



**PEER-LED HEPATITIS C ENGAGEMENT
AND TESTING IN OUTER GLASGOW:
PILOT EVALUATION REPORT**



This report is an output of a collaborative working project between the Hepatitis C Trust and Gilead Sciences Limited

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Background

Scotland's National Drugs Mission Plan 2023-26 highlights the extent of drug deaths in Scotland – the highest rates in Europe – and estimates that 57,300 people use opiates and/or benzodiazepines in Scotland, equating to approximately 1.6% of the population.ⁱ An estimated 19% of people who inject drugs in Scotland have hepatitis C (HCV).ⁱⁱ

Less than half of these people are not accessing drug treatment, and are not known to services.ⁱⁱⁱ Untreated, HCV can cause liver disease and cancer. In line with the World Health Organisation's hepatitis C goals, the Scottish Government has pledged to eliminate hepatitis C in Scotland.

"I feel we have been left behind and forgotten about – it's sad but it's like what is the point trying to get better? I hope things change soon"

– Bluevale community member

This report describes a project jointly undertaken by The Hepatitis C Trust (HCT), Gilead Sciences Ltd, Bluevale Community Club and Favor UK. The project was undertaken under a Collaborative Working Project, funded by Gilead Sciences Ltd.

The project aimed to engage with people with lived experience of addiction and/or blood-borne viruses (BBVs) in relation to stigma and barriers to testing in outer central Glasgow, Scotland, by creating a community-based, peer-led hepatitis C outreach programme, supported by antibody testing.

The project was based in Bluevale's Community Hub, located in Haghill, one of the most deprived areas of Glasgow.^{iv} Staff and volunteers – all of whom understand the addiction issues locally and all have relevant personal experience – provide support and help create routes to treatment for people experiencing addiction and associated issues.

Project aims

The project aimed to create a peer-led service to support hepatitis C prevention, testing and treatment among people who struggle to access health services in outer Glasgow. In particular, we sought to work with people experiencing homelessness who were living on the outskirts of north central Glasgow, around two miles from the city centre. This area had been identified as having particularly poor testing and treatment coverage alongside high levels of deprivation.

The project built on a recent consultation with local residents experiencing issues with substance misuse. This showed that most people who were injecting drugs were also suffering from additional issues such as isolation, poor mental and physical health, with many reporting use of multiple prescription drugs over a long period of time, even without regular medical interventions. Respondents described these issues as resulting in disconnection from support services, including healthcare and testing services.

The Hepatitis C Trust delivers projects in other parts of Scotland and the UK, training people who have lived experience (peers) to work in community and criminal justice settings to engage people who might otherwise struggle to access healthcare. HCT peers work in partnership partners including NHS services to build trust, improve treatment pathways, and provide peer support throughout the critical period from HCV testing through treatment.

The use of peer workers in HCV in Scotland is relatively limited; we sought to understand the potential peer role, embedded within a community services, in an area of high need to increase access to HCV testing. Our pilot project was born.

Project Development

From the outset, the project took a peer-led approach and the Bluevale peer group were actively involved in its design at every stage. There were two workshops with peers to develop the service and come up with a project name.

The team aimed to develop an inclusive service which recognised the multiple barriers faced by people experiencing exclusion – including homelessness and addictions – in Glasgow, and provide a holistic service. Seven specific aims were identified:

1. The recruitment and training of 2 staff members
2. The recruitment of volunteer peers
3. Assessing access to HCV testing and need for testing and treatment
4. The roll-out of HCV antibody testing as part of the service
5. Building partnerships across community-based support services to increase HCV testing
6. Linking people with HCV to peer support staff to ensure support throughout treatment

A central dimension of the resulting service was a person-centred approach: this meant that it needed to reach into communities by going “to them” and being explicitly “for them”. A largely street-outreach based model, the agreed approach aimed to improve individual outcomes by not only designing a service that people need, want and are happy to access – but also one that they can then become involved in, supporting its delivery and creating a sense of ownership and belonging.

The project would employ both paid staff and volunteers. These staff would be tasked with developing partnerships to facilitate engagement, and would use their own lived experience as a way of engaging people who are often isolated, for various reasons, from mainstream services.

Target locations for the outreach were identified using a map of hepatitis C testing and treatment which had been developed by Glasgow Managed Care Network (MCN, see Figure 1). This map demonstrated a likely gap in testing and treatment services in the outer parts of

North and East central Glasgow, approximately 2-3 miles from the city centre. These locations were therefore set as the primary sites for street outreach by the project team.

