NHS Addictions Provider Alliance (Formally the NHS Substance Misuse Alliance) – Hepatitis C Patient Identification

Joint Working Outcomes Summary

Parties to the Joint Working:

1. The Midlands Partnership NHS Foundation Trust (MPFT) of Trust Headquarters, St Georges Hospital, Corporation Street, Stafford ST16 3SR

2. Gilead Sciences Ltd, a company registered in England (registration number: 02543818), having a principal place of business at 280 High Holborn, London WC1V 7EE

Start Date: July 2019

This report summarises outcomes to March 2022.
The Programme of Work was extended in March 2022 and again in September 2024 and completed in March 2026.

For further details please see HepCULater - Hepatitis C Patient Identification Collaboration Executive Summary - UKI-UNB-2821

UKI-UNB-2825 | Date of Preparation 06/2026

Outcome Summary and Project Learnings:

A full impact report is available – for further details please see HepCULater Impact Report – UK-UNB-2529 / November 2022

Highlights:

Using Data and Information to support Micro-Elimination

Within the last year, following extensive consultation, we have focused on building an improved system for monitoring the NDTMS data we receive from our NHS APA members. This new 'dashboard on a page' report, sent monthly, allows each member Trust to monitor their own data across a number of fields, track progress, identify barriers and mark their progress against micro-elimination measures.

Using the 'dashboard on a page report' has led the Hep C U Later project to identify:

- Issues with NHS APA member data systems where hepatitis C data is not pulled through to NDTMS effectively
- Where training may be required for staff to ensure the correct recording of hepatitis C data
- Anomalies within the data
- Which services may require additional resources or input
- Which services are closest to micro-elimination
- The level of testing required by each recovery worker in a service to reach micro-elimination
- Cohorts of people to target testing

As a result, the Hep C U Later Project have undertaken schemes of work to resolve issues or address trends which the data has identified, for example:

- A high rate of the status 'offered and refused' was identified in one area, which led to the Hep C U Later team delivering training to staff. This training focused on engaging service users in testing using the 'opt out' approach and utilising peers from the Hepatitis C Trust.
- A member Trust reported that their testing numbers did not appear in line with the data held by the Hep C U Later team. This led to the Hep C U Later team undertaking a deep data dive and discovering that data was being inputted in a different area of the system and therefore the testing data was not captured by NDTMS. The service produced guides to support their staff in the correct process for recording.
- Several deep data dives in partnerships with ODNs – ensuring service user's records across both disciplines are accurate. As a result, one service updated 71 sustained viral response results (Sustained Virologic Response (SVA) – post treatment results).

Patient numbers of those who require testing have been sent monthly to a number of member Trusts to support them in inviting cohorts who are at risk of hepatitis C in for testing. Equally, lists of people with a hepatitis C RNA (ribonucleic acid) positive status have been sent to providers on a regular

