Driving Elimination through HCV Case Finding in Primary Care

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Contents

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Foreword

Between 2015 and 2021, the number of patients living with Chronic Hepatitis C has dropped by 47%.[1] This is a remarkable feat and there is much to celebrate in this achievement; however, there are worrying signs that HCV transmission and rates of reinfection remain high. It is concerning that a significant portion of individuals who may have HCV are yet to be fully identified or may not be in contact with services that would usually offer them testing.[2]

Within this backdrop, the HCV Elimination Programme has played a critical role in supporting NHS England (NHSE) to deliver on its aims of fully eliminating HCV in England by 2025. As part of this unique programme, we are working with 24 Operational Delivery Networks, which were set up across England help manage Hepatitis C services at a local level. I'm deeply proud of the fantastic work that we've done in combatting HCV, but as we enter the last phase of the programme, a new set of challenges now hinder our efforts, from the NHS backlog to the COVID pandemic and broader issues of stigma about HCV within primary care and among the general public. It is now more important than ever that we redouble our efforts to work alongside our partners at NHSE, industry and the third sector to ensure that the primary care workforce feels empowered to utilise the tools available to them to achieve our targets by 2025.

Our Driving Elimination through HCV Case Finding Roundtable, which brought together leading experts from across the HCV space, is the latest in such efforts. During the discussions, our panel identified the main barriers towards improving best practice in primary care settings, such as finding the most effective means to increase the uptake and use of the Patient Search Identification (PSI) software, so that all patients are offered the care that they deserve. I, and everyone at the Hepatitis C Elimination Programme, hope that the 'Driving Elimination through HCV Case Finding' report can ignite a conversation on this important and often unfortunately overlooked area of care. I am thankful to all our colleagues who gave up their time to share their experiences, insights and perspectives and I look forward to building on this work in the months and years to come.

Professor Graham Foster
National Clinical Chair, Hepatitis C Delivery Networks and NHSE HCV Elimination Programme

Executive Summary

On 12th September 2022, Merck Sharp & Dohme (MSD) convened a roundtable bringing together some of the country's leading healthcare professionals. The purpose of the roundtable was to provide a forum to discuss the ways in which HCV case finding could be improved and increase the uptake and use of the Patient Search Identification (PSI) software.

The PSI software is a case-finding tool which searches for coded HCV risk factors in patient records in primary care settings to identify potentially at-risk patients that should be reviewed and, if appropriate, tested.

'Driving Elimination through HCV Case Finding in Primary Care' shines a light on the best approaches to empowering Healthcare Professionals and third sector organisations with the tools needed to tackle HCV rates in England. Our set of experts came up with eight recommendations which would bring improvements to the pathway, which are summarised here and have been included throughout the report.

Attendees at the roundtable were:

Rachel Halford (Co-Chair)
Chief Executive Officer, The Hepatitis C Trust

Mark Gillyon-Powell (Co-Chair)
Head of Programme, HCV Elimination at NHS England

Professor Graham Foster
Professor of Hepatology, Queen Mary University of London and the Clinical Lead for Hepatology at Barts Health

Dr Stuart Flanagan
HIV-BBV Consultant, Central and North West London NHS Foundation Trust and Chair of BASHH HIV-BBV Special Interest Group

Dr Debbie Frost
Deputy Medical Director, NHS England & Partner, Ravenscroft Medical Centre

Hala Zendah
Practice Manager, NHS England

Stephanie Broughton
BBV CNS, Health Inclusion Team, Vulnerable Adults and Prevention Services, Integrated Local Services at Guy's and St Thomas' NHS Foundation Trust

Dr Grace Bottoni
Clinical Lead for South East London Clinical Effectiveness Group, NHS South East London Clinical Commissioning Group

Dr Mamoona Tahir
Consultant in Communicable Disease Control, West Midlands East Team, UK Health Security Agency

Dr Christopher Sargeant
Director of Arch and GP Lead in the Pathway Homeless Team in Brighton