Project implementation

Having successfully recruited 2 staff members, initial training was facilitated by The Hepatitis C Trust. Training included key operational skills including safeguarding, data collection, confidentiality and GDPR, engagement and listening skills, alongside the development of knowledge of HCV, risks and treatment. This training was well received by the two staff members, and both staff reported feeling they were equipped with right the tools and training to initiate the project and begin rolling out testing.

In the early phase of the project, staff developed partnerships with a range of services in order to better understand need and existing service provision. Staff in particular sought out “front facing” services working with people likely to benefit from hepatitis C testing.

The first to these services was The Lodging House Mission, a long-established Glasgow-based charity providing care and support to homeless and socially excluded people, and located relatively close to Bluevale’s community hub. Workers within the service were extremely supportive of the testing offer, and provided a private room for testing.

Staff also shadowed the NHS “Street Team”, providing an excellent opportunity to engage in Glasgow city centre people who are facing multiple exclusions, many of whom are at risk of BBVs. This enabled staff to better understand the barriers individuals face with regards to testing and treatment.

Staff additionally engaged with a BBV (Blood Borne Virus) nurse, based at Hunter Street Homeless Addiction Team, the main statutory homeless addiction service in Glasgow and again within walking distance of Bluevale’s community hub.

These partnerships, combined with early conversations with those attending the mission, provided an excellent initial grounding for the project among local target communities.

"With Hepatitis C in Glasgow it is like a revolving door - those who do go through treatment will often come back in a few months positive again."

- *BBV Nurse. Homeless Addiction Team*

Point of care HCV testing (POCT) can provide an initial HCV antibody test result within twenty minutes. These tests are recognised as important to increasing engagement and testing for HCV, particularly among marginalised populations where long term service engagement can be challenging.^{v,vi} The project initially aimed to trial point of care antibody testing using blood samples collected through a finger prick. However, within the Glasgow health network there was an established approach for using dried blood spot testing (DBST), an approach which allows concurrent HIV testing and a definitive HCV test result but requires a wait of up to five weeks for test results to be returned from a laboratory.

Limitations on trialling POCT brought a significant change to the original project design, as staff were not trained to deliver DBST tests nor permitted to use these, and this approach to testing required capacity to re-engage all people tested several weeks after their test to deliver results. This can be a considerable challenge among the populations this project was targeting.

"A big struggle is tracking patients down to go through treatment. Some patients test positive, and we are unable to track them down".

- *BBV nurse, Hunter Street.*

To maintain some testing provision, project staff engaged the Simon Community Access Hub in Glasgow city centre and Waverly Care, an HIV organisation, both of whom were able to provide DBS testing. Later, following engagement with the Glasgow Managed Clinical Network (MCN) – a coordinated group of health professionals and organisations within primary, secondary and tertiary care – staff also began working with nurses from the Walton Liver Unit at the Glasgow Royal Infirmary, opening up another pathway. This had the added benefit of much faster test results: in this setting results were returned within a week, rather than 4-5 weeks common for tests conducted in other settings.

Whilst feedback regarding these services was positive among those attending, project staff remained concerned by the need for service users to travel a substantial distance both to be tested and to receive their test results and, if needed, enter treatment. Moreover, these tests would not be available 'on demand' and as such clients would need to attend with their peer supporter at a pre-agreed appointment time for both testing and results deliver.

These types of requirements had already been identified by people with lived experience as likely to create significant barriers for many of the people the project hoped to support, for whom both attending appointments and attending remotely located services were likely to introduce barriers to uptake.

Project delivery

Having established many community partnerships, staff continued to engage people and provide support to take them for testing in partner services. Project staff also offered further support where necessary, particularly for people requiring HCV treatment. This included welfare rights advice, money and debt management, and housing advice. This integrated approach ensured that anyone entering the treatment pathway would not need to endure other significant stresses alone, without support, alongside the HCV treatment process. HCV treatment requires daily medication for up to 12 weeks, a commitment which can be difficult, in particular where those undertaking it are managing other, challenging personal circumstances such as homelessness and/or addictions.

As project staff attended increasing numbers of services, a significant lack of testing was identified. The manager of one service described their provision: "*once a year we have someone here for testing is just not enough*". This sentiment was echoed by several services engaged in the pilot; staff also noted that support workers expressed a lack of knowledge in the pathways to testing, treatment, and/or harm reduction advice within local services. As anticipated, many of the people engaged through the pilot had a range of needs, often very complex, and some were isolated and did not want to leave the local area. This strongly limited the uptake of testing.

Results

Over six months, the pilot engaged 268 individuals who we assessed as being likely to need testing for HCV, based on discussions around previous injecting and other behaviour.