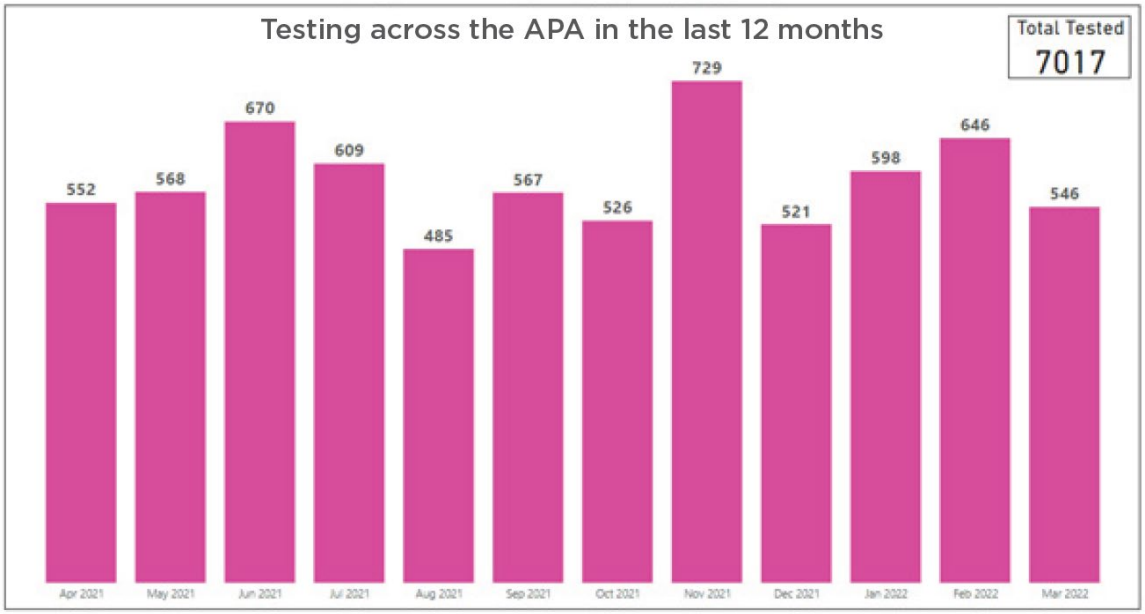
basis to support their internal data quality work and to compare with the ODNs to ensure those who have had treatment are updated on their system.

Each NHS APA provider who is supplying the Hep C U Later team with data has received a bespoke presentation on their data, what it shows and what steps they need to take to reach micro-elimination. We have found this method to be extremely motivating for services.

Hep C U Later recognise there is more work to be done to resolve system issues which have an impact on data and have launched a quarterly Hep C U Later Data Forum in May 2022.

Testing Data:

The bar chart below shows the NDTMS testing data for the NHS APA for active service users from April 2021 to March 2022. A total of *7017* hepatitis C tests were taken.

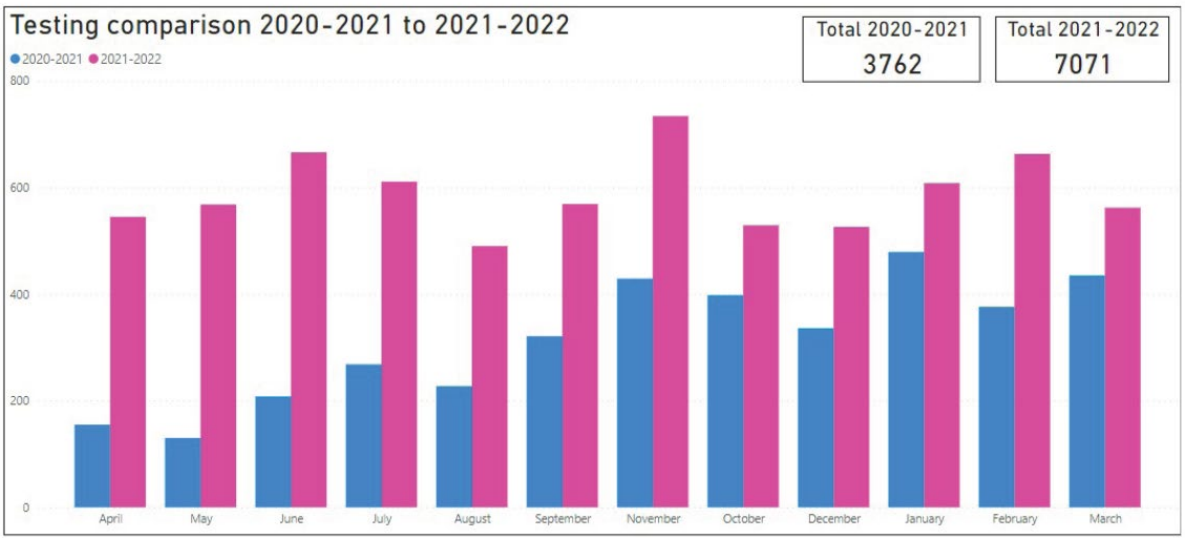


The bar chart below shows the monthly testing numbers for each month, comparing the year April 2020 - March 2021 to the year April 2021- March 2022. Every single month in the year April 2021-March 2022 saw an increase in the numbers of people tested in comparison to the previous year. The highest testing month was November 2021.