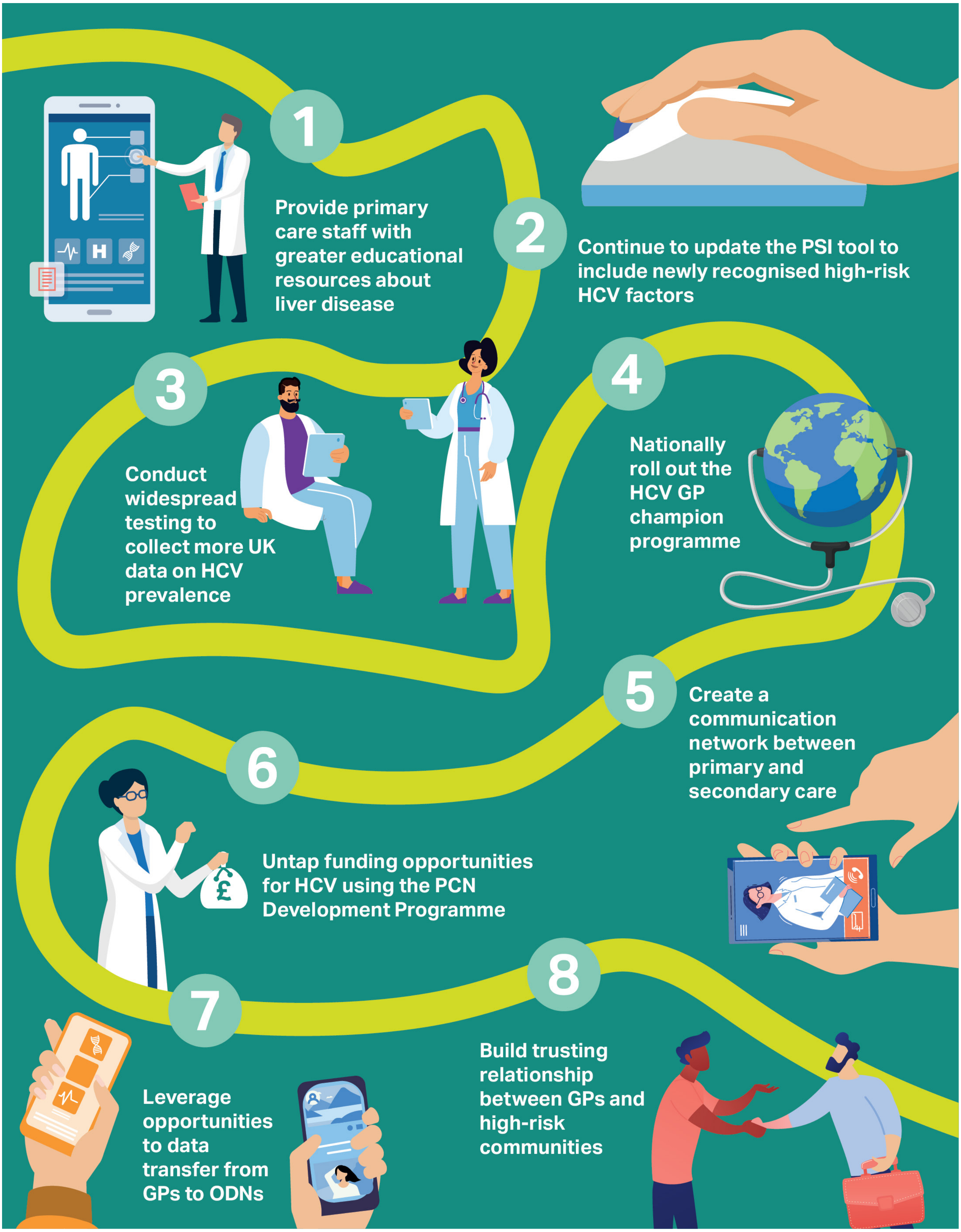
Vanessa Hebditch
Director of Policy and Communications, The British Liver Trust

Additional contributors:

Dr Aneesha Noonan
Deputy Medical Director, NHS England. National Primary Care Clinical Lead for the Hepatitis C (HCV) Programme

David Byrne
Senior Project Manager, Liverpool University Hospitals NHS Foundation Trust

