

# The blood-borne virus opt-out testing policy for prisons in England: An analysis of need towards full implementation

February 2016

*“So far we are in infancy but we are really quite excited about it [introducing opt-out BBV testing]. I think that it’s really good news that we are doing something much more organised and structured than before. It’s really well overdue in prisons I think.” (Healthcare manager, prison H)*

THE HEPATITIS  TRUST

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The Hepatitis C Trust also thanks Public Health England, NHS England and the National Offender Management Service for their commitment and work in this area, and for the input they have given to the development of this report.

## Abbreviations

|             |  |
|-------------|--|
| <b>BBV</b>  | Blood borne virus  |
| <b>DBS</b>  | Dried blood spot test  |
| <b>HCV</b>  | Hepatitis C virus  |
| <b>MDT</b>  | Multi-disciplinary team  |
| <b>NHSE</b> | NHS England  |
| <b>NICE</b> | National Institute for Health and Care Excellence                |
| <b>NOMS</b> | National Offender Management Service                             |
| <b>PCR</b>  | Polymerase chain reaction test which tests for current infection |
| <b>PHE</b>  | Public Health England  |

## Foreword



We at The Hepatitis C Trust are inspired by a clear goal – to effectively eliminate hepatitis C as a public health concern in the UK by 2030. In 14 years' time we want to have consigned hepatitis C to the history books in this country and to shut up shop.

That means that over the next 14 years we need to ensure that everyone living with hepatitis C is diagnosed and offered treatment, reducing the prevalent pool of infection to practically zero and stopping any new infections. It's an ambitious target but, with the new, NICE approved treatments that have recently become available, entirely achievable.

Prisons are central to this. Nearly a third of people in prison have injected drugs and almost half of people who inject drugs in England have hepatitis C. Yet historically very few people entering prison or serving sentences have been offered tests and hardly any have received treatment.

Prisons present a unique opportunity to test this high-risk group, ensuring people living with hepatitis C are diagnosed and enter a care pathway so they can be treated and cured. We know from our helpline and support groups that for some people, receiving treatment for hepatitis C and achieving a cure can be a trigger for long term addiction recovery and can help them to take control of other areas of their lives which may previously have been chaotic.

We are therefore delighted that Public Health England, NHS England and the National Offender Management Service have committed to ensuring that everyone in prison is offered a BBV test on an opt-out basis. Furthermore, the development last year of Operational Delivery Networks to coordinate the treatment of hepatitis C patients across communities, including in prisons, presents an ideal opportunity for specialist services to renew and improve their connections with prisons.

We hope that this report contributes to our shared goal of finding all those living with an undiagnosed BBV, and ensuring that every person living with hepatitis C, hepatitis B or HIV is offered the best available treatment and care.

*By Charles Gore, Chief Executive, The Hepatitis C Trust*

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# 1. Executive summary

In recognition of the exceptionally high prevalence of blood borne viruses (BBVs), in particular hepatitis C, amongst people in prisons<sup>i</sup> and previously very low rates of testing<sup>ii</sup>, in October 2013 Public Health England (PHE), NHS England and the National Offender Management Service (NOMS) agreed to introduce opt-out testing for hepatitis B, hepatitis C and HIV across the prison estate by 2016/17<sup>iii</sup>.

This report aims to uncover practical advice from prisons that are now offering BBV testing to all people entering prison on an opt-out basis and to highlight issues for resolution in prisons not yet implementing opt-out testing. Interviews were conducted with senior healthcare representatives from eight prisons in July and August 2015.

## Awareness and perceptions of the policy

Awareness of the opt-out policy and the health benefits that it could bring was high. For example, one interviewee highlighted the life and death nature of the issue and the potential benefits of increasing testing:

*“We have successfully treated quite a lot of people over the past few years which is great but we’ve also seen quite a lot of people with decompensated liver [disease] and who have liver cancer because it hasn’t been picked up.” (Prison D)*

Three of the prisons participating in the interviews were already offering BBV tests to people on an opt-out basis. These three prisons were generally positive about their experiences and the initial outcomes. One explained that perceived fears around offering the tests were often unfounded:

*“I have met with some prisons that are about to start and I think the anxiety is often the cost and the numbers. But actually in reality... I don’t think we’ve really experienced any problems. So I think there’s more anxiety about doing it than there is in reality the process of actually doing it.” (Prison G)*

## Need for further information and support

The interviews revealed a lot of activity around BBV testing and care pathway development, although in half of the prisons interviewed there remain issues to be resolved before they start offering BBV tests to all people on an opt-out basis. Further, the healthcare representatives from prisons already offering testing on an opt-out basis identified areas where they would find additional national guidance and support beneficial.

