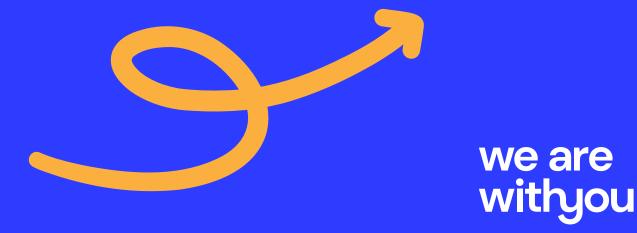
# Hepatitis C Elimination Impact Report

2022 - 2023



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## Introduction



It's an honour to be part of such a valuable and rewarding project. I'm enormously proud of the partnerships, the project, the services and all of the dedicated champions and teams who are working tirelessly to make the ambition a reality and providing life-saving interventions."

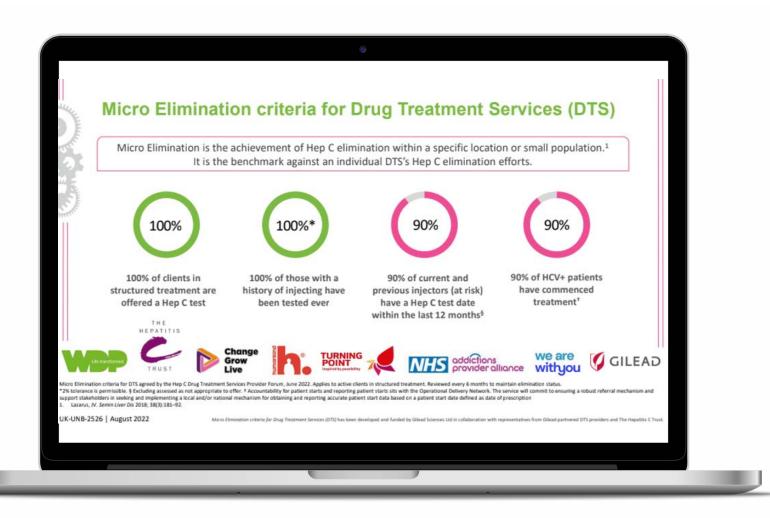
Emma Lamond, Director of Integrated Treatment and Project Lead

The With You National Hepatitis C Elimination Project, funded by Gilead Sciences, was set up in response to NHS England's ambition to eliminate viral hepatitis by 2025, as part of the international effort to eliminate viral hepatitis as a global health threat by 2030.

To strengthen our ability to achieve this goal, we extended our partnership with Gilead Sciences until March 2024. As a result, we restructured the project team to include two Regional Coordinators. By introducing Regional Coordinators and adopting a strategic, clinical and data analytical

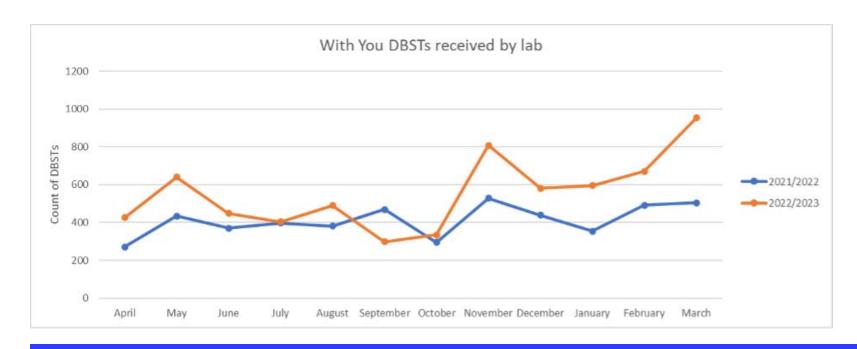
approach, we were able to better support our services and intensify our efforts. We're extremely grateful for the investment and support provided by Gilead Sciences, which has been instrumental in helping us and our wider partners work together in our mission to eliminate hepatitis C.

## Micro-Elimination



The Provider Forum, a collaboration with Gilead Sciences, NHS England, The Hepatitis C Trust and Drug and Alcohol Providers, worked together to develop a set of criteria for measuring Micro-Elimination. This measure (shown in the image above) serves as an important milestone towards the wider ambition of elimination, testing and earlier intervention and treatment for those in a higher-risk population within Drug and Alcohol Services.