Eight Recommendations for Effective Implementation



1. Provide primary care staff with greater educational resources about liver disease
2. Continue to update the PSI tool to include newly recognised high-risk HCV factors
3. Conduct widespread testing to collect more UK data on HCV prevalence
4. Nationally roll out the HCV GP champion programme
5. Create a communication network between primary and secondary care
6. Untap funding opportunities for HCV using the PCN Development Programme
7. Leverage opportunities to data transfer from GPs to ODNs
8. Build trusting relationship between GPs and high-risk communities

The Importance of HCV Case Finding

Early, accurate identification and diagnosis of HCV is critical to ensure that patients can access the life-saving treatments they deserve to live long and healthy lives. If left untreated, HCV can cause serious and potentially life-threatening damage, leading to cirrhosis, possible liver failure and cancer.[3]

The HCV Elimination Programme is managed by NHS England, with the overall goal of eliminating HCV. To achieve this, the programme must coordinate healthcare systems, namely those in primary and secondary care, to provide an effective patient pathway so that individuals with HCV can be identified, tested, and treated. Operational Delivery Networks (ODNs) are the key driving force in this and are funded through the elimination programme.

For many patients, primary care services provide an important route to diagnosis, as it is in this setting that unidentified HCV cases are often found and tested, before being referred to ODNs. The latest UK Health Security Agency (UKHSA) data estimate 74,600 people in England are currently living with HCV, with a further 35,060 individuals estimated to be unknowingly living with the illness but have yet to be properly identified within the primary care system.[1]

One way in which the NHS can target and identify these patients is through using the PSI tool. The PSI tool is a software system, developed by MSD, to look for coded risk factors in patients records who may be at risk of HCV infection and who may not have been tested for HCV in the past. The software picks up historical records, which otherwise may be overlooked, to decipher whether the patient may be high-risk for HCV. HCV begins as a symptomless and acute infection where individuals can go years unaware that they have the disease.

This software is therefore a vital tool in the identification of patients. The tool can be used on the 3 main GP clinical systems in England; EMIS, SystmOne and Vision and is available to 100% of the GP practices in England. The PSI software has been rolled out by NHSE to GP computer systems, to help the primary care workforce search through patient records for patients who have a coded HCV positive test, but no clear treatment record, and those with factors, such as intravenous drug use, blood transfusions or organ transplantation before 1992.[4] The software picks up historical records from patients to alert healthcare providers of whether they may be at risk of HCV infection or have a previous positive diagnosis of HCV infection.

Our panel was acutely aware of the critical role that the PSI software can play in early screening of vulnerable patients and reflected on some of the major obstacles which have historically posed significant challenges for improving case finding in England.

One identified issue was the burden on primary care services that currently exists. With GP practices already stretched to capacity and without specific funding from the elimination programme, challenges arise within the primary care arm of the case finding pathway.

Through effective use of the PSI case finding tool; working collaboratively between primary and secondary systems; and utilising the elimination programmes resources, a solution can be achieved to ensure patients continue along the pathway to identify and test patients at risk of HCV.

Our expert panel offered their perspectives as to how the current patient pathway for HCV case finding can be transformed into a best practice model.

81,000

people in England are currently living with HCV

50,000

people in England are estimated to be unknowingly living with HCV

Identified challenges in the pathway

Awareness & Understanding

A lack of understanding amongst the wider population regarding the need for early interventions in HCV remains a particular area of concern. This is especially true amongst individuals from high prevalence communities, such as Pakistani or Eastern European communities, where prevalence in their countries of origin is high.[5,6] In addition, there are a high proportion of individuals living with HCV who are unaware they have the virus, with approximately 40-50% of the total estimated number in the UK going unidentified or diagnosed. Often, if individuals do not experience immediate symptoms, they are less likely to come forward to receive treatment and can simply drop out of the care pathway.[7]

In addition, awareness amongst many GPs around the crucial need for early testing and the use of HCV case finding is relatively low.[8] Indeed, GPs act as an essential cornerstone to increasing awareness amongst the general public and referring patients to specialists for treatment.[9] It is therefore essential that they are adequately provided with the tools needed to ensure effective HCV screening and linkage to care.