All of the prison healthcare representatives who were interviewed – both from prisons offering testing to all people in prison and from prisons not yet implementing the policy – raised areas where they would benefit from additional information and support to facilitate the implementation of BBV testing on an opt-out basis to all people in their prisons. The most pressing support needs highlighted were:

- **Clarity on who pays for what:** Half of the interviewees were extremely concerned about the lack of clarity on the funding of testing and treatment pathways and saw this as a major barrier to improving testing rates;
- **Guidance on a 'gold standard' care pathway:** Further guidance on what constitutes a good hepatitis C pathway, including how to ensure continuity of care in the community for people diagnosed positive, was requested by six interviewees;
- **Guidance on training requirements:** Additional training around BBVs for healthcare or wider prison staff was seen as useful by interviewees from six of the eight prisons that participated.

## Recommendations

To assist prisons in their development of opt-out BBV testing for all people in prison, this report indicates that additional national information and guidance is required in the following areas:

- **Clarity on the funding of testing and treatment pathways, for example through provision of publically available information listing clearly the responsible commissioners for different aspects of the pathway**
- **Details on what constitutes a good hepatitis C care pathway, including how to ensure continuity of care in the community for people diagnosed positive**
- **Additional training around BBVs for healthcare and wider prison staff to challenge the stigma surrounding BBVs and to ensure effective testing and treatment pathways, with national guidance made available to prisons on the level of training required.**

## 2. Background

In October 2014 PHE, NHSE and NOMS agreed on a joint priority of offering all people in the prison estate a BBV test on an opt-out basis, as set out in the National Partnership Agreement in October 2013<sup>iv</sup>. This policy is currently being rolled out with the aim of full implementation across the prison estate in England by April 2017.

Currently only around half of the estimated 160,000 people living with hepatitis C in England have been diagnosed<sup>v</sup>, yet around 7% of the prison population are estimated to be hepatitis C positive<sup>vi</sup>.

The Hepatitis C Trust believes that the BBV opt-out testing policy has the potential to vastly increase diagnosis rates within prisons and could bring added benefits of raising awareness of the virus among a very high-risk population, encouraging harm reduction practices among those testing negative, and reducing onward transmission in the community, beyond the prison estate.

Soon after the policy was announced, 11 'pathway' prisons started offering opt-out BBV testing and as a result testing rates across these prisons doubled from 11% to 22%<sup>vii</sup>. At the point of these interviews (August 2015), 11 further 'pathfinder 2' and 8 'pathfinder 3' prisons have started offering opt-out testing and Public Health England estimate that over half of the 136 prisons across England are either offering opt-out BBV testing or are in the process of setting up systems for its introduction.

At this mid-way point in the roll-out of opt-out BBV testing across the prison estate, The Hepatitis C Trust decided to conduct in-depth interviews with healthcare managers from a selection of prisons, both those implementing opt-out testing and those who have not yet started implementing the policy, to explore in detail what is working and what support may be helpful to prisons not yet offering opt-out testing.

This report also builds on findings and insights from the Preliminary Evaluation of the Pathfinder Programme, April to September 2014 (Public Health England, April 2015<sup>viii</sup>) and the report from the National Event for Early Lessons Learnt from the Opt-Out BBV Testing Policy in Prisons (Public Health England, August 2015<sup>ix</sup>).

### 3. Methodology

Twenty prisons (full list in appendix 1), reflecting a spread of locations, sizes and categories, were selected for interviews by The Hepatitis C Trust, in conjunction with PHE. The healthcare manager of each prison was invited by email to take part in a 20-30 minute semi-structured telephone interview about the implementation of opt-out BBV testing in their respective prison. All the London prisons were included within the twenty that were invited to interview in recognition of specific issues highlighted in PHE’s Hepatitis C in London 2015 report. This report highlighted particular concerns around testing rates in London prisons, with 6.4% of new receptions reported as having been tested in London, compared with 7.8% in England in 2013, and only a quarter of London prisons reporting that they have a written care pathway in place.<sup>x</sup>

Nine of these twenty healthcare managers responded to the invitation and eight interviews were conducted between the 10<sup>th</sup> July and 14<sup>th</sup> August 2015 (one of the managers was unable to find a suitable time for the interview). Two of these healthcare managers asked their clinical matron to take part in the interview on behalf of the prison, and one asked their charge nurse to take part.