## **Impact in Numbers**





A higher number of people tested, combined with a smaller number of positive cases found, indicates that we are on our way to eliminating hepatitis C.

#### Over the last year, With You has achieved some fantastic results:

- We completed
   6652 Dry Blood
   Spot tests (DBSTs).

- This is a 35% increase in testing across our services compared to the previous year.
- those tests came back **positive**, compared to 1 in 11 the previous year.
- 308 people started hepatitis
   C treatment.



# Raising Awareness and Enhancing Education

A large part of our project centres around actively raising awareness and changing the culture towards testing and treatment. Whilst the micro-elimination approach enables us to focus our efforts on the high-risk areas, our ethos from the beginning has been to normalise testing and embed it as part of core services.

We recognise that clients may not always disclose their past injecting history or other risk factors. That's why we want to challenge the stigma that surrounds hepatitis and normalise carrying out a DBS test when accessing our services. We still hear many whispers and misconceptions that prevent individuals from seeking testing or treatment. Through this intervention, we have an opportunity to bust those myths, raise awareness, and empower people to stay safe and make informed decisions.

The awareness sessions, training, and continued focus across all levels of our organisation are creating a positive impact already. Our staff are finding positive results for people they wouldn't have expected, which only further reinforces the need for and importance of testing. These successes serve as motivation to have those vital conversations and encourage testing.



"Sarah\* initially accepted a test, but later refused stating she hadn't put herself at risk. As part of the awareness work we're doing on the Elimination project, her worker revisited and she tested positive. Sarah was really shocked, and I think because she had always smoked drugs while in treatment it would be easy to miss that she had injected at some point. She's now cleared the virus and is currently doing really well"

Kate House, Service Manager Scunthorpe \*Sarah's name has been changed for confidentiality



"From the moment I joined With You, it's been highlighted how important BBV testing is and the benefits of testing for our clients. But with the demands of the role and the everyday emergencies that arise at times, I would push testing to the back burner. I could not be more thankful, thankful is the only word I can think of really, that on that day my client arrived, I made the time to do a DBST. This positive result has shown me how vital these tests are."

Hannah, Project Worker Wigan and Leigh

#### To facilitate these successes further, we:

- successfully implemented an online BBV learning package and toolkit in collaboration with the Learning and Development team.
- tailored the resource to suit front-line workers & designed a supplementary toolkit to assist managers in

- supporting their teams in effective BBV interventions.
- made our introduction to BBVs and the Elimination project a mandatory induction segment for all new staff.
- continue to run workshops and refresher sessions on specific topics, such as managing hesitancy for testing or treatment, at team meetings, team workshops or info sessions.

Our hepatitis C staff champions and Regional Coordinators play an essential role in guiding the success of the project. In each service we have champions who provide support, raise awareness, and drive testing and treatment. To help promote knowledge sharing and teamwork, the project runs monthly champion forums where representatives across the organisation come together to:

- · share what's working well.
- address challenges.
- · review project performance.
- engage in continued professional development with both external and internal speakers or skills practice sessions.

Managers within the project also meet regularly at either the Managers Hepatitis C Elimination Forum or internal board meetings where BBV and hepatitis C elimination is a standing agenda item. By running the project from the Board of Trustees and Senior Leadership all the way to the frontline workers, we ensure our commitment to eliminating hepatitis C is embraced and understood at every level.

"Having an Eliminating Hepatitis C Regional Coordinator supporting us has enabled me to have the exact data needed to target our more reluctant clients, and has increased my confidence in knowing who to target more efficiently. She's helped us to have a greater understanding of what we are trying to achieve and how much progress we are making towards that goal."

Donna Waugh, Health Care Assistant With You Boston



"Being a Regional Coordinator has been incredibly rewarding, and allowed the project to build upon existing relationships

with services and tailor support to their specific needs. We've seen a marked increase in testing since the role began, and it's been an absolute pleasure to see services make increasing progress toward the goal of elimination".

Susanna Rhodes, Hep C Elimination Regional Coordinator





# **Testing**

"The client was adamant that they wouldn't test positive for hepatitis and were certain they had not put themselves at risk. The client did a test and tested positive. The positive result was really unexpected for them, and they struggled with the diagnosis as they were so shocked. It was a catalyst for them to engage with treatment, which they are continuing to do so. The impact of being tested highlighted the importance of getting a test and enabled them to then prioritise their health. It also emphasised the likelihood of putting themselves at risk without remembering that they had."

