is an initiative of the NHS Addiction Provider Alliance (APA).

The reach of the APA extends to over 46,000 service users who are in contact with community addiction services in 78 Local Authority areas and Prison Services across the country. These services have contracts which align with 17 of the 22 Hepatitis C Operational Delivery Networks (ODNs) in England. The 2,133 staff and volunteers of APA members provide addiction services to approximately 35% of all drug and alcohol service users engaged in the English treatment system, and there are strong links between providers.

Data from the Unlinked Anonymous Monitoring (UAM) Survey of HIV and viral hepatitis amongst people who inject drugs<sup>1</sup> (PWID) shows that the number of participants with antibodies to hepatitis C (HCV) and markers of chronic infection (RNA) has decreased from 58% in 2011 to 42% in 2019. According to PHE, 2020 this corresponds with the timing of the scale-up of direct acting antiviral treatment for HCV among PWID. The same report also details that we have an aging cohort of people who inject drugs with the median age increasing from 35 years in 2010 to 40 in 2019. The UAM reports no marked reduction in the number of new hepatitis C (HCV) infections over recent years

**Hep C U Later draws on the existing best practice and by forming a system-wide partnership to address and eliminate HCV, we can encourage the innovation necessary to better address the needs of this cohort of people, and we can support more than 6,000 additional patients into HCV treatment.**

<sup>1</sup> PHE, 2020 Unlinked Anonymous Monitoring (UAM) Survey of HIV and viral hepatitis among PWID: 2020 report: Health Protection Report Volume 14 Number 18.

### Partners

The HCV Operational Delivery Networks (ODNs) are key partners for Hep C U Later. ODNs are focussed on coordinating patient pathways between providers over a wide area to ensure access to HCV resources, expertise, and treatment.

A second key partner for Hep C U Later is Gilead. NHS England has entered into an innovative 'new deal' with three major pharmaceutical companies including Gilead. Hep C U Later is working jointly with Gilead to identify and facilitate access to treatment for large numbers of hepatitis c patients within APA member Trust services.

A third key partner for Hep C U Later is the Hepatitis C Trust. Throughout the country where APA member Trust services are, teams of Hepatitis C Trust trained peer volunteers – people with lived experience – are helping to identify and test high risk individuals for HCV. They engage with them, and provide them with the support and help they need to access effective HCV treatment.

## ***The annual NHS APA Conference***

Due to Covid-19, this year's APA conference took place online and free of charge for all on 9th September 2020. The title was "What does good look like during and after Covid-19?". The conference was very well-attended and well-evaluated. All presentations are available to watch online here: <https://www.nhsapa.org/conference-2020>

As part of the conference, the Hep C U Later team delivered a Breakout Session on the project and social media campaign. It is available to watch here: <https://www.nhsapa.org/post/bos-1-2020conf>

We were keen to hear the views and feedback from those who attended the session to find out what they took from it and suggestions for the future.

**We asked *Francine Cooper*, Commissioning Officer for substance misuse services in Tameside, on the East of the Greater Manchester conurbation. She is also the Lead commissioner for BBVs across Greater Manchester, and works closely with PHE, the Greater Manchester Health and Social Care Partnership, and Greater Manchester Combined Authority.**

*"It was a pleasure to see the Hep C U Later workshop at the online NHS APA conference this year and listen to the views of experts in the field of Hepatitis all in one place. During the current Covid-19 pandemic, issues such as hepatitis c are in danger of being neglected, so it is more important than ever that we pursue the target of eliminating this virus.*

*The presentations covered a lot of ground and were impressive. I was particularly pleased to see such a good coordination of the programme and a focus on the shared work the programme is doing nationally.*

*At a Greater Manchester level, along with Public Health England we have agreed a set of Minimum Service Standards we are proud of. These were developed fully with all providers who were working in the GM field of work and agreed with Commissioners and all GM Directors of Public Health. Implemented last year, we have come a long way in our local understanding of this virus.*

## ***What do we need to be focusing on?***

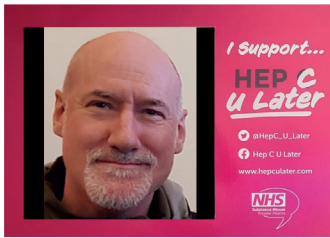
*The Who, Where, How & When - A lot of areas in GM now have a good handle on their 'in treatment' population. This is a great step forward. Now we have to be thinking further ahead: viruses spread, people re-infect, treatment is key, but learning is important. We know that hepatitis c can lay dormant for decades and around 80% of people do not even know they have contracted it. A lot of the myths around this virus can be dispelled easily and the virus is upwards of 95% curable. Treatment is not the dinosaur it once was(!) but hepatitis c can cause serious damage to the liver or even death if left to its own devices. So we need to work together to find the undiagnosed population and engage them in an understanding and treatment.*

*Who is next? Where are they? Could a partner help us? How do we engage people in testing and treatment? When is the best time and place to capture their interest?*

*Data - One issue is the reliability of our data. Recording issues can be difficult in busy services with multiple clients and multiple client issues, repeat requests and revisits. However, more than ever we need recording to be accurate. We need data we can rely on and we need it in real time.*

*Funding - If we want to go further and eliminate, there has to be more understanding of the costs involved in reaching those people who are undiagnosed and who are unwittingly carrying this virus. This issue has to be recognised for what it is - a largely curable virus with easy treatment that could save the lives of thousands."*

# Meet our team of coordinators



**Hello. I'm Simon** and I'm the Hep C U Later Coordinator for the North. My job is to help and support staff from our member Trusts in their work on HCV micro-elimination. So, if you are employed by Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW); Derbyshire Healthcare NHS Foundation Trust; Greater Manchester Mental

Health NHS Foundation Trust (GMMH); Leeds and York Partnership NHS Foundation Trust (L&YPFT); Pennine Care NHS Foundation Trust; or our newest member, Rotherham Doncaster and South Humber NHS Foundation Trust (RDASH), then this means you!