All interviews were recorded and transcribed for accuracy and analysis. It was agreed that interviews would be used to draw out key themes, examples and issues but that individuals would not be named in this report. Quotes are therefore attributed to each prison anonymously and each of the 8 prisons has been assigned a letter between A and H at random. The prisons that took part in the interviews were as follows:

| Prison          | Region        | Category   | Capacity | Pathfinder involvement |
|-----------------|---------------|------------|----------|------------------------|
| HMP Bristol     | South West    | B          | 614      | Phase 3 pathfinder     |
| HMP Brixton     | London        | C/D        | 798      | Not a pathfinder       |
| HMP Haverigg    | North West    | C/D        | 644      | Not a pathfinder       |
| HMP Holloway    | London        | Women’s    | 501      | Not a pathfinder       |
| HMP Lewes       | Kent & Sussex | Local male | 742      | Not a pathfinder       |
| HMP Pentonville | London        | Local male | 1310     | Phase 3 pathfinder     |
| HMP Stocken     | East Midlands | C          | 842      | Phase 2 pathfinder     |
| HMP Wandsworth  | London        | Local male | 1877     | Not a pathfinder       |

### Limitations

The prison estate in England is vast and complex and this report can only provide a snapshot of issues and solutions experienced by a small number of prisons.

Questions were asked about the introduction of BBV opt-out testing and supplementary questions were asked about patient care pathways focusing on the care pathway for people diagnosed with hepatitis C. The questions are listed in appendix 2.

## 4. Analysis of need towards full implementation of the BBV opt-out testing policy

### 4.1 Current level of implementation of the policy

Three of the eight prisons interviewed are offering BBV tests to people in prison on an opt-out basis and one prison is in the process of setting up protocols and procedures for the imminent introduction of opt-out testing.

Four of the prisons stated that they were not yet offering BBV testing on an opt-out basis. Worryingly, one of the interviewees stated that they had not yet heard of the national policy decision, and misunderstood the nature of it:

*“I haven’t actually heard about a policy as such, my understanding is that there is a pilot of hepatitis C opt-out at HMP Pentonville” (Prison E).*

Of the three prisons offering BBV tests on an opt-out basis (prisons B, D and G), two offered dried blood spot tests and the other offered oral swabs which were followed up by sexual health services when someone showed positive antibodies. As recommended by Public Health England, BBV testing is a ‘continual offer’ and is integrated into health screens, substance misuse services and other health services. For example, one prison healthcare manager describes the points when testing is offered:

*“At the moment when they come in, in their initial screening, we talk about it then. We have a big substance misuse team as well so they are clearly getting into conversations about the risks with their patient group often. So they will always talk to their patient groups about having hep C screening. We do a general health assessment within 48 hours of arrival and they’re asked then, and then, if we see a patient for whatever reason, if we think it’s appropriate, we would ask them then. So I think that it’s at least 5 times.” (Prison B)*

It is positive to note that interviewees from prisons offering BBV testing on an opt-out basis reported a significant increase in testing rates. For example:

*“There’s definitely been an increase in testing over the past 18 months.” (Prison D)*

*“We’re testing the majority, so 75-80% are being tested when they come in. That is quite an increase because we were testing about 50% previously.” (Prison G)*

However, all three interviewees from prisons offering testing on an opt-out basis identified issues within their services that would still benefit from further guidance.

## 4.2 Lessons from prisons implementing BBV opt-out testing

Interviewees from prisons offering opt-out testing were happy to share experiences and gave some practical advice for prisons that are about to start implementing the policy in their prisons.

**Project management:** One interviewee highlighted that a named project manager for the roll-out of BBV testing, external to the prison healthcare service, would have been beneficial due to the number of different agencies involved in the project:

*“I think that for something like this you might need to have someone specific. There might be a lead with PHE, a lead within NHS England for the commissioning and then there will be a lead within the provider – me, for example. But actually that doesn’t necessarily mean that there’s someone on top of all of the things and I think that with something as big as this you probably need somebody, and it might not necessarily be from the provider side as the provider still has the whole service to run... so I would say that when the three organisations get together to decide that something like this will be implemented... a project manager is needed, maybe from the outside, who makes sure everybody jumps in and does things within the timescales and in a timely manner. And then you use that person as a conduit and that person is the holder of the information and the progress. So if someone leaves, that information’s not lost. That’s not something I’ve seen, so whilst we’ve had a lot of conference calls and a lot of distribution lists, no single person has been identified as the lead person who might be able to answer any questions we have.” (Prison H)*

**Ensuring continuity of care:** Several interviewees from prisons not yet offering tests on an opt-out basis raised concerns about continuity of care for anyone diagnosed positive or initiated on treatment if they were moved between prisons or released (see section 4.3). One prison that offers opt-out BBV testing addressed this through close relationships with the community link nurse who delivers treatment inside the prison. Another addressed this through putting anyone on treatment on medical hold and taking next of kin details in case a person diagnosed positive, or who is on treatment, is released back into the community:

*“They will not be moved to other prisons [if they are on hepatitis C treatment] because we have put them on medical hold so they cannot be taken anywhere else so we can ensure that they have that follow-up. But if they ever leave and go back to the community, as part of our process we take details of their next of kin so we can chase that up and the person that is in-reach here will follow it up in the community.” (Prison H)*

**Piloting testing on a small scale within the prison before full roll-out:** The prison that is about to start implementing opt-out BBV testing is piloting it in their substance misuse unit first to ensure that the pathways and protocols are working:

*“We will roll out to the substance misuse unit specifically for a few weeks to see how it goes and then go bigger, to the rest of the prison once we are clear that all the pathways we have set up and the things that we have implemented are working fine. It is a big prison with high turnover, lots of movement, so we just want to make sure that we have nailed all of the details before we roll it out big, avoiding a situation where it becomes a disaster because we cannot cope with the amount of work or we haven’t we considered this, that or the other, so that’s where we are.” (Prison H)*

**Drying dried blood spot testing cards:** One interviewee explained that they had found it hard to find space for drying the DBS tests when opt-out testing was first introduced, and that sometimes batches came back for repeat testing if they were insufficiently filled. In this case, the issue was addressed through training, indicating a need for training around these practices to be recommended on a larger scale across prisons in England

**Ensuring the policy is maintained:** One healthcare manager saw it as important to take measures to ensure that testing standards are maintained and that healthcare staff don’t revert back to old practice:

*“My band 6 pops into reception periodically to make sure the nursing staff haven’t reverted to ‘opt-in’ questions as opposed to phrasing it as ‘opt-out’. But as far as we are aware, all the staff are doing that. So that’s just about keeping on top of that and ensuring that we don’t revert back to old practice.” (Prison G)*

## 4.3 Support requirements identified

The support requirements identified by the prison healthcare representatives interviewed apply principally to prisons not yet implementing opt-out testing, although the prisons that are offering opt-out BBV testing also raised areas where they would benefit from additional support.

### Clarity around funding

In three of the four prisons not yet offering BBV tests on an opt-out basis, confusion around the funding of the tests was identified as a barrier to implementing opt-out BBV testing:

*“We’ve had conversations about it but I think the issue is about funding – who is going to fund it. Just to get guidance on who is going to fund it as regards to testing kits and then obviously, looking at the logistics.” (Prison F)*

*“It sounds really awful but I think the money is the big side of things and clarity around that would be really helpful.” (Prison E)*

*“There’s still disagreement between NHS England and PHE on opt-out testing. So if NHS England are responsible for our budget and PHE are saying that we do it and they’re not, then we don’t have the funding to do it. So there’s a conflict at commissioning level between NHS England and PHE. (Prison A)*

The other prison not yet offering opt-out BBV tests identified the commissioned pathology contract as a practical barrier to the introduction of opt-out BBV testing:

*“The reason that we can’t do the opt out testing at the moment is one, that our pathology contract is not set up to do that testing in large numbers and secondly, we want to use dried blood spot tests because that’s easier for our people and that needs to be tied up in the pathology contract. And that’s being reviewed and renewed as part of the whole tender process.... Because we’re not saying that we won’t do it, we’re saying that contractually at the moment we can’t do it.” (Prison C)*

An interviewee from one of the prisons offering opt-out testing expressed concern about the long term sustainable funding of the programme as sexual health services were paying for the tests but did not consider themselves to be responsible for this:

*“With the commissioning for primary care, the cost of the testing hasn’t been factored into the budget. Sexual health services are doing the testing for us but it’s not really within their remit... you can’t shy away from the funding issue – who is paying for the testing.” (Prison D)*

The confusion around who pays for what in the hepatitis C diagnosis and care pathway extends in some prisons beyond testing and can be a barrier to service delivery. For example, one interviewee stated:

*“We’ve got the consultant hepatologist [at our local hospital] keen to run a clinic here on site. We haven’t been able to pull this off because of lack of clarity around funding for it.” (Prison E)*

**It is concerning that, two years after the policy was agreed, a lack of clarity around funding streams remains a key barrier for almost half of the prisons interviewed in starting to improve their BBV testing offer. This needs to be addressed as a matter of urgency, with clear information on commissioning arrangements for testing made publically available to prisons.**

## Developing the care pathway

Public Health England guidance states that anyone diagnosed with a BBV in a prison setting should be referred to a secondary care treatment pathway and that the patient should receive assessment by a specialist.<sup>xi</sup> Therefore, it is vital that pathways are in place to ensure that anyone diagnosed positive will receive information, care and access to treatment.