Liverpool Staff member on the experience of one of our Liverpool clients

Despite the impact of the pandemic on our testing activity, we were determined to make significant progress towards micro-elimination. To assess the situation, our project conducted a thorough analysis to forecast the potential outcome if testing continued at the same rate. Unfortunately, the results indicated that our services would not achieve micro-elimination by our internal deadline.

This served as a serious call for action. Whilst the testing activity required looked

challenging as a whole, breaking it down into individuals made it more achievable. We worked out how many tests each keyworker would have to undertake on a monthly basis to achieve micro-elimination and, in response, each service developed an action plan to turn this picture around.

As a result of this change, we witnessed a remarkable 51% increase in the number of tests and an overall increase across the micro-elimination criteria. This piece of work put us in a good position for micro-

elimination, and we have continued to see progress and positive impact since then. The findings were shared within the Provider Forum, and have since influenced the inclusion of a forecast measure in the Tableau dataset developed by Gilead.

At With You, we recognise the importance of champions and leads to help drive testing and progress towards elimination, but we firmly believe it cannot sit with one person. The magic happens when it becomes a collective responsibility.

### A Closer Look: Darlington

With You Darlington exceeded the call for action challenge by achieving a 141% increase in testing activity compared to the previous year.

Initially, the service faced obstacles in making progress towards elimination, primarily due to only one person leading the testing. Realising the need for transformation, they came together as a team to tackle the challenge head-on. Along with a number of elimination initiatives, testing was introduced as part of the assessment process, and all staff were to undertake testing.

The service's collective efforts had a remarkable impact on their elimination performance. Referring back to the micro-elimination measures:

- Criteria 3 saw an increase from 37% to 71% over a 6-month period.
- In the non-injecting cohort, we saw an increase of 13% to 48% (Criteria 3) & 32% to 64% (Criteria 2).
- The no. of positive incidences within the service showed a reduction of 26% compared to the previous year.



## **Making Every Test Count**

At With You, we know that testing someone can often be a challenge, so reducing the need for retests and making sure every test counts is essential.

To reduce the number of failed tests, promote accurate testing and further understand the picture, we:

- completed a full audit.
- introduced a monitoring framework development.
- shared additional guidance and refresher sessions.
- raised awareness by sending out communications.

## **Ensuring Internal Accessibility**

Our passionate and committed BBV and hepatitis C elimination champions across the country are always looking for ways to help colleagues and simplify the BBV testing process. By introducing easy-to-use prompt cards in all rooms with testing equipment, staff have a visual reminder of the process to hand.



#### **Campaigns and Community Outreach**

"With the implementation of joint working groups, testing stations and drive days, we have seen a significant increase in the amount of people we are testing, which in turn moves us closer to the goal of elimination. It's been inspiring to see everyone pull together for such an important cause!"

Sophie Morgan, Team Leader, Shropshire Recovery Partnership

In addition to our business-as-usual testing, services run a series of testing drives and campaigns within services and out in the community. These initiatives not only intensify our testing activity but also expand our reach and raise awareness. We enjoy utilising all these important and wonderful events to educate the wider public and get ourselves known in the community. For those a little further out, the use of community testing vans help us gain that reach and ensure access to testing and treatment for those in need.

Scunthorpe service getting ready for testing



With You Cornwall raising awareness at Pride in partnership with The Hepatitis C Trust and Royal Cornwall Hospitals NHS Trust.





Joint testing event in Birmingham, With You Shropshire with The Hepatitis C Trust, ODN and Hospital Trust.



## **Treatment**

"I can't believe that people do actually care. I couldn't get into the service, I wasn't feeling well and it's hard to get into town. The nurse and a Hepatitis C Trust Peer came to me. I'm so glad they did, I had a scan and the nurse said I had liver cirrhosis. I couldn't believe how quickly my treatment started. I'm so glad I got tested."