With testing only available in the city centre, 76% of the people engaged stated they would not attend testing, even with peer support. A number of reasons were cited for this, in some cases clients described a fear of meeting someone they did not wish to meet, while others felt that repeated journeys to unfamiliar settings could be overwhelming, and others too described concerns around stigma when accessing an unfamiliar setting. Staff reported that it was those clients who might be considered most at risk of HCV who did not attend for testing.

Testing uptake was particularly low among people offered testing through the liver nurse service at GRI. Fewer than 15% of those who engaged with project staff agreed to attend the hospital for testing.

"I haven't been tested in a long time as I have been in a bad way for a while. I would have taken a test with you today, but I am not going to hospital. I don't like hospitals".

- Bluevale Client

"Today we engaged with Pamela, a woman who uses drugs and who has many different support needs. She was not engaging with services. She has no phone and was sofa surfing for accommodation. She was extremely vulnerable; Pamela would have agreed to a test if we were able to test however was not willing to attend hospital with us."

- Project staff member

Project staff continued to visit services including homeless services, hostels, missions, and soup kitchens - primarily based away from the city centre in the northeast of Glasgow.

The majority of the people engaged - 77% - came from areas of high deprivation, high levels of drug related harm and high rates of drug-related death. Among those able to provide a postcode (who were not deemed as homeless), the majority resided in the target areas for the project: post codes G31, G32, G33, G40 in the east, and G20, G21, G22 in the north. G21 and G22 presented with the most individuals deemed at risk.

All of these areas are at least two miles from testing available through the Simon Community and Glasgow Royal Infirmary, requiring any patient to either walk for an hour each way or spend a minimum of £3.90 on bus fares in order to obtain established testing.

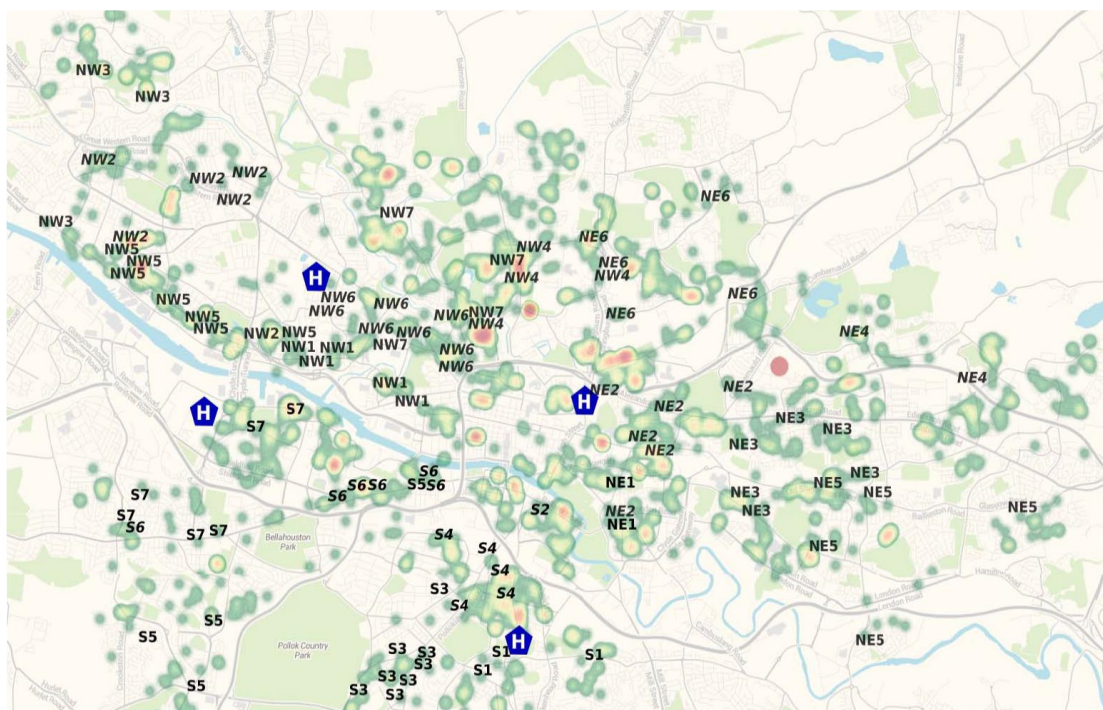


Figure 1: Heatmap of HCT testing in Glasgow. Source: Glasgow MCN.

The majority of those who presented had multiple support needs including addictions, poor mental and poor physical health. These people were receiving little support from mainstream services; our engagement indicates that they considered themselves to be both physically and socially isolated from attending these services.

We had asked all 268 individuals if they have been tested in the past six months and 73.9% reported that they had not.

As the main issue for many seemed to be the delay in seeking testing and/or treatment – and getting this - we asked *“if Bluevale were able to test you today would you have agreed to a test today”*. 98.9% stated they would take a test “there and then”.