It is important to note that this data shows structured and active clients only, not those who have been discharged, and therefore testing overall will be a higher number. Also of note is that due to a delay in the more recently taken results being received, a lag can occur in the last 3 months the data captures. This means when each subsequent monthly report is compiled there is an increase seen in these months.

- The number of tests carried out across the NHS APA in April 2020 – March 2021 was *3762*.

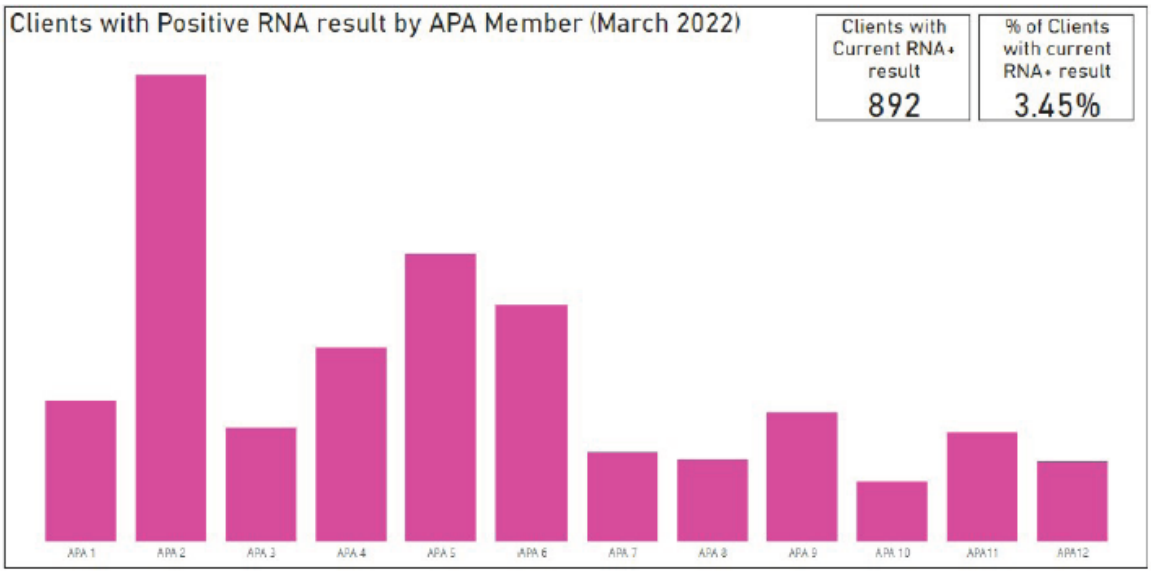
- The number of tests carried out across the NHS APA in April 2021 – March 2022 was *7071*.
- We have nearly doubled our testing in April 2021 - March 2022, with an *86.97%* increase in testing over 2020-2021.