The interviews highlight that this as an area where more support and guidance could help facilitate the development of working pathways and therefore allow prisons to move forward with opt-out testing, ensuring the goal of full roll-out by 2016/17 is achieved.

Prison A exemplifies this issue. They started to offer BBV testing on an opt-out basis over a year ago and, when they started to diagnose people with hepatitis C, found that their care pathway and local services were not prepared for the demand. They stopped offering testing and have spent the last year developing their care pathway and strengthening links with local hepatology services:

*“We were doing DBS testing in the prison and we were getting a lot of positive hep C patients and so I was referring them to hospital. When I referred them I realised that there was no secondary care service and they had a really limited service at the time, so I asked NHS England and explained what we were doing, and they were mortified because they said that they didn’t have the provision to provide this service and they got in contact with PHE... So now we’ve got access to the specialist services, we’ve got a consultant, so we have got a pathway in terms of getting people on treatment and it’s literally being set up as we speak. So we’re about to have one person on treatment.” (Prison A)*

Two interviewees explained that they need to develop and agree a care pathway for people testing positive for hepatitis C:

*“I don’t think it’s a big deal to offer the opt-out testing, I think that we could conduct that reasonably well. I think that when you do that you have to have in place what you are going to do about treatment. So until all of that is very clear, I only want to do it when we’ve got a proper pathway and everything is all clear. Because one of the things I’ve found is that you can start implementing something to try to do good and then, you know, it’s all made easier years down the track when you’ve got it all sorted out.” (Prison E)*

*“I think first of all we need a pathway, to make sure it is understood by all so drugs treatment providers, ourselves, primary care, mental health services as well.” (Prison D)*

Another stated that their care pathway protocols were old and probably needed revisiting:

*“...our [pathway] is quite old. I was involved when I first got here which was 7 years ago. We were having meetings with the then head of healthcare, the consultant, the nurse and the other local prisons. So we were quite heavily involved in putting the protocols together and I don’t think they’ve changed greatly, but there’s probably just a little bit of work to be done in updating them.” (Prison G)*

Six of the eight representatives interviewed stated that they would find more national guidance on what constitutes a ‘gold standard’ hepatitis C pathway in prisons to be helpful. For example:

*“Because there are other prisons doing good things... my line manager manages healthcare at 4 prisons and she says that the care pathway at Eastwood Park Prison is brilliant.... But again, that’s not a nationally agreed gold standard pathway. There’s nothing coming out centrally for people to think – that’s really good, that’s a gold standard that’s been agreed nationally. It does seem that its individual prisons doing their own thing.” (Prison B)*

*“I think guidelines [are needed] around the pragmatic stuff – who’s funding what, what do you do in a busy prison re. treatment? So, for example, do you offer prisoners on remand a test if you don’t know whether or not they are going to stay in prison until after they’ve been sentenced? So it’s that kind of thing...because you don’t want to spend all this money starting people on, say, hepatitis C treatment, and 90% of them don’t complete it. What’s required is a whole prison approach and acknowledgement that you’ve got to work in the pragmatics of a prison.” (Prison E)*

*“I would say the things we need are, definitely training, one hundred percent. For leaflets to be made clearer and some kind of national guidelines of what a gold standard service is.” (Prison B)*

**The variations in size, categories and operational procedures in the prison estate mean that prisons need to be allowed a degree of flexibility to implement BBV opt-out testing and care pathways that best suit their circumstances. However, these interviews indicate that most prisons – both those offering testing on an opt-out basis and those not yet offering opt-out testing – would find additional guidance on setting up testing and care pathways useful.**

## Continuity of care

A lack of continuity of care was highlighted as a serious issue that is impeding the implementation of opt-out BBV testing by two interviewees. They explained that more needs to be done to ensure patients diagnosed with a BBV, or who are initiated on treatment, are followed up in the community on release.

*“We released prisoners into the area... and we can’t guarantee that they’ll have the support they need because there’s not a link nurse or anyone there.” (Prison A)*

*“Prisons are such different beasts. You know, our average stay here is 4-6 weeks so continuity of care is a big issue for this type of prison, but it won’t be for your long-term lifer prisons or for your resettlement prisons. But when you’re a majority remand prison, what we do is mostly identify and start somebody on the patient pathway but then, where do they go after that?” (Prison B)*

Interviewees were not specifically asked about medical holds, although two raised the issue – one saying that they were no longer able to use medical hold for people who have started hepatitis C treatment, “it’s a clear direction from our Governor: Medical holds – can’t do it unless it’s a life or death emergency treatment”, and

one saying that they could use medical holds for people receiving hepatitis C treatment.