## John, Service User, Cornwall

Across all of our services, we have strong partnerships and pathways into hepatitis C treatment with our local hospitals and ODNs. These collaborations have proven instrumental in reducing barriers to access. Our services have been successfully hosting treatment clinics within our centres, bringing care closer to those in need. As we grow nearer to elimination in Drug and Alcohol services, we recognise that these treatment clinics may be required in other areas of the community. To achieve a sustainable future, we need to widen our partnerships with Hepatology for other liver-related conditions which will allow us to keep our work ongoing.

We're working with our wider partners and the Provider Forum to share learning and explore different models as to how we can each play a role in bringing treatment to the point of contact. Watch this space as we continue to take proactive steps towards creating a more accessible system for all.

## A Closer Look: Wigan and Leigh

Our Wigan and Leigh services have made great strides in supporting service users into treatment. This year, they've managed to engage **seven service users** who had previously declined treatment for up to three years.



"The first thing
I did was an
audit of every
opiate service
user, so I knew
who needed
support. We
identified those
who hadn't been
retested and

encouraged them to test and if still positive, enter treatment. We have hepatitis C nurses delivering a clinic on site and we now offer testing as standard at our needle exchange. We work with a number of different organisations: local prisons, local hospitals, the ODN and The Hepatitis C Trust so we can provide the best support possible in the community."

Harriet Hardaker, Specialist Substance Misuse Nurse

## A Closer Look: Cornwall and North Somerset

Following a successful integrated model of care\* for those with hepatitis C developed by our Cornwall service, we expanded this programme into North Somerset. Our North Somerset service introduced a variation of this model where the Bristol Royal Infirmary (BRI) established a hepatitis C outreach clinic at our centre, and since it started, the uptake for hepatitis C treatment has risen from 25% to 80%.

\*The Cornwall model is a flexible serviceuser-focused model. The model facilitates community-based treatment, significantly reducing the barriers to accessing treatment.

As we came closer to elimination and the number of positive hepatitis C diagnoses declined, this approach became unsustainable for the hospital. Drawing from our valuable experience in Cornwall, we were able to offer an alternative solution. Our With You Nurse Prescriber, James Brazier, took on the role of delivering hepatitis C treatment under an honorary prescribing contract with the BRI. Equipped with assessment and prescription training from the BRI, James began working as part of the

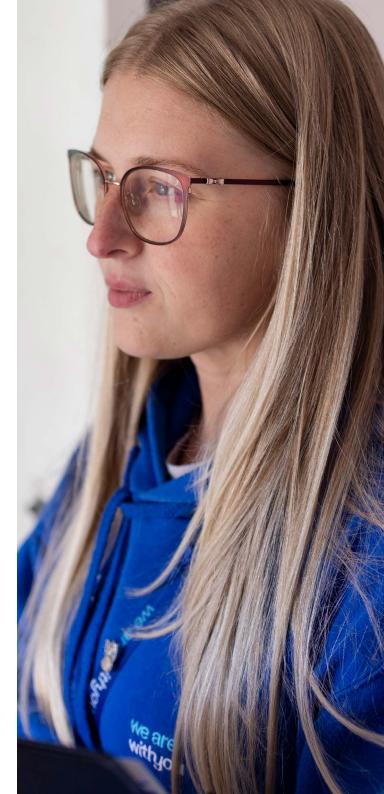
multidisciplinary team, making decisions regarding treatment. This proactive measure not only helped to relieve hospital resources, but it compressed the time between diagnosis and commencement of treatment.



"Our service users are not hard to reach. Using our inhouse clinical expertise, we are working on bringing prescribing

of HCV treatment into more of our services. Our ultimate vision is that all of our prescribers are trained to prescribe HCV treatment, bringing the service closer to the service user".

Helen Hampton, Queen's Nurse, National BBV Lead and Viral Hepatitis Nurse Specialist



**Working in Partnership** 



## Thank you!

We've seen first-hand the immense value of working in partnership. Sharing insights and ideas, reflecting on our learnings, and collectively tackling challenges have been the backbone of the partnership's successes.

We extend our heartfelt appreciation to all our invaluable partners: The Hepatitis C Trust, the ODNs and treating hospitals, our colleagues in other Drug and Alcohol services, Gilead Sciences, Patient Access to Care teams, NHS England, and our wider partnerships. Your unwavering support, guidance, and collaboration have been instrumental in our achievements.