An additional and recurring theme emerged from discussions with the people engaged related to stigma, in particular when it comes to not seeking support or testing for BBVs. The people engaged described the importance of having peers with a similar experience to support them, and indicated that this would encourage them to not only take a test but also provide an opportunity to build a trusting relationship to help ensure that they go on to access treatment if needed.

By engaging with those directly on the street staff identified a pattern of social, emotional, and physical disconnection. More than 90% of the people engaged with stated they felt lonely, and a recurring theme was the lack of hope or opportunity in these individuals' lives with many describing feelings that there was no point in trying to access help.

“I’ve totally lost control of my life, now I think what the point is trying to get help - nothing changes. Everything I have tried before, nothing has worked, so what’s the point”.

- Bluevale Client

Case study

On an outreach visit to a recovery service in the Springburn area of Glasgow, one staff member engaged a service user named John*. While having a chat, John said that if he ever attends a recovery service it is only for a cup of tea or some hot food, and he normally leaves without participating in any form of recovery work. After a while John seemed to be relaxed and project staff brought up that Bluevale were working with The Hepatitis C Trust running a project in Glasgow. John told the staff members that he had hepatitis C, having been diagnosed in prison in 1999. However, John did not receive treatment as it was interferon at the time; interferon-based HCV treatment was a very lengthy, difficult and relatively ineffective treatment which was often not available to people with more complex needs. John also noted that he was still injecting drugs and not currently accessing any support for this, and described a number of ongoing challenges in his life: John had recently suffered a significant bereavement, had addiction needs, rent arrears, and benefits sanctions. John described regularly missing healthcare appointments and noted that he mainly attended services for food.

Following this initial engagement, John agreed to attending the Simon Community for testing with project staff. He also accepted a referral to Bluevale's recovery café and to other partner organisations for support with his drug use, and project staff supported John to attend a meeting with GEMAP – a financial inclusion and money advice service – to obtain money and debt support. During this meeting GEMAP staff were able to contact John's housing provider directly, solve the issues with arrears and stop any further benefit sanctions.

Six weeks after the initial HCV test, John's results came back as positive, and he was supported to attend the Simon Community hub once again so that their staff could go through treatment process with him. Project staff were also able to ensure John gained a bus pass in order to access treatment and recovery services.

*all names have been changed

Limitations and Improvements

Despite considerable barriers, this pilot demonstrates that it is feasible to recruit a peer workforce and, through them, to engage highly marginalised populations in HCV education, testing and treatment in a setting in outer Glasgow. It is also clear that there is a strong appetite for this type of approach among local services.

Testing being offered in a way which is both physically and emotionally accessible is clearly pivotal to the success of these types of models. This is well documented within the evidence on healthcare access for marginalised populations – including people with hepatitis C – and it was clear from the project outcomes that the absence of on-request testing reduced the number of people who were able to access testing.^{vii} In all likelihood, the numbers diagnosed and treated were similarly reduced. That 198 of 268 people assessed as needing an HCV test not having received one within the past six months suggests substantial gaps in testing coverage among this population in this area. Yet almost everyone asked about their willingness to be tested was keen for this to happen, should it be available in an accessible way.

It is clear that the people who were engaged through this service have a wide range of needs over and above their hepatitis C, and any service seeking to address this will need to take a person-centred approach and integrate hepatitis C testing with wider BBVs, and additional health, care and housing needs, and including widespread needs around mental health and isolation. Requiring these people to make long and expensive trips for testing is likely to be very ineffective; a community-led model may assist in expanding this access.

Primarily, the project would have been strengthened by staff being able to deliver testing to those who needed it, on demand, and where possibly with some provision of point of care testing to give an immediate initial result. Local health services have, however, suggested that a longer-term project might be able to obtain training for staff to enable them to deliver DBS testing.

Project staff identified multiple service improvements, in addition to being able to deliver testing on demand to people in need. Staff suggested being able to distribute injecting equipment would have supported their harm reduction work, and that this would be

strengthened further with access key systems such as the NEO 360 portal, a system used by pharmacists to record BBV testing and the delivery of injecting equipment.

Conclusion

This project sought to pilot a series of service innovations which people with lived experience of exclusion of HCV told us they felt would work. While its delivery faced several challenges, project staff were successful in engaging people and identifying substantial gaps in HCV awareness and testing among the target populations in greater Glasgow.

Peer supported hepatitis C testing and treatment has the potential to support people to find a voice to help others and empower them to seek the support needed to improve mental and physical health. Partnership working, enabling an integrated approach to supporting these people's needs, is critical for success.

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