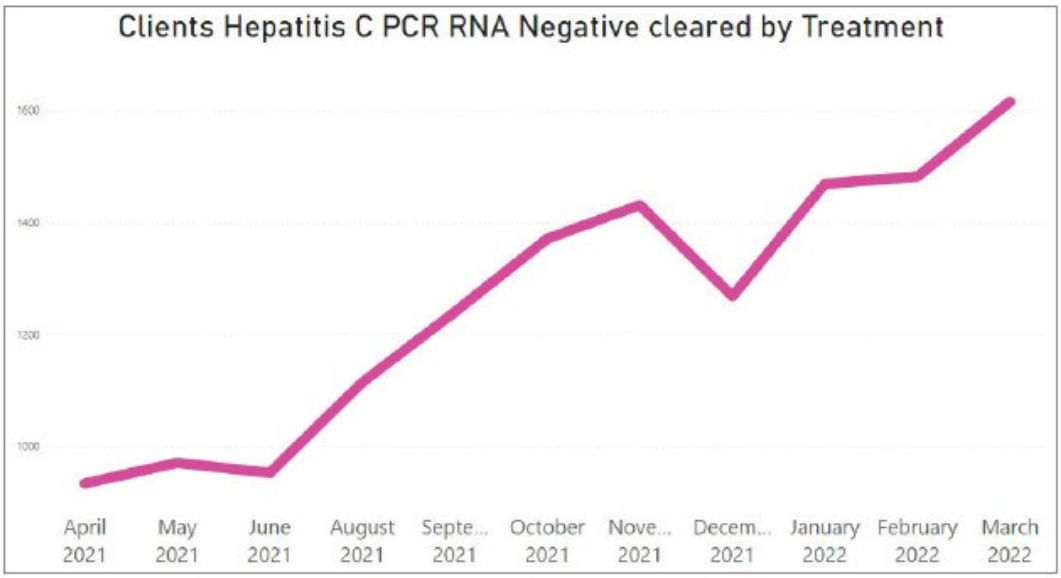
Treatment Data:

The data below shows the number of RNA positives listed within each NHS APA service. It is worth noting that the number displayed on the graph will include those who have treatment planned, or have had treatment and are awaiting a sustained viral response test and therefore this has not yet been changed on the clinical systems. Therefore, the number of service users left to treat is lower than shown.

The total number of people listed as RNA positive across the APA on the 31st March 2022 was *892*.



The data below shows the 'RNA negative – cleared by treatment' data for active service users across the NHS APA from April 2021 to March 2022. There was a noticeable dip in December 2021 which is likely due to a mixture of the Christmas holidays and staff sickness reported by member services at that time, however, the number of those listed as 'RNA negative – cleared by treatment' has continued to increase steadily



We have significantly increased the number of those listed as 'cleared by treatment' compared to the previous year.

In this past year we have referred an average of 40 people per month to treatment across the NHS APA.

Contributions from Each Party:

Gilead Resources

Gilead will directly fund a number of new NHS posts to work on this project at a cost of £250,000 per annum, contribute some of its own staff time and expertise, and provide at its discretion further direct financial investment to the project, as follows:

- HCV data analyst – 0.6 FTE

- HCV Coordinators – 3 FTE

Gilead staff who will contribute time and expertise:

- Regional Market Access – 0.5 FTE
- Gilead Regional Leads – 1.75 FTE
- Therapeutic Specialists – 0.8 FTE

Additionally:

Gilead will make available a development and Testing fund against which competitive bids can be made to aid pathway development and remove barriers in local services and will also make available a year 1 contribution of £15,00 to support NHSE's development of the HepCULater awareness raising campaign.

NHS partners will contribute significant staff time and resource:

• Medical Lead – Inclusion will support pathway management
• Clinical Care Director and Head of Quality will provide quality assurance
• Head of Inclusion and Commercial and Information Lead will provide staff management
• Head of Inclusion will support trust engagement with partners
• Head of Inclusion will provide representation on project steering group
• Development Officer will support organisation of project steering group meetings
• Medical Lead – Inclusion, Clinical Care Director and Head of Quality will provide support on clinical governance and design

Above and beyond activity for which they are currently commissioned and working at a local level each participating hospital trust with be contributing time and resources to the project to ensure that effective provision is in place to test people at risk, identify and engage people and to ensure specialist treatment is in place at the point of need.
This may include, but not be limited to, the provision of testing kits, phlebotomy, nursing time and key worker staff time, line management, operational and logistical support, clinical space and resources, internal training, supervision and governance and wider networking activity with local partners that engage with at risk individuals.

The Hep C U Later campaign will be developed and delivered solely by the NHS. They will contribute staff time and expertise to:

- Development and dissemination of the campaign, supporting materials, website and social media feed
- Creation and dissemination of monthly project bulletins to key stakeholders;
- Organisation of bi-annual engagement events
- Development of expert patient involvement group to support the project
- Development and dissemination of case studies and Service User stories