**As exemplified by some of the prisons offering opt-out BBV tests, continuity of care for patients returning to the community can be ensured through close links with community health teams and continuity of care within the prison estate can be ensured using SystmOne and good communications between prison healthcare teams. Ensuring these systems are in place is a critical part of a prison developing its opt-out testing offer and related care pathways.**

## Training requirements

When asked about what training the prisons ran for both healthcare and non-healthcare staff, most prisons identified that, although healthcare staff receive some training in BBVs, there was probably a need for further training amongst wider prison staff and that some healthcare staff may benefit from additional training too:

*“It’s a training area where there’s probably benefit in a recap for the healthcare team as well. We have three officers who are currently seconded into the substance misuse team, and they see all prisoners where there’s evidence or suspicion that they’ve been using drugs... It might be something they would benefit from as well.” (Prison G)*

*“For the nurses, you have the online training and we have had people coming in delivering sessions but I think it’s been a while and I think it would be good for [someone] to maybe come in and do a talk about BBVs and training. Incidentally, I think that when the opt-out testing does come in I think that, obviously, there’s going to be a number of us that will need to know how to do testing... But I think that we could probably do with an update regarding BBVs anyway.” (Prison F)*

*“To train our nurses, I think that I will have to link with our local university to see what kind of diploma might be available, because I can’t find much else, I’ll be perfectly honest with you.” (Prison B)*

*“I’m not a specialist in BBVs, which is fine as I’m not expected to be in my role, but my manager who does have a lot of background in BBVs talks to me about this genotype and that genotype and I have no idea what she’s talking about. So there’s a step up, more in-depth training, needed.” (Prison B)*

One interviewee highlighted a nervousness amongst healthcare staff about talking about hepatitis C that needs to be addressed through training:

*“People need to be comfortable with it [BBV testing] because I think there’s currently a historical thing about nursing staff being scared about talking to someone about hep C, its implications. They all get wrapped up in the minutia about, ‘what do I say about insurance’ and stuff. So I think we need to break down that barrier of professional reluctance to get involved.” (Prison D)*

One prison ensures that prison officers as well as healthcare staff receive training in BBVs:

*“Yes, the prison officers will cover BBVs on a very general level in all of their prison induction training so when they first sign up to be a prison officer. They do an 8/9 week course and infectious diseases, of which hep C is one, is presented in that. In terms of what healthcare do, we go along to the local prison induction for all new staff, so that’s prison officers, teachers, instructor, anyone really and the health adviser does a bit of a talk in that induction too.” (Prison C)*

Tailored training for all staff members, in particular health teams, substance misuse teams and prison officers, so BBV transmission routes, symptoms and treatment options are better understood would help to normalise testing, treatment and care in the prison setting.

**The fact that most prison healthcare representatives interviewed felt that there were training needs within their prison on BBVs indicates that additional guidance on what training should be delivered would be beneficial.**

## Tailored information for people in prison

Two interviewees raised a need for more accessible, tailored information for people diagnosed, or at risk from, hepatitis C or other BBVs.

*“The average reading age of a prisoner here is 7 and so the literature has to be produced in a way they understand, and sometimes it’s quite complicated. So I think there needs to be some thought put into the literature to make it more accessible.” (Prison B)*

This is an area where more best-practice sharing across prisons could assist.

## Complexities of working in a prison

Delivering healthcare services in a prison setting can be complex and requires prison officers to ensure patients can attend appointments. This can be a barrier to healthcare, as explained by one interviewee:

*“Just delivering day to day services in a prison is unbelievably hard and also, I think that you can’t get away from the fact that we’re entirely dependent on prison officers to deliver healthcare services. I’m just writing a report now about all the services that we can’t offer or services that are being compromised because there’s not enough prison officers. You know, nationally they’ve cut prison officers hugely. We’ve lost, since I’ve been here, 25% of prison officers and there was a cut before I*

*arrived... Who would have thought that 'do not attends' are a massive problem in prisons? The other day I had a GP there for a 3 hour clinic and he managed to see 3 people." (Prison E)*

Another interviewee stressed the need to get prison management involved and on-board with the implementation of opt-out BBV testing:

*"... at the moment, although it's coming [opt-out testing], the Deputy Governor doesn't see it as a priority. We know it's coming and that NOMS are pushing us to do that. It's something that further down the line we need discussions about... Obviously it's about getting the whole prison on board as well because if we're looking at doing opt-out testing to everybody that comes in, there will be an increase in services. So basically we've got to get the prison on board." (Prison F)*

## Delivery of negative results to people in prison

The delivery of negative test results to people provides an important opportunity to provide prevention information so people can stay negative.