Since the pandemic started, most of my work has involved working from home remotely. Nevertheless, it's been busy and exciting.

My working week is varied but one day it might involve attending one of your service meetings to hear about progress you are making, or sharing some best practice guidance with you and your team that may help you in your work. Another day, I may be talking with colleagues in our partner organisation The Hepatitis C Trust to think about how we can help their trained peers get involved in your service in order to help make testing and access to treatment even better for the people on your caseloads.

Every day can be different. But it is all about helping you do the best job you can to help the people using your service get free of HCV, and micro-eliminate HCV from your service. Good luck, and I look forward to working with you!



**Hello. I'm Paul** and I am the lead coordinator for the Hep C U Later programme but also the coordinator working specifically in the Midlands. The coordinator role is incredibly varied and enables me to work directly with the partner trusts across the area as well as ODNs and individual services. This means I have the opportunity to get

a real sense of how services are functioning and what's important, to all teams, an on the ground as well as at the Trust and ODN levels. Ultimately its about relationships so make sure you find out more about the Hep C U Later programme and what we , together, can do to improve the knowledge and access to hepatitis c treatment for your service users.

The second part of my role, as the lead coordinator is to ensure we are bringing together the many elements that make up the complex world of hepatitis c in such a way that we share the best practice and information across our regions but also support implementation of those best practices, latest research, access to training or other resources and to help create more efficient pathways.





**Hello. I'm Louise** and I'm the Hep C U Later Coordinator for the South. Having waited 2 years for this project to start you can imagine how frustrated I was when COVID hit. However never one to miss an opportunity I have focused my efforts on meeting people virtually and supporting some of my services to do patient auditing. Along with this I have been involved in several testing events across the region,

I have worked in substance misuse for over 14 years and I am passionate about empowering people to make changes and tackling discrimination. I bring my experience of setting up hep c peer to peer schemes, delivering training and applying for innovation project funding to the Hep C U Later mission. I am also in recovery and had my own experience of hepatitis c which I will freely share to empower others

I'm excited to be part of the once in a lifetime opportunity to eliminate hepatitis C, and would say to anyone working in this field, persevere it is very rewarding and you never know when your intervention will sink into place and the person will take action. I'm looking forward to the day that I can tell my grandchildren what my part was in a worldwide quest to eliminate hepatitis.



Join us and like, share or retweet our posts on social media channels to raise awareness. You can also promote your hepatitis c elimination activities by tagging us and using the #HepCULater hashtag

@HepC\_U\_Later Hep C U Later  
[www.hepculater.com](http://www.hepculater.com)



## ***Charles Stewart...a sad loss...***

We are saddened to hear of Charlie's passing on the 9th October. Charlie was diagnosed with liver cancer in 2018, after living with hep c for around 20 years. He received life-

saving intervention and treatment quickly and successfully overcame cancer (and hep c). Unfortunately this September he was diagnosed with secondary cancers and after a very short illness he passed away peacefully. Charlie was a huge advocate of early testing and treatment, following his own experience and his story of hep c elimination can be found on our website.

***This story emphasises the importance of early testing and treatment.***

## ***A time to remember...***

During the development of this newsletter we were made aware of the passing of several people who have contributed significantly towards addictions services and their wider communities during their lifetimes.

We were unsure how best to pay tribute to those concerned in a respectful manner, and without causing their families or loved ones further upset.

Therefore, we shall be asking close colleagues and family of those concerned to pen a short tribute to be included in future editions if they are happy to do so.

### **10th November 2020: The next All-Party Parliamentary Group on Liver Health**



The Hep C Trust have made us aware of the next meeting of the All-Party Parliamentary Group on Liver Health, which they help to run.

Part of the meeting will feature an update from Mark Gillyon-Powell from NHS England on hep C services amid Covid and the impact on progress towards the elimination target. The meeting agenda is to the right and the joining instruction are below.

**Location:** <https://us02web.zoom.us/j/84937687011>

**Meeting ID:** 849 3768 7011

**Time:** 15.00-16.00

#### **Agenda:**

**15:00 - 15:05**

Welcome and introductions (*Sir David Amess, Chair, APPG on Liver Health*)

**15:05 - 15:30**

Effect of Covid-19 on hepatitis C services and progress towards elimination (*Mark Gillyon-Powell, Head of Programme - HCV Elimination, NHS England*)

**15:30 - 15:55**

The Commission on Alcohol Harm's 'It's Everywhere' report (*Jennifer Keen, Head of Policy, Institute of Alcohol Studies*)

**15:55 - 16:00**

AOB

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

For general enquiries, please email us at [HepC.ULater@mpft.nhs.uk](mailto:HepC.ULater@mpft.nhs.uk)

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