We also express gratitude to our internal teams: the data and transformation team, communications team, executive members, trustees, senior leadership team, clinical team, and all our dedicated colleagues in front-line services. Your tireless dedication and commitment have made a profound impact on our project's success.

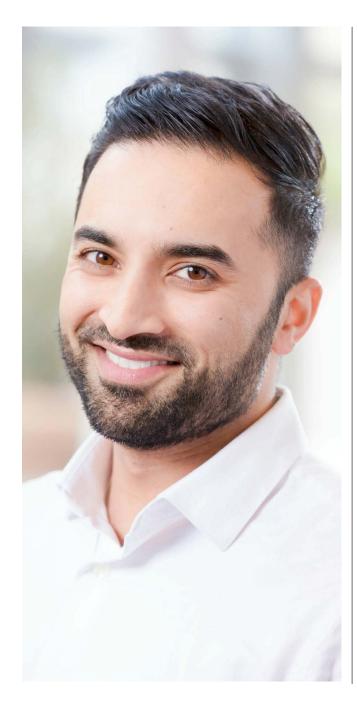
We simply could not achieve our goals without your support - **thank you**.

## Partnership in Action

The partnership created by Gilead has helped the Drug and Alcohol sector transform from a position of competition to collaboration. Set up and led by Gilead, the Drug and Alcohol Providers forum brings together providers, the Hepatitis C Trust, NHSE and Gilead leads.

Together with support from the dedicated Gilead Patient Access to Care Team, the partnership has achieved so much – from planning large–scale joint testing campaigns and shared communication plans to the introduction of micro–elimination measures and BBV quality standards.

The impact of this partnership can be seen throughout our organisations, and in the progress we're making towards elimination. With thanks to Gilead and the wider partners, a supportive, passionate and determined community has been developed that continues to grow from strength to strength.



"Gilead Sciences and We Are With You have forged an exceptional collaboration, seamlessly operating as a cohesive team. Together, we have spearheaded targeted testing, assisted on data analysis, facilitated smooth linkage to care, ensuring stakeholders are working together effectively, and shared invaluable insights for swift implementation. This true partnership has been instrumental in devising and executing strategic plans, and driving us closer to our shared mission of eliminating hepatitis C in England by 2025."

Irfan Chhipa, Patient Access to Care, Senior Manager

We've had the opportunity to speak at a variety of national or local events and conferences to share and hear from others. Owing to our partnership with The Hepatitis C Trust and Nottingham Operational Delivery Network (ODN), a great opportunity arose for our Lincolnshire service to introduce rapid testing for hepatitis C.

We recognised a higher rate of positive diagnosis compared to other sites, and as a result of the established partnership, our service was able to gain access to a Cepheid machine. This transformed their ability to quickly diagnose and support positive clients into treatment. The service now runs regular drop-is for instant testing and, with its transportability, is taking the machine out to rural satellite locations.

### During the Cepheid pilot:

- Lincolnshire completed 201 tests and found 19 positive results
- Boston completed 77 tests and found 8 positive results.



Lincolnshire at the ODN meeting in partnership with The Hepatitis C Trust



"Partnership working and sharing information has been essential to our micro-elimination efforts as we track down those last patients that require access to testing and medication to ensure that no one is left behind.

Our partnership working has been exemplified by the Cepheid project. Led by our Hepatitis C Trust Peer Lead in collaboration with With You and the Pilgrim Hospital, Clint (Hepatitis C Peer Lead), Donna (Healthcare Assistant With You Boston) and the team have been able to reach clients across rural Lincolnshire and tested 206 clients with 20 positives detected."

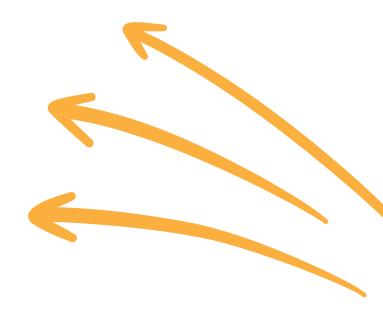
Sarah Montague, Nottingham ODN





"By working in partnership with
The Hepatitis C Trust the service
not only managed to dramatically
increase its testing figures but
also saw a greater interest in
hepatitis C and its prevention and
treatment, as the word spread
amongst clients and staff. Clint
really caught the attention of
those who were having the test as
they could relate to him and felt at
ease asking him questions."