Although not specifically asked about how negative BBV test results were delivered to patients, one interviewee raised this as an area for improvement:

*"Obviously if it's a positive result, an appointment is made. One of the things that prisoners have fed back to us that we're not very good at is, when tests are normal – this is blood tests in general because of the high number of tests we do – we're not very good at giving feedback when everything's just normal. So it's one of our areas to look at." (Prison E)*

## 5. Conclusions, recommendations and next steps

### Conclusions

This research has highlighted some constructive lessons from prisons implementing opt-out BBV testing. However, there is still a long way to go to achieve the goal of full implementation of BBV opt-out testing in many prisons, including over half of the prisons interviewed for this report. Even the prisons implementing opt-out testing identified areas where they required additional support or information.

It is clear from the interviews conducted for this report that additional guidance would be of use to many prison healthcare teams in setting up BBV opt-out testing and related pathways, particularly in clarifying who pays for what along the pathway and what a 'gold standard' care pathway looks like. Guidance on how to ensure continuity of care for patients moving between prisons or on release, and on what training healthcare and other prison staff should receive on BBVs, would also be beneficial.

Due to the differing sizes, categories, prisoner turnover and other logistical issues related to providing healthcare in a detention setting, it is clear that one size will not fit all when it comes to offering tests on an opt-out basis and developing the care pathway for anyone diagnosed positive. Any guidance must be pragmatic and allow for flexibility to accommodate the different logistical issues prisons face, and should complement PHE's current algorithm and guidance on testing.

### Recommendations

To assist prisons in their development of opt-out BBV testing for all people in prison, additional national information and guidance is required in the following areas:

- **Clarity on the funding** of testing and treatment pathways;
- Details on **what constitutes a good hepatitis C pathway**, including how to ensure continuity of care in the community for people diagnosed positive;
- Additional **training around BBVs** for healthcare and wider prison staff to challenge the stigma surrounding BBVs and to ensure effective testing and treatment pathways, with national guidance made available to prisons on the level of training required.

### Next steps

Based on the findings of these interviews, The Hepatitis C Trust will convene an expert group of prison healthcare specialists and commissioners with the aim of developing constructive pathway guidance to assist prison healthcare teams in offering BBV testing on an opt-out basis to all people in prison and to ensuring anyone testing positive is initiated on an effective care pathway.

## 6. References

- i. In the Annual Report of the Chief Medical Officer's Surveillance Volume 2012, it is stated that among those tested between 2008 and 2012, hepatitis C antibodies were discovered in a greater proportion of prisoners (14%) than in people in the general population (3%), suggesting that prevalence of hepatitis C is considerably higher in the prison population than in the general population: Annual Report of the Chief Medical Officer's Surveillance Volume 2012, On the State of the Public's Health <https://www.gov.uk/government/news/chief-medical-officer-publishes-annual-report-on-state-of-the-publics-health>
- ii. PHPQI data from 2012-13 shows hepatitis C tests performed on 6.3% of receptions <http://www.nta.nhs.uk/uploads/presentations-nin-040614.pdf>
- iii. NOMS, NHS England and PHE National Partnership Agreement, 2013: <http://www.justice.gov.uk/about/noms/working-with-partners/health-and-justice/partnership-agreement>
- iv. NOMS, NHS England and PHE National Partnership Agreement, 2013: <http://www.justice.gov.uk/about/noms/working-with-partners/health-and-justice/partnership-agreement>
- v. Hepatitis C in the UK: 2015 Report (Public Health England, July 2015): [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/448710/NEW\\_FINAL\\_HCV\\_2015\\_IN\\_THE\\_UK\\_REPORT\\_28072015\\_v2.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/448710/NEW_FINAL_HCV_2015_IN_THE_UK_REPORT_28072015_v2.pdf)
- vi. The latest unlinked anonymous survey of BBVs in prisons was conducted in 1998 and found 7% of prisoners were infected with hepatitis C (Prevalence of HIV, hepatitis B and hepatitis C antibodies in prisoners in England and Wales: a national survey. Weild A. R., Gill O. N., Bennett D., Livingstone S. J. M., Parry J. V., Curran L. (2000). Communicable Disease and Public Health 2000;3:121-6.): <http://www.publications.parliament.uk/pa/cm200708/cmhansrd/cm080716/text/80716w0028.htm>
- vii. BBV Opt-out testing in prisons: Preliminary evaluation of pathfinder programme April – September 2014 (Public Health England, April 2015), <https://www.gov.uk/government/publications/blood-borne-virus-opt-out-testing-in-prisons-evaluation-of-pathfinder-programme>
- viii. Ibid
- ix. National event for early lessons learnt from the opt-out BBV testing policy in prisons (Public Health England, August 2015), <https://www.gov.uk/government/publications/early-lessons-learnt-from-opt-out-blood-borne-virus-testing-policy-in-prisons-summary-report>
- x. Hepatitis C in London (Public Health England, January 2015): <http://www.hcvaction.org.uk/sites/default/files/resources/Hepatitis%20C%20in%20London.pdf>
- xi. PHE guidance on BBV testing and pathways in prisons can be found here: <https://www.gov.uk/government/publications/improving-testing-rates-for-blood-borne-viruses-in-prisons-and-other-secure-settings>