It was suggested that it is important to learn from the parallel experience of the HIV prevention programme, replicating its model for HCV. It was explained that in order to boost awareness and understanding, webinars had been organised by the designated HIV champions, in some areas, to provide education for nurses. Panellists agreed that similar approaches should be developed for HCV, focused on both nurses and GPs / primary care professions, managed and provided by ODNs to utilise the HCV programme funding. To maximise the opportunity, the contents of this webinar would include information on HCV, but offer education on liver disease more widely, thus engaging a broader range of GPs. This programme would educate GPs on the aims and delivery of the HCV elimination plan, the importance of early detection and diagnosis and value of utilising the PSI tool.

In addition to learning about HCV more generally, it's important that GPs are aware of the elimination programme and its patient pathways. Mark Gillyon-Powell suggested the creation of a one-pager of all the necessary information. This would be distributed centrally from an ICB (Integrated Care Board) to all actors within the HCV pathway, to allow them to see their respective roles within the pathway, and how their roles interact.

(Please contact the Terrence Higgins Trust for further information on the HIV Prevention Programme.)

> ***I'm surprised that GPs are unaware of the HCV pathway. From my perspective, the pathway is so clear and simple. It shows that there is a lack of information sharing between ODNs and HCV leads and GPs.***
>
> **Rachel Halford,** Chief Executive Officer, The Hepatitis C Trust

Stigma

Societal stigma surrounding HCV within high prevalence communities was considered by attendees to now be significantly higher than with HIV. This is particularly true for those from a South Asian background where treatment rates are typically lower and there are perception issues around what it means to have the virus. Similarly, Injecting Drug Users (IDUs) often live very chaotic lifestyles and it is difficult to reach and then engage them with essential HCV services.

Indeed, attendees identified that the difference between the two conditions was that whilst HIV has increasingly been normalised in society, this has not yet been the case for HCV. This stigma then has a subsequent devastating impact on the number of vulnerable patients coming forward for screening and treatment.[10,11] Individuals who have HCV have also reported a marked level of stigma in their treatment within the healthcare system which also acts as major barrier towards the lower levels of test uptake.[12]

It is therefore critical that patient data confidentiality is at the heart of the response – patients need to believe that their data is safe when the PSI tool is used. The communication between the healthcare professionals involved in the pathway, as well as the identified patient must be sensitive.

Updating Guidelines around the PSI Tool

The expert panel highlighted the user friendliness of the PSI tool, with wider feedback from the 200 sites the tool currently operates, that it was "quick and easy to use". However, it was highlighted that there was a need for updated guidelines and advice around its use. Currently, the tool remains in-line with the National Institute for Health and Care Excellence (NICE) guidelines, which were last updated in 2012 and therefore do not include codes for newly discovered factors which increase the risk of an individual having HCV, such as whether the individual has previously had an ALT liver test.[13]

It was therefore identified that there is a pressing need to update NICE guidance, and that by including additional codes, the PSI tool will be able to incorporate new risk-factors that enable the identification of more at-risk HCV patients.

> *It was very important to hide codes when possible. This is especially important when moving patients from primary care to secondary care, where a relationship between patient and secondary healthcare provider may not yet exist.*
>
> **Dr Debbie Frost,** Deputy Medical Director, NHS England & Partner, Ravenscroft Medical Centre

Testing

Currently, there is not a universal approach to HCV testing in primary care, resulting in those with high-risk factors slipping underneath the radars of healthcare providers. Moreover, testing within primary care settings is often limited and fails to offer re-testing for vulnerable patients who may need greater levels of monitoring.

Utilising the current HIV Programme by rolling HCV testing into a triple test with HIV and Hepatitis B, was considered to offer an effective route to test efficiently. During situations where patients are already giving bloods samples for HIV and Hepatitis B, they are more willing to accept a HCV test proposal. Moreover, simplifying the testing system for GPs will improve testing efficiency. Changes like introducing an automatic reflex test, as well as automatically scheduling follow-up tests for vulnerable patients will ensure cases aren't missed without additional administrative input from healthcare professionals.