Roger Firth, BBV Lead With You Lincolnshire



# System and Data Collection

"Whether it's being able to help develop the system improvements, create solutions for better information sharing or share the insights from the data analysis to inform or change practice, I'm really proud of what we've been able to achieve so far and the role data has played in our ability to progress towards elimination and help our services and ultimately our clients".

Zivile Sarakauskiene, National Data Analyst

The project's forums, connections with frontline services and expertise in data have allowed us to enhance and improve our systems. These improvements have empowered our workforce to record BBV interventions, highlight risks and track treatment progress. Notably, the data quality has seen a significant

improvement, with a noticeable reduction in the number of errors and anomalies. Our teams are reporting back with pockets of positive feedback thanks to these system improvements, and we've even worked with our wider partners to make recommendations to national data sets to help us track and evidence microelimination in the future.

"The system improvements and live reports have really helped us as a service, we can more easily track positive cases to ensure no one slips through the net and better identify and monitor those who need to be (re)tested. As a result of the improvements and joint working we're making really good progress towards elimination".

Kay Warwick, Clinical Lead Redcar and Cleveland



"Since the Hep C Test Due Date function went live, keyworkers have more ownership and awareness of their clients BBV

status. The colour coded prompt that is live in the system serves as a visual reminder and encourages them to ensure they are testing and continually reviewing their clients' BBV status. It also flags those who are positive so they can help to keep track of the treatment journey."

Serena Lenz, Hep C Regional Coordinator

## Recognition and Accomplishments

After making it through to the finals at both awards, we are thrilled to have won the HSJ Partnerships Award for the category of Best Healthcare Analytics Project for the NHS, as part of the Hepatitis C Elimination Providers Forum.

This was a huge achievement for the partnership and a positive recognition of what can be achieved by working together. Developing a common data set and a mechanism to report and analyse the data was no mean feat, but a testament to collaboration. Our wider partnership with NHS England and Gilead Sciences was instrumental in achieving this recognition, and we're very proud to have been part of this wonderful achievement.



# **Learnings and Looking Forward**

"I'm proud of the team's progress this year. It's been fantastic to see the ramping up of our testing and treatment programme and the encouraging feedback from clients and staff to the changes made. I'm also delighted that our work, alongside partners, was recognised at the HSJ awards. We still have work to do as we near the wider NHSE elimination ambition and we are committed to ensure Harm Reduction initiatives like this continue to be high priority for the organisation."

## Belinda Phipps, CEO

We know that the closer we get to microelimination, the harder the goal will become. Reflecting on all our work this past year, one challenge that stands out is those who refuse testing or treatment. Whilst people have the right to decline a test or treatment, we want to make sure we fully understand the reasons why someone may choose not to be tested or treated. Building on the work we completed in developing the managing hesitancy toolkit, we'll work with our experienced practitioners, The Hepatitis C Trust and our in-house psychologists to further support healthy conversations and make sure our managing hesitancy framework is fit for purpose. We're planning to run a series of focus groups to better understand and explore additional

ways we can equip our staff, help clients make informed decisions and have the skills and knowledge to manage and respond to hesitancy.

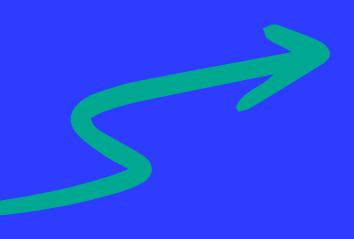
Next year will be an even more rewarding year for achieving micro-elimination milestones and becoming one step closer to the NHS deadline of 2025.

We're also looking ahead to a time where the number of positive clients will be few and far between. To achieve this, we need a sustainable solution for treatment at the point of contact or care. Sharing our expertise in delivering treatment within Drug and Alcohol settings and building on our existing in-house treatment provision is an opportunity we're excited to develop.

To sustain the positive impact we've had with testing and treatment, we must continue to strengthen our harm reduction approach to prevent new infections and reinfections. Working with others across With You and beyond, we're collaborating to build a future where elimination can be effectively maintained. With the strengthening of our harm reduction provisions, and all our work so far, we're in a better position to understand and measure the elimination picture within this group of clients.

Together, we are ensuring a brighter and healthier future for all.

We are With You. It's not just our name, it's who we are.



we are withyou