## Appendix 1: List of prisons invited to take part in interviews

| Prison                              | Region          | Category   | Capacity |
|-------------------------------------|-----------------|------------|----------|
| HMP Belmarsh (Belmarsh cluster)     | London          | Local male | 910      |
| HMP Bristol                         | South West      | B          | 614      |
| HMP Brixton                         | London          | C/D        | 798      |
| HMP Dovegate                        | HMP Dovegate    | B          | 1060     |
| HMP & YOI Feltham                   | London          | YOI        | 762      |
| HMP Haverigg                        | HMP Haverigg    | C/D        | 644      |
| HMP & YOI Holloway                  | London          | YOI        | 501      |
| HMP Lewes                           | Kent & Sussex   | Local male | 742      |
| HMP Manchester                      | North West      | A          | 1238     |
| HMP New Hall                        | East of England | Women's    | 446      |
| HMP Northumberland                  | North East      | C          | 1348     |
| HMP Norwich                         | East of England | B/C/D      | 769      |
| HMP Pentonville                     | London          | Local male | 1310     |
| HMP Stanford Hill (Sheppey Cluster) | Kent & Sussex   | D          | 464      |
| HMP Stocken                         | East Midlands   | C          | 842      |
| HMP Stoke Heath                     | West Midlands   | C          | 766      |
| HMP Thameside (Belmarsh cluster)    | London          | B          | 900      |
| HMP Wansdworth                      | London          | Local male | 1877     |
| HMP Wormwood Scrubs                 | London          | B          | 1279     |
| YOI Isis (Belmarsh cluster)         | London          | YOI        | 622      |

## Appendix 2: Semi-structured interview questions

1. When did you first hear about the BBV opt-out testing policy? (Included in the National Partnership agreement here)
2. How did you hear about it?
3. Have you started to implement opt-out testing for BBVs?

### If yes:

4. When did you start to implement opt-out testing?
5. Is it fully operational now?
6. At which reception are people in prison offered BBV testing?
7. Who offers the test and what training have they received?
8. How is the result delivered? Is it by the same person?
9. Do you have an integrated care pathway / protocol for testing and follow-up care for anyone testing positive? If so, are you able to share this with us?
10. Are you currently treating hepatitis C patients?
11. What changes did you have to make to implement BBV opt-out testing?
12. Do you think more people are being diagnosed as a result of introducing BBV opt-out testing? If so, how many more (this can be approximate)?
13. Are you experiencing any issues as a result of the policy?
14. Do you have any advice for prisons who are about to start implementing opt-out testing?
15. Were there any barriers that you had to overcome in introducing opt-out testing?

### If no:

4. Are people in prison currently offered BBV testing at any point during their stay?
5. Who offers the test?
6. What training have they received in BBV testing and care?
7. How is the result delivered?
8. Do you have an integrated care pathway / protocol for testing and follow-up care for anyone testing positive? If so, are you able to share this with us?
9. Are you currently treating hepatitis C patients?
10. Why have you not yet started BBV opt-out testing?
11. Have you faced any barriers to rolling out opt-out testing?
12. Do you foresee any barriers / problems in rolling out BBV opt-out testing in your prison?
13. Do you require any support in the roll-out of BBV opt-out testing? E.g. information, training?
14. When do you anticipate you will be offering BBV testing on an opt-out basis to all prisoners?
15. Do you feel sufficiently confident of the commissioning system and patient pathways available to roll-out opt-out testing?

### Additional questions for all:

16. What information is given to the patient if they have a positive result? (Would you like us to send you any patient leaflets?)
17. Do you run any support groups in BBVs?
18. Are you aware of the Hepatitis C Trust's free helpline for people in prison? (Would you like us to send you cards with the number?)
19. Do any other staff members receive training in BBVs – e.g. prison officers?
20. Is there any other support you need to deliver opt-out testing in your prison?