Furthermore, the NICE guidance advises that GPs should be testing for all possibilities.[14] However, attendees highlighted that any changes to procedures should not be seen to create unnecessary work, which just increases the burden on already busy healthcare professionals. Any requirement with NICE guidance for additional testing on top of blood tests, needs a strong evidence base. Primary Care representatives on the panel stressed the point that evidence-based testing is important for GP targets. Furthermore, to aid in the supply of sufficient evidence for GPs there must be a degree of testing-all, to improve understanding of prevalence. Without prevalence data, it becomes difficult to illustrate the importance in HCV case finding in primary care or incentivise to GPs to use the PSI tool.

HCV GP Champions

Primary care systems play a central role in the disease prevention and elimination, and GPs are regularly required to embed or work with new systems or processes. With the continuous build-up of disease specific programme agendas, it was identified that the workload of GPs is becoming increasingly difficult to manage.

Despite this challenge, it was identified that providing GPs with assigned and defined leadership roles was an important way to drive forward case finding and ultimately the elimination of HCV. Specifically, this can be achieved with HCV GP champions, an idea that NHS England have already put together as part of their plans to implement a pilot scheme in London.[15] The panel emphasised the importance of the champion's role within the programme delivery, ensuring there is greater HCV education for both GPs and patients, helping them to develop an understanding of their condition through awareness-raising measures. However, a key component of success is ensuring that there is strong communication between the GP champion, healthcare practitioners, and patients within the designated area. Indeed, this can be achieved by working closely with the GP federation and the PCNs.

The participants of the roundtable suggested champion identification should be based off the existing HIV model[16], and utilising this already well-established programme to avoid duplicating work.

> *We are working on an initial pilot model of GP champions in London, and if feasible, we can expand this out across England.*
>
> **Mark Gillyon-Powell,** HCV Elimination at NHS England

Funding

The HCV programme requires GPs to give additional time and resources from their already busy schedule. Currently, without additional funding or patients presenting with severe health complications caused by HCV, GPs are not appropriately incentivised to carry out the extra work that is asked of them.

Attendees highlighted that with HIV testing, NICE guidance states that GPs should be testing in places with high prevalence, but with HCV, NICE guidance says to offer tests for those with high-risk factors. There was a consensus that for the improved case finding and testing to occur we would need to incentivise GPs to prioritise this over and above a range of competing priorities. The current challenge for the HCV elimination programme is selling the idea of multiple testing to GPs without significant evidence to show that there is a high-risk.

One expert discussed a potential solution for the funding issue by leveraging on the 'PCN Development Funding Guidance'.[17] As a result of this policy initiative, each PCN must have a health inequalities lead. As part of their role, they must address health inequalities challenges within the area, which could also include HIV and HCV. This could involve managing the running of the PSI search tool, identifying patients, and best approaching high-risk patients.

Data Collection and Transfer

The expert panel concluded that there is a need to share responsibility for data collection and transfer between primary and secondary care, namely between GPs to Operational Delivery Networks (ODNs). Improving the quality and shareability of data collected on HCV prevalence and incidence is critical to enabling more effective allocation of resources and monitoring of progress towards the overall aim of elimination nationally by 2030.

Enabling effective data transfer alleviates the unnecessary burden on GPs workload, by providing ODNs with the information and data to follow-up on specific actions required for that patient, such as follow-up counselling.

A roundtable expert explained that the GP Federation can offer consent for ODNs to receive the data transfer. ODNs are then able to send a letter to identified patients at risk, clearly explaining the next steps for the individual– whether this is via primary care, or via an at-home test. An additional letter can be shared with the GP surgery, stating which HCV test is required, to allow GP receptionists to action the letter without the need of a GP.

The expert panel highlighted learnings from the HIV programme to expand this idea, where letters sent on behalf of HIV patients to secondary care systems provided comprehensive information on the patient, including blood types, past treatment, and relevant records. It was agreed that the approach of utilising these letters should be replicated for HCV.

Approaching Patients with HCV

A key challenge in the elimination agenda is the lack of compliance from patients who are identified as priorities for testing. Unfortunately, there still remains a significant number of patients who are identified as high-risk, who are approached, but then do not come forward to be tested. The reasons for this are numerous however; identified individuals may not believe that they are at high-risk for HCV, due to a lack of knowledge or understanding of HCV, or may lack a dialogue or relationship with their local GP practice. This leads to a scenario where potential HCV cases are undiagnosed and untreated.

Henceforth, our panel agreed that building up a trusting relationship between the healthcare provider and patient was important to generate a receptive response. Namely, they felt this was important when approaching ethnic minority communities, where the UK healthcare system may not be as familiar to them. For instance, for communities where there might be a language or cultural barrier – such as the Pakistani or Eastern European communities – it was much more effective to engage on a face-to-face level, as opposed to writing a letter.

> *There is a lot of value in a good relationship between the GP practice and community. Having this relationship not only offers much more effective response from patients, but also encourages patients to come forward for an HCV test.*
>
> **Dr Stuart Flanagan,** HIV-BBV Consultant

> *Simply sending a letter to a patient requesting they take a Hepatitis C test may not be enough for individuals part of high prevalence community groups such as Pakistan, or Eastern Europe. From my own HCV testing experience, it was highly effective to have one-on-one appointments, spoken in the patient’s native tongue. It enabled the GP surgery to build relationships of trust with the patient community, making them feel comfortable to take a HCV test.*
>
> **Hala Zendah,** Practice Manager, NHS England

MSD

Eight Recommendations for Effective Implementation

Throughout this roundtable, the panel identified a number of key recommendations which can improve HCV case finding, diagnosis of patients and ultimately support the HCV elimination programme.

1

Provide primary care staff with greater educational resources about liver disease

ODNs should provide primary care staff with educational webinars, lectures, and reading resources about liver disease, to ensure they have sufficient awareness of the need for the HCV Elimination programme.

2

Conduct widespread testing to collect more UK data on HCV prevalence

By widespread testing, NHS England can collect more data to generate a stronger evidence-base of HCV prevalence in the UK. A more robust evidence base will also incentivise GPs to test for HCV, if their surgery is located in a community identified with high prevalence.

3

Continue to update the PSI tool to include newly recognised high-risk HCV factors

For most effective use, the PSI Tool must pick up on all factors which increase a patient's risk of contracting HCV, such as whether the patient has had an ALT liver test or has a tattoo. MSD must re-evaluate the software's current code guidelines to ensure a newly recognised factors which increase HCV risk are included.

4

Nationally roll out the HCV GP champion programme

As a measure to manage the HCV elimination programme in primary care, NHS England should define the job specification of a HCV GP champion and, if successful following the pilot scheme, roll out the champion programme nationally.

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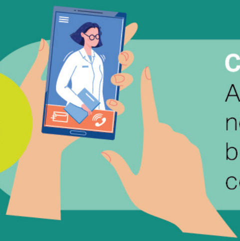

Create a communication network between primary and secondary care

As opposed to keeping NHS bodies separate, the creation of an 'eliminating HCV network', managed centrally via the ICB, will build better communication links between NHS structures. As part of this network, up-to-date communications could come through the ICB via monthly newsletters and information one-pagers.

6

Untap funding opportunities for HCV using the PCN Development Programme

ICBs should centrally distribute a one-pager to communicate the link between the Health Inequalities PCN Development Programme and HCV, and the development programme's funding opportunities that GPs can request for HCV activity. This funding will financially incentivise GPs to engage in the HCV elimination programme and use the PSI tool.

7

Leverage opportunities to data transfer from GPs to ODNs

This allows ODNs to take a leading role in the case finding process and GPs have more time spared. For example, with the necessary data, ODNs can share a letter with the GP surgery, providing details of specific tests and next steps required so that GP receptionists can action the letter without the need of a GP.

8

Build trusting relationship between GPs and high-risk communities

Creating a trusting patient-GP relationship is vital to make them feel more at ease and willing to take a HCV test. Where possible, GPs should offer; face-to-face appointments, the option for consultations to be delivered in the patient's native tongue, and a pre-discussion to provide information on HCV for the patient.

> *The HCV Elimination Programme has and continues to do so well, but we won't be able to truly reach elimination until we get over this final hurdle [identification and surveillance].*
>
> *It's been a long journey we've had with the PSI toolkit and we hope we can use it in other disease areas and if we can smooth it out further... we can use it for the years to come.*
>
> **Rachel Halford,** Chief Executive Officer, The Hepatitis C Trust

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